

# Living Life to the Fullest With Ehlers-Danlos Syndrome

*A Guide for a Person  
Living with EDS to  
Achieve a Better  
Quality of Life*

KEVIN MULDOWNEY, PT

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Guide to Living a Better Quality of Life While Having EDS  
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Outskirts Press, Inc.  
<http://www.outskirtspress.com>

ISBN: 978-1-4787-5888-4

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PRINTED IN THE UNITED STATES OF AMERICA

## **Living Life To The Fullest With Ehlers-Danlos Syndrome**

- Step By Step Instructions For How A Person With EDS Can Considerably Decrease Their Pain
- Exercise Protocol For The Person With EDS That Will Stabilize Every Joint In The Body
- Explanation Of The Healthcare Professionals That Can Help A Person With EDS Live A Better Quality Of Life
- Helping A Physical Therapist Better Understand Ehlers-Danlos Syndrome And The Issues That May Occur With This Condition
- Step By Step Instructions For A Physical Therapist On How To Treat A Person Diagnosed With EDS



## **Disclaimer**

This book is intended for a person with Ehlers-Danlos Syndrome (“EDS”) and parties treating patients with EDS to purchase and read. However, in order for the content to be helpful, the patient with EDS should retain a licensed physical therapist familiar with the Muldowney Exercise Protocol (“MEP”) in order to monitor and guide the patient with EDS through it. This book is not intended as a replacement for such direct physical therapy and the clinical decisions made pursuant thereto. The author and the publisher do not assume and hereby disclaim any liability to any party for any loss, damage, or harm caused by the failure to follow this recommendation and the errors and omissions of others, including treating professionals.



# Living Life To The Fullest With Ehlers-Danlos Syndrome

## Testimonials

*“Many EDS patients have encountered healthcare professionals who dismissed their symptoms, offered ineffectual (or even harmful) treatments, or simply gave up on them. I was one of those EDS patients. I was fortunate to find physical therapist Kevin Muldowney. Kevin’s compassion, persistence, and analytical mind drove him to understand EDS and look for better ways to treat people who have EDS. In doing so, Kevin has re-defined the standard of care EDS patients can expect from physical therapists. Using his profound knowledge of biomechanics, Kevin has systematically tested and tweaked protocols and exercise routines for his EDS patients and designed a treatment program tailored to our needs. The program’s consistent end-results are joint stabilization, reduced pain, fewer physical limitations, and better quality of life. Kevin’s protocol allowed me to re-take control of my life and regain my ability to do the things I love to do. I hope Kevin’s book will help your physical therapist do similar things for you.”*

**Rachel Stevenson**

*“Over the last seven or so years, I have taken my daughter to numerous facilities, none of which had the expertise and understanding of my daughter’s medical issues like Muldowney Physical Therapy. Kevin met with Nicole and he outlined the issues she was having, and how he would be able to help her. Kevin explains what is occurring and how best to fix it or manage the issue. Kevin is totally ‘hands on,’ correcting issues as they arise. He asked me to learn some corrections to help Nicole in between visits. Kevin is very knowledgeable, thoughtful, caring and compassionate and he has the best sense of humor, which is necessary, especially for Nicole. Nicole has had two surgeries and Kevin and his*

*team has been unbelievably supportive and instrumental in Nicole staying in college and living life to the fullest. Prior to seeing Kevin, Nicole was bedbound and using a walker or a wheelchair. The medical team and the exemplary team at Muldowney Physical Therapy made it possible for Nicole to be a college student, living in a dorm with her service dog, Watson. Kevin has seen Nicole at her worst and works with her to get better and better. Following his protocols and going to physical therapy regularly have been the keys to her successes. You will not find a better team anywhere – with a leader that is truly the best. Thank you, Kevin, and your wonderful practice for giving my daughter her life back.”*

**Jamie Toscano**

*“As most everyone else who has been diagnosed with Ehlers-Danlos Syndrome, I have spent many doctor and physical therapy appointments being the one who had to educate the very person I had been referred to, had looked to, for help and answers - only to be disappointed when they had nothing to offer me. When I was first referred to Muldowney Physical Therapy, I was expecting the same thing to happen - I would be the educator, and not much would be offered in the way of help. With Kevin, not only was help offered, but - more importantly - HOPE. As one who hates exercising, because it has always meant an increase in pain and mobility problems in the past, I have found the protocol very “do-able” because of the slow, steady pace. Following Kevin’s exercise protocol has brought my chronic pain level down to a 1/10, which I have not experienced for decades. It has also given me a step-by-step planned guide to build up my strength and it has helped me deal with my setbacks when falls and problems occur. Now, instead of Ehlers-Danlos having a grip on me and my life with a steady decline and no relief to expect for my future, I can live my life with strength and hope as a person who just happens to also have EDS. Thanks, Kevin!*

**Diane Weeks**

## Dedication

***“The needs of the many outweigh the needs of the few or the one.” Mr. Spock***

This book is dedicated to all of my patients with EDS who had faith in me and allowed me to work with them to develop this treatment protocol. Their trust in me and their willingness to help the greater EDS population is the only way this protocol could have ever been developed. I would like to say a special thanks to Ellen Lenox Smith, who was the first EDS patient I ever treated. If it were not for Ellen’s patience with me as I determined how best to help her, I would never have taken a special interest in this genetic disorder. Everyone who is helped by this book owes a debt of gratitude to Ellen as well.

This book is also dedicated to my wife Kathleen and son George who sacrificed family time with me to allow me to write this book as quickly as I could so it could help people right away. Hopefully, a family who is dealing with EDS can now spend quality time together just like my family does on a regular basis.



## Special Thanks

To write a book like this one, it takes a village of people to make it work. There are certain people who went above and beyond to make this book as readable and user-friendly as possible. Special thanks goes out to my chief editor Justin Laferrier, PT, Ph.D, OCS, SCS, ATP, CSCS. I also want to thank my patients with EDS and family members of my patients with EDS who helped with editing: Ellen Lenox Smith, Patrice Davis and Donna Sullivan. Another thanks goes out to my professional colleagues who also helped edit: Matthew Fontaine, PTA, Linda Letourneau, PT and Kathleen Muldowney, PT.

A special thanks goes to Linda Letourneau, PT who is an expert in craniosacral therapy and who developed the craniosacral exercises and TMJ exercises for the EDS population.

Thank you to the people who were models for this book: Matthew Fontaine, Paula Taylor, Michaela Sullivan, Patrice Davis and Kimberly Valentino.

Thank you to the transcribers of my dictation: Crystal Verrier, Roberta Accetturo and Nelia Costa.

Thank you to Jim Janeczek who hand drew figures for the book (Figures 1, 2 and 3: the double rotation of T10 on T11).



## About This Book

*"It is sometimes fun to do the impossible." Walt Disney*

After treating patients with Ehlers-Danlos Syndrome (EDS) for ten years, I developed The Muldowney Exercise Protocol to stabilize the hypermobility created by EDS in the body. This protocol worked so well with my patients who have EDS that I wanted to share this with colleagues and other people affected by this genetic disorder. Hopefully, therapists, healthcare providers and people with EDS will find this book helpful in treating this complex genetic disorder. This book is intended to be used by individuals with EDS under the guidance and close supervision of a physical therapist as they progress through this exercise protocol.

This book was written for an individual with EDS as a resource for how to treat this genetic disorder. This book will outline and explain how to use The Muldowney Exercise Protocol, which I developed specifically for people who are hypermobile, focusing on the EDS population. Following this exercise protocol can and has significantly decreased pain throughout the body that is caused by subluxation of joints. A person with EDS will need to find a physical therapist who will use manual therapy techniques to realign the joints of the body and decrease pain while progressing you through this protocol. In conjunction with receiving treatment from a physical therapist, a person with EDS will need to use this book as a home exercise program as they progress through the Muldowney Exercise Protocol. If the physical therapist is unfamiliar with EDS, they would benefit from reading this book before working with this population. Therefore, a person with Ehlers-Danlos Syndrome does not need to find a physical therapist who specializes in EDS, but rather they need to find a manual physical therapist who is willing to read this book and follow its guidelines.

Do not be overwhelmed with the size of this book. It was written with the intention of being read over a six-month to one-year period. First, read Section One and Section Two up through Level 0.5 Mat. Then find a physical therapist who will be willing to read the same

sections. This book is written for two audiences: people with EDS and physical therapists. This allows me to explain to people with EDS how EDS affects their body and to explain to physical therapists, what to look for and how to treat people with EDS appropriately. People with EDS and physical therapists should read the sections that pertain to them.

Section One discusses what causes joint pain in the EDS population. It also addresses what other healthcare professionals will be needed to help manage problems that the patient with EDS may face that are not handled by a physical therapist. This book provides extensive information regarding evaluation and treatment of these complex patients for a physical therapist who does not have experience treating this population.

Sections Two, Three and Four will systematically explain how each joint in the body is affected by EDS. Specific exercises used to help stabilize each joint will be outlined. I have included a section for each exercise, explaining what a physical therapist should pay attention to while the patient performs each exercise to ensure proper technique, avoid injury and maximize results with each exercise.

Section Five begins the functional training needed for a person with EDS to live life to the fullest. This section will focus on twisting, walking on uneven terrain and throwing. Achieving these goals will make possible many activities that this population may have thought they could never perform again. Life is more than just surviving. Life is those enjoyable moments you share with your family and friends without worrying that you will be in terrible pain the following day. This section works on achieving these goals.

At completion of The Muldowney Exercise Protocol, an exercise chart is given to each patient outlining their final home exercise program. I have also listed all of the exercises in this protocol in the appendices at the end of this book. At this point, the person with EDS should be living with much less pain and much higher functional capacity. My goal is to have patients live life to the fullest. Good Luck!

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# Section One:

## Ehlers-Danlos Syndrome

*“The beginning of knowledge is the discovery of something we do not understand.”*

Frank Herbert

### What do I do if I think I have Ehlers-Danlos Syndrome?

#### **FOR THE PERSON WITH EDS:**

If you think you have Ehlers-Danlos Syndrome (EDS), you may become overwhelmed quickly as you scour the internet for information. Hopefully, this section will help to simplify the understanding of this genetic disorder. EDS affects many structures in the body, and, for more in-depth information, you may go to the Ehlers-Danlos National Foundation website at [www.ednf.org](http://www.ednf.org). This site has the most updated and accurate information about EDS.

EDS is an inherited connective tissue disorder which affects collagen in the body. Collagen is the glue that supports many structures in the body, such as: skin, ligaments, muscles, organs and blood vessels. Since people with EDS have problems with collagen, their ligaments are weak and overstretched. Therefore, their joints have excessive movement, which is called hypermobility.

If someone suspects that they may have EDS and have not yet been diagnosed, they need to go to their primary care physician and ask them to refer them to a geneticist.

**Only a geneticist can confirm a diagnosis of Ehlers-Danlos Syndrome**, as there are many other diseases that can affect the body and cause hypermobility. There are six types of EDS: Classical Type, Hypermobility Type, Vascular Type, Kyphoscoliosis Type, Arthrochalasia Type and Dermatosparaxis Type. Once you have a confirmed diagnosis of EDS, the specific type will be determined by the geneticist. Once you know the type of

EDS you have, you can visit the EDNF website to receive more detailed information about your specific type of EDS. The Muldowney Exercise Protocol, which I developed, will work primarily on hypermobility and multiple subluxations that can occur, regardless of the type of EDS.

Once a person is diagnosed, they need to start developing a team of healthcare professionals who will address the numerous problems that may occur with this genetic disorder. A person with EDS is susceptible to multiple subluxations/dislocations at many joints, which this protocol will address. However, there are many other problems caused by EDS that may need to be monitored by other health care professionals (See Appendix E). The other healthcare professionals to consider include:

- 1. Primary Care Physician:** This healthcare professional is the coach for this disorder. They will evaluate all of the information from the other healthcare professionals. With this information, they will decide what other healthcare professionals you will need to be referred to in order to properly address specific health issues that can occur. They will coordinate your overall health care. Make sure all other healthcare professionals are sending their findings to your primary care physician.
- 2. Pain doctor:** This doctor will help control pain and inflammation, which will allow you to get through your day more comfortably. Pain control is important because pain inhibits muscle strength, and without muscle strength, there will be additional stress on your ligaments and joints as you walk and move around through the course of your day. Let's be honest, if a person is in pain all the time, they will be less active throughout their day. A person with EDS also has a major problem with inflammation in the joints because they are hypermobile. Excessive movement in a joint will cause additional inflammation in that joint. Inflammation causes pain and decreases muscle strength. Therefore, controlling inflammation is as important as controlling pain while beginning any exercise program or becoming more active. Due to several medication sensitivities common in this population, only a physician who understands the comprehensive medical history of a person with EDS should prescribe medicine for them.
- 3. Orthotist:** This person will work closely with the physical therapist to develop

customized braces for people with EDS to help support subluxations. The additional support of a custom designed brace can significantly help people with EDS to get through their daily routine with less pain. It should be noted that bracing a patient with EDS for a prolonged period of time can make that joint weaker due to disuse of muscles around that joint. A physical therapist's job is to strengthen the patient's muscles to support the joint so they can slowly wean them off the brace. Some joints may require bracing for certain activities throughout a patient's life, for example, bracing the wrist during computer work or bracing the knees while taking long walks. The person will be instructed to use the brace only during those certain activities. The orthotist and physical therapist can provide guidelines for brace usage.

4. **Cardiologist:** This healthcare professional will work on many issues dealing with the cardiovascular system including: POTS (postural orthostatic tachycardia syndrome), heart rate, blood pressure, heart contractility and aortic or abdominal aneurism. During the Muldowney Exercise Protocol, a patient with EDS can work out as much as ninety minutes a day. A cardiologist needs to make sure the patient is able to handle this amount of exercise before starting this protocol, especially if a patient is diagnosed with vascular EDS.
5. **Neurosurgeon:** This healthcare professional can help evaluate for: tethered cord, Chiari malformation, syringomyelia and cranial instability. All of these conditions have to do with the brain and spinal cord and should be assessed immediately. These conditions can decrease the ability of a patient with EDS to strengthen their joints, making it difficult for them to exercise. If you have bowel and bladder issues, have your primary care physician refer you to a neurosurgeon so that they can assess you for these conditions.
6. **Gastroenterologist:** This healthcare professional will address many GI problems, including leaky gut, gastroparesis and GERD. They may also refer the patient to a nutritionist who will help diagnose food allergies and develop diets. Food allergies can cause global inflammation throughout the body, making it easier for your joints to sublux.

7. **Endocrinologist:** This healthcare professional will evaluate for secondary conditions such as mast cell disorder and mitochondrial disorder.
8. **Pulmonologist:** This healthcare professional will assess for COPD (chronic obstructive pulmonary disease) and other breathing problems that may occur.
9. **Speech Therapist:** This healthcare professional can give you exercises to stabilize your throat while swallowing if issues arise.
10. **Manual Physical Therapist:** This healthcare professional works on aligning bones using muscle energy techniques, myofascial techniques and craniosacral techniques while guiding you through The Muldowney Exercise Protocol with the help of this book.

A team approach is essential in properly treating a person with EDS due to the multiple issues that may arise with this complex genetic disorder. The physical therapist and other health care professionals need to work closely with the patient's primary care physician to inform them about issues and secondary conditions that can be related to this disorder.

## Physiology of Joint Subluxations

### **FOR THE PERSON WITH EDS:**

For the purposes of this book a joint is defined as a place where two bones meet and there is movement between these two bones. Surrounding each joint are both ligaments and muscles. Ligaments attach from one bone to the next and provide primary stability to the joint. Muscles attach from one bone to the next and produce movement, and provide secondary stability to the joint. The difference between a muscle and a ligament is that a ligament is an inert tissue (has no ability to contract), and therefore, **cannot** be strengthened with exercise once it is injured. A muscle is an active tissue (can contract), and therefore, **can** be strengthened with exercise once it is injured. Strengthening decreases pain by stabilizing the joint, using the secondary stabilizers of the joint, which are the muscles. This is the major reason why going through this exercise protocol decreases pain in the EDS population.

Ligaments have two major roles. The first is to absorb forces from the external environment placed on the joint in order to prevent the two bones from moving excessively. The second is to provide proprioception to the joint. Proprioception is defined as the unconscious perception of movement and spatial orientation or our body's awareness of where it is in space. It tells your joints not to move too far so they do not sublux.

If an external force is placed upon a ligament and the ligament is overstretched, it will begin to deform (stretch out). In the non-EDS population, when a ligament is overstretched, it will heal with collagen. In the EDS population, there is a defect in the collagen, which does not allow the injured ligament to heal in a timely manner, if at all, making those ligaments ineffective as primary stabilizers. Once ligaments can no longer support the joint and prevent excessive motion, the joint then relies on the muscles for stabilization. This is the rationale behind applying this exercise protocol to injured joints in order to strengthen the secondary stabilizers to help the injured ligament. If you strengthen the muscles around an injured joint, you can decrease the hypermobility of that joint, making it less painful.

Dislocation is defined as a complete separation of two bones where they meet at a joint ([www.nlm.nih.gov](http://www.nlm.nih.gov)). A subluxation is defined as a partial separation of two bones where they meet at a joint ([www.nlm.nih.gov](http://www.nlm.nih.gov)). This distinction is an important one for a person with EDS to understand when discussing concerns regarding their joints with any physician. Most joints of people with EDS do not dislocate; instead, they sublux. The use of correct terminology while meeting with a physician will facilitate the most comprehensive follow-up care for the patient with EDS.

Ligaments are made up of collagen, which is structurally deficient in the EDS population. This will cause their ligaments to become weak. If a ligament is weak, it will not be able to absorb as large of an external force before it fails, therefore causing a subluxation and possibly a dislocation. If a ligament is weak, a person will need to rely upon their secondary stabilizers, which are the muscles, to protect the joint from external forces. Therefore, strengthening the muscles around all joints increases the joints' ability to handle increased external forces placed upon the body that occur with activities of daily living (things normally done in the course of a day). This is the rationale behind applying

this exercise protocol to all the joints, whether or not those joints hurt. Using exercise to protect a joint that does not hurt is of equal importance as using exercise to stabilize a joint that does hurt. By proactively strengthening the joints, it will help to make them less susceptible to subluxations in the future. Let's be honest; it is easier to exercise a joint that does not hurt than one that does hurt.

Since ligaments in the EDS population are weaker than normal, their capacity to sublux is greater. Identifying “triggers” is an important strategy to recognize what is causing the joints to sublux in your daily life. A trigger is defined here by me as something you unknowingly do that is harmful to you and results in subluxation of your joints. Remember, your ligaments are more fragile, so it may not take much to injure them. These triggers could be as simple as sleeping in a bad posture, using the wrong pillow while sleeping, getting on and off the bed improperly, or doing housework with poor body mechanics. When you work with your physical therapist, they can help you identify triggers as well as suggest changes for the way you do these activities in order to give you less pain. The more triggers identified and modified by you and your physical therapist, the less pain you will be in and the better quality of life you will achieve.

## **How Can You Say My Muscles Are Weak When They Feel So Tight?**

### **FOR THE PERSON WITH EDS:**

Most people with EDS do not see themselves as weak, but instead consider themselves to be very “tight.” Most of them want to be stretched and massaged to loosen up their tight muscles. This should not be done because the **muscles in your body are not tight, they are in spasm** (a sudden involuntary contraction of a muscle or group of muscles) as a direct result of your hypermobility. **A muscle that is in spasm is physiologically weak.** When a joint is hypermobile there will be inflammation and pain, causing the receptors in the surrounding muscles to become hyperactive. Therefore, the muscles around that joint will go into spasm in order to help stabilize that joint. If you try to take away the spasm with massage and stretching, it will feel great after you are done, but as you walk around, the joint becomes more hypermobile because you have taken away the spasm, which was supporting the joint. Now that the joint is more hypermobile, the muscles around it

will go back into spasm and the pain will return. This is the cycle that most people with EDS will experience if massage and stretching are performed too soon, before the joint is sufficiently strengthened.

The proper approach is to strengthen the muscles around the joint, which will decrease the muscle spasms. Once the muscles around the joint are adequately strengthened, the spasms will usually decrease. **Therefore, exercise is the most important tool that this population has to decrease their muscle spasms.** Manual techniques such as myofascial release and muscle energy are beneficial in conjunction with this exercise protocol. **No manual therapy techniques should be performed on a hypermobile joint unless the joint is being strengthened with the Muldowney Exercise Protocol outlined in this book.** The person with EDS and the physical therapist need to work together in order to determine when stretching and massage should be added back into a person's routine. This will vary greatly among different people depending on their overall strength and other health issues.

## What To Look For In A Physical Therapist

### **FOR THE PERSON WITH EDS:**

Very few physical therapists specialize in treating people with EDS throughout the country. I advise you to look for a manual physical therapist who is willing to follow this exercise protocol. At minimum, you should call a physical therapy facility and ask if their therapists have experience with the following manual therapy techniques: muscle energy techniques, myofascial release, Mulligan techniques, McConnell taping techniques, craniosacral therapy techniques and visceral therapy techniques. In a facility, one physical therapist does not need to specialize in all six techniques mentioned above. It is possible to see one therapist for several techniques and another therapist for the other techniques at one specific physical therapy facility. With this approach, you can still achieve the highest quality of care available for your condition.

A copy of this book should be given to the physical therapist before they treat you. The physical therapist must read the first two sections that are marked, "For The Physical

Therapist” before determining whether or not they can properly treat you. The physical therapy practice must provide one-on-one sessions for you. You will need between thirty and sixty minutes of one-on-one time with the physical therapist each visit. Our facility treats every patient one-on-one for forty-five minutes, which gives our physical therapists ample time to address all of the issues that may arise each session. You should not be frustrated if a clinic will not treat you. When you find the right physical therapist, you will know. The therapist will understand what you are going through because they have adequately researched EDS. Once the right facility and therapist are found, you need to work hard and trust them.

## **Rules Of The Muldowney Exercise Protocol**

### **FOR THE PERSON WITH EDS:**

In the next three sections, I am providing you with guidelines for how to strengthen and stabilize all of the joints in your body. My protocol will slowly strengthen a joint while taking into consideration pain in that specific joint. You need to go through this protocol while seeing a manual physical therapist who will both perform manual therapy techniques to align your joints as well as guide you through this exercise protocol. This entire protocol will take between six months to a year to complete, depending on your ability to exercise. I understand that this is a long time to go through an exercise program, but I want to slowly progress you through my protocol to ensure no problems arise when strengthening. These are rules that you need to follow while progressing through the Muldowney Exercise Protocol.

1. **Never ask the physical therapist to work on a part of the body that is not being strengthened.** All manual therapy techniques performed by a physical therapist are designed to align the joints and decrease muscle spasm to the area being strengthened. This will allow you to strengthen a specific joint with decreased pain. As mentioned earlier, muscle spasm is the only thing holding your joints together. Therefore, if you take away the muscle spasm without strengthening that joint, it will become more hypermobile. As the hypermobility of the joint increases, the muscle spasm will return and your pain level in that joint will increase. It is important that

the muscles around the joint have proper strength and endurance to be able to support that joint without muscle spasm. Discuss with your physical therapist types of braces that can be used on joints that are problematic and are not yet being addressed in the exercise protocol.

2. **The order of exercises and the order in which joints are addressed should be followed.**

The Muldowney Exercise Protocol is intended to be followed in the exact order in which it is explained. The reason why the order is so important is that some regions of the body, if not corrected first, will affect other regions of the body. Therefore, the order of exercises is specific to the EDS population. For example, we will always begin treating the low back and pelvis, whether or not it is painful. This is because until this region is aligned, the mid back, neck and head as well as the legs will never be aligned. I understand that it is frustrating for you to work on an area of the body that is not painful, when you have other areas that are painful. You need to trust me that this is the only way to ultimately align all your joints in your body.

3. **Progression of the Muldowney Exercise Protocol must be based on your tolerance to exercise.**

When performing this exercise protocol, we allow you to progress your exercises daily at home. Understand that, if while progressing your exercises at home something becomes painful, you need to stop that exercise and return to your physical therapist so they can determine how to modify the exercise so it does not cause pain. “No pain, no gain” does not work for your body and you must listen to your body and progress each exercise accordingly.

4. **Identifying and eliminating triggers at home will allow you to perform activities of daily living with less pain.**

Identifying and eliminating triggers will decrease the occurrence of subluxations of a joint at home. You and your physical therapist will need to work on modifying your activities of daily living (what you normally do in the course of a day) so you do not hurt yourself. If you do hurt yourself at home, this is called a “setback” and you need to refer to rule #5 on how to deal with a setback.

5. **Dealing with setbacks.**

A setback occurs when something happens at home that causes you increased pain and/or dysfunction in the joint. Setbacks can occur during any phase of treatment and it is important not to become discouraged. To deal with

a setback, you need to protect the joint and decrease inflammation for two weeks. You will also need to drop down one exercise level for the region that was injured, then slowly build yourself back up over the two weeks to your original exercise level that you were at before the setback. For example, if you are on Level Two of the SIJ and Low Back progression and you twisted your back and now your low back has increased pain. You need to go back to the physical therapist so they can assess you and realign your spine if appropriate. Next, you need to drop yourself back down to Level One of the SIJ and Low Back progression, then slowly progress yourself through level one and then advance to Level Two so you are back to the same exercises you were doing before the injury within two weeks. You can continue to progress through the rest of the SIJ and Low Back progression as long as your low back is feeling better. If your low back does not feel better within two weeks, you need to go back to your primary care physician for further evaluation.

6. **Address new issues immediately.** If all of a sudden, you get a new pain, have the physical therapist evaluate it immediately and contact your primary care physician. In the EDS population, new issues do not just go away, but have the potential to worsen quickly. By immediately addressing a new issue, the physical therapist and other healthcare providers will be able to hopefully manage the pain quicker. This may sound confusing because I said earlier not to jump around treating many issues at once. For example, when you began working with the physical therapist you gave them a list of regions of your body that hurt. These are old injuries that will take time to get better. You should not skip around the protocol to address these types of injuries. On the contrary, if you develop a new injury while performing activities of daily living, addressing this new issue immediately will help you prevent this problem from becoming a major issue. Taking two weeks to address a new issue immediately will save you months of pain down the road when you get to that injured joint in the protocol.
7. **Do not quit until you reach the end of the Muldowney Exercise Protocol.** Six months to a year is a long time. There will be ups and downs while completing this protocol. You will have moments when you might feel like you will never get better or reach the next level. Stay positive, you will get there. The following is a true story

of my patient with EDS, whom we will refer to as “Sue.” Sue came to my clinic like many patients with EDS, after seeing five other physical therapists, all claiming to have EDS expertise. She convinced herself that she could not exercise because all of the exercises that the other physical therapists had given her hurt too much. She convinced herself that she was a special case, and because of her condition, exercise could not help her. This could not be further from the truth. After much discussion, she agreed to give my clinic a try. She began to feel better in her low back rather quickly, but her mid back was still very bad and a major source of pain. Every day she complained she had increased mid back pain while performing the low back protocol. I encouraged her to continue with the low back protocol and told her that we would get to the mid back protocol next. Finally she completed the low back protocol and we began manual therapy and exercises of the mid back, neck, ribs and shoulders. Manual therapy gave her instant relief, but she could not hold the alignment for very long. This made sense because she was very weak in this area. When we reviewed her activities of daily living, we realized she was driving one hour each way to see me two times per week. We got her a mid-back brace for driving only, which helped improve her pain. She progressed very slowly through the neck, mid back, ribs, neck and upper extremity section of the protocol because of her weak muscles in that area. About four months into the protocol, her mid back was still in pain, she had not reached the top level of exercises in this section due to her weakness, and she decided she’d had enough. One day, she sat me down and said she wanted to quit physical therapy because it was not working for her mid back. I explained to her that she was not at the top level yet, and until she reached that level, this area would be problematic. She agreed to tough it out. After about another three months of going through the protocol, she reached the top level of exercise and the mid back pain subsided. She was discharged from my physical therapy facility about eleven months after she began with me with a zero to one out of ten pain level in her mid-back and no pain in the rest of her body. At discharge, I told her that if she had not had the faith in herself to achieve the goals, she would still have been in eight to nine out of ten pain and accepting that was her life. I tell you this story because I understand how difficult it is to take an entire year of your life to commit to this exercise protocol

and rehab program. There will be times you will be frustrated and want to quit. If you have faith in the Muldowney Exercise Protocol, you will be able to live a higher quality of life with much less pain within a year.

8. **Fight with everything you have to take back your life.** EDS is something you will have to live with your entire life. It is not going away. Do not let EDS define you. You will have to fight harder than most people, but in the end, it is worth it. Find a physical therapist and give them this book and begin the fight today to take back your life. Good luck in your new adventure to take back your life.

Hopefully this section has given you an overall picture of what EDS is about and the steps you need to perform in order to take back your life. Your next step is to call a physical therapy facility and find out if they have a manual therapist on staff and are willing to treat you, one-on-one for a minimum of thirty minutes. Ask if the physical therapist is willing to read this book and follow the exercise protocol outlined in Sections Two, Three, Four and Five. Once you find the facility, take this book with you to every treatment session, so when it is time to progress your exercises, the physical therapist and you can go over each exercise and check for proper technique. Never begin a new level without the physical therapist first watching you perform the new exercises. You will also need to find the other healthcare professionals and begin to assemble your team who will monitor you throughout your life. Once you find your physical therapist and he or she has read the first two sections, you may begin the SIJ and Low Back progression with them. The remainder of this section is for the physical therapist who will be treating you. You can now turn to Section Two and read the parts of this section labeled, “For The Person With EDS,” before beginning the SIJ and Lumbar Spine Exercise Progression. Good luck with beginning this program.

## **Ehlers-Danlos Syndrome**

### **FOR THE PHYSICAL THERAPIST:**

Ehlers-Danlos Syndrome (EDS) was first named in 1933 after Dr. Chernogubov Edvard Ehlers and Henri-Alexandre Danlos, who both individually wrote separate case studies about this disorder in the early 1900’s. Both individually defined the characteristics of

EDS as a patient presenting with lax joints, hyperextensible skin and a tendency to bruise. As a result of both of their efforts, this genetic disorder was named after them both. EDS is a connective tissue disorder that affects collagen in the body. Collagen is the glue that supports many structures in the body and affects many structures including: skin, ligaments, muscles, viscera and blood vessels. There are six major types of EDS, which are defined according to the signs and symptoms that manifest in the individual. These include: Classical Type, Hypermobility Type, Vascular Type, Kyphoscoliosis Type, Arthrochalasia Type and Dermatosparaxis Type. To learn more about the different manifestations for each type of EDS, please visit the Ehlers-Danlos National Foundation website at [www.ednf.org](http://www.ednf.org) or visit the Ehlers Danlos Network C.A.R.E.S. INC website at [www.ehlersdanlosnetwork.org](http://www.ehlersdanlosnetwork.org). Originally EDS was thought to occur in one in 250,000-500,000 people. Now, it is estimated to occur in about one in every 5,000 births worldwide. Most forms of EDS are inherited in an autosomal dominant pattern, which means only one of the two copies of the genes for EDS must be altered to cause the disorder ([www.ednf.org](http://www.ednf.org)). If a person has EDS, their child has a 50% chance of having the same type of EDS as the parent. Some types of EDS can be caused by a mutation in the gene in which neither parent has EDS. If a patient suspects they may have EDS and have not yet been diagnosed, you need to refer them to their primary care physician and they need to ask their doctor to refer them to a geneticist. You can first perform a Beighton Test which measures hypermobility (see Appendix D). A score of five or greater is positive for hypermobility and suggests that person should be referred to a geneticist who will determine whether or not the person has EDS. **Only a geneticist can confirm the diagnosis of Ehlers-Danlos Syndrome**, as there are many other disorders that can affect the body and cause hypermobility. Once a person is diagnosed by a geneticist with EDS, the geneticist will also determine the type of EDS. EDS affects many structures in the body and, therefore, the person with EDS needs to develop a team of healthcare professionals who will address the numerous problems that occur with this genetic disorder. As a physical therapist, you will be primarily addressing joint hypermobility and subluxations. You will be working with your patient two to three times a week for up to a year. Therefore, you will be a great resource for the other healthcare professionals if problems arise while they are under your care. Make sure the person with EDS is seeing the following healthcare professionals:

1. **Primary Care Physician:** This healthcare professional will coordinate all of the other healthcare professionals and evaluate all of the information from them. With this information, they will decide if the patient needs to be referred to additional healthcare providers in order to properly address specific health issues that arise. You should be in constant communication with your patient's primary care physician to keep them updated on any change of status with their patient when they are under your care.
2. **Pain doctor:** This doctor will help control pain and inflammation in order for your patient to strengthen more effectively as you attempt to stabilize their joints with manual therapy and this exercise protocol.
3. **Orthotist:** The protocol, which I developed, works on the joints of the person with EDS in a very specific order. Therefore, bracing joints, which you will not get to until later in the protocol, will help the patient to be in less pain while in physical therapy. You may also need to brace a joint that is too painful to exercise without additional support. Make sure the brace will allow the patient to perform all of the exercises while wearing it. The orthotist will work closely with you to develop customized braces for people with EDS to help support subluxations. The additional support of a custom designed brace can significantly help people with EDS to get through their daily routine with less pain. It should be noted that bracing a patient with EDS for a prolonged period of time can make that joint weaker due to disuse of muscles around that joint. Your job is to strengthen the patient's muscles sufficiently so the brace is no longer needed. Some joints may require bracing for certain activities throughout a patient's life, for example, bracing the wrist during computer work or bracing the knees while taking long walks. The person will be instructed to use the brace only during those certain activities. You and the orthotist can provide guidelines for brace usage.
4. **Cardiologist:** This healthcare professional will work on many issues dealing with the cardiovascular system including: POTS (postural orthostatic tachycardia syndrome), heart rate, blood pressure, heart contractility and aortic or abdominal aneurism. During the end phases of this protocol, a patient with EDS can work out as much

as ninety minutes a day. A cardiologist needs to make sure the patient is able to handle this amount of exercise before starting this protocol, especially if a patient is diagnosed by a geneticist with vascular EDS. Refer to EDNF website for more detailed information regarding vascular EDS.

5. **Neurosurgeon:** This healthcare professional can help evaluate for: tethered cord, Chiari malformation, syringomyelia and cranial instability. All of these conditions can decrease the ability of a patient with EDS to strengthen their joints, making it difficult for them to exercise.
6. **Gastroenterologist:** This healthcare professional will address many GI problems including leaky gut, gastroparesis and GERD. They may also refer the patient to a nutritionist who will help diagnose food allergies and develop diets.
7. **Endocrinologist:** This healthcare professional will evaluate for secondary conditions such as mast cell disorder and mitochondrial disorder.
8. **Pulmonologist:** This healthcare professional will assess for COPD (chronic obstructive pulmonary disease) and other breathing problems that may occur.
9. **Speech Therapist:** This healthcare professional can teach exercises to stabilize the throat while swallowing if issues arise and if you are unfamiliar with these exercises.

A team approach is essential in properly treating a person with EDS. The physical therapist and other healthcare professionals need to work closely with the patient's primary care physician to inform them about issues and secondary conditions that can be related to this disorder.

## Physiology Of The Person With EDS

### **FOR THE PHYSICAL THERAPIST:**

Ligaments are the primary stabilizers of all joints. The collagen in a ligament gives the ligaments its tensile strength. In the EDS population, the collagen in these ligaments is defective. Therefore, the tensile strength of all of the ligaments in this population is less

than normal. A ligament's primary job is to absorb external forces that are placed upon a joint during a certain activity. When the forces reach the plasticity phase on the stress/strain curve, the ligament will deform. Since the tensile strength of a ligament in the EDS population is less than normal, it will take a much smaller external force to reach the plasticity phase in these ligaments. Once a ligament is injured, it will heal with collagen, which is defective in this population. This will not allow the ligament to heal properly, causing a laxity in that ligament.

When a joint becomes hypermobile, the muscle around the joint will spasm in order to help stabilize the joint. If you remove this spasticity by performing manual techniques, the joint will become more hypermobile, causing more inflammation in the joint and pain. When a joint becomes painful, it will again increase the spasticity around the joint. Physiologically, a muscle that is in spasm, is weak due to both the lack of available actin-myosin cross bridges as well as the increase of lactic acid in the muscular system. So, if a person injures a joint and over stretches the ligaments, the muscles around the joint will go into spasm to help prevent the joint from subluxing. We need to strengthen the muscles around the joint before we take away the spasticity within the muscles. This is my rationale for not allowing any manual techniques to be performed on a joint that is not being simultaneously strengthened using this protocol.

## **The EDS Physical Therapy Evaluation**

### **FOR THE PHYSICAL THERAPIST:**

Evaluating a patient with EDS can be overwhelming due to the numerous problems that can occur with this complex disorder. My EDS evaluations are one and a half hours long. This gives me ample time to properly assess each patient's unique challenges and concerns. A problem list should be developed outlining each issue experienced by the patient. Remember, as a physical therapist, focus on the issues you are able to treat (musculoskeletal issues) and guide the patient to appropriate healthcare professionals for other issues (cardiac problems, gastrointestinal problems). The patient may also have non-EDS orthopedic problems such as bursitis, bulging disc and meniscal tears that can be addressed using traditional physical therapy interventions/modalities. You should

ask whether or not the patient has the following and notate this in a problem list: low back pain, mid back pain, rib pain, neck pain, shoulder pain (left or right), elbow pain (left or right), wrist pain (left or right), finger pain (left or right), hip pain or dislocation (left or right), knee pain (left or right), ankle or foot pain (left or right), dizziness, nausea, vomiting, bowel and/or bladder incontinence, GI pain, heart rate problems (measure this), blood pressure problems (measure this), breathing problems, COPD and any surgeries (especially fusions). Special considerations for this population include (See Appendix E for more information):

1. POTS (Postural Orthostatic Tachycardia Syndrome): This is a condition characterized by elevated heart rate when standing up. As a person's heart rate increases, their blood pressure can drop, causing syncope (fainting). Refer patients to a cardiologist if you suspect this. ([www.heartdisease.about.com](http://www.heartdisease.about.com)).
2. Tethered Cord: This is a neurological disorder that tightens the attachments of the spinal cord (filum terminale) which limits the movements of the spinal cord within the spinal column. This can occur with other conditions such as spina bifida, but is prevalent in the EDS population. People with tethered cord can have bowel and bladder problems as well as leg weakness. Refer patients to a neurosurgeon if you suspect this. ([www.ninds.nih.gov](http://www.ninds.nih.gov)).
3. Chiari Malformation: This is a condition in which part of the brain tissue extends down into the spinal canal. OA releases can cause increased dizziness and nausea on people with this condition. Refer patients to a neurosurgeon if you suspect this. ([www.mayoclinic.org](http://www.mayoclinic.org)).
4. Cranial Instability: The ligaments around C1 and C2 can be overstretched, causing severe headaches, nausea and vomiting as well as pain at the occiput. OA releases can cause increased dizziness and nausea on people with this condition. Refer patients to a neurosurgeon if you suspect this.
5. Vascular EDS: This is considered the most serious type of EDS due to the possibility of arterial or organ rupture. If a patient who has Vascular EDS presents with signs of chest or abdominal pain, it should be considered a trauma situation. Patient

should be sent immediately to the emergency room and checked using MRA, MRI or CT scan testing, not a chest x-ray. Spontaneous arterial ruptures are most likely to occur in people in their twenties and thirties, but can occur at any point in their life. Cerebral artery ruptures may also occur and present as altered mental status. If you have a patient with Vascular EDS, make sure to consult with their cardiologist before treating them.

Make sure the patient was diagnosed by a geneticist and notate the type of EDS they were diagnosed with. You will also need a list of other healthcare professionals who are involved in the patient's care. After this information has been gathered, I conduct a postural assessment and then a quick screen on range of motion and strength of all the joints. I will then perform a thorough low back and SIJ assessment because this is the region where I will begin my treatment. Next, I will explain to them why I start treatment at the SIJ and ask them if there are any joints other than the low back that they feel need to be braced to help them progress through this protocol with decreased pain. I usually have time to correct the SIJ and give them Level One Lumbar Stabilization exercises. This will enforce the importance of exercise and show them that this exercise protocol does not increase their pain. If you think the patient needs to be referred to another healthcare provider to address other issues, you need to write this in the evaluation that will be sent to the patient's primary care physician. You should not be overwhelmed with treating this population. When the Muldowney Exercise Protocol is followed and manual techniques are applied only to the areas that are being strengthened, the patient should feel better quickly. Good results are achievable.

## **How Does A Physical Therapist Treat People With EDS?**

### **FOR THE PHYSICAL THERAPIST:**

After the initial evaluation, you should have a global understanding of what the major issues are with your patient. Any identified issues that cannot be resolved with physical therapy need to be discussed with the primary care physician. This way, the primary care physician can refer the patient to the appropriate specialist. You will apply appropriate manual therapy techniques to the specific joints being strengthened in this exercise

protocol. Joints that are not being addressed at that time can either be braced or taped using McConnell taping and Mulligan taping techniques. Be careful of skin integrity issues and allergies when applying taping techniques to this population.

A person with EDS presents with increased hypermobility and possibly subluxations in multiple joints throughout their body. Be aware that a person with EDS can also have other orthopedic problems unrelated to EDS, which need to be addressed using traditional physical therapy interventions. Treating this population with manual therapy and exercise is the best way to decrease your patient's pain quickly. While treating this population, you need to be aware of the following: tethered cord, Chiari malformation, POTS, cranial instability, allergies to tape and latex, gastrointestinal issues, food and drug allergies and Vascular EDS. If the patient is unsure whether they have any of these conditions, ask the primary care physician to refer them to the appropriate healthcare professionals listed in this book. In the meantime, treat the patient as if they do have these conditions, taking all necessary precautions, for reasons listed below, until the conditions are ruled out by a specialist.

The following are special considerations when treating a patient with EDS:

1. **Cranial instability or Chiari malformation:** You should not perform OA releases on patients diagnosed with C1 instability or Chiari malformation because this technique can cause or increase dizziness and nausea.
2. **POTS (Postural Orthostatic Tachycardia Syndrome):** Be careful when the patient transfers from supine to sitting to standing, because they can become dizzy and lose consciousness. Twisting exercises may cause increased problems with patients diagnosed with this condition.
3. **Allergies to tape:** If a patient has allergies to tape, bracing may be the only option when additional stability is needed for a joint. Use of magnesium hydroxide on the skin prior to application of tape may help with patients who have allergies or sensitivities to the adhesive in tape.
4. **Gastrointestinal problems and food allergies:** Patients with these issues may have increased discomfort while performing core stability exercises that require

abdominal bracing. Food and drug allergies may cause increased inflammation throughout the body, which will make it more difficult to stabilize the joints. Contact a nutritionist if you suspect food allergies, or contact the patient's primary care physician if you suspect a drug allergy.

5. **Vascular EDS:** Contact the patient's cardiologist before treating this patient to discuss appropriate exercise tolerance. If there is any abdominal or chest pain or change in mental status, call the emergency room and have them checked for arterial rupture.

It is necessary for you to have between thirty minutes and one hour of one-on-one time with your patient each visit. My clinic works with this population for forty-five minutes one-on-one every session. Begin the Muldowney Exercise Protocol and begin treating the SIJ and lumbar spine during your first treatment session with the patient. In future physical therapy sessions, work on teaching the patient, caregiver or family member as many self-correction techniques as possible and work with patients to eliminate anything that may be hurting them at home while performing activities of daily living. Exercise is the most important component of the physical therapy treatment and should be approached in progressive levels that will be outlined in the following chapters. **Never perform a manual therapy technique unless you are strengthening that joint with this exercise protocol.** It is also important to note that stretching exercises should be avoided until the final level of this exercise protocol has been completed. When a joint is hypermobile, the body will cause the muscles around that joint to spasm. A patient with EDS relies on this spasticity to help stabilize the joint. If the spasticity is taken away before the muscles are strong, there will be increased motion and increased pain in that joint. Stretching and soft tissue mobilization can be used later when this exercise protocol has been completed, if tightness persists once proper strength has been restored to a joint. When a muscle is strengthened in this population, the use of timed exercise as opposed to repetition based exercise works well to build endurance and tone around a joint. It is suggested that a person with EDS should not ever lift more than ten pounds, to protect their joints from injury.

## Posture



### **FOR THE PHYSICAL THERAPIST:**

A patient's posture who has EDS will typically present with bilateral pronated feet, bilateral valgus knees and bilateral knee recurvatum. They will also often have a scoliotic curve usually caused by an upslip of the SIJ. They will commonly present with an increased lumbar lordosis, increased thoracic kyphosis, protracted scapulae, rounded shoulders and forward head. As physical therapists, we can teach patients to be aware of their posture, but because they are so weak, it is difficult for them to maintain proper postural alignment. Do not work on posture too much at the beginning, but rather wait until the patient begins the lower extremity progression so they will have enough strength to maintain proper postural alignment.

## **How The Muldowney Exercise Protocol Was Developed and Organized**

### **FOR THE PHYSICAL THERAPIST:**

The Muldowney Exercise Protocol was developed by me after I lectured at the 2013 EDNF Annual Conference. My lecture was on SIJ dysfunction in the EDS population. After my lecture, I decided to perform quick screens on many attendees who wanted me to evaluate them. This gave me the opportunity to assess a significant number of people with EDS in a relatively short period of time. I did this as a courtesy to the people attending the conference so they could find a physical therapist in their area to help them with their specific issues. While assessing these people, I realized quickly that they all presented similarly, meaning that if a joint was subluxed, it was usually subluxed the same way in every person. At that time, I tried to figure out how to fix these issues. Before the conference, I was under the assumption, like many others, that every patient with EDS was different. Once I realized that this was false, I could move ahead with this population and try to figure out how to help them, using specific muscle groups to stabilize problematic joints. As of 2015, I have had approximately fifty patients with EDS who either completed or are currently progressing through my exercise protocol and all of whom have improved. I understand that from a research point of view, this is a small number on which to base an entire protocol. Since I have had so much success with this exercise protocol, I wanted to share this information with patients and physical therapists as soon as possible, so they could have a tool to use to treat this disease. I will be beginning research on The Muldowney Exercise Protocol soon after this book is published. I have evaluated many patients with EDS all across the country in order to tell them that they need to find a physical therapist in their area to treat them and they tell me that there are none. Hopefully, this book can give you the tools you need to help give the EDS population living in your area a better quality of life.

This protocol is divided into two phases. Phase One focuses on strengthening joints throughout the body. In this phase, the body is divided into three exercise progressions: 1. Sacroiliac joint and lumbar spine, 2. Mid back, neck and upper extremities and 3. Lower extremities. Each section is given its own exercise progression. This distinction helps to

make it easier for you to focus on one region of the body while the patient with EDS is simultaneously strengthening that area with this exercise protocol. Once all levels of Phase One have been completed, the patient should be able to perform most activities of daily living without increased pain or subluxations. Once Phase One has been completed, Phase Two will begin. Phase Two is divided into three exercise progressions: 1. Twisting Progression, 2. Dynamic Balance Progression and 3. Throwing Progression. Each progression will have its own exercises and once the top level has been reached, it will be added to the final home exercise program. Your role as the physical therapist is to continuously evaluate and safely guide patients appropriately through this exercise protocol.

## Rules Of The Muldowney Exercise Protocol

### **FOR THE PHYSICAL THERAPIST:**

I am providing both you and your patients a guide for how to exercise a person who has EDS. My number one priority with this protocol is safety for the patient while you both guide them through this protocol as well as perform manual therapy to help decrease pain while exercising. Please keep in mind that manual therapy helps for only a short time. This exercise protocol is designed to stabilize hypermobile joints and is the best way to help permanently decrease joint pain. Joints will continue to be problematic (painful or subluxing) until the patient completes the end of Phase One.

I have developed rules to assist both you and your patient as they progress through this exercise protocol.

1. **Manual therapy techniques should never be performed on a part of the body that is not being strengthened.** Muscle energy, myofascial release and craniosacral therapy techniques all decrease muscle spasms to the area being treated. As mentioned earlier, spasticity is the only thing holding the patient's bones in alignment. Therefore, taking away this spasticity can greatly reduce a joint's ability to hold their alignment when forces act upon them. It is critical that strength and endurance of the muscles around each joint be developed so that the muscles will be able to support the joint without spasticity. If manual therapy is performed on

a patient before proper strengthening is initiated, the joints will become aligned, then immediately sublux, causing more injury, inflammation and pain to that joint. Bracing can be used to sustain a joint that is problematic and has not yet been strengthened in the protocol.

2. **The order of exercises and the order in which joints are addressed should be followed.** This exercise protocol is intended to be followed in the exact order in which it is explained. You should not deviate from this order and start to treat another joint or region. Physical therapy treatment should always begin with the sacroiliac joint whether or not it is painful. This is because the sacroiliac joint is considered to be the keystone to the body. If this joint is out of alignment, it affects all of the vertebrae up to the neck, as well as the hip, knee and ankle joints. Sometimes it is difficult for patients to go through this exercise protocol in an area that is not painful, while you are seemingly not addressing an area that hurts. So, explaining the progression of this protocol and how it is designed is imperative so that patients understand how the protocol works. They need to understand that it is necessary to treat the alignment of the SIJ first before focusing on specific areas of pain. Bracing a joint that has increased pain that is not yet being addressed in the early stages of the protocol could be beneficial to allow patients to have less pain during activities of daily living.
3. **Progression of this protocol must be based on patient tolerance.** In physical therapy, a patient's exercise routine is usually progressed either daily or weekly. This does not hold true for the patient with EDS. All patients with EDS have variable levels of exercise tolerance. Waiting until a patient with EDS completes all exercises in a given level before progressing them to the next level, is the only way to be certain not to injure this population. Allowing a patient to progress with their home exercises at their own pace will give them back some control of their situation and actually decrease the time spent progressing through this protocol. Typically, when starting a new level, the group of exercises in that level will be performed for one and a half minutes under the supervision of a physical therapist. Once the physical therapist has determined that the patient has performed each exercise in the new level correctly and safely with proper form, the exercises can

be added to the patient's home exercise program. The patient will be allowed to add ten seconds per day for each exercise until all the exercises in the level are performed for three minutes. Once the patient has reached three minutes for each exercise, they will remain at this time until they see you for their next scheduled appointment. At this next appointment, you will progress the patient to the next level in this protocol, beginning at a minute and a half. If the patient is complaining of pain, they should continue exercising at whatever level they have reached in the protocol, but not progress any further through the protocol until they are able to complete the exercise comfortably. If a patient is at three minutes for all exercises in a level except for one, you cannot progress the level. This will ensure muscle balance. Remember, the rule for progressing an exercise is safety first. Setbacks are common in patients with EDS and will be discussed in detail later in this book. If a patient is having difficulty progressing the exercises, they should discuss potential triggers or modifying exercises with you. Bracing or taping a joint while exercising may help this population to progress quicker through this protocol.

4. **Identifying and eliminating triggers at home will allow a patient with EDS to perform activities of daily living with less pain.** A trigger is defined by me as something a patient is doing at home that is hurting their joints, but they are unaware of this. It could be as simple as sleeping in a poor posture or working at a poorly set up work station. It is important to keep in mind that the ligamentous structures in this population are weaker, and therefore, cannot absorb large external forces. As long as the forces placed on the joint are less than the combined strength of the ligaments and muscles around the joint, the joint will not sublux. Therefore, identifying and eliminating triggers will decrease the occurrence of subluxations of a patient's joint while they are at home. Subluxations of a joint will cause increased pain and inflammation in that joint, causing a setback in the patient's progress.
5. **Dealing with setbacks.** A patient with EDS will have many setbacks while progressing through this exercise protocol. Life always gets in the way. Also, hormonal changes during menses can increase hypermobility and contribute to setbacks in female patients. Setbacks do not go away with this population and usually get bad quickly. When a patient with EDS has a setback, it should be addressed immediately.

Addressing setbacks sooner than later will make it easier for both the patient and the physical therapist down the road. After a setback, the patient should drop down one exercise level for two weeks, while slowly progressing back up to their original exercise level they were at before the setback. For example, a patient who is at Level Two lumbar stabilization and has a setback will have to go back down to Level One lumbar stabilization at one and a half minutes. Once they perform the Level One lumbar stabilization exercises for one and a half minutes, they will progress ten seconds a day until they have reached three minutes of Level One exercises. At that point, they can begin Level Two lumbar stabilization again at one and a half minutes, progressing ten seconds a day until they reach the same time in Level Two that they were at before the setback occurred. After the two weeks, progression of the protocol continues as normal. The use of anti-inflammatory and pain reducing drugs can help to allow the patient to perform the exercises during a setback with less pain. Contact the primary care physician or pain doctor to obtain the proper medication during a setback. You can perform manual therapy techniques as well as provide modalities such as icing to help decrease the inflammation in the joint during a setback. Do not ice or use electrical stimulation on any joint that has CRPS. Setbacks are normal in this population, but still might be frustrating to the patient. Assuring the patient that this is normal and encouraging the patient to continue progressing through the exercise protocol is necessary.

6. **Pay close attention to the final level of exercise in each region of the body.** In my clinic, we push our patients with EDS as hard as we can to get them to the highest functional level possible. Some patients with EDS may not be able to achieve the final level of the protocol in a specific joint because the ligamentous structures are too lax. This is okay. The second to last progression will become their final exercise progression for that joint. As long as the joint is stable, it is not as important that they achieve the final level of the progression. If a patient cannot achieve the final level of a progression and the joint continues to be a problem, then other options should be considered including: taping, bracing, Prolotherapy or surgery as a last resort. Also consider systemic issues if not addressed already by the other healthcare providers.

7. **Do not get frustrated.** Some patients may take a very long time to get through this exercise protocol. Completion time will vary greatly. Some patients may progress quickly, while others may remain on a specific level for weeks. Estimate six to twelve months to get through the entire protocol, progressing as the patient's body can tolerate. If a patient becomes stuck on a specific level for a period of time, taping or bracing a joint in place so that they can perform the exercise with less pain may help a patient to progress through that level quicker. At the higher levels, having a person perform their home exercise program every other day will allow the body to rest, while still facilitating progression through the protocol. Remember, it is important to have patients perform exercises after you have performed manual therapy techniques on the joint because this is when the joint is aligned, and the patient should experience the least amount of pain. Most importantly, you need to find out what rate of progression and what type of taping or bracing works best for each patient and they need to adjust accordingly as the patient progresses through the protocol.
8. **Work closely with the patient's primary care physician.** You will be working with a patient with EDS and will be observing them two to three times a week for up to a year. You will be a great resource for the patient's primary care physician as you can observe and report changes with the patient, both positive and negative. You should contact the primary care physician immediately regarding a significant setback or a new issue that arises so you can work together to help the patient solve the problem. It is always better to take care of a problem immediately before it becomes a bigger problem.
9. **Do not try to treat everything at once.** As a manual therapist, you want to help patients feel better right away and decrease their pain level. Your intuitive approach would normally be to perform manual therapy techniques to the joint that hurts in order to help the patient feel better. This seemingly practical approach does not work with a patient who has multiple joints that are subluxed and hurting. If you attempt to fix all the joints each session, the patient will have no time to exercise and the situation can become counterproductive and quite overwhelming. I explain to my patients with EDS that it is better to give a complete treatment for one body

part each visit, as opposed to giving a ten percent treatment to many body parts. Remember that manual therapy is an adjunct to exercise. The most important treatment for problems associated with EDS is not manual therapy, but exercise. You perform manual therapy only to allow the patient to exercise with proper alignment and ideally, less pain. Until a patient is strong enough to hold the joints in alignment, they will always have pain, regardless of how much manual therapy is performed on the joints. Old injuries can take many weeks to improve in physical therapy. These injuries need to be addressed using this protocol. However, if a patient who is using the protocol suddenly injures a body part, then it is important to evaluate and treat that body part immediately so it does not become a bigger problem.

**10. Address new issues immediately.** When a patient complains of something new that has happened to their body, you will need to evaluate it immediately and contact the correct healthcare professional (usually the primary care physician). In this population, new issues do not just go away, but have the potential to worsen quickly. By immediately addressing a new issue, you will be able to hopefully manage the pain sooner and minimize any delay in progression of the exercise protocol. This may sound confusing because, I said earlier not to jump around treating many issues at once. For example, in the evaluation you will have a problem list for the patient. These are old injuries that will take time to get stronger. You should not skip around the protocol to address these injuries. Conversely, if a patient develops a new injury while performing activities of daily living, addressing this new issue immediately will help the patient maintain progress through the exercise protocol. Taking two weeks to address a new issue immediately will save you months down the road when you get to that injured joint in the protocol.

**11. Do not let your patient quit until they reach the end of the Muldowney Exercise Protocol.** Six months to a year is a long time. There will be ups and downs while completing this protocol. Patients have moments where they might feel like they will never get better or reach the next level. Stay positive for them; they will get there. The following is a true story of my patient with EDS who will be called “Sue.” Sue came to my clinic like many patients with EDS, after seeing five other

physical therapists, all claiming to have expertise in EDS. She convinced herself that she could not exercise because all of the exercises that the other physical therapists had given her hurt too much. She convinced herself that she was a special case and because of her condition, exercise could not help her. This could not be further from the truth. After much discussion, she agreed to give my clinic a try. She began to feel better in her low back rather quickly, but her mid back was still very bad and a major source of pain. Every day she complained she had increased mid back pain while performing the low back protocol. I encouraged her to continue with the low back protocol and told her that we would get to the mid back protocol next. Finally she completed the low back protocol and we began manual therapy and exercises of the mid back, neck, ribs and shoulders. Manual therapy gave her instant relief, but she could not hold the alignment for very long. This made sense because she was very weak in this area. When we reviewed her activities of daily living, we realized she was driving one hour each way to see me two times per week. We got her a mid back brace for driving only, which helped improve her pain. She progressed very slowly through the neck, mid back, ribs, neck and upper extremity section of the protocol because of her weak muscles in that area. About four months into the protocol, her mid back was still in pain, she had not reached the top level of exercises in this section due to her weakness, and she decided she had enough. One day, she sat me down and said she wanted to quit physical therapy because it was not working for her mid back. I explained to her that she was not at the top level yet, and until she reached that level, this area would be problematic. She agreed to tough it out. After about another three months of going through the protocol, she reached the top level of exercise and the mid back pain subsided. She was discharged from my physical therapy facility about eleven months after she began with me, with a zero to one out of ten pain level in her mid-back and no pain in the rest of her body. At discharge, I told her that if she had not had the faith in herself to achieve the goals, she would still have been in eight to nine out of ten pain and accepting that was her life. I tell this story because, as a physical therapist, it is important to understand how hard it is to go through this protocol as a person who is in pain all the time. There will be times the patient will be frustrated and want to

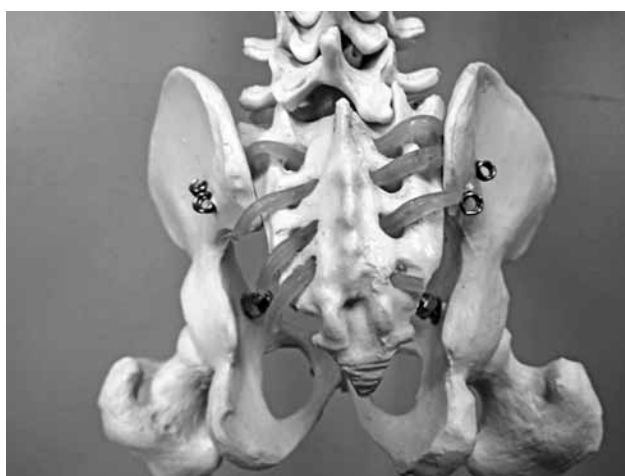
quit. If the patient has faith in you and this protocol, they will be able to live a higher quality of life with much less pain within the next year.

Hopefully, after reading this section, you have a better understanding of what to do with your patients who have EDS. You are now ready to have them begin the first level of the SIJ and Lumbar Spine Progression. Please read the paragraph before each exercise level marked, “For The Person With EDS” and “For The Physical Therapist.” This will give you some suggestions about what you should be addressing as a manual physical therapist while the patient is exercising in each level. Good luck with this protocol. Remember, this is just a guide and you will need to use your clinical expertise in order to effectively treat each patient with EDS.

## Section Two

# Sacroiliac Joint (SIJ) and Lumbar Spine Exercise Progression

*"It is what it is, but it becomes what you make of it."* Coach Pat Summitt



*The sacroiliac joint (SIJ) is comprised of a middle upside down triangle bone called the sacrum and two large bones on either side called the ilia. The two joints between the sacrum and each ilia are the sacroiliac joints.*

## Why This Protocol Begins At The Sacroiliac Joint

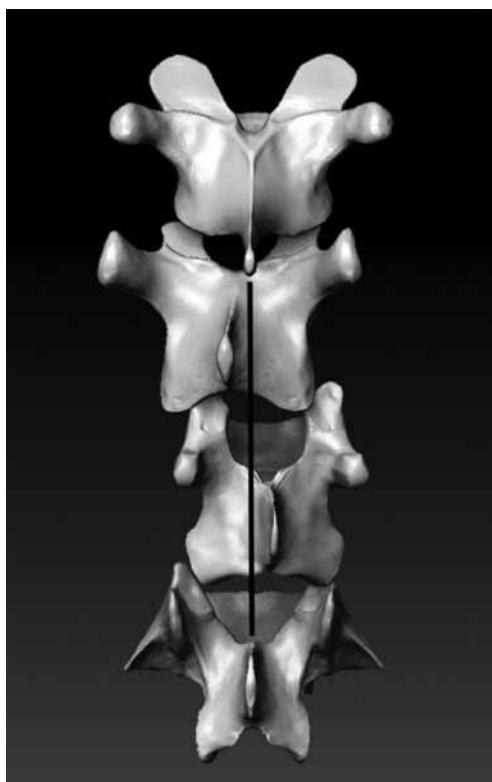
### **FOR THE PERSON WITH EDS:**

The two sacroiliac joints (SIJ) are the joints in your back where your sacrum meets each of your ilia (see picture). You have a right and a left SIJ, which can be located by finding the dimples of your buttocks. If pressing on the dimples of your buttocks causes pain, you may have an SIJ dysfunction. These dysfunctions can lead to problems with joints above the SIJ (low back, mid back and neck) and the joints below the SIJ (hips, knees, ankles and feet). Aligning the SIJ first will help the physical therapist treat the joints above and below

it more effectively. The ilia are considered the top part of the leg. A problem with the ilia may cause subluxations and pain in the legs and feet because you are walking improperly when you have a dysfunction with either one of these bones. The sacrum is considered the bottom part of the spine. Dysfunction with the sacrum can also lead to mid back and neck pain due to poor spinal alignment. Activities such as running, jumping, hopping, sitting in a slumped position, bending and twisting can all cause an SIJ dysfunction. Try to avoid these activities while advancing through this exercise progression.

In an individual with an SIJ dysfunction, the knees can become “knock-kneed” and the feet can become flat (pronated). As this posture worsens, it can lead to a number of issues including hip bursitis and/or subluxations, meniscal tears and plantar fasciitis. Malalignment of the SIJ can also cause rotations of the bones that make up the spine known as the vertebra or vertebral bodies. One of the major causes of pain in the spine is something I refer to as a “double rotation.” This occurs when one vertebra is turned one way (right or left) and the vertebra above is rotated in the opposite direction (see Figure 1). Most of the pain in the spine occurs at the site of double rotations in the EDS population. These double rotations can appear multiple times throughout their spine. No matter how many double rotations are present, they cannot be addressed until the SIJ

is aligned. This is why the SIJ is addressed first in this exercise progression.



**Figure 1. Picture of T9 To T12, Showing A Double Rotation Of T10 and T11 (The Middle Two Vertebrae).**

*A double rotation is depicted by the middle two bones. The part of the bone in the center of the vertebra is called the spinous process. Notice the spinous process of the second vertebra is to the left of the midline (represented by the black vertical line), while the spinous process of the third vertebra is to the right of the midline. This is how a double rotation will present in your spine.*

### **FOR THE PHYSICAL THERAPIST:**

It can be overwhelming to a physical therapist when a new patient with multiple subluxations enters the clinic stating that everything hurts. Where do you begin treating a patient like this? Begin at the sacroiliac joint (SIJ). The SIJ is considered the keystone of the body because any dysfunction here can affect other joints up and down the kinetic chain. Both ilia are considered the top of the legs, whereas the sacrum is considered the bottom part of the spine. Dysfunctions of the ilium, such as upslips and posterior rotations, will cause the involved leg to appear shorter. An anteriorly rotated innominate can cause the involved leg to appear longer. When a person with EDS ambulates with an apparent leg length discrepancy, it will cause increased stress on the ligaments in the lower extremities and can cause increased subluxations in these joints over time. This is the reason why a patient with EDS may say their low back hurts, but then over time for no reason, they say their knee and hip hurt. This knee and hip pain is the result of increased stress placed on these structures due to an abnormal gait pattern produced by the “functional” leg length discrepancy. It is extremely important to recognize the difference between a functional leg length discrepancy that can be corrected with manual therapy, and an anatomic leg length discrepancy that will require orthotic intervention. Any dysfunction in the sacrum will place increased stress on the ligamentous structures up the spine including any vertebrae up to C1. This may cause compensatory ERS/FRS dysfunctions throughout the lumbar, thoracic and cervical spine. Once you stabilize the SIJ using muscle energy and lumbar stabilization exercises, it will normalize the patient’s gait pattern and posture to allow treatment of other joints up and down the kinetic chain.

## **Things To Consider While Going Through The SIJ And Lumbar Spine Exercise Progression**

### **FOR THE PERSON WITH EDS:**

If diagnosed with a bulging disc or spondylolisthesis, inform the physical therapist because they will need to make modifications to the exercises. Purchase a physioball from the physical therapy facility you are working with and have them blow it up with a compressor to the proper height for you. Buy all bands and tubing from the physical therapy facility because the

tension is universal among our profession and other companies outside of physical therapy do not observe the same tension standards. Purchase a pair of one pound, two pound, three pound, four pound and five pound dumbbell weights. If your hands and wrists are painful, you can purchase wrist weights instead of dumbbells. You and the physical therapist will be working only on the low back area for the first six to eight weeks. Tell your physical therapist if you need to brace other joints that have increased pain until it is time to strengthen that joint in the protocol. Discuss with a pain doctor or primary care physician whether or not it is appropriate for you to take an anti-inflammatory because the exercises in the beginning may cause inflammation in the joints before you stabilize the SIJ. Progress only ten seconds a day and do not rush the exercise progression, and you will be in less pain. The protocol is split into three levels of mat and three levels of ball exercises. Once you progress to the next level of the mat exercises, you do not need to perform the level below. The same is true for the ball exercises. You will be performing mat and ball exercises together. You may need to return to a previous level of ball or mat exercises again if you have a setback. (See #5 in “Rules of The Muldowney Exercise Protocol”). Before you perform the exercises, you should first complete self-correction techniques (shown to you by your physical therapist) to fix your SIJ alignment. If you cannot perform the self-corrections, then just do the exercises. No real change happens until you reach Level Three Mat and Level Three Ball exercises, so be persistent with the exercises until you get to these levels. Once the SIJ becomes stable, the mid back and neck may hurt more. If this occurs, you can perform Level One neck, mid back and upper extremity exercise progression. Always work closely with your physical therapist as a team to address any issues that may arise and to facilitate progress through the exercise protocol.

## **What SIJ Dysfunctions Occur In This Population And How To Treat Them**

### **FOR THE PHYSICAL THERAPIST:**

A person with EDS will have multiple dysfunctions of the SIJ and spine. Systematically addressing each issue with manual therapy techniques, especially muscle energy techniques will prevent you from becoming overwhelmed. There are four special conditions to consider when treating this population.

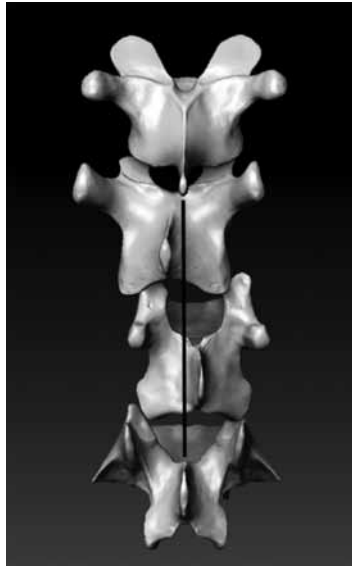
First, it is important to know that most patients with EDS will present with an upslip. This is due to a dysfunction primarily of the interosseous ligament in the SIJ. Usually a patient with EDS will have an upslip on both sides, which can only be observed after an upslip is corrected on one side first. Therefore, if you observe an upslip on the right side and after you correct it, recheck the ilium for an upslip on the left side. If the patient has a left upslip, use appropriate muscle energy techniques to correct it. The traditional technique used to correct an upslip is long axis distraction of the leg at the ankle. Using this technique would place undue stress on the patient's knees and hips. Instead of performing distraction of the leg, push the ilium inferiorly (at the iliac crest), holding for two minutes with the patient in the supine hooklying position. This will correct the upslip without placing stress on the leg. You can teach a family member to perform this technique at home for the patient. A patient cannot perform this on themselves, because it would stress their wrist and arm.

Second, there maybe an anterior rotated innominate which can cause increased lumbar lordosis, and may allow for further narrowing of the foramen as well as facet joint hypertrophy over time. It can also cause increased knee recurvatum, leading to increased stress on the structures of the knee, most prominently the ACL and anterior portion of the menisci.

Third, the sacrum is usually extended (counter-nutated) on one side and flexed (nutated) on the opposite side. Using proper muscle energy techniques to both sides will be necessary to fully correct the sacral torsion. Pay close attention to the hips, knees and ankles of the patient so you do not injure them when correcting the sacrum using muscle energy techniques.

Fourth, the lumbar spine will have what I coined a "double rotation." This means a vertebra has a FRS/ERS to one side and the vertebra above it will have a FRS/ERS to the opposite side (see Figure 3). The part of the spine where double rotations occur is where the majority of pain occurs in the spine of a person with EDS. Double rotations can occur throughout the lumbar, thoracic and cervical spine. Identifying these double rotations and using muscle energy techniques or indirect techniques to correct them will decrease pain throughout the spine. All other SIJ and lumbar spine dysfunctions should be evaluated and addressed with appropriate muscle energy techniques.

**Figure 3. Picture Of T9 To T12, Showing A Double Rotation Of T10 And T11**



If a patient has a bulging disc, a Mackenzie Protocol may need to be initiated before beginning the Muldowney Exercise Protocol. If a patient has a spondylolisthesis, limit any low back hyperextension while patient is performing any of the exercises in this protocol. A physical therapist who is confident with muscle energy techniques should be able to assess all of the SIJ dysfunctions associated with this disorder. There are some considerations a physical therapist needs to keep in mind when progressing a patient with EDS through the SIJ and lumbar spine exercise progression. These include:

1. Always recheck the ilium after correcting and upslip. Most patients with EDS have a double upslip (upslip on both sides). This is caused by jumping, running, falling, bending or twisting in this population. Double upslips do not usually occur in the non-EDS population, but may occur frequently in patients with EDS. The only way to assess a double upslip is to correct the upslip you see first using muscle energy and then reassess the ilia to evaluate an upslip on the opposite side. The normal muscle energy for this dysfunction is pulling the leg. **DO NOT PULL THE LEG OF A PERSON WITH EDS!** This can damage their knees and ankles. Instead, push the iliac crest inferiorly and hold for two minutes. Repeat this on the other side if a patient has a double upslip.

2. Pelvic rotations, in-flares, out-flares and pubic shear all present the same in patients with EDS and patients without EDS, and should be treated using traditional muscle energy techniques.
3. Always recheck the sacrum after correcting the first dysfunction you observe. Sacral dysfunctions usually occur on both sides. Usually the sacrum is stuck in nutation on one side and counter-nutation on the opposite side. Proper assessment of both sides of the sacrum and appropriate muscle energy techniques need to be performed to both sides of the sacrum. Remember to protect the hips, knees and ankles of the patient when correcting all sacral dysfunctions.
4. Teach patients or caregivers within the first four visits to self-correct all SIJ dysfunctions that they present with. Caregivers can be taught traditional muscle energy techniques.
5. Call an orthotist who can help by making custom braces for other painful joints that are not yet being addressed with the SIJ and Lumbar Stabilization Exercise Progression.
6. Identify and eliminate as many triggers as possible. Discharge all other exercises except Muldowney Exercise Protocol exercises. Wean SIJ brace usage once a patient has completed Level Three Mat and Level Two Ball exercises. Manual therapy can be performed on the SIJ and L5-T12 each visit once patient begins Level One Mat exercises. Myofascial release can be performed to the quadratus lumborum, piriformis and psoas muscle groups once Level One Mat exercises have begun. However, no stretches should be given at this point to the patients.
7. Patients with EDS whose hips sublux will progress through the protocol at a slower rate. Wearing an SIJ belt around the hips while performing painful exercises may help with hip pain.
8. I have found that correcting the spine of patients who have EDS works best in the supine position using indirect techniques, but the physical therapist can determine the appropriate positioning for them and their patients.

## **SIJ And Lumbar Spine Exercise Progression**

### **FOR THE PERSON WITH EDS AND THE PHYSICAL THERAPIST:**

This progression consists of three levels of mat exercises as well as three levels of exercises on a physioball. The mat exercises are intended to stabilize the ilia, while the ball exercises are intended to stabilize the sacrum and L5-T12. If a patient cannot perform Level One Mat exercises due to increased pain, then they must begin on Level 0.5 Lumbar Stabilization. Once the patient has completed Level 0.5 Lumbar Stabilization, they can progress to Level One Mat exercises. In order to provide muscle symmetry, all exercises in a particular level need to be performed for three minutes until a patient can progress to the next level. Mat and ball exercises can be performed at the same time. The exercise progression will be as follows:

1. Begin with Level One Mat exercises. Once completed, progress to Level Two Mat exercises.
2. Once Level Two Mat exercises have begun, Level One Ball exercises will be introduced.
3. Once Level Two Mat exercises have been completed, Level Three Mat exercises will be introduced.
4. Once Level One Ball exercises have been completed, Level Two Ball exercises will be introduced.
5. Once Level Two Ball exercises have been completed, Level Three Ball exercises will be introduced along with Level One Neck, Mid Back And Upper Extremity exercises.
6. Once Level Three Mat and Ball exercises have been completed, they will be added to the patient's final home exercise program and performed only on Mondays and Thursdays.

**All exercises in this progression are listed in Appendix A.**

## Level 0.5 Mat Exercises

### **FOR THE PHYSICAL THERAPIST:**

This level of exercise consists of supine abdominal bracing and supine glut sets. Perform this level only if a patient's SIJ or hip is too painful to allow lower extremity movement. Otherwise, always begin with Level One Mat exercises. While a patient is performing this level, the physical therapist should provide muscle energy to the SIJ only. Also, have a patient wear an SIJ belt, especially while driving or riding in a car. Teach the patient self-correction techniques as soon as possible.

## 1. SUPINE ABDOMINAL BRACING



### **POSITION:**

-Lie on your back with knees bent and feet hip-width apart on the mat. Perform pelvic neutral with abdominal bracing, holding for ten seconds and relaxing for one second. Repeat this process for one and a half minutes.

-Pelvic Neutral With Abdominal Bracing: This is defined as a range of motion somewhere between the low back being fully arched and fully flattened in which the position that the low back is in does not hurt. This position is different for every person. Find pelvic neutral, then take your hands and place them on the front part of your hips. Find the two bumps on your pelvis (ASIS) that your physical therapist will teach you to find. From the bump, move your hands one to two inches inward toward the midline (belly button). Press your hands into your stomach and say the words, “ha, ha, ha.” The muscle contraction you feel under your hands is your transverse abdominus. Now, pull your belly button in while performing a Kegel exercise (tighten as if you are attempting to hold your stream of urine). You will feel the same muscle contraction as when you said, “ha, ha, ha.” If you feel this, you have achieved pelvic neutral with abdominal bracing. Hold pelvic neutral for ten seconds, then rest for one second. Repeat this process for one and a half minutes.

**PROGRESSION:**

-Begin this exercise at one and a half minutes and add ten seconds each day until you reach three minutes. Once you reach three minutes for this exercise, you are ready for Level One Mat exercises.

**YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:**

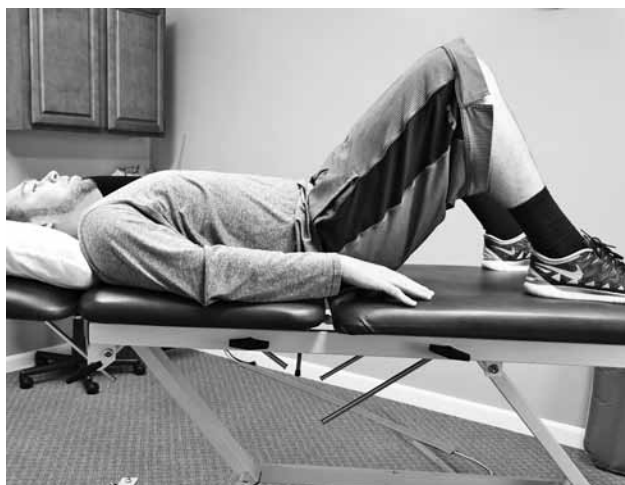
-Transverse abdominus (lower stomach)

**FOR THE PHYSICAL THERAPIST:**

- A pillow may or may not be used for this exercise, depending upon the pain level in the neck region when performing this exercise.

-Make sure the patient's knees and hips are in neutral (not rotated) to avoid hip, knee or ankle pain.

## 2. SUPINE GLUT SETS



### **POSITION:**

-Lie on your back with knees bent and feet hip-width apart on the mat. Squeeze and tighten your buttocks muscles. Hold for ten seconds and relax for one second. Repeat this process for one and a half minutes.

### **PROGRESSION:**

-Begin this exercise at one and a half minutes and add ten seconds each day until you reach three minutes. Once you reach three minutes for this exercise, you are ready for Level One Mat exercises.

### **YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:**

-Gluteus maximus (buttocks)

### **FOR THE PHYSICAL THERAPIST:**

- A pillow may or may not be used for this exercise, depending upon the pain level in the neck region when performing this exercise.

-Make sure the patient's knees and hips are in neutral (not rotated) to avoid hip, knee or ankle pain.

## Level One Mat Exercise

### **FOR THE PHYSICAL THERAPIST AND THE PERSON WITH EDS:**

This exercise level will be performed first in the Muldowney Exercise Protocol for the majority of patients with EDS, unless the patients need to start at level 0.5 because of SIJ or hip pain as explained previously. Patients who have bulging discs may need to perform a MacKenzie Protocol of exercises for two weeks before beginning Level One Mat exercises. Patients with bulging discs will also need to have an extension bias when performing all of the exercises in the SIJ and lumbar spine exercise progression. If patients began this protocol at Level 0.5, then Level One Mat exercise will be their second level of exercises they are performing. During this exercise level, the physical therapist should perform muscle energy and manual therapy techniques to the SIJ as well as to the spine at the levels of L5 to T12. Self-corrections need to be taught to the patient as soon as possible. You can also teach a family member or caregiver muscle energy techniques for your patient's specific problems. Myofascial release can be performed on the quadratus lumborum, piriformis and psoas muscle groups. No stretches should be given to the patients during this exercise level. Patients need to eliminate all other exercises and need to concentrate on stabilizing the SIJ before cardiovascular exercises can be added again. Running and elliptical machines produce increased stress on the SIJ and should be avoided in the EDS population. Contact an orthotist for bracing of any other joint that is painful and that is not being strengthened yet in this exercise progression. If the patient has an SIJ belt, they may continue to use it during activities of daily living while progressing through this exercise level. Do not have the patient exercise while wearing the SIJ belt unless they are in too much pain during the exercise without the SIJ belt. Level One Mat exercises consists of: bridges, supine marches, prone hip extension, ball squeezes and clam with yellow tubing. All five exercises need to be performed for three minutes before progressing to Level Two Mat exercises. Tubing should measure between nine and ten inches in length after being tied for consistency.

## 1. BRIDGING



### **POSITION:**

-Lie on your back with knees bent and feet hip-width apart on the mat. Then, squeeze your buttocks muscles, while lifting your buttocks off mat and hold the pelvis steady up off the mat for five seconds. Then bring buttocks back down onto mat and relax for one second. Repeat this process for one and a half minutes.

### **PROGRESSION:**

-Begin this exercise at one and a half minutes and add ten seconds each day until you reach three minutes. Once you reach three minutes for this exercise, you are ready for Level Two Mat exercises.

### **YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:**

-Gluteus maximus (buttocks) and hamstrings (back of legs).

### **FOR THE PHYSICAL THERAPIST:**

- Make sure the patient's hips do not externally rotate.

-If hamstrings cramp, have patient squeeze buttocks first, then lift buttocks off of mat. If hamstrings continue to cramp, have the patient perform glut sets for one and a half minutes adding ten seconds per day until they reach three minutes (see Level 0.5 mat for exercise description). Then, have them perform bridging.

- Remove pillow from under the head if neck hurts while patient lifts buttocks off of mat.
- Hands can be by their side for this exercise to assist with trunk stability while buttocks are being lifted.

## 2. SUPINE MARCHES



### **POSITION:**

-Lie on your back with knees bent and feet hip-width apart on the mat. Tighten your stomach and perform pelvic neutral.

-Pelvic Neutral With Abdominal Bracing: This is defined as a range of motion somewhere between the low back being fully arched and fully flattened in which the position that the low back is in does not hurt. This position is different for every person. Find pelvic neutral, then take your hands and place them on the front part of your hips. Find the two bumps on your hip (ASIS) that your physical therapist will teach you to find. From the bump, move your hands one to two inches inward toward the midline (belly button). Press your hands into your stomach and say the words, “ha, ha, ha.” The muscle contraction you feel under your hands is your transverse abdominus. Now, pull your belly button in while performing a Kegel exercise (tighten as if you are attempting to hold your stream of urine). You will feel the same muscle contraction as when you said, “ha, ha, ha.” If you feel this, you have achieved pelvic neutral with abdominal bracing.

-While performing pelvic neutral with abdominal bracing, lift one foot up one to two inches off the mat and hold for five seconds. Then return the foot to the mat and switch to the opposite foot, lifting it one to two inches off the mat, holding for five seconds and returning the foot to the mat.

-Repeat this process for one and a half minutes, while maintaining pelvic neutral with

abdominal bracing throughout the entire exercise (do not relax abdominal bracing when switching legs).

**PROGRESSION:**

-Begin this exercise at one and a half minutes and add ten seconds each day until you reach three minutes. Once you reach three minutes for this exercise, you are ready for Level Two Mat exercises.

**YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:**

-Transverse abdominus (stomach) and hip flexors (front of thighs)

**FOR THE PHYSICAL THERAPIST:**

-Patient should feel a tightening underneath the stomach muscles while performing this exercise. If tightening is not felt during this exercise, then the patient is not in performing abdominal bracing.

-If the patient is unable to perform the exercise due to increased low back pain, the patient should perform supine abdominal bracing as discussed in Level 0.5 mat exercises for one and a half minutes and progress ten seconds a day until the patient reaches a total of three minutes. Then, supine marches can begin.

-Patient should keep hips in neutral to avoid knee pain.

-The pillow should be removed from under head if there is increased neck pain while performing this exercise.

-A towel roll can be placed under the low back during this exercise to increase extension bias for patients with bulging discs.

-Patients may contract neck muscles inadvertently if their abdominals are weak. If this occurs, they should perform Level 0.5 mat exercises for one and a half minutes and progress ten seconds a day until the patient reaches a total of three minutes. Then, supine marches can begin.

## 2A. ALTERNATE POSITION FOR SUPINE MARCHES HEEL UPS



-Patients with hip subluxations may have increased hip pain when lifting the leg one to two inches off the mat. In this case, the patient will perform pelvic neutral with abdominal bracing and then they will go up on their tip toes (heel ups) only and hold for five seconds, then switch going up on their tip toes on the opposite leg. Begin this exercise at one and a half minutes, adding ten seconds per day until reaching three minutes. Once a person is able to progress this exercise to three minutes, they should be able to perform supine marches at one and a half minutes.

## 2B. ALTERNATE POSITION FOR SUPINE MARCHES TOE UPS



This position is used if a patient has pain in the ankle when performing alternate position 2a (Heel Ups). Patients with hip subluxations may have increased hip pain when lifting the leg one to two inches off the mat. In this case, the patient will perform pelvic neutral with abdominal bracing and then will go up on their heels (toe ups) only and hold for five seconds, then switch going up on their heels on the opposite leg. Begin this exercise at one and a half minutes, adding ten seconds per day until reaching three minutes. Once a person is able to progress this exercise to three minutes, they should be able to perform supine marches at one and a half minutes.

### 3. PRONE HIP EXTENSION



#### **POSITION:**

- Lie on your stomach with a pillow underneath your hips, which prevents your low back from arching excessively while lifting your leg.
- Place a towel roll under your forehead to keep neck in neutral position (looking straight down toward bed or mat). Do not turn your head to one side while performing this exercise. It will hurt your neck.
- Place your hands by your side
- Lift right leg up until feeling your buttocks squeeze, hold the position for five seconds then switch legs. Repeat this process for one and a half minutes.

#### **PROGRESSION:**

- Begin this exercise at one and a half minutes and add ten seconds each day until you reach three minutes. Once you reach three minutes for this exercise, you are ready for Level Two Mat exercises.

#### **YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:**

- Lumbar paraspinals (back muscles)

#### **FOR THE PHYSICAL THERAPIST:**

- Do not allow the patient to arch their back when lifting their leg. Excessive arching will increase the lumbar lordosis, causing irritation to the facet joints and causing pain.
- Try using two pillows under the hips for patients with increased lumbar lordosis.

- Do not allow patient to lift leg too high to avoid anterior subluxation of hip and increased low back pain.
- Make sure that the forehead is resting on a towel roll.
- If the patient has increased ankle and foot pain lying prone while performing this exercise, feet should be dangled off the end of the bed.

### **3A. ALTERNATE POSITION FOR PRONE HIP EXTENSION LEANING ON BALL**



**-This is an alternate position used for patients who cannot lie on their stomach due to neck, chest, rib or shoulder pain in the prone position.**

#### **POSITION:**

-Place a physioball on a couch or mat and lean over the ball, with hands resting on the couch or mat for balance. Kick one leg out behind and hold that position for five seconds then switch legs. Repeat this process for one and a half minutes.

#### **PROGRESSION:**

-Begin this exercise at one and a half minutes and add ten seconds each day until you reach three minutes. This is an alternate position, therefore, once three minutes is reached, you will progress to Level Two prone swimmer alternate position.

#### **FOR THE PHYSICAL THERAPIST:**

-This position puts more stress on the hip and knee that is standing on the floor during this exercise. Make sure the patient does not perform excessive hip adduction (Trendelenburg) on the stance leg because this may injure the hip overtime.

- Do not allow the patient to twist their upper body as they switch legs.
- Do not allow patient to arch their back when lifting their leg. Excessive arching will increase the lumbar lordosis, causing irritation to the facet joints and causing pain.
- Do not allow the patient to lift their leg too high, to avoid anterior subluxation of hip.
- Make sure that the head and shoulders are straight to avoid neck pain.

## 4. BALL SQUEEZES



### **POSITION:**

-Lie on your back with knees bent. Place a ball (size of a soccer ball) between your thighs and with your feet hip-width apart. Squeeze the ball for a count of five seconds, rest for one second, then squeeze again for five seconds. Repeat this process for one and a half minutes.

### **PROGRESSION:**

-Begin this exercise at one and a half minutes and add ten seconds each day until you reach three minutes. Once you are able to do this exercise for three minutes, keep this exercise the same and at three minutes for both Level Two and Level Three Mat exercises. There is no progression for this exercise.

### **YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:**

-Hip adductor muscles (inner thigh muscles)

### **FOR THE PHYSICAL THERAPIST:**

-If the knees hurt, have the patient move the ball down toward the inner thighs.

-Have the patient keep feet and knees at hip-width apart. Too much hip internal rotation with this exercise could bother the patient's ankles or sublux their hips.

-The size of the ball should be the same as the circumference of a soccer ball.

## 5. CLAM WITH TUBING



### **POSITION:**

-Lie on your back with knees bent and yellow theraband wrapped and tied around both thighs. Spread both knees apart a few inches (not too far) and hold for five seconds, then, return to hip neutral (do not let knees touch), then back out again. Repeat this process for one and a half minutes.

### **PROGRESSION:**

-Begin this exercise at one and a half minutes and add ten seconds each day until you reach three minutes. Once you reach three minutes for this exercise, you are ready for the Level Two.

### **YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:**

-Hip abductors (outside part of the hip)

### **FOR THE PHYSICAL THERAPIST:**

-Do not let the patient's knees touch each other and have them control the eccentric contraction of the hip. If not, the hips could sublux. Hip neutral is defined as having the knees aligned with the hip joint. Do not allow the patient's hips to move into internal rotation with this exercise.

-If the patient's knees move too far out to the side, that can cause the sacrum or pelvis to sublux.

-Tubing should measure between nine and ten inches in length once tied, for consistency.

## Level Two Mat Exercises

### **FOR THE PERSON WITH EDS AND THE PHYSICAL THERAPIST:**

This level can be performed once the patient achieves three minutes of **all five** exercises in Level One Mat. Level Two Mat exercises consist of: bridges with ball squeeze, supine kick outs, prone swimmer, ball squeezes for three minutes (same as Level One Mat) and clam with green tubing. Also, have the patient sit on the physioball with feet hip-width apart and hands on thighs for three to five minutes to learn how to balance on the physioball before adding Level One Ball exercises at the next physical therapy visit. Physical therapists should perform manual therapy techniques on the SIJ and on L5 to T12. Myofascial release can continue to be performed on the quadratus lumborum, piriformis and psoas muscle groups. Continue to work with patients on self- corrections and on identifying and eliminating triggers. Patients should be self-correcting at home before performing their home exercises. After two to three days of sitting on the ball, the patient can begin Level One Ball exercises under the supervision of the physical therapist at the next scheduled appointment.

## 1. BRIDGES WITH BALL SQUEEZES



### **POSITION:**

- Lie on your back with knees and hips bent and a ball between your thighs (ball should be the circumference of a soccer ball). Squeeze your buttocks and then lift your buttocks off the mat into a bridge position, keeping the ball between your thighs.
- While up in the bridge position, squeeze the ball five times repeatedly in between your thighs. Then lower your hips down and rest for one second.
- Repeat this process for one and a half minutes.

### **PROGRESSION:**

- Begin this exercise at one and a half minutes and add ten seconds each day until you reach three minutes. Once you reach three minutes for this exercise, you are ready for Level Three Mat exercises.

### **YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:**

- Gluteus maximus (buttocks) and hip adductors (inner thighs)

### **FOR THE PHYSICAL THERAPIST:**

- Remove the pillow from under the head if the neck hurts while the patient lifts their buttocks off of the mat.
- Hands can be by their side for this exercise to assist with trunk stability.

- Do not allow the patient to just squeeze the ball and hold. Squeezing the ball five times repeatedly facilitates proprioception for the hips.
- If the patient complains of cramping in the hamstrings, they need to squeeze their buttocks first before lifting into the bridge position.
- The ball should be the circumference of a soccer ball.

## 2. SUPINE KICK OUTS



### **POSITION:**

-Lie on your back with your knees bent and hip-width apart and perform pelvic neutral with abdominal bracing. Slowly kick your leg out by straightening your knee. (Do not hyperextend your knee; keep it slightly bent). Hold your leg out for five seconds, then return the leg to the bent knee position and then switch legs. Repeat this process for one and a half minutes, keeping stomach tight the entire time, even through the transition from the right to the left leg.

### **PROGRESSION:**

-Begin this exercise at one and a half minutes and add ten seconds each day until you reach three minutes. Once you reach three minutes for this exercise, you are ready for Level Three Mat exercises.

### **YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:**

-Transverse abdominus (stomach), quadriceps muscles (front of thigh) and hip flexor muscles (front of hip).

### **FOR THE PHYSICAL THERAPIST:**

-Remove the pillow from under the head if the neck hurts while the patient lifts their legs.

-Patients who have chronic subluxations of the hips may need to decrease how far they are kicking out their leg (decreasing the moment arm).

## 2A. ALTERNATE POSITION FOR SUPINE KICKOUTS/ SUPINE HEEL TOUCHES



### **POSITION:**

-This exercise will be performed if patient has increased pain in their back or hips when performing supine kickouts. Have the patient lie on their back with feet hip-width apart. Have the patient perform pelvic neutral with abdominal bracing. Then have them kick their leg out straight and touch their heel to the mat.

-If a patient's hips hurt, do not have them kick out too far with the heel touches. Have them hold this position for five seconds, return to the bent knee position, then switch legs. Have them keep their stomach tight the entire time even through the transition from right to left legs. Repeat for one and a half minutes, then add ten seconds per day until they reach three minutes. After they reach three minutes with supine heel touches, have them attempt supine kickouts again at one and a half minutes. If the patient is unable to perform supine kickouts at this time, then have them progress to the alternate position of Level Three Mat (dying bug).

### 3. PRONE SWIMMER



#### **POSITION:**

- Lie on your stomach with a pillow underneath your hips and a towel roll under your forehead. Bring shoulders out to the side to about eighty degrees of shoulder abduction (elbows even with your chest) and elbows bent to ninety degrees (keeping elbows below shoulder height), like a field goal post in football.
- Lift your bent arm up toward the ceiling and, at the same time, lift the opposite leg up until you feel your scapula (shoulder blade) and opposite buttock squeeze.
- Hold this position for a count of five seconds and then lower arm and leg down and then repeat this process on the opposite side. Head should be resting on a towel roll, face down to avoid neck pain.

#### **PROGRESSION:**

- Begin this exercise at one and a half minutes and add ten seconds each day until you reach three minutes. Once you reach three minutes for this exercise, continue this exercise for three minutes in Level Three Mat, because there is no progression for this exercise.

#### **YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:**

- Lumbar paraspinals (low back) and lower trapezius muscles and latissimus dorsi (mid back)

**FOR THE PHYSICAL THERAPIST:**

- If the patient lifts the shoulder up too high, they may rotate the vertebrae in the cervical spine, which will cause neck pain or sublux the shoulder anteriorly.
- Do not allow the patient to arch their back when lifting their leg. Excessive arching will increase the lumbar lordosis, causing irritation to the facet joints and causing pain.
- Make sure the patient keeps their shoulders below eighty degrees of abduction to avoid shoulder impingement with this exercise.
- Do not allow patient to lift their leg too high to avoid anterior subluxation of hip.
- If the patient has increased ankle and foot pain lying prone while performing this exercise, feet should be dangled off the end of the bed.

### 3A. ALTERNATE POSITION PRONE SWIMMER LEANING OVER BALL

-This is an alternate position used for patients who cannot lie on their stomach due to neck and shoulder pain in the prone position.



#### **POSITION:**

-Place a physioball on a couch and lean over the ball, hugging it (their hands can touch the couch if they need more support to balance on the ball). Bring their shoulders to about eighty degrees of shoulder abduction and elbows bent to ninety degrees (keeping elbows below shoulder height), like a field goal post in football.

-Lift their arm up toward the ceiling and opposite leg up until they feel their buttocks and scapula (shoulder blade) squeeze.

-Hold this position for a count of five seconds and then lower their arm and leg down and then repeat this process on the opposite side. Repeat this process for one and a half minutes.

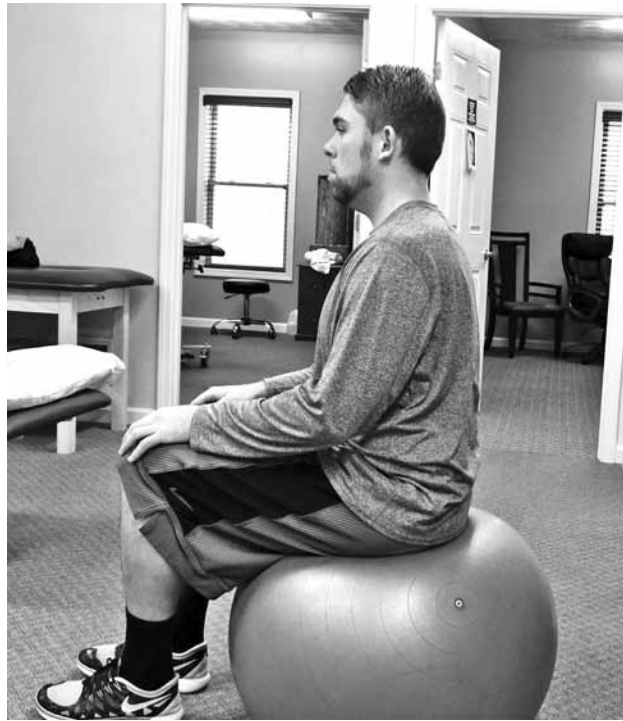
#### **PROGRESSION:**

-Begin this exercise at one and a half minutes and add ten seconds each day until you reach three minutes. Once you reach three minutes for this exercise, continue at this level because there is no level three for this exercise.

**FOR THE PHYSICAL THERAPIST:**

- This alternate position puts more stress on the hip and knee of the stance leg during this exercise. Do not allow the patient to have excessive hip adduction (Trendelenburg) on the stance leg to avoid the hip from being injured.
- Do not allow their upper body to twist as they switch legs and opposite arms. Have the patient put their hands on the mat to help avoid excessive twisting.
- Do not allow the patient to arch their back when lifting their leg. Excessive arching will increase the lumbar lordosis, causing irritation to the facet joints and causing pain.
- Do not allow the patient to lift their leg too high, to avoid anterior subluxation of hip.
- If the patient lifts the shoulder up too high, they may rotate the vertebrae in the cervical spine, which will cause neck pain or sublux the shoulder anteriorly.

#### 4. SIT ON BALL WITH FEET AND KNEES TOGETHER



##### **POSITION:**

-Sit on physioball with your knees and feet hip-width apart and hands on thighs. Do not arch your back. Hold this position for three to five minutes. This exercise works on your balance on the physioball before adding Level One Ball exercises in two to three days. Perform this exercise in a hallway so you can hold onto the walls if you lose your balance. Do not continue this exercise once Level One Ball exercises are added. Your physical therapist needs to determine if you are safe to perform this exercise at home.

## 5. CLAM WITH GREEN TUBING



-This exercise is the same as clam performed in Level One Mat, with the exception of now using green tubing instead of yellow. Begin this exercise at a minute and a half until you reach three minutes. Once you reach three minutes, you are ready to progress to Level Three Mat exercises. The tubing should be nine to ten inches in length once tied, for consistency.

## 6. BALL SQUEEZES



-This exercise is the same as ball squeezes in Level One Mat. Patients should perform this exercise for three minutes every day.

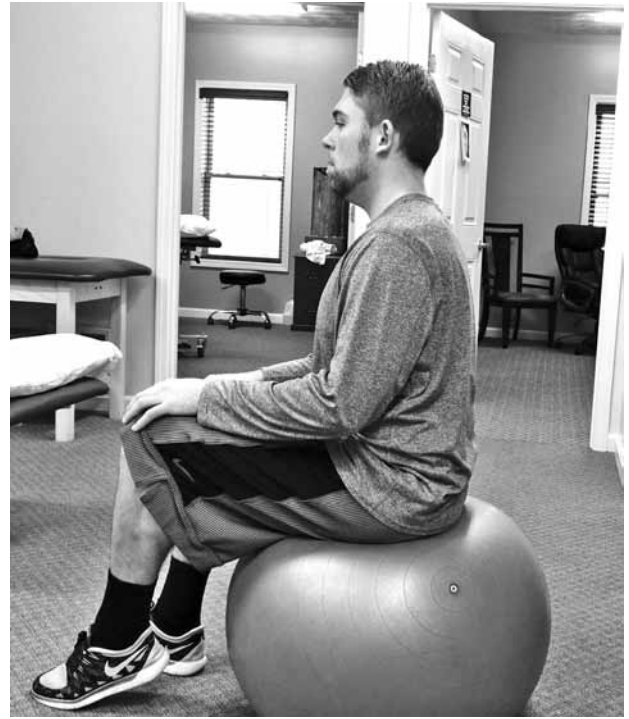
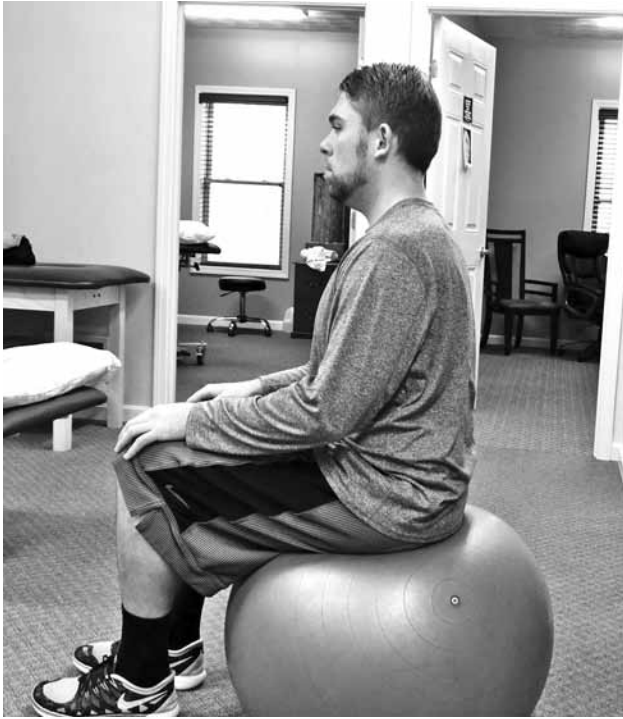
## Level One Ball Exercises

### **FOR THE PERSON WITH EDS AND THE PHYSICAL THERAPIST:**

Level One Ball exercises will be given two to three days after beginning Level Two Mat exercises. Therefore, you will be progressing Level One Ball exercises and Level Two Mat exercises at the same time. The ball exercises were developed to help stabilize the sacrum. All of these exercises need to be first performed under the supervision of the physical therapist so they can assess safety before beginning them at home. All ball exercises are to be performed in a hallway at home to allow you to hold onto the wall if you lose your balance while performing these exercises. Only your physical therapist can determine if you can perform any ball exercises safely at home.

There are three exercises in this level: sitting alternating heel ups, bridging with legs on the ball, and ball multifidus. Once Level One Ball exercises are begun, you no longer need to sit on the ball with feet and knees together for three to five minutes. Physical therapists should perform manual therapy techniques on the SIJ and on L5 to T12. Myofascial release can continue to be performed on the quadratus lumborum, piriformis and psoas muscle groups. Continue to work with patients on self-corrections and on identifying and eliminating triggers. Patients should be performing self-corrections at home before performing the home exercises.

## 1. SEATED ALTERNATING HEEL UPS



### **POSITION:**

- Sit on the ball while performing pelvic neutral with abdominal bracing.
- Hands should be on your thighs and knees and feet should be hip-width apart. Raise one heel off the ground, lower it down and then switch to the other heel. Do not hold your heel up. Instead, just raise the heel up and down slowly, alternating left and right heels. Holding your heel up can increase pain in your ankle.

### **PROGRESSION:**

- Begin this exercise at one and a half minutes and add ten seconds each day until you reach three minutes. Once you reach three minutes for this exercise, you are ready for Level Two Ball exercises.

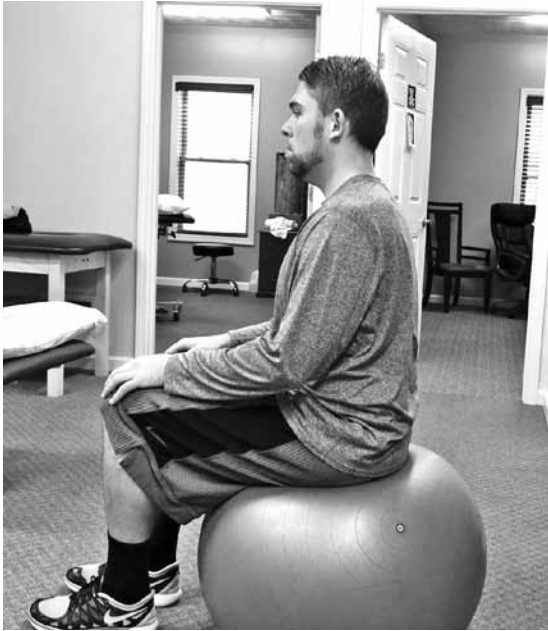
### **YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:**

- Calf muscles (back of leg), transverse abdominal (stomach), obliques (side of stomach) and multifidus (back)

**FOR THE PHYSICAL THERAPIST:**

**1A. ALTERNATE POSITION SEATED ALTERNATING TOE UPS:**

If a patient is unable to raise heels up due to increased ankle pain, then the patient can lift the toes up instead. This will decrease stress on the talocrural joint.



- Maintain abdominal bracing while performing this exercise.
- Have the patient contract the oblique opposite to the leg that is performing the heel/toe up in order to stabilize their body on the ball.
- Instruct patient to perform all ball exercises in a hallway at home, so they will be able to hold onto a wall in case they lose their balance.
- Do not allow the patient to excessively arch the low back because this will lock out the facet joints and not allow the lumbar paraspinal muscles to be activated.

## 2. BRIDGING WITH LEGS ON BALL



### **POSITION:**

- Lie on your back with calves on the physioball and both hands by your side on the mat.
- Squeeze your buttocks and lift your hips up off the mat in a bridge position and hold that position for five seconds. Then return to the mat and rest for one second. If you sway to the right or left while on the ball, tighten your stomach to stabilize your body on the ball.
- Repeat this process for one and a half minutes.

### **PROGRESSION:**

- Begin this exercise at one and a half minutes and add ten seconds each day until you reach three minutes. Once you reach three minutes for this exercise, you are ready for Level Two Ball exercises.

### **YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:**

- Gluteus maximus (buttocks) and hamstring (back of legs)

### **FOR THE PHYSICAL THERAPIST:**

- Keep the hips and knees in the neutral position, avoiding any rotation.
- Place calves on the ball, not the heels. If the heels are placed on the ball instead of the calves, an increased stress will be placed on the subtalar joint or talocrural joint and could possibly cause subluxations of these two joints.

-Remove the pillow from under the head if the neck hurts while the patient lifts their legs.

Hands can be by the side to assist with trunk stability.

### 3. BALL MULTIFIDUS



#### **POSITION:**

- Kneel on the mat, leaning over the physioball, hugging it. Then lift your knee straight up off the mat about once inch while keeping the foot on the mat at all times.
- Hold the knee up for five seconds, then switch legs.
- Repeat this process for one and a half minutes.

#### **PROGRESSION:**

- Begin this exercise at one and a half minutes and add ten seconds each day until you reach three minutes. Once you reach three minutes for this exercise, you are ready for Level Two Ball exercises.

#### **YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:**

- Multifidus muscles (low back). These are the only uni-segmental stabilizers of the lumbar spine.

**FOR THE PHYSICAL THERAPIST:**

**3A. ALTERNATE POSITION FOR BALL  
MULTIFIDUS WITH HANDS ON MAT**



-If the patient cannot avoid twisting their back, have them place their hands on the bed or mat to stabilize their body. Perform this position for one and a half minutes. Add ten seconds per day until they reach three minutes. Then, perform Ball Multifidus exercise without touching the mat (original position), beginning at one and a half minutes and progressing to three minutes in that position. Only once the patient has completed the Ball Multifidus exercise without touching the mat (original position) can they progress to Level Two Ball exercises.

-Make sure the patient does not twist their back when lifting their knee off the bed or mat. If this occurs, it means the patient is lifting their knee too high, or they are not contracting their stomach muscles needed to stabilize their body.

## Level Three Mat

### **FOR THE PERSON WITH EDS AND THE PHYSICAL THERAPIST:**

This level can be performed once the patient achieves three minutes of **all five** exercises in Level Two Mat. Level Three Mat exercises consist of: bridges with kick outs, dying bug, either prone swimmer or prone swimmer over the ball for three minutes from Level Two Mat, clam with blue tubing, ball squeezes for three minutes from Level One Mat. This is the top level for mat exercises. Once you achieve three minutes in all of these exercises, you need to perform all the exercises in this level only on Mondays and Thursdays to maintain strength.

I created this level to be difficult for this population. Therefore, it may take longer to progress through this level than the previous levels. While progressing through Level Three Mat exercises, the patient may need a day of rest in between each exercise session. If this occurs, perform the exercises in this level only every other day until you reach three minutes with each exercise. Continue to progress ball exercises every day. Progress ten seconds a day as tolerated.

This level is intended to stabilize the ilia upon the sacrum. Physical therapists should continue to perform manual therapy techniques on the SIJ and on L5 to T12. Myofascial release can continue to be performed on the quadratus lumborum, piriformis and psoas muscle groups. Continue to work with patients on self-corrections and on identifying and eliminating triggers. Finding triggers will become easier once the ilia has stabilized upon the sacrum. The patient should be self-correcting at home before performing their home exercises.

## 1. BRIDGES WITH KICK OUTS



### **POSITION:**

- Lie on your back with your knees bent, squeeze the buttocks and lift your pelvis into a bridge position.
- While in the bridge position, kick one leg out straight and hold this position for five seconds, then return the foot to the mat. Maintaining the bridge position, kick the opposite leg out straight and hold that for five seconds. Keep buttocks in the air for the entire exercise.
- Repeat this process for **one minute**.

### **PROGRESSION:**

- Begin this exercise at **one minute** and add ten seconds per day until you reach three minutes. If you get too fatigued with this exercise every day, then perform this exercise every other day until you reach three minutes. Once you reach three minutes, perform this exercise two times per week to maintain your strength.

### **YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:**

- Gluteus maximus (buttocks), hip abductors (outside of hip), hip adductors (inside of hip), hamstrings (back of leg), quadriceps (front of leg), obliques (side of stomach), transverse abdominus (stomach)

**FOR THE PHYSICAL THERAPIST:**

**1A. ALTERNATE POSITION FOR BRIDGES WITH KICKOUTS/  
BRIDGING WITH HEEL UPS:**



-Use this position for patients who cannot stabilize their hip joint when kicking their leg out straight (the hip subluxes or the patient complains of hip pain when kicking leg out). If the patient's ankle hurts with heel ups, have the patient perform toe ups instead (raising toe up off mat).

**POSITION:**

- Have the patient lie on their back, squeeze their buttocks and lift into a bridge position.
- Have the patient stay in this bridge position the entire time. Have them raise their heel off the mat, then switch to the opposite foot. Alternate heel ups right and left, without holding.
- Repeat this process for **one minute** then adding ten seconds a day until you reach three minutes. Once they reach three minutes of this exercise, progress to bridging with kick outs for one minute. If the patient still cannot perform bridging with kick outs, have them continue the alternate position until the lower extremity progression has been completed. Then have them try bridging with kick outs again. Some people with EDS cannot perform bridging with kick outs due to hypermobility of the hips. Therefore, the alternate position will be added to their final home exercise program.

- Make sure that the knee of the leg that is on the mat does not move into valgus while the opposite leg is being kicked out. Moving the knee into valgus could cause the hip or the knee to sublux.
- Make sure the ankles are stable enough to hold position. If not, have the patient perform this exercise in the alternate position.
- Remove the pillow from under the head if the neck hurts while the patient lifts their legs.

## 2. THE DYING BUG



### **POSITION:**

- Lie on your back with your knees and hips bent and arms straight up toward the ceiling, like performing a bench press.
- Perform pelvic neutral with abdominal bracing, then take your right arm and bring it backwards toward your head while simultaneously kicking your left leg out.
- Hold this position for five seconds, then return to the original position.
- Then bring the left arm overhead and kick right leg out, holding for five seconds. Hold pelvic neutral through the transition as well.
- Repeat this process for one minute.

### **PROGRESSION:**

- Begin this exercise at **one minute** and add ten seconds per day until you reach three minutes. If you have increased fatigue performing this exercise every day, then perform this exercise every other day until you reach three minutes. Once you reach three minutes, perform this exercise on Mondays and Thursdays only to maintain your strength.

### **YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:**

- Transverse abdominus (stomach), obliques (side of stomach)

**FOR THE PHYSICAL THERAPIST:**

- If the patient cannot lift their arm over their head, they can modify the amount of shoulder flexion in order to perform the exercise in a pain-free range.
- Keep slight bend in knees at all times while kicking out (do not hyperextend knee).
- Limit the range of motion of the leg kicking out if the patient has hip subluxations or pain.

**2a. Alternate Position Dying Bug With Heel Touches**

-If the patient's hips hurt, they can touch their heel to the mat (like supine kickouts alternate position) as they kick out their leg. Begin at **one minute**, adding ten seconds per day until reaching three minutes of this alternate position. Then attempt the original position at **one minute**. If the patient cannot perform the original position, then add the alternate position to their final home exercise program performed on Mondays and Tuesdays to maintain strength. They can perform this exercise every other day if they are fatigued performing this every day.

### 3. PRONE SWIMMER



-Perform this same exercise as described in Level Two Mat for three minutes on Mondays and Thursdays only to maintain strength in the final home exercise program.

### 3A. ALTERNATE POSITION PRONE SWIMMER LEANING OVER BALL



-Perform alternate position as described in Level Two Mat for three minutes on Mondays and Thursdays only to maintain strength in the final home exercise program.

#### 4. BALL SQUEEZES



-Perform this same exercise as in Level One Mat for three minutes on Mondays and Thursdays only to maintain strength in the final home exercise program.

## 5. CLAM WITH BLUE TUBING



-Perform this same exercise as in Level One Mat every day, beginning at one and a half minutes and progressing ten seconds each day. Once you have reached three minutes of this exercise, begin clam with black tubing every day for **one minute** and progressing ten seconds every day until you reach three minutes. This is the final level of this exercise. Once you have achieved three minutes with black tubing, you will add this to your final home exercise program on Mondays and Thursdays only to maintain strength.

Once you have achieved three minutes of all Level Three Mat exercises, you can perform these exercises on Mondays and Thursdays only. Level Three Mat exercises include: either dying bug or dying bug with heel touch for three minutes, prone swimmer or prone swimmer over the ball for three minutes, bridging kickouts or bridging toe raises for three minutes, clam with black tubing for three minutes and ball squeezes for three minutes. Continue to progress ball exercises every day (see Appendix A for a list of all exercises).

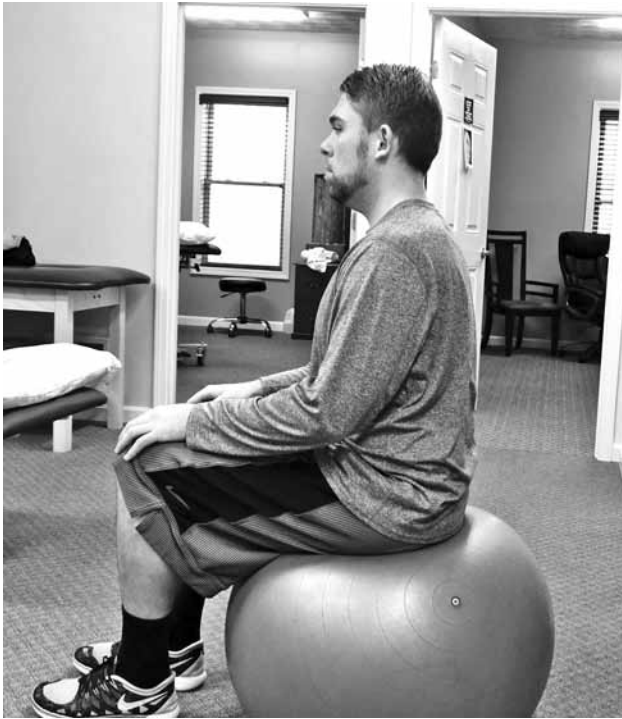
## Level Two Ball Exercises

### **FOR THE PERSON WITH EDS AND THE PHYSICAL THERAPIST:**

These exercises should be performed once the patient has completed all Level One Ball exercises for three minutes. Level Two Ball exercises consists of: seated on ball marching, bridging with legs on the ball and arms across the chest, rolling out on the ball in a bridge position and hugging the ball kicking out with toe touching. You should be having your patient perform these exercises along with Level Three Mat. Physical therapists should continue to perform manual therapy techniques on the SIJ and on L5 to T12. Myofascial release can continue to be performed on the quadratus lumborum, piriformis and psoas muscle groups. Continue to work with patients on self-corrections and on identifying and eliminating triggers. Patients should be self-correcting at home before performing all exercises.

**All ball exercises are to be performed in a hallway at home so the patient can hold onto the walls if they lose their balance.**

## 1. SEATED ON BALL MARCHING



### **POSITION:**

- Maintain pelvic neutral with abdominal bracing throughout entire exercise.
- Sit on the ball with knees and feet hip-width apart, lift right leg up approximately two inches off the ground and hold this position for five seconds.
- Then return the foot to the ground and switch to the left foot, also lifting it two inches off the ground.
- Repeat this process for one and a half minutes.

### **PROGRESSION:**

- Begin this exercise at one and a half minutes and add ten seconds each day until you reach three minutes. Once you reach three minutes for this exercise, you are ready for Level Three Ball exercises.

### **YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:**

- Hip flexors (front of thigh), obliques (side of stomach), transverse abdominus (stomach), multifidus (low back), hip abductors (outside of hip) and hip adductors (inside thigh) of

the leg that is on the ground.

**FOR THE PHYSICAL THERAPIST:**

- Make sure the patient does not arch their back (maintains pelvic neutral).
- Limit the range of motion of hip flexion for the patient who has subluxing hips.
- Maintain hip, knee and foot alignment throughout entire exercise in order to protect these areas.
- Contract the core muscles on the opposite side of the leg that is being lifted off the ground in order to maintain balance on the ball.

## 2. BRIDGING WITH LEGS ON THE BALL AND ARMS ACROSS CHEST



### **POSITION:**

- Lie on your back with your calves on the physioball with arms folded across your chest.
- Squeeze buttocks and lift hips up off the mat in a bridge position and hold that position for five seconds. Then return to the mat and rest for one second.
- Perform abdominal bracing to help stabilize your body and prevent twisting on the ball.
- Repeat this process for one and a half minutes.

### **PROGRESSION:**

- Begin this exercise at one and a half minutes and add ten seconds each day until you reach three minutes. Once you reach three minutes for this exercise, you will keep this exercise for Level Three Ball. There is no progression for this exercise.

### **YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:**

- Gluteus maximus (buttocks), hamstrings (back of legs) and obliques.

### **FOR THE PHYSICAL THERAPIST:**

- Have the patient keep their hips and knees in the neutral position, avoiding any rotation.
- Have the patient place their calves on the ball, not their heels. If their heels are placed on the ball instead of their calves, an increased stress will be placed on the subtalar

joint or talocrural joint and could possibly cause subluxations of these joints.

- Remove the pillow from under the head if the neck hurts while the patient lifts their legs.

- Do not allow the patient to use their arms to help stabilize their body while performing the bridge.

- Have the patient use their core muscles for balance.

### 3. ROLLING OUT ON THE BALL IN A BRIDGE POSITION



#### **POSITION:**

- Sit on the ball and roll body out until your head and shoulders are resting on the ball.
- The neck should be in a neutral position (looking at the ceiling), resting on the ball like a pillow, not placed in extension (looking backwards).
- Your buttocks must be squeezed and the back flat in order to keep your body flat, like a table top.
- The knees and legs need to be hip-width apart, knees bent to ninety degrees and the arms can be resting on your hips.
- Hold this position steady for one and a half minutes. There should be no movement with this exercise, just a static hold.
- After one and a half minutes, return to the sitting position by dropping the buttocks down, walking toward the ball while allowing the ball to roll down the spine and onto the buttocks.

#### **PROGRESSION:**

- Begin this exercise at one and a half minutes and add ten seconds each day until you reach three minutes. Once you reach three minutes for this exercise, you are ready for Level Three Ball exercises.

**YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:**

-Gluteus maximus (buttocks), quadriceps (front of thigh), hamstrings (back of thigh), multifidus (low back), hip abductors and adductors (outside and inside of hip), obliques (side of stomach), transverse abdominus (stomach).

**FOR THE PHYSICAL THERAPIST:**

- Pay attention to the patients whose hips sublux and make sure that they do not fall with this exercise.
- Support of the body on the ball should come from the shoulder blades and not the neck. Have the patient use the ball as a pillow for their neck.
- Make sure the neck is resting on the ball in the neutral position and is not extended.
- Instruct the patient to be like a table with a glass of water resting on their stomach. Instruct them not to spill the water by sagging their buttocks down.
- Make sure the knees are bent at ninety degrees in order to protect the knees and feet.
- Have the patient place their hands on the thighs in order to protect their shoulders.

## 4. HUGGING THE BALL WITH TOE TOUCHING



### **POSITION:**

- Kneel on mat leaning over the physioball, hugging it. Then kick leg out straight while touching toe to the mat.
- Hold the leg out for five seconds, then switch legs.
- Do not twist your back while kicking your leg out backwards.
- Repeat this process for one and a half minutes.

### **PROGRESSION:**

- Begin this exercise at one and a half minutes and add ten seconds each day until you reach three minutes. Once you reach three minutes for this exercise, you are ready for Level Three Ball exercises.

### **YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:**

- Gluteus maximus (buttocks), lumbar paraspinals, multifidus (low back), obliques (side of stomach), transverse abdominus (stomach), hip abductors (outside of hip) and adductors (inside of thigh) of the leg which has the knee on the ground.

**FOR THE PHYSICAL THERAPIST:**

**4A. ALTERNATE POSITION HUGGING THE BALL  
WITH TOE TOUCHING WITH HANDS ON MAT**



-If the patient cannot avoid twisting their back, have them place their hands on the mat to stabilize their body. Perform this position for one and a half minutes. Add ten seconds per day until they reach three minutes. Then, perform Hugging The Ball With Toe Touching exercise without touching the mat (original position) and progress to three minutes in that position. Once the patient has completed the Hugging The Ball With Toe Touching exercise without touching the mat with their hands (original position), they can progress to Level Three Ball exercises.

-Do not allow the patient to hyperextend the knee. Have them keep a slight bend in the knee while kicking leg out backwards.

-Make sure the patient contracts the core muscles on the opposite side of the leg that kicks out. This will provide balance to the patient.

-Do not allow the patient to hyperextend their low back.

## Level Three Ball

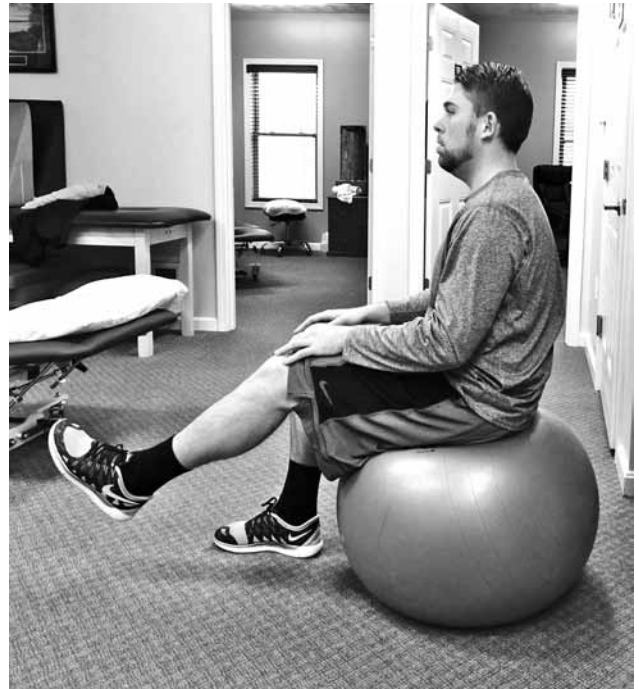
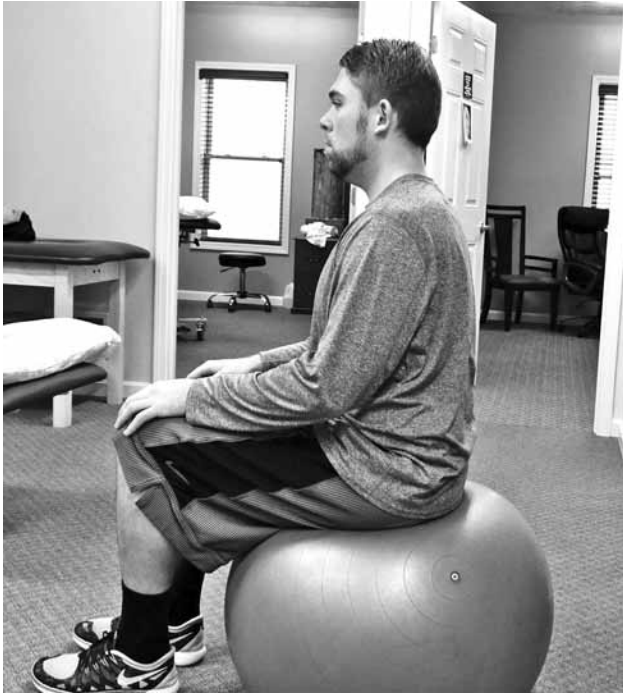
### **FOR THE PERSON WITH EDS AND THE PHYSICAL THERAPIST:**

This is the final level of the SIJ and Low Back Progression. Once **all four** exercises from Level Two Ball have been completed, they can begin this level. Level Three Ball exercises include: seated on ball with kickouts, ball roll outs with heel ups, bridging on ball with arms across chest for three minutes (from level two) and hugging the ball with kick outs. Once this level is complete, they may perform Level Three Mat (all five exercises) and Level Three Ball (all four exercises) on Mondays and Thursdays only which will be part of their final home exercise program for Phase One (see Appendix A).

Also at this time, begin the Level One Neck, Mid Back And Upper Extremity progression with this level. This is important at this point in the protocol because problems may arise in the vertebrae above the newly aligned and stabilized sacroiliac joint. Physical therapists should continue to perform manual therapy techniques on the SIJ and L5 to T12. Myofascial release can continue to be performed on the quadratus lumborum, piriformis and psoas muscle groups. Continue to work with patients on self- corrections and on identifying and eliminating triggers.

Begin each exercise for **one minute** and progress ten seconds a day until the patient reaches three minutes. The patient may have to perform this level every other day, depending on their exercise tolerance. Patients should be self-correcting at home before performing their home exercises.

## 1. SEATED ON BALL WITH KICKOUTS



### **POSITION:**

- Sit on the ball with knees and feet hip-width apart and hands on thighs.
- Kick one leg out, keeping a slight bend in the knee (do not lock out knee) and hold for five seconds, then switch legs.
- Maintain pelvic neutral with abdominal bracing throughout the entire exercise (do not allow low back to arch).
- Repeat this process for one minute.

### **PROGRESSION:**

- Begin at **one minute** and add ten seconds a day until you reach three minutes. Then perform on Mondays and Thursdays along with Level Three Mat exercises.

### **YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:**

- Quadriceps (front of thighs), obliques (side of stomach), transverse abdominus (stomach), multifidus (low back)

**FOR THE PHYSICAL THERAPIST:**

- Make sure the patient does not arch their back (maintains pelvic neutral).
- Have the patient maintain hip, knee and foot alignment throughout the entire exercise in order to protect these areas.
- Make sure the patient contracts the core muscles on the opposite side of the leg that is being lifted off the ground in order to maintain balance on the ball.
- Make sure the knees do not hyperextend when kicking out.

## 2. BALL ROLLOUTS WITH HEEL UPS



### POSITION:

- Sit on the ball and roll body out until the head and shoulders are resting on the ball.
- The neck should be in a neutral position, not placed in extension (bent backwards).
- Your bottom must be squeezed and the back flat, in order to look like a table top.
- The knees and legs need to be hip-width apart, knees should be bent at ninety degrees and the arms can be resting on the stomach.
- Raise heel off the ground slowly, then return to ground. Then switch by raising the opposite heel off the ground. Alternate lifting heels slowly. **Do not** hold the heel up for five seconds. Repeat this process for **one minute**.
- After **one minute**, return to the sitting position by dropping the buttocks down, walking toward the ball while allowing the ball to roll down the spine and onto the buttocks.

### PROGRESSION:

- Begin at **one minute** and add ten seconds a day until you reach three minutes. Then perform on Mondays and Thursdays along with Level Three Mat exercises.

### YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:

- Transverse abdominus (stomach), gluteus maximus (buttocks), hamstrings (back of leg), calves (back of lower leg), obliques (side of stomach)

**FOR THE PHYSICAL THERAPIST:**

**2A. ALTERNATE POSITION BALL ROLL OUTS WITH TOE UPS**



- If your patient's ankles hurt during heel raises, have the patient raise their toes instead. This will put less pressure on the talocrural joint.
- Support of the body on the ball should come from the shoulder blades and not from the neck. Use the ball as a pillow for the neck.
- Make sure the neck is resting on the ball in the neutral position and is not extended.
- Instruct the patient to be like a table with a glass of water resting on their stomach. Instruct them not to spill the water by sagging their buttocks down.
- Make sure the knees are bent at ninety degrees in order to protect the knees and feet.
- Have the patient place their hands on their thighs in order to protect their shoulders.
- Have the patient contract their core muscles on the opposite side of the leg that is being lifted off the ground in order to maintain balance on the ball.

### 3. HUGGING THE BALL WITH KICK OUTS



#### **POSITION:**

- Kneel on mat leaning over the physioball, hugging it. Perform pelvic neutral with abdominal bracing, then kick leg out straight while holding leg in the air for five seconds. Then switch legs.
- Keep a slight bend in the knee of the leg you are kicking out.
- Repeat this process for **one minute**.

#### **PROGRESSION:**

- Begin this exercise at **one minute** and add ten seconds each day until you reach three minutes. Once you reach three minutes for this exercise, add these exercises to the Monday and Thursday exercise routine along with Level Three Mat exercises.

#### **YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:**

- Gluteus maximus (buttocks), lumbar paraspinals, multifidus (low back), obliques (side of stomach), transverse abdominus (stomach), hip abductors (outside of hip) and adductors (inside of thigh) of the leg which has the knee on the floor

**FOR THE PHYSICAL THERAPIST:**

**3A. ALTERNATE POSITION HUGGING THE BALL  
WITH KICKOUTS WITH HANDS ON MAT:**



-If the patient cannot avoid twisting their back, have them place their hands on the mat to stabilize their body. Perform this position for **one minute**. Add ten seconds per day until reaching three minutes. Once they reach three minutes of this exercise, the patient should perform Hugging The Ball With Kickouts exercise without touching the mat (original position) for **one minute** and then progress to three minutes in that position.

-Do not allow patient to hyperextend their knee while kicking leg out backwards.

-Make sure the patient contracts the core muscles on the opposite side of the leg which kicks out. This will provide balance to the patient.

-Do not allow the patient to hyperextend their low back.

-Do not allow the patient to twist on the ball.

#### 4. BRIDGING WITH LEGS ON BALL AND ARMS ACROSS CHEST



-This exercise is the same one you performed in Level Two Ball. Continue to perform this exercise for three minutes on Mondays and Thursdays only in your final home exercise program to maintain your strength.

**-Once you have reached three minutes for all of the exercises in Level Three Ball, you will add these exercises to the Monday and Thursday exercise routine along with Level Three Mat exercises as your final home exercise program.**

## Level One Neck, Mid Back And Upper Extremity Progression

### **FOR THE PERSON WITH EDS AND THE PHYSICAL THERAPIST:**

Now that Level Three Ball exercises have begun, the patient is ready to advance to the next exercise progression and to begin strengthening the neck, mid back and upper extremity muscles. With the sacrum and pelvis stabilized, new forces will be created up the kinetic chain, requiring increased strength in the neck, mid back and upper extremities. These two exercises should be added at the same time as performing Level Three Ball exercises.

## 1. SUPINE SHOULDER EXTENSIONS



### **POSITION:**

-Lie on your back with your elbows bent to ninety degrees and your knees bent with feet on the mat. Push both arms down into the mat, squeezing the shoulder blades together and down. Hold for five seconds, then rest for one second.

-Repeat this process for one and a half minutes.

### **PROGRESSION:**

-Begin this exercise at one and a half minutes and add ten seconds each day until you reach three minutes. Once you reach three minutes for this exercise, you are ready for Level Two Neck, Mid Back And Upper Extremity exercises.

### **YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:**

-Rhomboids and trapezius (in between the shoulder blades).

### **FOR THE PHYSICAL THERAPIST:**

-Have the patient squeeze their shoulder blades in a pain-free range of motion.

-Do not let the patient arch their back while squeezing the scapulae.

-The patient should push down with their upper arm (triceps) and not with the elbow to avoid elbow subluxation.

## 2. SUPINE CHIN TUCKS



### **POSITION:**

- Lie on the mat with your knees bent, feet on the mat, with or without a pillow, depending on the comfort level of your neck.
- Push the back of the head down into the pillow/mat and tuck your chin (like you are giving yourself a double chin). Keep eyes looking up toward the ceiling (do not move forehead and eyes, like you are trying to look behind you).
- Hold for five seconds and then rest for one second.
- Repeat this process for one and a half minutes.

### **PROGRESSION:**

- Begin this exercise at one and a half minutes and add ten seconds each day until you reach three minutes. Once you reach three minutes for this exercise, you are ready for Level Two Neck, Mid Back And Upper Extremity exercises.

### **YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:**

- Upper trapezius (neck muscles), occipital muscles (base of skull)

### **FOR THE PHYSICAL THERAPIST:**

- Decrease the range of motion of the chin tuck if the patient gets dizzy or nauseous. These may be signs of cranial instability.
- Pillow may or may not be used depending on the patient's comfort level.

## Completion Of The SIJ And Lumbar Spine Exercise Progression

### **FOR THE PERSON WITH EDS:**

Congratulations! You have completed your first exercise progression. At this point, your low back should feel better. The reason for this is that you have now achieved a level of strength that will help you to maintain the alignment of your SIJ and low back with most activities of daily living. In order to maintain this level of strength, you will need to perform Level Three Mat and Level Three Ball exercises two times per week indefinitely. We have placed both Level Three Mat and Level Three Ball on a Monday and Thursday schedule. Jumping and twisting activities need to continue to be avoided at this time because the mid back and legs are not strong enough to participate in these activities. You may have a setback in the SIJ or low back while working through the next two exercise progressions (neck, mid back and upper extremity progression and lower extremity progression). If you have a setback, inform your physical therapist immediately so that they can address this area with appropriate manual therapy. Once a setback occurs, you will need some time to heal before you resume the level at which you were prior to the set back. If you have a setback in the SIJ or low back, you need to stop doing Level Three Mat and Level Three Ball exercises and revert to Level Two Mat and Level Two Ball exercises, beginning at one and a half minutes and adding ten seconds per day until you reach three minutes. Once you reach three minutes of Level Two Mat and Level Two Ball exercises, you may resume Level Three Mat and Level Three Ball exercises, beginning at one and a half minutes and adding ten seconds per day until you reach three minutes. At this point, Level Three Mat and Level Three Ball exercises can be performed again on the Monday and Thursday schedule. If you have already started exercises for other joints, and they were not affected by the setback, continue with these progressions as originally instructed. Only adjust the exercises for the joints directly affected by your set back. Good luck with the neck, mid back and upper extremity progression.

(Home Exercise Sheet To Detach And Use For Quick Reference)

**MONDAYS AND THURSDAYS:**

-SIJ And Lumbar Spine Progression Final Home Exercise Program:

*-All Exercises Are Performed For Three Minutes*

Level Three Mat And Level Three Ball Exercises:

- Dying Bug (Alternate Position With Heel Touches)
- Prone Swimmer For Three Minutes (Alternate Position Leaning Over Ball)
- Bridges With Kickouts (Alternate Position Bridges With Heel Raises)
- Seated On The Ball Kickouts
- Ball Roll Outs With Heel Ups (Alternate Position Ball Roll Outs With Toe Ups)
- Bridging With Legs On Ball Arms Across Chest
- Hugging The Ball With Kickouts (Alternate Position Hugging The Ball With Hands On The Mat )
- Clam With Black Tubing
- Ball Squeezes

# **Section Three -**

## **Neck, Mid Back And Upper**

### **Extremity Exercise Progression**

***“Even if you are on the right track, you will get run over if you just sit there.”***

**Mark Twain**

### **About This Exercise Progression**

#### **FOR THE PERSON WITH EDS:**

Congratulations! You have completed your first of three exercise progressions. At this point, your low back should be feeling better. Unfortunately, other parts of your spine may have increased pain. We will be addressing these issues in this exercise progression. The physical therapist will begin to work on your mid back, ribs, neck, shoulders, elbows, wrists and hands to help decrease pain in these areas. You will be strengthening all of these areas at the same time, which means you will be getting a lot of new exercises, taking approximately forty-five minutes a day to complete. Since you have completed the SIJ and Lumbar Spine Exercise Progression, you will be performing these exercises only on Mondays and Thursdays. Therefore, on those days, you will be performing up to ninety minutes of exercise (forty-five minutes of SIJ and Lumbar Spine exercises and forty-five minutes of Neck, Mid Back and Upper Extremity exercises). On Tuesdays, Wednesdays, Fridays, Saturdays and Sundays, you will be performing forty-five minutes of exercise (Neck, Mid Back and Upper Extremity exercises only). You should have completed Level One of this exercise progression while performing Level Three Ball in the SIJ and Lumbar Spine Progression. So, begin this progression at Level Two. There are seven levels to this progression, so it will take time to advance through this. You will not feel a significant difference until you reach Level Seven. Be patient.

## Anatomy For The Person With EDS



### **FOR THE PERSON WITH EDS:**

At the bottom of your skull, there are seven cervical vertebrae bones that make up your neck. Beneath your seven cervical vertebrae, are twelve thoracic vertebrae that make up your mid back. Each thoracic vertebrae is connected to a rib. The triangular bones on either side of the rib cage are called your scapulae (shoulder blades). Your humerus (arm bone) is connected to your scapula with ligaments, a joint capsule and the rotator cuff muscles. The elbow consists of the humerus (arm bone) and your two forearm bones, which are the radius (thumb side of forearm) and the ulna (pinky side of forearm). Your wrist consists of eight carpal bones, which attach your forearm to your hand and fingers.

## Biomechanics For The Person With EDS



### **FOR THE PERSON WITH EDS:**

Most people with EDS have a forward head posture. This posture rounds out the mid back, referred to as kyphosis, and pushes the shoulders forward. Due to weakened ligaments, this posture can cause subluxation of the ribs, which are one and a half to two inches on either side of the spine (middle of the back). It can also lead to rotations of the vertebrae in both the mid back and neck. Rotations of vertebrae in the neck and mid back can cause a number of dysfunctions, including but not limited to: headaches, pain in the spine, pain down the arms, dizziness and difficulty breathing. Having forward shoulders can cause pain in the shoulder including the rotator cuff muscles and eventually lead to shoulder subluxations. When your head is slumped forward (not aligned over your shoulders), this can cause pain behind your head at the base of your skull that can eventually work its way to the front of your head and even affect the eyes and vision. Most people perceive this as a headache, but it is in fact a result of your poor posture. Migraines can also arise from this forward head posture, and a technique called craniosacral therapy may help (this will be addressed at level five of this exercise progression). Excessive computer work can lead to increased pain in the elbows, wrists and hands as well as subluxations in these joints. You will strengthen all joints, regardless of whether or not they hurt, in order to protect them from injury. Good luck with this exercise progression. It is long, but it is worth it in the end (see Appendix B for a list of all exercises in this progression).

## About This Exercise Progression

### **FOR THE PHYSICAL THERAPIST:**

The patient has completed the SIJ and Lumbar Spine exercise progression. Their pain should be greatly improved in this area. Twisting activities will still be a problem in this area, which will be addressed in Phase Two of this protocol. Avoid twisting activities at this time. Being that the SIJ is the keystone of the body, once it is aligned, the rest of the spine may not be strong enough to absorb the forces being created by this new posture in sitting, standing, walking, and ADL's. If these new forces are not absorbed, the patient may have increased pain and subluxations in both the lower extremities, cervical spine and/or thoracic spine. Address any new issues in the lower extremities with bracing and orthotics and address any new issues in the neck, mid back and upper extremities with manual therapy, taping (if tolerated), bracing and this exercise progression. There are seven levels to this progression and the patient will not feel a significant change until reaching Level Seven. They will often become frustrated at some time during this progression. Encourage them and remind them that this is the most difficult progression to get through. Each level of this exercise progression will take approximately forty-five minutes a day to complete. Since patients have already completed the SIJ and Lumbar Spine progression, they will be performing that exercise progression on Mondays and Thursdays in addition to the neck, mid back and upper extremity progression. On those two days, your patients will be performing ninety minutes of exercise (forty-five minutes of SIJ and Lumbar Spine exercises and forty-five minutes of Neck, Mid Back and Upper Extremity exercises). This is a long time to be exercising, so make sure that the patients do not skip the SIJ and Lumbar Spine exercises or the SIJ will become problematic again. Manual therapy can be performed at this point on the SIJ, L5 to C1, ribs, shoulder, elbows, wrists, hands and fingers as needed.

## Biomechanics of The Neck, Mid Back And Upper Extremity



### **FOR THE PHYSICAL THERAPIST:**

The typical posture in this area is an increased thoracic kyphosis, protracted scapulae, rounded shoulders and forward head. The dysfunctions that typically occur in the EDS population are as follows:

1. Mid Back: This area has an increased kyphosis causing a stretch weakness to the thoracic paraspinal muscles. There may be several vertebral rotations in this area, including double rotations. Using indirect techniques in the supine position to align the thoracic spine will be the safest technique. Other muscle energy techniques can be used with this population with caution and your clinical judgement. Address sitting posture, especially at work or at school. If the kyphosis worsens over time, the trachea and sternum can become involved, causing increased breathing and swallowing problems. Refer the patient to a speech therapist if you are uncomfortable addressing these issues.
2. Ribs: Rotations of the thoracic spine, increased kyphosis and protraction of the scapulae cause increased stress on the costovertebral and costotransverse ligaments and can lead to subluxation of the ribs. The ribs can sublux anteriorly, posteriorly, in internal rotation or in external rotation. This will cause muscle spasms of the iliocostalis muscles as well as pain in the costotransverse joints. If there is pain one

and a half inches laterally from the spinous process, then check for subluxed ribs. There can be more than one rib subluxed, so check ribs twelve through three. The first two ribs sublux differently and will be discussed with the neck. Always fix the thoracic spine rotations first, and then the ribs next with this population. If a rib keeps subluxing after you fix it with indirect techniques, check the thoracic spine for rotations again. Taping the scapula, shoulder and/or back may help with posture while progressing through this protocol.

3. Neck: The cervical spine has a forward head posture, causing the lower cervical spine to be flexed and the upper to be extended. The first and second ribs are usually subluxed, causing spasm of the scalene muscles. Address the rotations of the cervical vertebrae and subluxations of the first two ribs with indirect techniques or muscle energy. Hold off on craniosacral techniques if you can until the cervical spine is adequately strengthened. No OA releases should be performed if you suspect or if the patient has Chiari Malformation or cranial instability because it can cause increased dizziness and/or nausea. **Mechanical traction should not be used in patients with EDS.**
4. Shoulders: I believe that shoulder dysfunctions play a major role in most issues of the neck, mid back and ribs. Most shoulders in patients with EDS will sublux inferiorly due to laxity of the anterior and posterior portions of the inferior glenohumeral ligament. Once the head of the humerus subluxes inferiorly, it may also sublux either anteriorly or posteriorly. If the shoulder subluxes inferiorly and anteriorly, it pulls the scapula forward into protraction, which can cause subluxations of the ribs and rotations of the thoracic spine. Also, as the shoulder subluxes inferiorly, it pulls the clavicle and scapula inferiorly, creating increased tension on the upper trapezius, and may cause increased rotations in the cervical spine. Finally, as the shoulder subluxes anteriorly, it can also cause the acromioclavicular joint to move forward, affecting problems with that joint as well as with the sternoclavicular joint. Strengthening the deltoid, rotator cuff muscles, and peri-scapular muscles will help stabilize the shoulder. Taping the shoulder will also help decrease pain as your patient goes through the exercise progression.

5. Elbow: The elbow usually subluxes medially or laterally due to the laxity of the medial and lateral collateral ligaments. Mulligan techniques and bracing may help decrease pain while patient is advancing through this exercise progression. Work station assessment will benefit the patient's elbow, wrist and hand.
6. Wrist: All carpal bones have the potential to sublux in the wrist, depending on which of the ligaments in the wrist are lax. This joint tends to become more problematic with patients who perform excessive writing or computer work. Assess computer work stations for proper set up. Bracing and manual therapy techniques may help decrease pain while both working at the computer and progressing through these exercise levels. Voice activated typing programs may help as well. No muscles attach to the wrist and, therefore, this joint may not get better with this protocol if ligaments are overly lax. Therefore, bracing or prolotherapy may benefit this joint once the patient completes this progression. Surgery is always the last option with this population.
7. Fingers: Fingers may sublux at the MP, PIP or DIP joints. Mulligan Techniques and ring splints may help with these joints.

The physical therapist should perform appropriate manual therapy techniques and apply bracing or taping to any joints that are painful or problematic while the patient progresses through the neck, mid back and upper extremity exercise progression (See Appendix B for a list of exercises in this progression). Level One Neck, Mid Back and Upper Extremity exercises have been listed with Level Three Ball exercises in the SIJ and Lumbar Spine exercise progression. The patient should have performed these exercises along with the Level Three Ball exercises. If they have not, go to the Level Three Ball exercises and perform Level One Neck, Mid Back and Upper Extremity exercises. Have your patient perform these exercises before beginning Level Two Neck, Mid Back and Upper Extremity exercises.

## Level Two Neck, Mid Back And Upper Extremity Progression

### **FOR THE PERSON WITH EDS AND THE PHYSICAL THERAPIST:**

Progress to this level once Level One neck, mid back and upper extremity progression has been completed (Level One exercises are listed with Level Three Ball exercises in the SIJ and Lumbar Spine Exercise Progression). The stability and protection of C1 is the major priority when performing all of the exercises in this progression. Any increase in dizziness or nausea and any significant change in blood pressure or heart rate need to be assessed immediately by the physical therapist before the exercises can be continued. If these symptoms continue, then the patient needs to be assessed by a neurosurgeon immediately before continuing with this exercise progression. The physical therapist can continue to perform manual therapy to the SIJ and lumbar spine as needed. Focus manual therapy on T11 to C1 and the ribs as well as shoulder, elbow, wrist and hand. Taping of the shoulder, if tolerated by the patient, may help with the exercise progression. Using magnesium hydroxide on the patient's skin before applying the tape may help decrease skin irritations with patients who have skin allergies to the adhesive in the tape. Place the magnesium hydroxide on the skin, allow it to dry and then place the tape over the area to be treated. Bracing of the mid back may assist in such activities as driving and computer work. The exercises in this level are: isometric neck, TYI, shoulder internal rotation/external rotation, full can, chicken dances, hand ball squeezes and four way wrist.

## 1. ISOMETRIC NECK



1



2



3



4

### **POSITION:**

1. Sit up straight with your neck in the neutral position. Place right hand on forehead and gently (about three to five pounds of pressure) push your head into your hand using your neck muscles. Hold for five seconds without allowing your head to move and then relax. This is an isometric contraction, so the head should not be moving during this exercise.
2. Next, place right hand on right side of head and gently push the head into the hand

using the neck muscles. Hold for five seconds and then relax.

3. Next, place left hand on left side of head and gently push head into the hand using the neck muscles, holding for five seconds and then relax.
4. Next, place left hand in back of head and gently push head backwards into hand holding for five seconds and then relax. **If this position hurts your shoulder, you can stand against a wall with a pillow behind your head, and then push the back of your head into the pillow.** Remain standing for all four positions of this exercise if a pillow is required.

-Repeat this process of pushing on the head forward, to the right side, backward and to the left side for four minutes (total time).

### **PROGRESSION:**

-Begin this exercise at **four minutes** and add **twenty seconds** per day until you reach eight minutes. Once you reach eight minutes, you are ready for Level Three Neck, Mid Back And Upper Extremity exercise progression.

### **YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:**

-You are working on all muscles around the neck to help stabilize the entire neck.

### **FOR THE PHYSICAL THERAPIST:**

- Make sure the patient pushes the head into the hand by contracting the neck muscles.
- Make sure the patient switches hands while performing the isometric neck exercise (right hand for right side and front/left hand for back and left side), in order to protect the shoulders.
- Keep head/neck in the neutral position, not allowing movement of the neck in any direction during the exercise (maintain an **isometric** contraction), in order to protect the neck.
- Do not allow the patient to tilt their head. Remain in the neutral position.
- If the patient's shoulder hurts with providing resistance for isometric cervical extension,

have them stand with their back facing a wall and use a pillow behind their head for resistance. Have them perform isometric cervical flexion, side bending right and left normally at the wall.

Shoulder internal and external rotation, full can and chicken dance exercise are intended to stimulate the rotator cuff muscles and the deltoid in order to assist in the stabilization of the shoulder with an inferior subluxation. The rotator cuff consists of four muscles in the shoulder, which are: supraspinatus, infraspinatus, subscapularis and teres minor.

## **2. SHOULDER INTERNAL AND EXTERNAL ROTATION**



### **POSITION:**

- Sit with elbows bent to ninety degrees and at your side. Elbows should not leave the side of the body during the entire exercise. Rotate hands/forearms out to the side and back in toward the belly button.
- Perform this in a small range of motion to prevent shoulder subluxation.
- Repeat this process moving hands in and out slowly, without stopping for one and a half minutes.

### **PROGRESSION:**

- Begin this exercise at one and a half minutes and add ten seconds a day until you reach three minutes. Once you reach three minutes, you are ready for Level Three Neck, Mid Back And Upper Extremity exercise progression.

### **YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:**

- Infraspinatus, teres minor (back of shoulder) and subscapularis (armpit)

**FOR THE PHYSICAL THERAPIST:**

-Have the patient limit the range of motion when moving their hands both in toward the belly button as well as away from the belly button (limit to forty-five degrees of shoulder internal and thirty degrees of external rotation). If the hand moves outward excessively, this may cause an anterior subluxation of the shoulder. If the hand moves inward excessively, the shoulder could sublux posteriorly.

-Have the patient keep their elbows touching the sides of their body throughout this exercise in order to stimulate the rotator cuff.

-This is an active range of motion exercise (AROM). Therefore, do not have the patient hold the position in or out. Have them keep moving their shoulders in a slow and controlled range of motion to stimulate proprioception.

### 3. FULL CAN



#### **POSITION:**

- While sitting, hold arms out with elbows slightly bent (don't lock elbows) with palms facing each other. Arms should be about halfway between directly in front of you, and out by your side (thirty degrees of horizontal abduction).
- Lift arms up so that hands do not go above shoulder height, then bring them down to your hips.
- This is an active range of motion exercise, so do not hold the position. Move the arms in a slow and controlled manner.
- Repeat this process for one and a half minutes.

#### **PROGRESSION:**

- Begin this exercise at one and a half minutes and add ten seconds a day until you reach three minutes. Once you reach three minutes, you are ready for Level Three Neck, Mid Back And Upper Extremity exercise progression.

#### **YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:**

- Supraspinatus (top of shoulder in back near the neck)

**FOR THE PHYSICAL THERAPIST:**

- Do not let the patient lift their shoulder higher than sixty degrees of flexion.
- This is an active range of motion (AROM) exercise; therefore no holding.
- Arms should be in plane the scapula with palms facing each other.

## 4. CHICKEN DANCE



### **POSITION:**

- While sitting, place elbows by your side and bend them to ninety degrees. Lift arms out to the side. Do not allow elbows to go above shoulder height (like the movements in “the chicken dance”). Keep elbows bent at ninety degrees throughout exercise.
- This is an active range of motion exercise, so do not hold the position. Raise the arms up and down continuously in a slow and controlled manner.
- Repeat this process for one and a half minutes.

### **PROGRESSION:**

- Begin this exercise at one and a half minutes and add ten seconds a day until you reach three minutes. Once you reach three minutes, you are ready for Level Three Neck, Mid Back And Upper Extremity exercise progression.

### **YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:**

- Deltoid (on outside of shoulder)

**FOR THE PHYSICAL THERAPIST:**

- Do not have the patient raise their shoulders above eighty degrees of abduction.
- This is an active range of motion (AROM) exercise; therefore no holding.
- Have the patient keep their elbows bent to ninety degrees the whole exercise to decrease the lever arm (moment arm).

## 5. FOUR-WAY WRIST (FLEXION, EXTENSION, RADIAL DEVIATION AND ULNAR DEVIATION) WITH NO WEIGHTS

**Beginning position for wrist flexion, wrist extension, wrist radial deviation and wrist ulnar deviation**

- The first three exercises (wrist flexion, wrist extension and wrist radial deviation) have the same position which is sitting in a chair with one or two pillows on your lap.
- Elbows are bent to ninety degrees with forearms and hands resting on the pillows.
- Keep arms at the side of the body (do not reach forward).
- Do not shrug your shoulders because it will hurt your neck.
- Perform the next three exercises in this position.
- Ulnar deviation position will be discussed with the description of the exercises.

### **POSITION:**

#### **A. Wrist Flexion**



-With palms facing the ceiling, move hands up toward the ceiling and then back to the pillow. This is an active range of motion exercise, so there is no holding. Move hands up and down continuously in a slow and controlled manner.

Repeat this process for one and a half minutes.

## B. Wrist Extension:



-With palms facing the floor and in a fist position, raise hands up toward the ceiling and then back down to the pillow. This is an active range of motion exercise, so there is no holding during this exercise. Move hands slowly up and down continuously.

-Repeat this process for one and a half minutes.

### C. Radial Deviation:



-With palms facing each other and hands in fist position, raise hands up toward the ceiling then back to the pillow. This is an active range of motion exercise, so there is no holding. Move hands up and down continuously in a slow and controlled manner.

-Repeat this process for one and a half minutes.

#### **D. Ulnar Deviation:**



-Stand with palms facing legs in the fist position and elbows straight. Move hands backwards and then back to neutral position. This is an active range of motion exercise, so there is no holding during this exercise. Move hands slowly, backwards, then to neutral.

-Repeat this process for one and a half minutes.

#### **PROGRESSION FOR ALL FOUR EXERCISES:**

-Begin these four exercises at one and a half minutes and add ten seconds a day until you reach three minutes. Once you reach three minutes, you are ready for Level Three Neck, Mid Back And Upper Extremity exercise progression.

#### **YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:**

-There are no muscles that attach to the wrist bones. The muscles being strengthened attach from the elbow to the hand to help stabilize the wrist and elbow.

-You will feel these muscles contracting in your forearm while performing all four exercises.

#### **FOR THE PHYSICAL THERAPIST:**

-Have the patient move their wrist in a limited range of motion to stimulate proprioception in the wrist for all four exercises.

-During the three seated exercises (wrist flexion, wrist extension and wrist radial deviation) make sure the patient is sitting up straight (not slouched forward). This will protect the neck and back. If they have pain in the neck, mid back and shoulders during this exercise, add an extra pillow on their lap. Keep elbows close to their side in order to protect their shoulders from subluxations during exercise. If shoulders shrug up too much while performing these three seated exercises, remove a pillow (always keep at least one pillow).

-For the standing exercise (ulnar deviation), do not allow the patient to arch their back or lock their knees out. Maintain the wrists in the neutral position when returning from moving hand backwards.

-Do not allow the patient to swing their shoulders forward and back during exercise (move wrists only).

## 6. HAND BALL SQUEEZES



### **POSITION:**

- Perform this exercise after the four way wrist and maintain the same sitting posture.
- While sitting, keep wrist in the neutral position and elbow bent at ninety degrees. Gently squeeze tennis ball, holding for five seconds and resting for one second.
- Repeat this process for one and a half minutes.

### **PROGRESSION:**

- Begin this exercise at one and a half minutes and add ten seconds a day until you reach three minutes.
- Once you reach three minutes, continue this exercise through all seven levels of the neck, mid back and upper extremity progression.

### **YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:**

- Hand, finger and forearm muscles. This exercise is intended to prepare the hand, fingers, wrist and forearm for tubing exercises which will be introduced in the next level.

### **FOR THE PHYSICAL THERAPIST:**

- Keep the wrist in the neutral position during this exercise.

## 7. PRONE TYI EXERCISE

The prone TYI exercise is a series of three exercises which begin to activate the trapezius muscles. This will help decrease the kyphosis (bending forward) in your mid back, thus helping to hold the alignment of the mid back, ribs and shoulder blades. **If you are unable to lie on your stomach, do not perform the TYI exercises in this level and wait until Level Three to begin an alternate position for this exercise.**

### POSITION FOR ALL THREE EXERCISES:

- All three exercises can be performed on a bed. Lie on your stomach with a pillow under your hips, one pillow under shins and your forehead resting on a small towel roll, keeping your neck in the neutral position (looking down at the bed). **Do not turn your head to the side while performing all three exercises.**

### The “T”



**T:** Bring arms straight out to side with elbows slightly bent (don't lock elbows). Lift arms up toward ceiling while squeezing shoulder blades together. Hold arms up for five seconds and then return down without allowing upper arms to touch the mat. Repeat this process for one and a half minutes.

-Add ten seconds per day until you reach three minutes. Once you reach three minutes, you will be ready for Level Three Neck, Mid Back And Upper Extremity progression.

## The “Y”



**Y:** Place arms out to side with elbows bent to ninety degrees (like a field goal post). Lift arms up while squeezing the shoulder blades together and down toward buttocks. Hold for five seconds and then return down without allowing arms to touch the mat. Repeat this process for one and a half minutes.

-Add ten seconds per day until you reach three minutes. Once you reach three minutes, you will be ready for Level Three Neck, Mid Back And Upper Extremity progression.

## The “I”



**I:** Place the hands by the hips with elbows slightly bent (don't lock elbows). Keep palms facing down so you can activate triceps muscles as well as neck muscles. Lift arms up toward the ceiling and squeeze the shoulder blades together. Hold arms up for five

seconds and then return down without allowing arms to touch the mat. Repeat this process for one and a half minutes.

-Add ten seconds per day until you reach three minutes. Once you reach three minutes, you will be ready for Level Three Neck, Mid Back And Upper Extremity progression.

**YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:**

- Prone T: middle trapezius (between shoulder blades)
- Prone Y: lower trapezius (just below shoulder blades)
- Prone I: upper trapezius (neck)

**FOR THE PHYSICAL THERAPIST:**

- Hands should never be higher than one inch above their back (Do not allow the patient to hyperextend their shoulders).
- Do not allow the patient to arch their back when performing “Y” exercise (chest stays on the bed).
- Do not allow the patient to rotate their neck right or left when performing these exercises (keep neck in neutral).

## Level Three Neck, Mid Back & Upper Extremity Progression

### **FOR THE PERSON WITH EDS AND THE PHYSICAL THERAPIST:**

Once all exercises in Level Two have been completed, it is time to advance to Level Three. If the patient is unable to perform the TYI's in Level Two, have them begin with one of the two alternate positions for TYI's at this level. Level Three exercises consist of: prone chin tucks, TYI using one pound weights lying on a bed or TYI alternate position over ball with no weight, hand ball squeezes for three minutes from Level Two, four way wrist using one pound weights, shoulder internal rotation with yellow tubing, shoulder external rotation with tubing, full can with one pound weights, shoulder abduction with no weights, triceps push downs with yellow tubing and bicep curls with one pound weights. Continue manual therapy on T12 to C1 and ribs. Mulligan techniques can be performed on elbow, wrists and fingers and taping the shoulder may decrease pain. Elbow and wrist braces and finger ring splints can be used as needed to control pain.

- 1.

## 1. PRONE CHIN TUCKS



### **POSITION:**

- Lie on stomach with a pillow under the hips and another pillow under the shins. Lift head off the mat and tuck chin (like you're giving yourself a double chin).
- Eyes should stay focused on one spot on the bed while maintaining chin tuck. Only lift head up in a pain-free and dizziness-free range of motion.
- Hold this position steady for one and a half minutes (do not move head/neck up and down throughout exercise). Then rest after one and a half minutes, because you have finished the exercise. If you have increased pain in your neck or have increased dizziness, then stop this exercise immediately and whatever time you have reached will be the time at which you will begin this exercise. Then, follow the ten second per day rule progression until you reach three minutes.

### **PROGRESSION:**

- Begin this exercise at one and a half minutes or whenever pain and dizziness begin, and add ten seconds a day until you reach three minutes. Once you reach three minutes, you are ready for Level Four Neck, Mid Back And Upper Extremity exercise progression.

### **YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:**

- Occipital muscles to help stabilize C1 and C2 vertebrae (top of neck at base of skull).
- Deep cervical muscles including longus colli to stabilize C3-T1 (bottom of neck).

**FOR THE PHYSICAL THERAPIST:**

**1A. ALTERNATE POSITION PRONE CHIN TUCK OVER BALL**



- Have patient perform this alternate position if they are unable to lie on their stomach due to pain.
- Have the patient lie over the ball with their arms resting on ball.
- Have the patient lift their head up and tuck their chin and hold the position for one and a half minutes. Add ten seconds per day until they reach three minutes.
- Do not allow the patient to lift their head too high off the ball because it can cause dizziness.
- The patient may have to begin the exercise for a shorter time than one and a half minutes, but keep the ten seconds per day progression the same.
- Do not allow the patient to lift their chest off the ball because it will increase low back pain.
- Do not let patient hyperextend their neck because this can cause dizziness.
- Maintain a static hold of the chin tuck. Do not move head/neck up and down because this will cause stress to C1.

## 2. TYI USING ONE POUND WEIGHTS

### “T” Using One Pound Weights



### “Y” Using One Pound Weights



### “I” Using One Pound Weights



-The TYI exercises will be performed the same as described in Level Two, except now a one pound weight will be held in each hand. If you are unable to hold weights, then use wrist weights instead.

### **PROGRESSION:**

-Begin this exercise at one and a half minutes. Add ten seconds per day until you reach three minutes. Once you reach three minutes, you will be ready for Level Four Neck, Mid Back And Upper Extremity progression.

### **FOR THE PHYSICAL THERAPIST**

**-If using either of the alternate positions, the patient should perform these exercises WITHOUT weights since they have not performed these exercises in Level Two.** Begin this exercise between thirty seconds to one minute, or whatever time the patient can tolerate. This is the first time the patient is performing a chin tuck, therefore, their deep cervical extensors may not be able to handle a prolonged hold in this position. If the patient complains of any increased neck, rib or shoulder pain, the patient should stop immediately and that will be the amount of time for them to start this exercise (this exercise should always be performed for a length of time that is pain-free and dizziness-free).

## 2A. TYI ALTERNATE POSITION KNEELING OVER BALL WITHOUT WEIGHTS

-Use this position if the patient is unable to lie on their stomach and do not have knee pain in the kneeling position. The neck will need to be held in the chin tuck position for the entire length of each exercise (TYI). This position will place more stress on the neck muscles and if the patient gets increased neck pain or dizziness, then limit the time of the exercise to complete it without neck pain or dizziness. **This is performed WITHOUT weights since they have not performed these exercises in Level Two.** Begin this exercise between thirty seconds to one minute or whatever time they can tolerate. Then follow the ten seconds per day progression until reaching three minutes.

### “T” Kneeling Over Ball Without Weights



-Place physioball on mat, bed or floor, whichever is most comfortable and easiest to get up from. Kneel down and lean over the ball so that your stomach is resting on the ball and perform a chin tuck.

-Rest arms on the ball and lift them straight out to the side, squeezing the shoulder blades together. Hold this position for five seconds and return down to the original position, resting for one second.

-Repeat this process for thirty seconds to one minute, depending on neck pain. Add ten seconds per day until you reach three minutes. Then you are ready for Level Four alternate position.

### **“Y” Kneeling Over Ball Without Weights**



- Place physioball on mat, bed or floor, whichever is most comfortable and easiest to get up from. Kneel down and lean over the ball so that your stomach is resting on the ball and perform a chin tuck.
- Rest your hands on the ball with elbows bent to ninety degrees and shoulders abducted to eighty degrees (like “touch down” position).
- Lift your arms up toward the ceiling while squeezing your shoulder blades together and down. Hold this position for five seconds. Then return down to the original position, resting for one second.
- Repeat this process for thirty seconds to one minute, depending on neck pain. Add ten seconds per day until you reach three minutes. Then you are ready for Level Four alternate position.

### **"I" Kneeling Over Ball Without Weights**



-Place physioball on mat, bed or floor, whichever is most comfortable and easiest to get up from. Kneel down and lean over the ball so that your stomach is resting on the ball and perform a chin tuck.

-Have your arms straight, resting on the ball palms facing the floor. Lift your arms straight up to ceiling squeezing the shoulder blades together. Hold this position for five seconds. Then return to original position, resting for one second.

-Repeat this process for thirty seconds to one minute, depending on neck pain. Add ten seconds per day until you reach three minutes. Then you are ready for Level Four alternate position.

## 2B. TYI ALTERNATE POSITION LEANING OVER BALL WITHOUT WEIGHTS

-Use this position if patients are unable to lie on their stomach and have knee pain in the kneeling position. Their neck will need to be held in the chin tuck position for the entire exercise (TYI). This position will place more stress on the neck muscles and if the patient gets increased neck pain, then limit the time of the exercise to complete it without neck pain. **This is performed WITHOUT weights, since they have not performed these exercises in Level Two.** Begin this exercise between thirty seconds to one minute or whatever time they can tolerate. Then follow the ten seconds per day progression until reaching three minutes.

### “T” Leaning Over Ball Without Weights



- Place the ball on a couch, stand the facing the ball and lean over it. Maintain a chin tuck with this position.
- Make sure your back is bent forward to only forty-five degrees and not lower. This will protect your back.
- Your stomach should be resting on the ball. Let neck and shoulder pain determine how long to perform each exercise.
- Rest your arms on the ball and lift them straight out to the side, squeezing your shoulder blades together. Hold this position for five seconds and return down to the original position, resting for one second.

-Perform this exercise for thirty seconds to one minute, depending on neck pain. Add ten seconds per day until you reach three minutes. Then you are ready for Level Four alternate position.

### **“Y” Leaning Over Ball Without Weights**



-Place the ball on a couch, stand the facing the ball, and lean over it. Maintain a chin tuck with this position.

-Make sure your back is bent forward to only forty-five degrees and not lower. This will protect your back.

-Your stomach should be resting on the ball. Let neck and shoulder pain determine how long to perform each exercise.

-Rest hands on ball with elbows bent to ninety degrees and shoulders abducted to eighty degrees (like the “touch down” position).

-Lift arms up toward ceiling while squeezing shoulder blades together and down. Hold this position for five seconds. Then return to original position resting for one second.

-Repeat this process for thirty seconds to one minute, depending on neck pain. Add ten seconds until you reach three minutes. Then you are ready for Level Four alternate position.

## **“I” Leaning Over Ball Without Weights**



- Place the ball on a couch, stand facing the ball, and lean over it. Maintain a chin tuck with this position.
- Make sure your back is bent forward to only forty-five degrees and not lower. This will protect your back.
- Your stomach should be resting on the ball. Let neck and shoulder pain determine how long to perform each exercise.
- Have arms straight, resting on the ball palms facing the floor. Lift arms straight up to ceiling squeezing shoulder blades together. Hold this position for five seconds. Then return to original position, resting for one second.
- Repeat this process for thirty seconds to one minute, depending on neck pain. Add ten seconds per day until you reach three minutes. Then you are ready for Level Four alternate position.

### 3. SHOULDER EXTERNAL ROTATION WITH YELLOW TUBING



#### **POSITION:**

- Hold a yellow theraband in your hand, keeping the wrist straight and elbow bent to ninety degrees, with your elbow at your side and hand near the belly button. Move hand out to about neutral, keeping wrist rigid. If unable to hold the band, loop it around your wrist/forearm.
- Stand up straight and keep shoulder blades squeezed together.
- This is an active range of motion exercise, so there is no holding. Move the arm in and out continuously in a slow and controlled manner.
- Repeat this process for one and a half minutes.

#### **PROGRESSION:**

- Begin this exercise at one and a half minutes. Add ten seconds per day until you reach three minutes. Once you reach three minutes, you will be ready for Level Four Neck, Mid Back And Upper Extremity progression.

#### **YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:**

-Infraspinatus and teres minor (behind the shoulder)

**FOR THE PHYSICAL THERAPIST:**

- Loop the tubing around the distal forearm if the hand hurts.
- Have the patient move in a pain-free range of motion.
- Limit the range of motion only to neutral to prevent possible shoulder subluxation.
- Keep the wrist rigid, elbow at the side, and palm facing inward.
- Do not allow patient to arch their back or hyperextend their knees.

## 4. SHOULDER INTERNAL ROTATION WITH YELLOW TUBING



### **POSITION:**

- Hold a yellow theraband in your hand, keeping the wrist straight and elbows bent to ninety degrees with the elbow at your side and forearm at neutral. Move your hand inward, touching your belly button and then back out to neutral.
- Keep the wrist rigid, elbow at the side, and palm facing inward.
- Stand up straight and keep shoulder blades squeezed together.
- This is an active range of motion exercise, so there is no holding. Move the arm in and out continuously in a slow and controlled manner.
- Repeat this process for one and a half minutes.

### **PROGRESSION:**

- Begin this exercise at one and a half minutes.
- Add ten seconds per day until you reach three minutes. Once you reach three minutes, you will be ready for Level Four Neck, Mid Back And Upper Extremity progression.

**YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:**

- Subscapularis and pectoralis major (front of shoulder)

**FOR THE PHYSICAL THERAPIST:**

- Loop the tubing around the distal forearm if the hand hurts.
- Move in a pain-free range of motion to avoid shoulder subluxations.
- Limit shoulder external rotation to avoid anterior shoulder subluxations.
- Keep the wrist rigid, elbow at the side, and palm facing inward.
- Do not allow the patient to arch their back or hyperextend their knees.

## 5. FULL CAN EXERCISE USING ONE POUND WEIGHTS



-The Full Can exercise will be performed the same as in Level Two with the exception that now you are standing instead of sitting, and now a one pound weight will be added and held in each hand. If you are unable to hold weights, then use wrist weights instead.

-Don't arch your back when lifting the arms.

-Keep hands below shoulder height.

### **PROGRESSION:**

-Begin this exercise at one and a half minutes.

-Add ten seconds per day until you reach three minutes. Once you reach three minutes, you will be ready for Level Four Neck, Mid Back And Upper Extremity progression.

**FOR THE PHYSICAL THERAPIST:**

- Do not let the patient lift their shoulder higher than sixty degrees of flexion.
- This is an active range of motion (AROM) exercise; therefore no holding.
- Arms should be in plane the scapula with palms facing each other.
- Have patients use wrist weights if their hands or wrists hurt while holding dumbbells.

## 6. SHOULDER ABDUCTION WITH NO WEIGHTS



### **POSITION:**

- Stand with your hands by your sides and slowly raise both arms out to the side to shoulder height with elbows slightly bent and palms facing the floor. Then return back down to the starting position.
- Do not raise hands above the shoulders. Keep in a pain free range of motion.
- Do not arch the back when lifting the arms.
- This is an active range of motion exercise, so there is no holding. Move the arms up and down continuously in a slow and controlled manner.
- Repeat this process for one and a half minutes.

### **PROGRESSION:**

- Begin this exercise at one and a half minutes. Add ten seconds per day until you reach three minutes. Once you reach three minutes, you will be ready for Level Four Neck, Mid Back And Upper Extremity progression.

### **YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:**

- Deltoids (outside of shoulder)

**FOR THE PHYSICAL THERAPIST:**

- When the patient raises their arms out to the side, their hands should not go above shoulder height.
- The patient should lift their shoulders out to the side in a pain free range of motion.
- The patient should not shrug shoulders when raising arms because this can hurt their neck.
- The patient should not arch their back or hyperextend their knees.

## 7. FOUR WAY WRIST EXERCISE USING ONE POUND WEIGHTS

### A. Wrist Flexion



### B. Wrist Extension



### C. Wrist Radial Deviation



### D. Wrist Ulnar Deviation



-The four way wrist exercises will be performed in the same position as Level Two, except now a one pound weight will be held in each hand. If you are unable to hold weights, then use wrist weights around hands.

### **PROGRESSION:**

-Begin exercise at one and a half minutes. Add ten seconds per day until you reach three minutes. Once you reach three minutes, you will be ready for Level Four Neck, Mid Back And Upper Extremity progression.

## 8. HAND BALL SQUEEZES



- This exercise is the same as described in Level Two.
- Perform this exercise for three minutes on Tuesdays and Fridays only.

## 9. TRICEPS PUSH DOWN WITH YELLOW TUBING



### **POSITION:**

- Stand with yellow tubing secured at the top of a door (tie a knot in the tubing, place the knot on the opposite side of the door, then shut the door).
- Elbow should be bent to ninety degrees and palm facing inward toward midline of body.
- Straighten the elbow so the hand moves downward toward the hip and then return back up to ninety degrees of elbow flexion.
- This is an active range of motion exercise, so there is no holding. Move the arm up and down continuously in a slow and controlled manner.
- Repeat process for one and a half minutes. Then repeat same process for one and a half minutes with other arm.

### **PROGRESSION:**

- Begin this exercise at one and a half minutes for each arm. Add ten seconds per day until you reach three minutes. Once you reach three minutes for each arm, you will be ready for Level Four Neck, Mid Back And Upper Extremity progression.

**YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:**

- Triceps (back of arm)

**FOR THE PHYSICAL THERAPIST:**

- The patient should stand up straight. Do not allow patient to lean toward the side of the arm with the tubing.
- Do not allow the patient to lean forward with their body when pushing the tubing down. Have them keep their body steady and move only the forearm up and down.
- The patient should keep their wrist rigid in the neutral position (they should not bend at the wrist).
- The patient can loop tubing around the forearm if their wrist and hand hurts.
- Do not allow the patient to shrug their shoulders up.

## 10. BICEP CURLS USING ONE POUND WEIGHTS



### **POSITION:**

- Stand with arms by your side holding a one pound weight and palms facing inward toward your body.
- Curl one arm up at a time, while twisting the forearm so the palm of the hand faces up when you reach the top of the curl.
- Lower the arm down twisting the forearm again so the palm faces inward toward your body when it returns to the starting position. Repeat this process with the other arm.
- Continue alternating right and left arm curls for one and a half minutes total.
- This is an active range of motion exercise, so there is no holding. Move arms up and down continuously in a slow and controlled manner.
- Do not twist your body to one side while lifting the weight.

### **PROGRESSION:**

- Begin this exercise at one and a half minutes. Add ten seconds per day until you reach three minutes. Once you reach three minutes, you will be ready for Level Four Neck, Mid Back And Upper Extremity progression.

**YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:**

- Biceps (front of arm)

**FOR THE PHYSICAL THERAPIST:**

- Have the patient maintain a slow and controlled speed throughout this exercise, while alternating left and right arms.
- Have the patient keep their stomach tight throughout the exercise and stand up straight so they will not lean backwards or to the side while curling the weights.
- Make sure to have the patient supinate their arm with elbow flexion.
- The patient can use wrist weights if the hands and wrists are a problem.
- Do not allow the patient to shrug their shoulders up, as that can cause neck pain.
- Control eccentric contraction to avoid shoulder and elbow subluxations.

## Level Four Neck, Mid Back And Upper Extremity Progression

### **FOR THE PERSON WITH EDS AND THE PHYSICAL THERAPIST:**

Once you have completed all of the exercises in Level Three, you are ready to advance to Level Four. Level Four exercises consist of: TYI with chin tucks using one pound weights, either with or without the ball (see alternate positions), shoulder internal rotation with red tubing, shoulder external rotation with red tubing, full can using two pound weights, shoulder abduction with one pound weights, four way wrist using two pound weights, triceps pushdowns with red tubing, bicep curls with two pound weights and hand ball squeezes for three minutes. With the exception of prone TYI with chin tucks, all of the other exercises are the same as in level two or three with the exception of increased resistance. Refer to Level Two and Level Three for information on positioning, muscles strengthened and “For The Physical Therapist” sections to ensure proper completion of Level Four exercises. Continue manual therapy on the sacrum, L5 to C1 and the ribs. Taping the shoulder and bracing the elbow and wrist can be done as needed. Mulligan techniques can also be performed on the elbow, wrist and hand as well.

## 1. TYI WITH PRONE CHIN TUCK USING ONE POUND WEIGHTS

-For all three exercises, lie on stomach with a pillow under the hips and another pillow under the shins. Perform a prone chin tuck as described in Level Three for the entire time of the exercise. Never rest the chin tuck.

### “T” Using One Pound Weight With Chin Tuck



-While maintaining a chin tuck throughout the duration of this exercise and holding a one pound weight in your hands, bring arms straight out to side with elbows slightly bent (don't lock elbows). Lift arms up toward ceiling while squeezing shoulder blades together. Hold arms up for five seconds, and then return down without allowing upper arms to touch the mat. Repeat this process for one and a half minutes or whatever time you can tolerate. Then rest your arms and chin tuck until you are ready to perform “Y” exercise.

### **“Y” Using One Pound Weight With Chin Tuck**



-While maintaining a chin tuck throughout the duration of this exercise and holding a one pound weight in your hands, place arms out to the side with elbows bent to ninety degrees (like a field goal post). Lift arms up while squeezing the shoulder blades together and down toward buttocks. Hold for five seconds and then return arms down without allowing arms to touch the mat. Repeat this process for one and a half minutes or whatever time you can tolerate. Then rest arms and chin tuck until you are ready to perform the “I” exercise.

### **“I” Using One Pound Weight With Chin Tuck**



-While maintaining a chin tuck throughout the duration of this exercise and holding a one pound weight in your hands, place the hands by the hips with elbows slightly bent (don't lock elbows). Keep palms facing down so you can activate triceps muscles as well as neck muscles. Lift arms up toward the ceiling and squeeze the shoulder blades together. Hold arms up for five seconds and then return down without allowing the arms to touch the mat. Repeat this process for one and a half minutes or whatever time you can tolerate. Then rest your arms and chin tuck when you are finished.

**PROGRESSION:**

-Begin these exercises for one and a half minutes and add ten seconds per day until you reach three minutes. Once you reach three minutes, you are ready for Level Five Neck, Mid Back And Upper Extremity progression.

**YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:**

- Deep neck extensors (back of neck) for the T, Y and I
- Prone T: middle trapezius (between shoulder blades)
- Prone Y: lower trapezius (just below shoulder blades)
- Prone I: upper trapezius (neck)

**FOR THE PHYSICAL THERAPIST:**

-Begin these exercises at one and a half minutes or whatever time the patient can tolerate. Add ten seconds per day until reaching three minutes for each exercise. If the patient complains of any increased neck, rib or shoulder pain or increased dizziness, the patient should stop immediately and that will be the amount of time for them to start this exercise (this exercise should always be performed for a length of time that is pain-free).

## **1A. TYI ALTERNATE POSITION KNEELING OVER BALL WITH CHIN TUCK WITH ONE POUND WEIGHTS**

-Use this position if you are unable to lie on your stomach and do not have knee pain in the kneeling position. The neck will need to be held in the chin tuck position for the entire length of each exercise (TYI). This position will place more stress on the neck muscles and if the patient gets increased neck pain, then limit the time of the exercise to complete it without neck pain. Begin this exercise at one and a half minutes or whatever time you can tolerate. Then follow the ten seconds per day progression until reaching three minutes.

### **“T” Kneeling Over Ball With One Pound Weights**



-Place physioball on mat, bed or floor, whichever is most comfortable and easiest to get up from. Kneel down and lean over the ball so that your stomach is resting on the ball and perform a chin tuck.

-Holding a one pound weight in your hands, rest arms on the ball and lift them straight out to the side, squeezing the shoulder blades together. Hold this position for five seconds and return down to the original position, resting for one second.

-Repeat this process for one and a half minutes or whatever time you can tolerate. Add ten seconds per day until you reach three minutes. Once you reach three minutes, you are ready for Level Five alternate position.

## **“Y” Kneeling Over Ball With One Pound Weights**



-Place physioball on mat, bed or floor, whichever is most comfortable and easiest to get up from. Kneel down and lean over the ball so that your stomach is resting on the ball and perform a chin tuck.

-Hold one pound weights in your hands and rest your hands on the ball with elbows bent to ninety degrees and shoulders abducted to eighty degrees (like the “touch down” position).

-Lift your arms up toward the ceiling while squeezing your shoulder blades together and down. Hold this position for five seconds. Then return down to the original position, resting for one second.

-Repeat this process for one and a half minutes or whatever you can tolerate. Add ten seconds per day until you reach three minutes. Then you are ready for Level Five alternate position.

### "I" Kneeling Over Ball With One Pound Weights



-Place physioball on mat, bed or floor, whichever is most comfortable and easiest to get up from. Kneel down and lean over the ball so that your stomach is resting on the ball and perform a chin tuck.

-Hold one pound weights in your hands and have your arms straight, resting on the ball palms facing the floor. Lift your arms straight up to ceiling squeezing the shoulder blades together. Hold this position for five seconds. Then return to original position, resting for one second.

-Repeat this process for one and a half minutes or whatever you can tolerate. Add ten seconds per day until you reach three minutes. Then you are ready for Level Five alternate position.

## **1B. TYI ALTERNATE POSITION LEANING OVER BALL WITH ONE POUND WEIGHTS**

-Use this position if you are unable to lie on your stomach and have knee pain in the kneeling position. Your neck will need to be held in the chin tuck position for the entire exercise (TYI). This position will place more stress on the neck muscles and if you get increased neck pain, then limit the time of the exercise to complete it without neck pain. Begin this exercise for one and a half minutes or whatever time they can tolerate. Then follow the ten seconds per day progression until reaching three minutes.

### **“T” Leaning Over Ball With One Pound Weights**



- Place the ball on a couch, stand the facing the ball, and lean over it. Maintain a chin tuck with this position.
- Make sure your back is bent forward to only forty-five degrees and not lower. This will protect your back.
- Your stomach should be resting on the ball. Let neck and shoulder pain determine how long to perform each exercise.
- Hold a one pound weight in your hands and rest your arms on the ball and lift them straight out to the side squeezing your shoulder blades together. Hold this position for five seconds and return down to the original position, resting for one second.
- Perform this exercise one and half minutes or whatever you can tolerate. Add ten

seconds per day until you reach three minutes. Then you are ready for Level Five alternate position.

### **“Y” Leaning Over Ball With One Pound Weights**



-Place the ball on a couch, stand the facing the ball, and lean over it. Maintain a chin tuck with this position.

-Make sure your back is bent forward to only forty-five degrees and not lower. This will protect your back.

-Your stomach should be resting on the ball. Let neck and shoulder pain determine how long to perform each exercise.

-Hold a one pound weight in your hands and rest hands on ball with elbows bent to ninety degrees and shoulders abducted to eighty degrees (like the “touch down” position).

-Lift arms up toward ceiling while squeezing shoulder blades together and down. Hold this position for five seconds. Then return to original position resting for one second.

-Repeat this process for one and a half minutes or whatever you can tolerate. Add ten seconds until you reach three minutes. Then you are ready for Level Five alternate position.

## **"I" Leaning Over Ball With One Pound Weights**



- Place the ball on a couch, stand facing the ball, and lean over it. Maintain a chin tuck with this position.
- Make sure your back is bent forward to only forty-five degrees and not lower. This will protect your back.
- Your stomach should be resting on the ball. Let neck and shoulder pain determine how long to perform each exercise.
- Hold one pound weights in your hands and have arms straight, resting on the ball, palms facing the floor. Lift arms straight up to ceiling squeezing shoulder blades together. Hold this position for five seconds. Then return to original position resting for one second.
- Repeat this process for one and a half minutes or whatever you can tolerate. Add ten seconds per day until you reach three minutes. Then you are ready for Level Five alternate position.

## 2. HAND BALL SQUEEZES



-Refer to explanation of this exercise shown in Level Two Neck, Mid Back And Upper Extremity progression.

Perform this for three minutes on Tuesdays and Fridays only.

### 3 FOUR WAY WRIST USING TWO POUND WEIGHTS

#### A. Wrist Flexion



#### B. Wrist Extension



### C. Wrist Radial Deviation



### D. Wrist Ulnar Deviation



-Perform all four exercises as described in Level Two Neck, Mid Back And Upper Extremity progression while holding a two pound weight.

-Begin these exercises for one and a half minutes. Add ten seconds per day until you reach three minutes. Once you reach three minutes, you will be ready for Level Five Neck, Mid Back And Upper Extremity progression.

## 4. SHOULDER INTERNAL AND EXTERNAL ROTATION WITH RED TUBING

### Internal Rotation



### External Rotation



-Perform each exercise individually, as described in Level Three Neck, Mid Back And Upper Extremity progression, but with using red tubing.

-Begin these exercises for one and a half minutes. Add ten seconds per day until you reach three minutes. Once you reach three minutes, you will be ready for Level Five Neck, Mid Back And Upper Extremity progression.

## 5. FULL CAN USING TWO POUND WEIGHTS



-Perform this exercise in standing as described in Level Three Neck, Mid Back And Upper Extremity progression, but with using a two pound weight.

-Begin this exercise for one and a half minutes. Add ten seconds per day until you reach three minutes. Once you reach three minutes, you will be ready for Level Five Neck, Mid Back And Upper Extremity progression.

## 6. SHOULDER ABDUCTION USING ONE POUND WEIGHTS



-Perform this exercise in the standing position as described in Level Three Neck, Mid Back And Upper Extremity progression, but with using a one pound weight.

-You can use wrist weights if hand and wrist hurt.

-Begin this exercise for one and a half minutes. Add ten seconds per day until you reach three minutes. Once you reach three minutes, you will be ready for Level Five Neck, Mid Back And Upper Extremity progression.

## 7. BICEP CURL USING TWO POUND WEIGHTS



-Perform this exercise while standing as described In Level Three Neck, Mid Back And Upper Extremity progression, but with using a two pound weight.

-Begin this exercise for one and a half minutes. Add ten seconds per day until you reach three minutes. Once you reach three minutes, you will be ready for Level Five Neck, Mid Back And Upper Extremity progression.

## 8. TRICEPS PUSH DOWNS USING RED TUBING



-Perform this exercise while standing as described in Level Three Neck, Mid Back And Upper Extremity progression, but with using red tubing.

-Begin this exercise for one and a half minutes. Add ten seconds per day until you reach three minutes. Once you reach three minutes, you will be ready for Level Five Neck, Mid Back And Upper Extremity progression.

## Level Five Neck, Mid Back And Upper Extremity Protocol

### **FOR THE PERSON WITH EDS AND THE PHYSICAL THERAPIST:**

Once all exercises from Level Four have been completed, you are ready to advance to Level Five. All the exercises in this level are the same as described in Level Four with the exception of the craniosacral and TMJ exercises. The exercises for this level are: TYI with chin tuck with a two pound weights with or without using a ball (see alternate position), shoulder internal rotation with green tubing, shoulder external rotation with green tubing, full can with three pound weight, shoulder abduction with two pound weight, four way wrist with three pound weight, hand ball squeezes for three minutes (Tuesdays and Fridays only), bicep curls with three pound weights, triceps push downs with green tubing, begin craniosacral exercises which are: criss-cross eyes, eyebrow raise, ear wiggle and TMJ isometrics. The physical therapist should continue to perform manual therapy on the SIJ, L5 through C1 and ribs as needed. Craniosacral therapy and manual therapy to the TMJ can begin at this level if needed. Mulligan techniques can be used for elbow, wrist and hand and taping of the shoulder can be performed. This level is the point at which patients often become frustrated with this exercise progression. They have received minimal pain relief in the areas being treated because they have not reached the top level yet. It is crucial that the physical therapist continues to reassure patients that the alignment will hold once they reach the top level.

## 1. TYI WITH PRONE CHIN TUCK USING TWO POUND WEIGHTS

-These exercises are the same as described in Level Four, except now perform these while holding a two pound weight. Perform either the standard position on the mat or the alternate positions on the ball.

### “T” Using Two Pound Weights



-Begin these exercises for one and a half minutes. Add ten seconds per day until you reach three minutes. Once you reach three minutes, you will be ready for Level Six Neck, Mid Back And Upper Extremity progression.

### “Y” Using Two Pound Weights



-Begin this exercise for one and a half minutes. Add ten seconds per day until you reach three minutes. Once you reach three minutes, you will be ready for Level Six Neck, Mid Back And Upper Extremity progression.

### **"I" Using Two Pound Weights**



-Begin this exercise for one and a half minutes. Add ten seconds per day until you reach three minutes. Once you reach three minutes, you will be ready for Level Six Neck, Mid Back And Upper Extremity progression.

### **FOR THE PHYSICAL THERAPIST:**

-Begin these exercises at one and a half minutes or whatever time the patient can tolerate. Add ten seconds per day until reaching three minutes for each exercise. If the patient complains of any increased neck, rib or shoulder pain or increased dizziness, the patient should stop immediately and that will be the amount of time for them to start this exercise (this exercise should always be performed for a length of time that is pain-free and dizziness-free).

## **1A. TYI ALTERNATE POSITION KNEELING OVER BALL WITH CHIN TUCK WITH TWO POUND WEIGHTS**

-Use this position if you are unable to lie on your stomach and do not have knee pain in the kneeling position. The neck will need to be held in the chin tuck position for the entire length of each exercise (TYI). This position will place more stress on the neck muscles and if you get increased neck pain, then limit the time of the exercise to complete it without neck pain. Begin this exercise for one and a half minutes. Then add ten seconds per day until you reach three minutes. Once you reach three minutes, you are ready for Level Six TYI alternate position.

### **“T” Kneeling Over Ball With Two Pound Weights**



-Perform this exercise for one and a half minutes. Add ten seconds per day until you reach three minutes. Then you are ready for Level Six alternate position.

### **“Y” Kneeling Over Ball With Two Pound Weights**



-Perform this exercise for one and a half minutes. Add ten seconds per day until you reach three minutes. Then you are ready for Level Six alternate position.

### **“I” Kneeling Over Ball With Two Pound Weights**



-Perform this exercise for one and a half minutes. Add ten seconds per day until you reach three minutes. Then you are ready for Level Six alternate position.

## **1B. TYI ALTERNATE POSITION LEANING OVER BALL WITH TWO POUND WEIGHTS**

-Use this position if you are unable to lie on your stomach and have knee pain in the kneeling position. Your neck will need to be held in the chin tuck position for the entire exercise (TYI). This position will place more stress on the neck muscles and if you get increased neck pain, then limit the time of the exercise to complete it without neck pain. Begin this exercise for one and a half minutes. Then add ten seconds per day until you reach three minutes. Once you reach three minutes, you are ready for Level Six alternate position.

### **“T” Leaning Over Ball With Two Pound Weights**



-Perform this exercise for one and a half minutes. Add ten seconds per day until you reach three minutes. Then you are ready for Level Six alternate position.

### **“Y” Leaning Over Ball With Two Pound Weights**



-Perform this exercise for one and a half minutes. Add ten seconds until you reach three minutes. Then you are ready for Level Six alternate position.

### **“I” Leaning Over Ball With Two Pound Weights**



-Perform this exercise for one and a half minutes. Add ten seconds until you reach three minutes. Then you are ready for Level Six alternate position.

## 2. HAND BALL SQUEEZES



-Refer to explanation of this exercise shown in Level Two Neck, Mid Back And Upper Extremity progression.

Perform this for three minutes on Tuesdays and Fridays only.

### 3. FOUR WAY WRIST USING THREE POUND WEIGHTS

#### A. Wrist Flexion



#### B. Wrist Extension



### C. Wrist Radial Deviation



### D. Wrist Ulnar Deviation



-Perform all four exercises as described in Level Two Neck, Mid Back And Upper Extremity progression while holding a three pound weight.

-Begin this exercise for one and a half minutes. Add ten seconds per day until you reach three minutes. Once you reach three minutes, you will perform this exercise for three minutes on Tuesdays and Fridays only.

## 4. SHOULDER INTERNAL AND EXTERNAL ROTATION USING GREEN TUBING

### Internal Rotation



### External Rotation



-Perform each exercise individually as described in Level Three Neck, Mid Back And Upper Extremity progression, but with using green tubing.

-Begin each exercise for one and a half minutes. Add ten seconds per day until you reach three minutes. Once you reach three minutes, you will be ready for Level Six Neck, Mid Back And Upper Extremity progression.

## 5. FULL CAN USING THREE POUND WEIGHTS



-Perform this exercise while standing as described in Level Three Neck, Mid Back And Upper Extremity progression, but with using a three pound weight.

-Begin this exercise for one and a half minutes. Add ten seconds per day until you reach three minutes. Once you reach three minutes, you will be ready for Level Six Neck, Mid Back And Upper Extremity progression.

## 6. SHOULDER ABDUCTION USING TWO POUND WEIGHTS



-Perform this exercise in standing as described in Level Three Neck, Mid Back And Upper Extremity progression, but with using a two pound weight.

-Begin this exercise for one and a half minutes. Add ten seconds per day until you reach three minutes. Once you reach three minutes, you will be ready for Level Six Neck, Mid Back And Upper Extremity progression.

## 7. BICEP CURL USING THREE POUND WEIGHTS



-Perform this exercise in standing as described in Level Three Neck, Mid Back And Upper Extremity progression, but with using a three pound weight.

-Begin this exercise for one and a half minutes. Add ten seconds per day until you reach three minutes. Once you reach three minutes, you will be ready for Level Six Neck, Mid Back And Upper Extremity progression.

## 8. Triceps Push Downs Using Green Tubing



-Perform this exercise as described in Level Three Neck, Mid Back And Upper Extremity progression, but with using green tubing.

-Begin this exercise for one and a half minutes. Add ten seconds per day until you reach three minutes. Once you reach three minutes, you will be ready for Level Six Neck, Mid Back And Upper Extremity progression.

## 9. CRANIOSACRAL EXERCISES

-These exercises are intended to stimulate muscles that attach to the cranial bones. They should begin at one and a half minutes and add ten seconds per day until you reach three minutes. Once you reach three minutes, add this to your Tuesday and Friday schedule. There are no progressions for these exercises. They are as follows:

### **1. Criss-cross eyes**

-Look down and inward (medially) toward the nose with both eyes and then elevate the eyelids. Make sure the patient does not overstrain with this exercise.

-Hold for five seconds then rest for one second. Repeat for one and a half minutes and add ten seconds per day until you reach three minutes.

#### **YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:**

-superior oblique, levator palpebrae (muscles for the sphenoid)

### **2. Eyebrow Raise**

-Raise eyebrows and wrinkle forehead (in “surprise” expression).

-Hold for five seconds then rest for one second. Repeat for one and a half minutes and add ten seconds per day until you reach three minutes.

#### **YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:**

-occipitals, frontalis (muscles for the occipital and frontal bones)

### **3 Ear Wiggle**

-Move ears backward (posterior) and forward as in a wiggle motion.

-Move in a continuous manner without holding.

-Repeat this for one and a half minutes, adding ten seconds per day until you reach three minutes.

#### **YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:**

-temporalis (muscle for the temporal bone)

#### 4. TMJ (Temporomandibular Joint) Isometrics

- These exercises help to stabilize the jaw.
- Perform gentle isometric contractions to the jaw (mandible).

A.



-Make sure the tongue is resting at the roof of the mouth while performing this exercise to avoid clenching.

-Place the right index fingertip on the right side of the jaw bone (below the cheek bone). Gently push the jaw toward the right using your jaw muscles, using your finger for resistance.

-Hold for five seconds, then relax. Repeat this for **one minute**.

B.



-Next, place the left index fingertip on the left side of the jaw bone (below the cheek bone). Gently push the jaw toward the left using your jaw muscles, using your finger for resistance.

-Hold for five seconds, then relax. Repeat this for **one minute**.

C.



-Next, place the tip of your index finger on top of the bottom row of front teeth. Gently try to close your mouth.

-Hold for five seconds, then relax. Repeat this for **one minute**.

D.



-Next, place your fist under the jaw/chin. Gently try to open your mouth.

-Hold for five seconds, then relax. Repeat this for **one minute**.

E.



-Place the tip of your index finger under the lower lip, but above the chin. Gently push the jaw forward into the fingertip.

-Hold for five seconds, then relax. Repeat this for **one minute**.

-If the last motion causes too much pain in the TMJ, decrease the time of the exercise, then add ten seconds per day until reaching three minutes.

**YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:**

-Masseter, lateral pterygoid, medial pterygoid and temporalis (jaw muscles)

## Level Six Neck, Mid Back & Upper Extremity Protocol

### **FOR THE PERSON WITH EDS AND THE PHYSICAL THERAPIST:**

Begin this level once all the exercises from Level Five have been completed. Level Six exercises are the same as Level Five exercises with the exception of adding weights. The exercises for this level are: TYI with chin tucks with three pound weights with or without using a ball (see alternate positions), hand ball squeezes on Tuesdays and Fridays only, four way wrist with three pound weights on Tuesdays and Fridays only, shoulder internal rotation with blue tubing, shoulder external rotation with blue tubing, full can with four pound weights, shoulder abduction with three pound weights, bicep curls with four pound weights, triceps push downs with blue tubing, criss-cross eyes on Tuesdays and Fridays only, eyebrow raise on Tuesdays and Fridays only, ear wiggle on Tuesdays and Fridays only and TMJ isometrics on Tuesdays and Fridays only.

For most patients with EDS, things will begin to feel better once reaching three minutes of this level. Patients with severe subluxing shoulders may take until Level Seven until feeling better. The physical therapist should continue to perform manual therapy to the SIJ, L5 to C1 and the ribs along with craniosacral therapy techniques as needed. Mulligan techniques can be performed on the elbow, wrist and hand as needed. Taping of the shoulder will continue to help throughout this exercise progression.

## 1. TYI WITH PRONE CHIN TUCK USING THREE POUND WEIGHTS

-These exercises are the same as described in Level Four, except now perform these while holding a three pound weight. Begin at **one minute** for each exercise and add ten seconds per day until you reach three minutes. If your shoulders hurt, perform these every other day while progressing slowly. This is the top level of the TYI's, so progress slowly.

### "T" Using Three Pound Weights



### "Y" Using Three Pound Weights



## "I" Using Three Pound Weights



### FOR THE PHYSICAL THERAPIST

-Begin these exercises at **one minute**. If the patient complains of any increased neck, rib or shoulder pain or increased dizziness, the patient should stop immediately and that will be the amount of time for them to start these exercises (these exercises should always be performed for a length of time that is pain-free and dizziness-free).

## 1A. TYI ALTERNATE POSITION KNEELING OVER BALL WITH CHIN TUCK WITH THREE POUND WEIGHTS

-Use this position if you are unable to lie on your stomach and do not have knee pain in the kneeling position. Begin these exercises at **one minute**, adding ten seconds per day until you reach three minutes. If you have increased pain in the shoulders, you can perform these exercises every other day. This is the top level of this exercise, so progress slowly.

### “T” Kneeling Over Ball With Three Pound Weights



### “Y” Kneeling Over Ball With Three Pound Weights



## **“I” Kneeling Over Ball With Three Weights**



## 1B. TYI ALTERNATE POSITION LEANING OVER BALL WITH THREE POUND WEIGHTS

-Use this position if you are unable to lie on your stomach and have knee pain in the kneeling position. Begin this exercise at **one minute**, adding ten seconds per day until you reach three minutes. If you have increased pain in the shoulders, you can perform these exercises every other day. This is the top level of this exercise, so progress slowly.

-These exercises are the same as described in Level Four, except now with three pound weights.

### “T” Leaning Over Ball With Three Pound Weights



### “Y” Leaning Over Ball With Three Pound Weights



## **“I” Leaning Over Ball With Three Pound Weights**



### **PROGRESSION:**

-Begin these exercises for **one minute**. Add ten seconds per day until you reach three minutes. If you have shoulder pain, you can perform these exercises every other day. Once you reach three minutes, you will perform these exercises on Tuesdays and Fridays only.

## 2. HAND BALL SQUEEZES



Refer to explanation of this exercise shown in Level Two Neck, Mid Back And Upper Extremity progression.

Perform this for three minutes on Tuesdays and Fridays only.

### 3 FOUR WAY WRIST USING THREE POUND WEIGHTS

#### A. Wrist Flexion



#### B. Wrist Extension



### C. Wrist Radial Deviation



### D. Wrist Ulnar Deviation



-Perform all four exercises while holding a three pound weight for three minutes on Tuesdays and Fridays only.

## 4. SHOULDER INTERNAL AND EXTERNAL ROTATION USING BLUE TUBING

### Internal Rotation



### External Rotation



-Perform each exercise individually as described in Level Three Neck, Mid Back And Upper Extremity progression, but use blue tubing.

-Begin each exercise for one and a half minutes. Add ten seconds per day until you reach three minutes. Once you reach three minutes, you will be ready for Level Seven Neck, Mid Back And Upper Extremity progression.

## 5. FULL CAN USING FOUR POUND WEIGHTS



-Perform this exercise while standing as described in Level Three Neck, Mid Back And Upper Extremity progression, but with using a four pound weight.

-Begin this exercise for one and a half minutes. Add ten seconds per day until you reach three minutes. Once you reach three minutes, you will be ready for Level Seven Neck, Mid Back And Upper Extremity progression.

## 6. SHOULDER ABDUCTION USING THREE POUND WEIGHTS



-Perform this exercise as described in Level Three Neck, Mid Back And Upper Extremity progression, but with using a three pound weight.

-Begin this exercise for one and a half minutes. Add ten seconds per day until you reach three minutes. Once you reach three minutes, you will be ready for Level Seven Neck, Mid Back And Upper Extremity progression.

## 7. BICEP CURL USING FOUR POUND WEIGHTS



-Perform this exercise while standing as described in Level Three Neck, Mid Back And Upper Extremity progression, but with using a four pound weight.

-Begin this exercise for one and a half minutes. Add ten seconds per day until you reach three minutes. Once you reach three minutes, you will be ready for Level Seven Neck, Mid Back And Upper Extremity progression.

## 8. TRICEPS PUSH DOWNS USING BLUE TUBING



-Perform this exercise while standing as described in Level Three Neck, Mid Back And Upper Extremity progression, but with using blue tubing.

-Begin this exercise for one and a half minutes. Add ten seconds per day until you reach three minutes. Once you reach three minutes, you will be ready for Level Seven Neck, Mid Back And Upper Extremity progression.

## 9. CRANIOSACRAL EXERCISES

-These exercises are intended to stimulate muscles that attach to the cranial bones. They should be performed for three minutes on Tuesdays and Fridays only. They are as follows:

### 1. Criss-cross eyes

-Look down and inward (medially) toward the nose with both eyes and then elevate the eyelids. Make sure the patient does not overstrain with this exercise.

#### YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:

-superior oblique, levator palpebrae (for Sphenoid)

### 2. Eyebrow Raise

-Raise eyebrows and wrinkle forehead (in a “surprise” expression).

#### YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:

-occipitals, frontalis (occipital bone and frontal bone)

### 3. Ear Wiggle

-Move ears backward (posterior) and forward as in a wiggle motion.

-Move in a continuous manner without holding.

#### YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:

-temporalis (temporal bone)

#### 4. TMJ (Temporomandibular Joint) Isometrics

A.



- Make sure the tongue is resting at the roof of the mouth to avoid clenching.
- Place the right index fingertip on the right side of the jaw bone (below the cheek bone). Gently push the jaw toward the right using your jaw muscles, using your finger for resistance.
- Hold for five seconds, then relax. Repeat for **one minute**.

B.



- Next, place the left index fingertip on the left side of the jaw bone (below the cheek bone). Gently push the jaw toward the left using your jaw muscles, using your finger for resistance.
- Hold for five seconds, then relax. Repeat for **one minute**.

C.



-Next, place the tip of your index finger on top of the bottom row of front teeth. Gently try to close your mouth.

-Hold for five seconds, then relax. Repeat for **one minute**.

D.



-Next, place your fist under the jaw/chin. Gently try to open your mouth.

-Hold for five seconds, then relax. Repeat for **one minute**.

**E.**



-Place the tip of your index finger under the lower lip, but above the chin. Gently push the jaw forward into the fingertip.

-Hold for five seconds, then relax. Repeat for **one minute**.

**PROGRESSION:**

-Perform all exercises for one minute on Tuesdays and Fridays only.

**YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:**

-Masseter, lateral pterygoid, medial pterygoid and temporalis (jaw muscles)

## Level Seven Neck, Mid Back And Upper Extremity Progression

### **FOR THE PERSON WITH EDS AND FOR THE PHYSICAL THERAPIST:**

Begin this level once all the exercises in Level Six have been completed. This is the final exercise level for this exercise progression. Once you begin this level, you can begin Level One lower extremity progression the next treatment session. Once you have completed the exercises in this level, you will perform them on Tuesdays and Fridays only, for your final home exercise program. Level Seven exercises are the same as Level Six exercises with the exception of adding weights. The exercises for this level are: TYI with chin tucks on mat or ball with three pounds weights for three minutes on Tuesdays and Fridays only, hand ball squeezes for three minutes on Tuesdays and Fridays only, four way wrist with three pound weights for three minutes on Tuesdays and Fridays only, shoulder internal rotation with black tubing, shoulder external rotation with black tubing, full can with five pound weights, shoulder abduction with four pound weights, bicep curls with five pound weights, triceps push downs with black tubing and craniosacral and TMJ exercises which include: criss-cross eyes, eyebrow raise, ear wiggle and TMJ isometrics on Tuesdays and Fridays only.

Begin this level at **one minute** and progress as tolerated. If the patient feels worse while performing this level of exercises, it may be necessary to reduce the frequency and perform these exercises every other day and progress as tolerated. If patient continues to feel worse after performing this level every other day for two weeks, discontinue this level and return to Level Six for one and a half minutes (as explained using the setback rules) and progress to three minutes. For those patients, Level Six will be their final home exercise level. Once you reach three minutes of all of Level Seven exercises, you will perform them on Tuesdays and Fridays as your final home exercise level. The physical therapist should continue to perform manual therapy to the SIJ, L5 to C1 and the ribs and craniosacral therapy techniques, all as needed. Myofascial release to the upper trap, scalenes, levator, posterior shoulder, pec major and minor, wrist flexor and extensor muscles, rhomboids and paraspinal muscles may also help with minor discomfort and tightness. Mulligan techniques can be performed on the elbow, wrist and hand as needed. Begin to wean patients off of taping techniques while progressing through this level.

This will be your final home exercise program (see Appendix B).

## 1. TYI WITH PRONE CHIN TUCK USING THREE POUND WEIGHTS FOR THREE MINUTES

-These exercises are the same as described in Level Six Neck, Mid Back And Upper Extremity exercise progression.

### “T” With Prone Chin Tuck Using Three Pound Weights



### “Y” With Prone Chin Tuck Using Three Pound Weights



### **“I” With Prone Chin Tuck Using Three Pound Weights**



-You will perform these exercises for three minutes on Tuesdays and Fridays only.

## 1A. TYI ALTERNATE POSITION KNEELING OVER BALL WITH CHIN TUCK WITH THREE POUND WEIGHTS

### “T” Kneeling Over Ball With Three Pound Weights



### “Y” Kneeling Over Ball With Three Pound Weights



### **“I” Kneeling Over Ball With Three Weights**



-You will perform these exercises for three minutes on Tuesdays and Fridays only.

## **1B. TYI ALTERNATE POSITION LEANING OVER BALL WITH THREE POUND WEIGHTS**

-These exercises are the same as described in level Six Neck, Mid Back And Upper Extremity exercise progression.

### **“T” Leaning Over Ball With Three Pound Weights**



### **“Y” Leaning Over Ball With Three Pound Weights**



### "I" Leaning Over Ball With Three Pound Weights



-You will perform these exercises for three minutes on Tuesdays and Fridays only.

## 2. HAND BALL SQUEEZES



- This exercise is the same as described in level Two Neck, Mid Back And Upper Extremity exercise progression.
- You will perform this exercise for three minutes on Tuesdays and Fridays only.

### 3. FOUR WAY WRIST USING THREE POUND WEIGHTS

#### A. Wrist Flexion



#### B. Wrist Extension



### C. Wrist Radial Deviation



### D. Wrist Ulnar Deviation



-These exercises are the same as described in level Six Neck, Mid Back And Upper Extremity exercise progression.

- Perform all four exercises for three minutes on Tuesdays and Fridays only.

## 4. SHOULDER INTERNAL AND EXTERNAL ROTATION USING BLACK TUBING

### Internal Rotation



### External Rotation



-Perform each exercise individually as described in Level Three Neck, Mid Back And Upper Extremity progression, but with using black tubing.

-Begin each exercise for **one minute**. Add ten seconds per day until you reach three minutes. Once you reach three minutes, add this to your final home exercise program and perform on Tuesdays and Fridays only.

## 5. FULL CAN USING THREE POUND WEIGHTS



-Perform this exercise while standing as described in Level Three Neck, Mid Back And Upper Extremity progression, but with using a five pound weight.

-Begin this exercise for **one minute**. Add ten seconds per day until you reach three minutes. Once you reach three minutes, add this to your final home exercise program and perform on Tuesdays and Fridays only.

## 6. SHOULDER ABDUCTION USING FOUR POUND WEIGHTS



-Perform this exercise while standing as described in Level Three Neck, Mid Back And Upper Extremity progression, but with using a four pound weight.

-Begin this exercise for **one minute**. Add ten seconds per day until you reach three minutes. Once you reach three minutes, add this to your final home exercise program and perform on Tuesdays and Fridays only.

## 7. BICEP CURL USING FIVE POUND WEIGHTS



-Perform this exercise while standing as described in Level Three Neck, Mid Back And Upper Extremity progression, but with using a five pound weight.

-Begin this exercise for **one minute**. Add ten seconds per day until you reach three minutes. Once you reach three minutes, add this to your final home exercise program and perform on Tuesdays and Fridays only.

## 8. TRICEPS PUSH DOWNS USING BLACK TUBING



-Perform this exercise while standing as described in Level Three Neck, Mid Back And Upper Extremity progression, but with using black tubing.

-Begin this exercise for **one minute**. Add ten seconds per day until you reach three minutes. Once you reach three minutes, add this to your final home exercise program and perform on Tuesdays and Fridays only.

## 9. CRANIOSACRAL EXERCISES

-These exercises are intended to stimulate muscles that attach to the cranial bones. They should be performed for three minutes on Tuesdays and Fridays. They are as follows:

### 1. Criss-cross eyes

-Look down and inward (medially) toward the nose with both eyes and then elevate the eyelids. Make sure the patient does not overstrain with this exercise.

-Perform this exercise for three minutes on Tuesdays and Fridays only.

### 2. Eyebrow Raise

-Raise eyebrows and wrinkle forehead (in a “surprise” expression).

-Perform this exercise for three minutes on Tuesdays and Fridays only.

### 3 Ear Wiggle

-Move ears backward (posterior) and forward as in a wiggle motion.

-Move in a continuous manner without holding.

-Perform this exercise for three minutes on Tuesdays and Fridays only.

### 4. TMJ (Temporomandibular Joint) Isometrics

A.



-Make sure the tongue is resting at the roof of the mouth to avoid clenching.

-Place the right index fingertip on the right side of the jaw bone (below the cheek bone). Gently push the jaw toward the right using your jaw muscles, using your finger for resistance.

-Hold for five seconds, then relax. Repeat for **one minute**.

**B.**



-Next, place the left index fingertip on the left side of the jaw bone (below the cheek bone). Gently push the jaw toward the left using your jaw muscles, using your finger for resistance.

-Hold for five seconds, then relax. Repeat for **one minute**.

**C.**



-Next, place the tip of your index finger on top of the bottom row of front teeth. Gently try to close your mouth.

-Hold for five seconds, then relax. Repeat for **one minute**.

**D.**



-Next, place your fist under the jaw/chin. Gently try to open your mouth.

-Hold for five seconds, then relax. Repeat for **one minute**.

**E.**



-Place the tip of your index finger under the lower lip, but above the chin. Gently push the jaw forward into the fingertip.

-Hold for five seconds, then relax. Repeat for **one minute**.

-Perform all five exercises for one minute each on Tuesdays and Fridays only.

**FOR THE PERSON WITH EDS:**

Congratulations! You have completed the Neck, Mid Back And Upper Extremity Exercise Progression. I bet you never thought it would end. You are now two thirds of the way there. Good luck with your final exercise progression of Phase One.

(Home Exercise Sheet To Detach And Use For Quick Reference)

**TUESDAYS AND FRIDAYS:**

-Neck, Mid Back And Upper Extremity Progression Final Home Exercise Program:

*-All Exercises Are Performed For Three Minutes*

-T,Y,I's With Chin Tucks With Three Pounds (Alternate Positions Kneeling On Mat Leaning Over Ball Or Standing Leaning Over Ball)

-Shoulder Internal Rotation With Black Tubing

-Shoulder External Rotation With Black Tubing

-Full Can With Five Pounds

-Shoulder Abduction With Four Pounds

-Hand Ball Squeezes

-Four Way Wrist With Three Pounds

-Bicep Curl With Five Pounds

-Triceps Push Downs With Black Tubing

-Criss-Cross Eyes

-Eyebrow Raise

-Ear Wiggle

-TMJ Isometrics One Minute Each Way

## Section Four -

# Lower Extremity Exercise Progression

*“When you come to the end of your rope, tie a knot and hang on.”*

Franklin D. Roosevelt

### About This Exercise Progression

#### **FOR THE PERSON WITH EDS:**

It has been a long journey, but you have finally reached the final exercise progression of Phase One of this protocol. Hopefully by now, you will be experiencing more good days than bad with your entire spine and arms. This is the last progression before you advance to Phase Two. You have your custom orthotics at this point, which with proper fitting, will help decrease pain in the foot as well as in the ankle and knee. If your hips severely sublux or you have balance issues, then you will need to go through the lower extremity progression twice, once while holding onto a counter and once without holding onto a counter. When performing these exercises while holding onto a counter, you will be able to focus on strengthening the hips, knees and ankles instead of worrying about controlling your balance. Once you have completed a level of exercises while holding onto the counter, you have gained enough strength to perform this exercise without holding onto the counter, thus allowing you to work on your balance. Once you have completed a level without holding onto the counter, you will be able to progress to the next level. Most people with EDS have difficulty climbing stairs and walking on uneven terrain. Climbing stairs will be addressed in this exercise progression, while walking on uneven terrain will be addressed in Phase Two. Take your time with this progression. You now have to perform this progression on Mondays and Thursdays with the SIJ and Lumbar Spine exercises and on Tuesdays and Fridays with the neck, mid back and upper extremity exercises. I know this is tough, but push through; you are almost there.

### **FOR THE PHYSICAL THERAPIST:**

Custom orthotics need to be purchased if not already in order to control the foot and knee during this exercise progression. For people with EDS who have severe subluxing hips, this protocol will take twice as long. The person with severe subluxing hips will need to perform each level of this progression twice, once while holding onto a counter to give stability to the hip and once without upper extremity support, in order to focus on balance and proprioception. This level is intended to focus on lower limb strengthening, balance and assist with climbing stairs. You can now perform manual therapy techniques on any region of the body. McConnell and Mulligan taping techniques may help with pain in the knees while going through this exercise progression. All therabands used in this progression should be between nine and ten inches in diameter after being tied and should be placed around the patient's ankles for consistency. Once the patient has completed the eight levels of this exercise progression, they will be ready to begin Phase Two of the exercise protocol (See Appendix C for a list of lower extremity exercises).

### **Anatomy For The Person With EDS**

The top bone in the picture is the femur (thigh bone). It is connected to your pelvis via the hip joint. Your knee joint is where your femur connects to your tibia (shin bone). The fibula is the thin bone that connects along the side of the tibia. The small round bone attached to the front of the femur is called your patella (knee cap). At the bottom of your tibia and fibula, lies your ankle joint (talocrural). This joint connects your lower leg to your foot and toes.



## Biomechanics Of The Lower Extremity



### **FOR THE PERSON WITH EDS:**

The legs are intended to control the body while walking and going up and down stairs. Walking is considered controlled falling. It is the responsibility of your legs to absorb the forces of the body as you take a step forward. Maintaining proper foot, knee and hip alignment during walking will decrease the stress on all of the ligaments of the legs, SIJ and low back. A physical therapist can assist with assessing your gait pattern as well as teaching you proper walking mechanics. The issues that arise in the lower extremities in this population which could hinder proper gait patterns are as follows:

Foot: When you walk, you transfer weight from one foot to the other with each step. When you take a step forward, the heel is usually the first thing that hits the ground and then weight is transferred from the opposite leg as the foot fully contacts the ground. The foot then flattens to absorb the weight of your entire body, which is being transferred from the opposite limb. As your opposite leg swings forward, your heel comes off the ground and the structures in your foot (muscles, ligaments, fascia)

stiffen your arch in order assist in propulsion to the next step (transferring weight to the opposite leg). Most people with EDS have a flat foot, which means they never build an arch before they push off. This can cause increased pain in the bottom of your foot, called plantar fasciitis. Flat feet unlock the bones in the foot, placing increased stress on all of the ligaments and joints in the foot, making them more susceptible to subluxation. A custom orthotic will correct this issue, decreasing pain with every step.

Knee: When your foot is flat, it will push the knee inward, which is referred to as being “knock-kneed.” This can cause pain on the side of your knee as well as cause a subluxation of your knee cap. Orthotics will work to improve the knock-kneed posture. Besides being knock-kneed, your knee has hyperextension (goes backward excessively). This can cause increased stress on ligaments on the inside of your knee called your ACL (anterior cruciate ligament). Trying to prevent your knee from snapping backwards as you stand and walk will help decrease pain in this area considerably.

Hip: The hip joint can sublux in the EDS population without a traumatic event. You can also have pain in your hip without having a subluxation. If you are knock-kneed, you have increased stress on your hip due to a poor gait pattern, which can lead to hip bursitis and is very painful if left untreated.

## Biomechanics Of The Lower Extremity



### **FOR THE PHYSICAL THERAPIST:**

Most patients with EDS have pronated feet, genu valgum, and genu recurvatum. They tend to walk with a Trendelenburg gait due to weakness in the hips and possibly subluxing of the hips. Walking is controlled falling, which places increased stress on the joints of the lower extremities if the patient has a faulty gait pattern. I will go through each joint of the lower extremities and how they may present.

Foot: A pronated foot is defined as a greater than ten millimeter navicular drop when a person is standing in subtalar neutral versus a resting stance. All patients with EDS who have pronated feet will need custom orthotics. Pronated feet can cause plantar fasciitis, mid tarsal joint hypermobility and subluxation of the MP joints. All of these dysfunctions can disrupt the windlass mechanism and cause or worsen gait deviations. Custom orthotics need to address all of these issues while controlling the talocrural joint and the knee.

Ankle: When the foot is pronated, the talus will excessively move anteriorly in this population. This may lead to wearing away of the talar dome and subluxation of the talus anteriorly. Properly fitted orthotics can help these issues.

Knee: The knee has two major problems in this population, which are increased recurvatum and increased valgus. Recurvatum will place increased stress on the ACL, menisci and retropatella. Manual therapy, Mulligan taping techniques and McConnell taping techniques can help with this. Watch for these issues while patients progress through this exercise program. Valgus of the knee can cause stress on the MCL, ACL and menisci. When the knee goes into valgus, the tibia will externally rotate, causing increased pain in the knee. Correcting this with Mulligan or McConnell taping techniques will decrease pain in the knee while advancing through this exercise progression.

Hip: When a patient walks with a Trendelenburg gait, there will be stress on the trochanteric bursa, which can cause hip bursitis. Also, the hips may sublux due to a faulty gait pattern over time. Strengthening the hip and instructing the patient on proper gait mechanics will help these issues. Treat the trochanteric bursitis with standard physical therapy protocol. An SI belt wrapped around a patient's hips can help to stabilize severely subluxing hips.

Custom Orthotics: A good custom orthotic will help with decreasing navicular drop, pain at the talar dome, decrease valgus at the knee, decrease trochanteric bursitis and help with hip subluxations. Therefore, getting the right orthotic is the most important thing you can do for controlling lower extremity pain. Because of the severity of the ligament laxity in this population, I have found that only custom fit orthotics work as compared with over the counter orthotics.

## Level One Lower Extremity Exercise Progression

### **FOR THE PERSON WITH EDS AND THE PHYSICAL THERAPIST:**

The exercises for Level One lower extremity are: side stepping at counter, walking forward and backward at counter, standing hamstring curls at counter and standing heel and toe raises at counter. Patients should perform Level One exercises at a counter in order to maintain balance while performing these new exercises. Patients with chronic hip subluxations or balance issues will perform all four exercises first while holding onto the counter, and then, once this level is completed, they will begin this level a second time without holding onto the counter. Patients without chronic hip subluxations will begin performing this level standing next to a counter, but not holding onto it. All lower extremity exercises will be done for repetitions rather than time, as in the previous exercise progressions. If custom orthotics have not already been purchased, the patient needs to do so at this time. Physical therapists can continue to perform manual therapy on the spine and upper extremities as needed. Modalities can be used if trochanteric bursitis is an issue. Mulligan taping of the knee and McConnell taping of the patella can help decrease pain in the knee while performing this exercise progression. Manual therapy of the foot, joint mobilization of the talocrural joint, manual therapy of the tibia and fibula and myofascial release to the iliotibial band can be performed once the patient begins this level.

## 1. SIDE STEPPING



### **POSITION:**

- Stand at one end of your kitchen counter, facing the counter with knees slightly bent and feet pointing toward the counter (do not hold onto the counter unless you have chronic hip subluxations or balance issues).
- Counter length should be six feet long. If the counter is too high, this exercise can be performed at the kitchen table.
- Side step down the length of the counter keeping feet pointed toward counter with each step (do not let toes/feet turn out).
- Once you get to the end of the counter, side step to the original end you started at while continuing to face the counter throughout the exercise.

-From one end of the counter to the other end, and back to the original spot equals one lap. Repeat this process for ten laps.

**PROGRESSION:**

-Begin this exercise for ten laps and add two laps per day until you reach twenty-six laps. Once you reach twenty-six laps without holding onto the counter, you are ready for Level Two.

**YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:**

- Gluteus medius and minimus (side of hip)

**FOR THE PHYSICAL THERAPIST:**

-Kitchen counter length should be six feet long.

-If the counter is too high, have the patient use their kitchen table.

-Do not allow the patient to hyperextend their knees or arch their back while side stepping (maintain pelvic neutral).

-If the patient feels increased pain in low back, hip, knee or ankle, decrease the size of the step being taken (Too large a step can cause increased pain in the SIJ).

-Do not allow the patient to arch their back.

-Have the patient keep their feet hip-width apart throughout exercise.

-Do not allow the patient to lean forward while side stepping.

-Have the patient maintain a slow and steady pace.

-If a patient has subluxing hips or balance issues, make sure they first perform this exercise while holding onto the counter and then perform it a second time without holding onto the counter. (Hold onto the counter for ten laps, adding two laps per day until reaching twenty-six laps. Then begin ten laps again without holding onto the counter. Progress two laps per day until reaching twenty-six laps. Then the patient is ready for Level Two. This procedure will be the same for all exercises in this protocol for patients with subluxing hips or balance issues.

## 2. WALKING FORWARD AND BACKWARD



### **POSITION:**

-Stand at one end of your kitchen counter, facing straight ahead with the counter on the side of your dominate hand or opposite side of painful leg. If that shoulder, elbow, wrist or hand hurts, then perform this exercise while holding onto counter with other hand. (Make sure you hold onto the counter if you have hip subluxations or balance issues).

-Keep feet hip-width apart during the entire exercise.

-Walk forward to the end of the counter. Once you reach the end of the counter, DO NOT turn around; instead walk backwards to the original end.

-Walking forward to one end and then backwards to the original end of the counter is considered one lap. Repeat this process for ten laps.

**PROGRESSION:**

-Begin this exercise for ten laps and add two laps per day until you reach twenty-six laps. Once you reach twenty-six laps without holding onto the counter, you are ready for Level Two.

**YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:**

- Psoas muscles (front of leg) while walking forward.
- Gluteus maximus (buttocks muscle) while walking backwards.

**FOR THE PHYSICAL THERAPIST:**

- Do not allow the patient to hyperextend their knees or arch their back.
- If the patient feels increased pain in low back, hip, knee or ankle, decrease the size of the step being taken (Too large a step can cause increased pain in the SIJ).
- Keep feet hip-width apart throughout exercise.
- Maintain a slow and steady pace.
- If a patient has subluxing hips, make sure they first perform this exercise while holding onto the counter and then perform it a second time without holding onto the counter.

### 3. STANDING HAMSTRING CURLS



#### **POSITION:**

-Stand up straight at the counter holding onto counter (whether or not you have hip problems) with two hands.

-Never perform this exercise without holding onto a counter for all levels of this exercise. It places too much stress on the opposite leg (stance leg) to the leg that is bending to perform the hamstring curl.

-Bend one knee up as if to kick your buttocks, keeping the thigh of that leg underneath you/behind you (do not bring the knee and thigh up in front of you to do the hamstring curl). Then return the leg back down to the ground.

-This is an active range of motion exercise, so do not hold the position. Maintain a slow and continuous motion until completing the appropriate number of repetitions that

you are on in the progression.

**PROGRESSION:**

-Begin this exercise ten repetitions and add two repetitions per day until you reach twenty-six repetitions. Once you reach twenty-six repetitions, you are ready for Level Two.

**YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:**

-Hamstrings (back of thigh)

**FOR THE PHYSICAL THERAPIST:**

- Do not allow the patient to hyperextend their knee on the stance leg.
- Do not allow the patient to arch their back (maintain pelvic neutral).
- Have the patient maintain a slow and steady pace.
- Make sure the patient holds onto the counter whether or not they have hip subluxations.
- No patient will perform this exercise without holding onto the counter because it places too much stress on the hip and knee of the opposite (stance) leg.

## 4. HEEL AND TOE RAISES



### **POSITION:**

- Stand up straight at the counter without holding onto the counter unless you have hip subluxation problems or balance issues (then you will hold onto the counter).
- Raise both heels off ground, then lower heels back to ground.
- Next raise toes of both feet off the ground and then return the toes back to the ground. One repetition is a cycle of a toe raise and then a heel raise.
- Continue to alternate heel raises and toe raises for ten repetitions.

### **PROGRESSION:**

- Begin with ten repetitions and add two repetitions per day until you reach twenty-six repetitions. Once you reach twenty-six repetitions without holding onto the counter, you are ready for Level Two.

### **YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:**

- Gastrocnemius (calf) when lifting heels off the ground.
- Tibialis anterior (shin) when lifting toes off the ground.

**FOR THE PHYSICAL THERAPIST:**

- Be aware that patients tend to fall backwards when performing toe raise.
- Do not allow the patient to hyperextend their knees.
- Do not allow the patient to arch their back (maintain pelvic neutral).
- Maintain a slow and steady pace.
- If a patient has subluxing hips or balance issues, make sure they first perform this exercise while holding onto the counter and then perform it a second time without holding onto the counter.

## Level Two Lower Extremity Exercise Progression

### **FOR THE PERSON WITH EDS AND THE PHYSICAL THERAPIST:**

Once all four exercises of Level One have been completed, Level Two can be performed. Physical therapists can continue to perform manual therapy on the spine and upper extremities as needed. Modalities can be used if trochanteric bursitis is an issue. Mulligan taping of the knee and McConnell taping of the patella can help decrease pain in the knee while performing this exercise progression. Manual therapy of the foot, joint mobilization of the talocrural joint, manual therapy of the tibia and fibula and myofascial release to the iliotibial band can be performed. If the SIJ becomes irritated while performing Level Two exercises, limit the range of motion of the leg during each exercise. The exercises for Level Two are as follows: side stepping with yellow tubing around ankles, walking forward and backwards with yellow tubing around ankles, hamstring curls with yellow tubing around the ankles while holding onto the counter, heel and toe raises progressing from twenty-six repetitions to fifty repetitions and quarter squats. Yellow tubing should be nine to ten inches across when tied to have consistency in this protocol.

## 1. SIDE STEPPING WITH YELLOW TUBING



### **POSITION:**

- Tie yellow tubing so that it is between nine and ten inches in length when tied.
- Place yellow tubing around both ankles.
- Stand at one end of your kitchen counter facing the counter with knees slightly bent and feet pointing toward the counter (do not hold onto the counter unless you have chronic hip subluxations or balance issues).
- Side step down the length of the counter keeping feet pointed toward counter with

each step (do not let toes/feet turn out).

- The counter length should be six feet long.

- Once you get to the end of the counter, side step to the original end you started at while continuing to face the counter throughout the exercise.

- From one end of the counter to the other end, and back to the original spot equals one lap. Repeat this process for ten laps.

### **PROGRESSION:**

- Begin this exercise for ten laps and add two laps per day until you reach twenty-six laps. Once you reach twenty-six laps without holding onto the counter, you are ready for Level Three.

### **YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:**

- Gluteus medius and minimus (side of hip)

### **FOR THE PHYSICAL THERAPIST:**

- Do not allow the patient to hyperextend their knees or arch their back while side stepping. Have them maintain pelvic neutral.

- If the patient feels increased pain in low back, hip, knee or ankle, decrease the size of the step being taken (too large a step can cause increased pain in the SIJ).

- Keep feet hip-width apart throughout exercise.

- Do not allow the patient to lean forward while side stepping.

- Have the patient maintain a slow and steady pace.

- If a patient has subluxing hips or balance issues, make sure they first perform this exercise while holding onto the counter and then perform it a second time without holding onto the counter.

## 2. WALKING FORWARD AND BACKWARD WITH YELLOW TUBING



### **POSITION:**

- Yellow tubing will already be around your ankles from performing the previous exercise (side stepping).
- Stand at one end of your kitchen counter facing straight ahead with the counter on the side of your dominant hand or opposite the painful leg. If that shoulder, elbow, wrist or hand hurts, then perform this exercise while holding onto counter with other hand. Make sure you hold onto the counter if you have hip subluxations or balance issues.
- Keep feet hip-width apart during the entire exercise.
- Walk forward to the end of the counter. Once you reach the end of the counter, DO NOT turn around; instead walk backwards to the original end.

- The counter length should be six feet.
- Walking forward to one end and then backwards to the original end of the counter is considered one lap. Repeat this process for ten laps.

### **PROGRESSION:**

- Begin this exercise for ten laps and add two laps per day until you reach twenty-six laps. Once you reach twenty-six laps without holding onto the counter, you are ready for Level Three.

### **YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:**

- Psoas muscles (front of leg) while walking forward.
- Gluteus maximus (buttocks muscle) while walking backwards.

### **FOR THE PHYSICAL THERAPIST:**

- Do not allow the patient to hyperextend their knees or arch their back (maintain pelvic neutral, especially while walking backwards).
- If the patient feels increased pain in low back, hip, knee or ankle, decrease the size of the step being taken (too large a step can cause increased pain in the SIJ).
- Keep feet hip-width apart throughout exercise.
- Maintain a slow and steady pace.
- If a patient has subluxing hips or balance issues, make sure they first perform this exercise while holding onto the counter and then perform it a second time without holding onto the counter.

### 3. HAMSTRING CURLS WITH YELLOW TUBING



#### **POSITION:**

- Keep yellow tubing around your ankles from previous exercises.
- Stand up straight at the counter holding onto the counter (whether or not you have hip problems) with two hands.
- Never perform this exercise without holding onto a counter for all levels of this exercise. It places too much stress on the opposite leg (stance leg) to the leg that is bending to perform the hamstring curl.
- Bend one knee up as if to kick your buttocks, keeping the thigh of that leg underneath you/behind you (do not bring the knee and thigh up in front of you to do the hamstring curl). Then return the leg back down to the ground.
- This is an active range of motion exercise, so do not hold the position. Maintain a slow

and continuous motion until completing the appropriate number of repetitions that you are on in the progression.

**PROGRESSION:**

-Begin this exercise for ten repetitions and add two repetitions per day until you reach twenty-six repetitions. Once you reach twenty-six repetitions, you are ready for Level Three.

**YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:**

-Hamstrings (back of thigh)

**FOR THE PHYSICAL THERAPIST:**

-Do not allow the patient to hyperextend the knee that is in the stance position.

-Do not allow the patient to arch their back (maintain pelvic neutral).

-Have the patient maintain a slow and steady pace.

-Make sure the patient holds onto the counter whether or not they have hip subluxations.

**-TAKE TUBING OFF AFTER THIS EXERCISE.**

#### 4. HEEL AND TOE RAISES



-This exercise is the same as described in Level One except, now you should continue to add two repetitions per day starting at twenty-six repetitions and progressing to fifty repetitions.

## 5. QUARTER SQUATS



### **POSITION:**

-Stand at counter with feet hip-width apart and feet pointing toward counter. Bend knees while sticking buttocks backwards (like sitting down in a chair). Knees should never move forward past toes. Knees should never move inward toward midline (belly button). Squat down so your knees are bent to approximately sixty degrees and then stand straight up again. Hold onto the counter if you have hip subluxations or balance issues.

**-Stay in a pain-free range of motion (limit depth of squat if knees, hips or ankles hurt).**

-Repeat this exercise for ten repetitions.

**PROGRESSION:**

-Begin at ten repetitions then add two repetitions per day until you reach twenty-six repetitions. Once you reach twenty-six repetitions without holding onto the counter, then you are ready for Level Three.

**MUSCLES:**

-Quadriceps (front of thighs), Gluteus maximus (buttocks)

**FOR THE PHYSICAL THERAPIST:**

-Do not allow the patient's knees to move forward past their toes.

-Do not allow the patient's knees to move into valgus.

-Have the patient stay in a pain-free range of motion.

-Do not allow the patient to lean their chest forward excessively.

-If a patient has subluxing hips or balance issues, make sure they first perform this exercise while holding onto the counter, and then perform it a second time without holding onto the counter.

## Level Three Lower Extremity Exercise Progression

### **FOR THE PERSON WITH EDS AND THE PHYSICAL THERAPIST:**

Once you have completed all of the exercises in Level Two, you may begin Level Three lower extremity progression. Physical therapists can perform manual therapy to any painful region in the body. McConnell and Mulligan taping techniques may help with knee pain. Address bursitis with modalities as needed. The exercises for this level are as follows: side stepping with green tubing, walking forward and backwards with green tubing, hamstring curls with green tubing, single leg heel raises and toe raises, partial lunges and standing feet together. Green tubing should measure between nine and ten inches across once it is tied for consistency.

## 1. SIDE STEPPING WITH GREEN TUBING



-This exercise is performed as described in Level Two, but with green tubing. Begin at ten laps and add two laps per day until you reach twenty-six laps. Once you reach twenty-six laps without holding onto the counter, you are ready for Level Four.

### **FOR THE PHYSICAL THERAPIST:**

-If a patient has subluxing hips, make sure they first perform this exercise while holding onto the counter and then perform it a second time without holding onto the counter.

## 2. WALKING FORWARD AND BACKWARDS WITH GREEN TUBING



-This exercise is performed as described in Level Two, but with green tubing. Begin at ten laps and add two laps per day until you reach twenty-six laps. Once you reach twenty-six laps without holding onto the counter, you are ready for Level Four.

### **FOR THE PHYSICAL THERAPIST:**

-If a patient has subluxing hips, make sure they first perform this exercise while holding onto the counter and then perform it a second time without holding onto the counter.

### 3. HAMSTRING CURLS WITH GREEN TUBING



-This exercise is performed as described in Level Two, but with green tubing. Begin at ten repetitions and add two repetitions per day until you reach twenty-six repetitions. Once you reach twenty-six repetitions, you are ready for Level Four.

-Make sure you hold onto the counter for this exercise whether or not you have a problem with hip subluxations or balance issues.

## 4. SINGLE LEG HEEL AND TOE RAISES



### **POSITION:**

- Stand at the counter and hold onto the counter (whether or not you have subluxing hips) to maintain balance. Bend right knee up to sixty degrees and keep it there throughout the exercise.
- Never perform this exercise without holding onto a counter for all levels of this exercise. It places too much stress on the leg on which you are standing.
- Raise left heel off the ground, then lower to the ground.
- Next, raise left toes off the ground, then lower to the ground.
- Repeat lifting heel then toes for ten repetitions. Once completed, perform ten repetitions with right leg.

### **PROGRESSION:**

- Begin with ten repetitions on each leg and add two repetitions per day until you reach twenty-six repetitions on each leg. Once you reach twenty-six repetitions, you are ready for Level Four.

### **YOU SHOULD FEEL THESE MUSCLES WORKING WITH THIS EXERCISE:**

- Gastrocnemius (calf) when lifting heels off the ground.
- Tibialis anterior (shin) when lifting toes off the ground.

**FOR THE PHYSICAL THERAPIST:**

- Be aware that patients tend to fall backwards when performing toe raises.
- Do not allow the patient to hyperextend their knee of the leg being exercised.
- Do not allow the patient to arch their back (maintain pelvic neutral).
- Have the patient maintain a slow and steady pace.
- Have the patient keep opposite foot off the ground for the duration of the exercise.
- Make sure the patient holds onto the counter whether or not they have subluxing hips.

## 5. PARTIAL LUNGES



### **POSITION:**

- Stand at the counter with feet hip-width apart and dominant hand next to the counter in case you lose your balance. Make sure you hold onto the counter if you have subluxing hips or balance issues. Step forward and bend both knees.
- Bend front knee to only about forty-five degrees. Then push up with your leg and step back to the original standing position. Make sure you step forward and then back to the original standing position each repetition in order to increase your balance.
- Repeat ten repetitions with one leg. Then switch legs and perform ten repetitions with the opposite leg.

**PROGRESSION:**

-Begin with ten repetitions each leg and add two repetitions per day until you reach twenty-six repetitions each leg. Once you reach twenty-six repetitions, you are ready for Level Four.

**MUSCLES:**

-Quadriceps (front of thigh), gluteus maximus (buttocks)

**FOR THE PHYSICAL THERAPIST:**

- Do not let the patient's leg that is lunging forward move in front of their toes.
- Do not let the patient's knee that is stepping forward go into valgus.
- Do not allow the patient to step too far forward.
- Have the patient stay in a pain-free range of motion.
- Allow the patient's heel of the leg that is in back to come off the ground.
- Have the patient return the foot to the original standing position after each time they lunge forward in order to build proprioception.
- If a patient has subluxing hips or balance issues, make sure they first perform this exercise while holding onto the counter and then perform it a second time without holding onto the counter.

## 6. STANDING WITH FEET TOGETHER



### **POSITION:**

- Stand at the counter with feet together and not holding onto the counter. This is a balance exercise, so standing unsupported challenges the balance system more than if you held onto the counter.
- Do not arch your back or hyperextend your knees.

### **PROGRESSION:**

- Begin this exercise for one and a half minutes, adding ten seconds per day until you reach three minutes. Once you reach three minutes, you are ready for Level Four.

**FOR THE PHYSICAL THERAPIST:**

- Do not allow the patient to hyperextend their knees or arch their back.
- Have the patient's hands close enough to the counter so they can grab the counter if they lose their balance.

## Level Four Lower Extremity Exercise Progression

### **FOR THE PERSON WITH EDS AND THE PHYSICAL THERAPIST:**

Once all the exercises in Level Three have been completed, Level Four can be performed. Physical therapists can continue to perform manual therapy on the spine and upper extremities as needed. Modalities can be used if trochanteric bursitis is an issue. Mulligan taping of the knee and McConnell taping of the patella can help decrease pain in the knee while performing this exercise progression. Manual therapy of the foot, joint mobilization of the talocrural joint, manual therapy of the tibia and fibula and myofascial release to the iliotibial band can be performed. If the SIJ becomes irritated while performing Level Four exercises, limit the range of motion of the leg during each exercise. The exercises for Level Four are as follows: side stepping with blue tubing, walking forward and backwards with blue tubing, hamstring curls with blue tubing, single leg heel and toe raises, lunges, standing with feet together on pillow, standing with feet together on the ground with eyes closed, steps ups forward with four inch step and step ups to the side with four-inch step.

## 1. SIDE STEPPING WITH BLUE TUBING



### **POSITION:**

-This exercise is performed as described in Level Three, but with blue tubing. Begin at ten laps and add two laps per day until you reach twenty-six laps. Once you reach twenty-six laps, you are ready for Level Five.

### **FOR THE PHYSICAL THERAPIST:**

-If a patient has subluxing hips or balance issues, make sure they first perform this exercise while holding onto the counter and then perform it a second time without holding onto the counter.

## 2. WALKING FORWARD AND BACKWARDS WITH BLUE TUBING



### **POSITION:**

-This exercise is performed as described in Level Three, but with blue tubing. Begin at ten laps and add two laps per day until you reach twenty-six laps. Once you reach twenty-six laps, you are ready for Level Five.

### **FOR THE PHYSICAL THERAPIST:**

-If a patient has subluxing hips or balance issues, make sure they first perform this exercise while holding onto the counter and then perform it a second time without holding onto the counter.

### 3. HAMSTRING CURLS WITH BLUE TUBING



#### **POSITION:**

-This exercise is performed as described in Level Three, but with blue tubing. Begin at ten repetitions and add two repetitions per day until you reach twenty-six repetitions. Once you reach twenty-six repetitions, you are ready for Level Five. Make sure you hold onto counter whether or not you have subluxing hips.

#### 4. SINGLE LEG HEEL AND TOE RAISES



##### **POSITION:**

-This exercise is performed as described in Level Three, but with progressing from twenty-six repetitions to fifty repetitions on each leg. Once you reach fifty repetitions while holding onto counter on each leg, you will perform this exercise on Wednesdays and Saturdays only.

##### **FOR THE PHYSICAL THERAPIST:**

-Do not have the patient perform this exercise without holding onto the counter secondary to increased stress on the knee and ankle that would occur.

## 5. LUNGES



-This exercise is performed as described in Level Three, but now allowing a deeper bend in the knees. The depth of the lunge should not cause increased pain. Begin at ten repetitions and add two repetitions per day until you reach twenty-six repetitions. Once you reach twenty-six repetitions, you are ready for Level Five.

-If a patient has subluxing hips, make sure they first perform this exercise while holding onto the counter and then perform it a second time without holding onto the counter.

## 6. STANDING WITH FEET TOGETHER ON A PILLOW



### **POSITION:**

- Stand at the counter with feet together on a pillow or couch cushion without holding onto the counter. This is a balance exercise, so standing unsupported challenges the balance system more than if you held onto the counter.
- Do not arch your back or hyperextend your knees.

**PROGRESSION:**

-Begin this exercise for one and a half minutes, adding ten seconds per day until you reach three minutes. Once you reach three minutes, you are ready for Level Five.

**FOR THE PHYSICAL THERAPIST:**

- Do not allow the patient to hyperextend their knees or arch their back.
- Have the patient's hands close to the counter so that they can grab the counter in case they lose their balance.

## 7. STAND WITH FEET TOGETHER ON THE GROUND WITH EYES CLOSED



### **POSITION:**

- Stand with feet together on the ground with eyes closed with hands hovering one inch over the counter (this is for safety in case you lose your balance). Then close your eyes and maintain balance for one and a half minutes.
- Grab onto the counter if you lose your balance.
- Do not arch your back or hyperextend your knees.

**PROGRESSION:**

-Begin at one and a half minutes, adding ten seconds per day until you reach three minutes. Once you reach three minutes, you are ready for Level Five.

**FOR THE PHYSICAL THERAPIST:**

- Do not allow the patient to hyperextend their knees or arch their back.
- Have the patient's hands close to the counter so that they can grab the counter in case they lose their balance.

## 8. STEP-UPS FORWARD ON A FOUR-INCH STEP



### **POSITION:**

- Perform this exercise using a four inch high aerobic step (a standard step height is eight inches).
- Place the step in front of the counter. Place your right foot on the middle of the step and keep it there for the entire ten repetitions. Step up with your left leg, then step backwards with left leg so it is on the floor again. Make sure you hold onto the counter if you have subluxing hips or balance issues.
- Repeat this process for ten repetitions on the left leg, then switch legs and place left foot on the middle of the step and step up and down with the right leg for ten repetitions.
- The reason why the foot is kept on the step the whole time is to prevent the step from tipping over while performing this exercise.

### **PROGRESSION:**

- Begin with ten repetitions on each leg and add two repetitions per day until you reach twenty-six repetitions on each leg. Once you reach twenty-six repetitions without holding onto the counter on each leg, you are ready for Level Five.

### **MUSCLES:**

- Quadriceps (front of thigh), gluteus maximus (buttocks)

**FOR THE PHYSICAL THERAPIST:**

- Do not let the patient's knees move into valgus while performing the step up. If the patient's knee moves into valgus, have them perform the exercise while holding onto the counter first. Once they complete twenty-six repetitions holding onto the counter, then have them attempt the exercise without holding onto the counter, starting at ten repetitions and progressing two repetitions per day until reaching twenty-six repetitions without holding on.
- While stepping up, have the patient push from the heel of the foot as opposed to the ball of the foot if the knee hurts.
- Do not allow the patient to hop up on step. Focus on using the leg that is on the step to control the step up.
- If a patient has subluxing hips or balance issues, make sure they first perform this exercise while holding onto the counter and then perform it a second time without holding onto the counter.

## 9. SIDE STEP-UPS TO THE SIDE WITH FOUR-INCH STEP



Use the same four-inch step as you did with the step up forward exercise.

### **POSITION:**

- Stand next to the counter so the step is to the right side of you. Place right foot on the middle of the step, where it will stay for the entire ten repetitions. Hold onto the counter if you have subluxing hips or balance issues.
- Step up and place left foot on step then back down on the ground in a side stepping motion.
- Repeat this process for ten repetitions. Then place the step on the left side of you (turn around) and place the left foot on the middle of the step and repeat the process for ten repetitions stepping up and down with the right foot.

### **PROGRESSION:**

- Begin with ten repetitions on each leg and add two repetitions per day until you reach twenty-six repetitions on each leg. Once you reach twenty-six repetitions without holding onto the counter on each leg, you are ready for Level Five.

**MUSCLES:**

-Quadriceps (front of thigh), gluteus maximus (buttocks)

**FOR THE PHYSICAL THERAPIST:**

-Do not let the patient's knees move into valgus performing the step-up. If the patient's knee moves into valgus, have them perform the exercise while holding onto the counter first. Once they complete twenty-six repetitions holding onto the counter, then have them attempt the exercise without holding onto the counter, starting at ten repetitions and progressing two repetitions per day until reaching twenty-six repetitions without holding on.

-While stepping up, push from the heel of the foot as opposed to the ball of the foot if the knee hurts.

-Do not allow the patient to hop up on the step. Focus on using the leg that is on the step to control the step-up.

-Do not allow the patient to step too far away from the step when coming off the step.

-If a patient has subluxing hips or balance issues, make sure they first perform this exercise while holding onto the counter and then perform it a second time without holding onto the counter.

## Level Five Lower Extremity Exercise Progression

### **FOR THE PERSON WITH EDS AND THE PHYSICAL THERAPIST:**

Once you have completed all the exercises in Level Four, you are ready to begin Level Five. The exercises for Level Five are as follows: side stepping with black tubing, walking forward and backwards with black tubing, hamstring curls with black tubing, single leg heel and toe raises on Wednesday and Saturdays only, lunges on Wednesdays and Saturdays only, step-ups forward on an eight-inch step, step-ups to the side on an eight-inch step, single leg stance, standing feet together on pillow with eyes closed and begin recumbent bike. Black tubing should be nine to ten inches in length after being tied.

The physical therapist can perform manual therapy on any region of the body that is problematic for the patient in order to decrease pain. Modalities can be used if trochanteric bursitis is an issue. Mulligan taping of the knee and McConnell taping of the patella can help decrease pain in the knee while performing this exercise progression. Manual therapy of the foot, joint mobilization of the talocrural joint, manual therapy of the tibia and fibula and myofascial release to the iliotibial band can be performed. If the SIJ becomes irritated while performing these exercises, limit the range of motion of the leg during each exercise. Work with an orthotist or podiatrist if knee or ankle is still problematic at this point. Have them modify the arch support to control these two parts.

## 1. SIDE STEPPING WITH BLACK TUBING



### **POSITION:**

-This exercise is performed as described in Level Four, but with black tubing. Begin at ten laps and add two laps per day until you reach twenty-six laps. Once you reach twenty-six laps without holding onto the counter, you are ready for Level Six.

### **FOR THE PHYSICAL THERAPIST:**

-If a patient has subluxing hips or balance issues, make sure they first perform this exercise while holding onto the counter and then perform it a second time without holding onto the counter.

## 2. WALKING FORWARD AND BACKWARDS WITH BLACK TUBING



### **POSITION:**

-This exercise is performed as described in Level Four, but with black tubing. Begin at ten laps and add two laps per day until you reach twenty-six laps. Once you reach twenty-six laps without holding onto the counter, you are ready for Level Six.

### **FOR THE PHYSICAL THERAPIST:**

-If a patient has subluxing hips or balance issues, make sure they first perform this exercise while holding onto the counter and then perform it a second time without holding onto the counter.

### 3. HAMSTRING CURLS WITH BLACK TUBING



#### **POSITION:**

-This exercise is performed as described in Level Four, but with black tubing. Begin at ten repetitions and add two repetitions per day until you reach twenty-six repetitions. Once you reach twenty-six repetitions, you are ready for Level Six.

-Make sure to hold onto the counter whether or not you have subluxing hips.

#### 4. SINGLE LEG HEEL AND TOE RAISES



##### **POSITION:**

-This exercise is performed as described in Level Four, doing fifty repetitions on each leg with holding onto the counter on Wednesdays and Saturdays only.

## 5. LUNGES



### **POSITION:**

-This exercise is performed as described in Level Three for twenty-six repetitions. Slowly continue to lower the knee of the leg that is in the back toward the floor until it eventually touches the floor. Not all patients with EDS will be able to allow the knee to touch the floor. Bend as far as you can without pain. This exercise should be performed on Wednesdays and Saturdays only.

### **FOR THE PHYSICAL THERAPIST:**

-The patient will perform this exercise without holding onto the counter. They will slowly lower the knee of the back leg toward the ground at their own pace over the next three months. Not all patients with EDS will touch the floor with their back knee.

## 6. STEP FORWARD ON AN EIGHT-INCH STEP



### **POSITION:**

-This exercise is to be performed the same as described in Level Four, except for now using an eight-inch step instead of a four inch step. Begin at ten repetitions and add two repetitions per day until you reach twenty-six repetitions. Once you reach twenty-six repetitions without holding onto the counter, you are ready for Level Six.

-Do not allow the knee that is on the step to bend inward when stepping up onto the step.

### **FOR THE PHYSICAL THERAPIST:**

-If a patient has subluxing hips, balance issues or their knee goes into valgus when performing this exercise, make sure they first perform this exercise while holding onto the counter and then perform it a second time without holding onto the counter.

## 7. STEP TO THE SIDE ON AN EIGHT-INCH STEP



### **POSITION:**

-This exercise is to be performed the same as described in Level Four, except for now using an eight-inch step instead of a four-inch step. Begin at ten repetitions and add two repetitions per day until you reach twenty-six repetitions. Once you reach twenty-six repetitions, you are ready for Level Six.

-Do not allow the knee that is on the step to bend inward when stepping up onto the step.

### **FOR THE PHYSICAL THERAPIST:**

-If a patient has subluxing hips, balance issues or their knee goes into valgus when performing this exercise, make sure they first perform this exercise while holding onto the counter and then perform it a second time without holding onto the counter.

## 8. STANDING WITH FEET TOGETHER ON A PILLOW WITH EYES CLOSED



### **POSITION:**

-Stand on cushion or pillow with feet together and hands hovering one inch off counter. Close eyes and maintain balance for one and a half minutes. Add ten seconds per day until you reach three minutes. Once you reach three minutes, add this to your Wednesday and Saturday schedule. Do not hyperextend your knees or arch your back.

### **FOR THE PHYSICAL THERAPIST:**

-Make sure the patient's hands are close enough to the counter so they can grab onto the counter if they lose their balance.

## 9. SINGLE LEG STANCE ON THE FLOOR:



### POSITION:

- Stand at the counter with hands hovering one inch over the counter and lift right leg (with knee bent to about sixty degrees) off the ground and stand on left leg only.
- Do not hold onto the counter when performing this exercise.

### PROGRESSION:

- Begin at **one minute** for each leg, adding ten seconds per day until you reach **two minutes** for each leg. Perform this exercise for **two minutes** on each leg. Once you can perform this exercise for **two minutes** on each leg, you are ready for Level Six.

**FOR THE PHYSICAL THERAPIST:**

- Do not allow the patient to hyperextend their knees or arch their back.
- If the patient is unable to perform single leg stance due to pain, have them toe touch with the opposite foot. Begin at **one minute** for the toe touch position, then add ten seconds per day until they reach **two minutes**. Once they reach **two minutes** in the toe touch position, have the patient perform single leg stance in the original position for **one minute** and progress as previously explained.

## 10. RECUMBENT BIKE



-Make sure that a physical therapist adjusts the seat height of the recumbent bike to maintain proper alignment of the hips and knees.

### **PROGRESSION:**

-Begin riding the bike for six minutes at Level One resistance. Add two minutes per day until you reach twenty minutes. Then increase to Level Two resistance, beginning that resistance for the first six minutes, then lower to Level One resistance for the remaining fourteen minutes. Add two minutes per day to the time you perform Level Two resistance until you can complete the entire twenty minutes at Level Two resistance. At this point, you can perform the first six minutes at Level Three resistance, then lower to Level Two resistance for the remaining fourteen minutes. Continue this progression as tolerated. You can increase the total time spent on the recumbent bike if you wish to get more cardiovascular endurance. Have your cardiologist to determine your maximum cardiac output (effort).

-Do not let your knees bend inward toward the midline (belly button).

-Perform on Wednesdays, Saturdays and Sundays only.

**FOR THE PHYSICAL THERAPIST:**

- Make sure the patient's knees do not go into valgus.
- Do not allow the patient to hyperextend their knees. When the pedal is the farthest away from them, the knee should be bent to approximately fifteen degrees.
- Have the patient sit up straight and look straight ahead.

## Level Six Lower Extremity Exercise Progression

### **FOR THE PERSON WITH EDS AND THE PHYSICAL THERAPIST:**

When you have completed all of the exercises in Level Five (except recumbent bike), you can perform Level Six exercises. The exercises for Level Six are: side stepping with black tubing, walking forward and backwards with black tubing, hamstring curls with black tubing, single leg heel and toe raises, lunges, step lowering forward on a four-inch step, step lowering to the side on a four-inch step, single leg stance while standing on pillow eyes open, single leg stance while standing on the floor eyes closed, standing with feet together on a pillow with eyes closed and recumbent bike. The physical therapist can perform manual therapy on any region of the body that is problematic for the patient in order to decrease pain. Modalities can be used if trochanteric bursitis is an issue. Mulligan taping of the knee and McConnell taping of the patella can help decrease pain in the knee while performing this exercise progression. Manual therapy of the foot, joint mobilization of the talocrural joint, manual therapy of the tibia and fibula and myofascial release to the iliotibial band can be performed. If the SIJ becomes irritated while performing these exercises, limit the range of motion of the leg during each exercise.

The following exercises that have been completed from Level Five will only be performed on Wednesdays and Saturdays. They are as follows: side stepping with black tubing for twenty-six laps, walking forward and backward with black tubing for twenty-six laps, hamstring curls with black tubing holding onto counter for twenty-six repetitions, single leg heel and toe raises for fifty repetitions holding onto the counter on each leg, lunges for twenty-six repetitions (range of motion as tolerated), standing feet together on a pillow with eyes closed for three minutes and recumbent bike for twenty minutes (resistance as tolerated). The following exercises will be performed daily for Level Six. Once they have been completed as described in the progression, you will advance to Level Seven. The exercises are: step lowering forward on a four-inch step, step lowering to the side on a four-inch step, single leg stance on the floor with eyes closed, single leg stance on a pillow with eyes open.

**The Following Exercises Will Be Performed On Wednesdays And Saturdays**

## **1. SIDE STEPPING WITH BLACK TUBING**



-Perform this exercise as described in Level Five for twenty-six laps on Wednesdays and Saturdays only.

## 2. WALKING FORWARD AND BACKWARDS WITH BLACK TUBING



-Perform this exercise as described in Level Five for twenty-six laps on Wednesdays and Saturdays only.

### 3. HAMSTRING CURLS WITH BLACK TUBING



-Perform this exercise as described in Level Five for twenty-six repetitions holding onto the counter on Wednesdays and Saturdays only.

#### 4. SINGLE LEG HEEL AND TOE RAISES



-Perform this exercise as described in Level Five for fifty repetitions on each leg, holding onto the counter on Wednesdays and Saturdays only.

## 5. LUNGES



-Perform this exercise as described in Level Five for twenty-six repetitions (range of motion as tolerated) on Wednesdays and Saturdays only.

## 6. STANDING WITH FEET TOGETHER ON A PILLOW WITH EYES CLOSED



-Perform this exercise as described in Level Five for three minutes on Wednesdays and Saturdays only.

## 7. RECUMBENT BIKE



-Perform this exercise as described in Level Five for twenty minutes (resistance as tolerated) on Wednesdays and Saturdays. You can also ride the recumbent bike on Sunday if you want.

**The Following Exercises Will Be Performed Daily For Level Six:**

**1. STEP LOWERING FORWARD ON A FOUR-INCH STEP**



**POSITION:**

- Begin with both of your feet on top of a four-inch step. The step should be perpendicular to the counter. You should hold onto the counter if you have subluxing hips or balance issues.
- Keep the right leg on the middle of the step throughout the entire exercise. Lower the left foot down toward the floor in front of the step. Lower until the foot lightly touches floor (as if you had an egg on the floor and you did not want to break it).
- Raise the left leg up to the step again.
- Repeat this process for ten repetitions then switch to lowering the right foot down for ten repetitions.

**PROGRESSION:**

- Begin with ten repetitions for each leg and add two repetitions per day until you reach twenty-six repetitions. Once you reach twenty-six repetitions without holding onto the counter, you are ready for Level Seven.

**MUSCLES:**

-Quadriceps (front of thigh), gluteus maximus (buttocks)

**FOR THE PHYSICAL THERAPIST:**

-Do not allow your patient to hyperextend their knees or arch their back.

-Patient should touch the floor gently. Do not allow full weight bearing.

-Do not let the patient's knee move into valgus.

-Have the patient hold onto the counter if they cannot control the knee, have subluxing hips or have balance issues. Once they perform twenty-six repetitions holding onto the counter, progress to ten repetitions without holding onto the counter, adding two repetitions per day until they reach twenty-six repetitions without holding onto the counter.

## 2. STEP LOWERING TO THE SIDE ON A FOUR-INCH STEP



### **POSITION:**

- Begin with both feet on top of four-inch step. Step should be parallel to the counter and you should be next to the counter. Hold onto the counter if you have subluxing hips or balance issues.
- Keep the right foot on the middle of the step for the entire exercise. Lower the left leg to the floor slowly and touch the floor lightly (as if you have an egg under your foot and you do not want to break it).
- Raise the left leg up to the step again.
- Repeat this process for ten repetitions then switch to lowering the right foot down for ten repetitions.

### **PROGRESSION:**

- Begin with ten repetitions for each leg and add two repetitions per day until you reach twenty-six repetitions. Once you reach twenty-six repetitions without holding onto the counter, you are ready for Level Seven.

**MUSCLES:**

-Quadriceps (front of thigh), gluteus maximus (buttocks), gluteus medius and minimus (side of hip)

**FOR THE PHYSICAL THERAPIST:**

- Do not allow the patient to hyperextend their knees or arch their back.
- Do not allow the patient to put full weight on the floor when lowering the leg down. Have the patient touch the floor gently.
- Do not let the patient's knee move into valgus.
- Have the patient hold onto the counter if they cannot control the knee, have subluxing hips or have balance issues. Once they perform twenty-six repetitions holding onto the counter, progress to ten repetitions without holding onto the counter, adding two repetitions per day until they reach twenty-six repetitions without holding onto the counter.

### 3. SINGLE LEG STANCE ON THE FLOOR WITH EYES CLOSED:



#### **POSITION:**

- Perform this exercise as discussed in Level Five, except now with eyes closed.
- Make sure your hands are close enough to the counter before closing your eyes.
- Begin at **one minute** for each leg, adding ten seconds per day until you reach **two minutes** for each leg. Perform exercise for two minutes on each leg.
- Once you can perform this exercise for two minutes on each leg, continue this exercise on Wednesdays and Saturdays only.

#### **FOR THE PHYSICAL THERAPIST:**

- You can allow the patient's toe to touch the floor in the beginning if needed as in

the Level Five alternate position. Then progress to single leg stance like the Level Five progression.

- Make sure the patient's hands are close enough to the counter so that they can grab the counter if they lose their balance.

#### 4. SINGLE LEG STANCE ON A PILLOW WITH EYES OPEN



##### **POSITION:**

- Stand on one leg while standing on a pillow or couch cushion for **one minute** on each leg. Add ten seconds per day until you reach **two minutes** on each leg.
- Once you can perform this exercise for **two minutes** on each leg, continue this exercise on Wednesdays and Saturdays only.

##### **FOR THE PHYSICAL THERAPIST:**

- You can have the patient perform a toe touch with the opposite leg if they cannot perform single leg stance. Have them perform single leg stance with a toe touch for **one minute** on each leg, then add ten seconds per day until reaching **two minutes** on each leg. Then have the patient attempt single leg stance on a pillow without a toe touch starting at one minute and progress as previously explained.

## Level Seven Lower Extremity Exercise Progression

### **FOR THE PERSON WITH EDS:**

Once you have completed all of the exercises from Level Six, you are ready for Level Seven. Level Seven exercises that should be performed on Wednesdays and Saturdays only are: side stepping with black tubing for twenty-six laps, walking forward and backward for twenty-six laps, hamstring curls with black tubing holding onto counter for twenty-six repetitions, lunges for twenty-six repetitions (range of motion as tolerated), single leg heel and toe raises holding onto the counter for fifty repetitions each leg, single leg stance on floor eyes closed two minutes each leg, single leg stance on a pillow with eyes open for two minutes on each leg standing with feet together on a pillow with eyes closed for three minutes and recumbent bike as tolerated. The two exercises that you will need to progress every day during this level are: step lowering forward on an eight-inch step and step lowering to the side on an eight-inch step.

### **FOR THE PHYSICAL THERAPIST:**

Physical therapists can perform manual therapy as needed to any region of the body that is painful. McConnell and Mulligan taping techniques should begin to be weaned off in order to protect patients' skin integrity.

The Following Exercises Will Be Performed On Wednesdays And Saturdays

## 1. SIDE STEPPING WITH BLACK TUBING



-Perform this exercise as described in Level Five for twenty-six laps on Wednesdays and Saturdays only.

## 2. WALKING FORWARD AND BACKWARDS WITH BLACK TUBING



-Perform this exercise as described in Level Five for twenty-six laps on Wednesdays and Saturdays only.

### **3. HAMSTRING CURLS WITH BLACK TUBING**



-Perform this exercise as described in Level Five for twenty-six repetitions holding onto the counter on Wednesdays and Saturdays only.

#### 4. SINGLE LEG HEEL AND TOE RAISES



-Perform this exercise as described in Level Five for fifty repetitions on each leg, holding onto the counter on Wednesdays and Saturdays only.

## 5. LUNGES



-Perform this exercise as described in Level Five for twenty-six repetitions (range of motion as tolerated) on Wednesdays and Saturdays only.

## **6. STANDING WITH FEET TOGETHER ON A PILLOW WITH EYES CLOSED**



-Perform this exercise as described in Level Five for three minutes on Wednesdays and Saturdays only.

## 7. SINGLE LEG STANCE ON THE FLOOR WITH EYES CLOSED:



-Perform this exercise for two minutes each leg on Wednesday and Saturday only.

## 8. SINGLE LEG STANCE ON A PILLOW WITH EYES OPEN



-Perform this exercise for two minutes each leg on Wednesday and Saturday only.

## 9. RECUMBENT BIKE



-Perform this exercise as described in Level Five for twenty minutes (resistance as tolerated) on Wednesdays and Saturdays only.

**The Following Exercises Will Be Performed Daily For Level Seven**

**1. STEP LOWERING FORWARD ON EIGHT-INCH STEP**



**POSITION:**

-This exercise is the same as in Level Six, with the exception of being performed on an eight-inch step instead of a four-inch step.

-Begin with ten repetitions and add two repetitions per day until you reach twenty-six repetitions. Once you reach twenty-six repetitions without holding onto the counter,

add this exercise to your Wednesday and Saturday schedule.

**FOR THE PHYSICAL THERAPIST:**

-If a patient has subluxing hips, balance issues or their knee goes into valgus while performing this exercise, make sure they first perform this exercise while holding onto the counter and then perform it a second time without holding onto the counter.

## 2. STEP LOWERING TO THE SIDE ON EIGHT-INCH STEP



### **POSITION:**

-This exercise is the same as in Level Six, with the exception of being performed on an eight-inch step instead of a four-inch step.

-Begin with ten repetitions and add two repetitions per day until you reach twenty-six repetitions. Once you reach twenty-six repetitions without holding onto the counter, add this exercise to your Wednesday and Saturday schedule.

### **FOR THE PHYSICAL THERAPIST**

-If a patient has subluxing hips, balance issues or their knee goes into valgus while performing this exercise, make sure they first perform this exercise while holding onto the counter and then perform it a second time without holding onto the counter.

## Final Home Exercise Program Only Phase One

### **FOR THE PERSON WITH EDS:**

Once you have achieved Level Seven lower extremity exercises, you are strong enough for high level physical therapy exercises. You should feel much better than when you began the protocol many months ago. The next page is a review of your final home exercise program. You will now begin Phase Two of the Muldowney Exercise Protocol. This will include higher level exercises that will allow you to twist, throw a ball and walk on uneven surfaces. Since these are higher level exercises, this phase should be monitored by a physical therapist at all times. Congratulations on completing the strength-building phase which allows you the strength to work with a physical therapist on more functional activities.

### **FOR THE PERSON WITH EDS AND THE PHYSICAL THERAPIST:**

This final home exercise program is broken up into a three day schedule. Mondays and Thursdays are the SIJ and lumbar spine progression, Tuesdays and Fridays are the neck, mid back and upper extremity progression and Wednesdays and Saturdays are the lower extremity progression. Have the patient perform only the exercises for that specific day in order not to over work their muscular system. One day a week, they will not perform any exercises (“rest day”) except for the recumbent bike for cardiovascular exercise if they choose. This will allow their body to recover from the week’s workout. If they miss a day, begin the next day with the exercises for the day they missed. For example, if they miss Monday’s lumbar stabilization progression exercises, then on Tuesday, proceed with the lumbar stabilization progression. Then, each successive day follow the outlined progression and their “rest day” will have become the day they originally missed (Monday in this example). When they reach Sunday, they will be caught up and back on schedule to begin as directed the following Monday.

## **1. MONDAYS AND THURSDAYS:**

-SIJ And Lumbar Stabilization Progression:

*-All Exercises Are Performed For Three Minutes*

- Dying Bug (Alternate Position With Heel Touches)
- Prone Swimmer For Three Minutes (Alternate Position Leaning Over Ball)
- Bridges With Kickouts (Alternate Position Bridges With Heel Raises)
- Seated On The Ball Kickouts
- Ball Roll Outs With Heel Ups (Alternate Position Ball Roll Outs With Toe Ups)
- Bridging With Legs On Ball Arms Across Chest
- Hugging The Ball With Kickouts (Alternate Position Hugging The Ball With Hands On The Mat )
- Clam With Black Tubing
- Ball Squeezes

**-At this point, attempt the original positions for the SIJ and Lumbar Stabilization exercise progression instead of the alternate positions. Begin at one minute, adding ten seconds per day until reaching three minutes. If you cannot perform the original positions without increased pain, then the alternate positions will be your final home exercise program.**

## **2. TUESDAYS AND FRIDAYS:**

-Neck, Mid Back And Upper Extremity Progression:

*-All Exercises Are Performed For Three Minutes*

-T,Y,I's With Chin Tucks With Three Pounds (Alternate Positions Kneeling On Mat Leaning Over Ball Or Standing Leaning Over Ball)

-Shoulder Internal Rotation With Black Tubing

-Shoulder External Rotation With Black Tubing

-Full Can With Five Pounds

-Shoulder Abduction With Four Pounds

-Hand Ball Squeezes

-Four Way Wrist With Three Pounds

-Bicep Curl With Five Pounds

-Triceps Push Downs With Black Tubing

-Criss-Cross Eyes

-Eyebrow Raise

-Ear Wiggle

-TMJ Isometrics One Minute Each Way

### **3. WEDNESDAYS AND SATURDAYS**

- Lower Extremity Progression
- Side Stepping With Black Band Twenty-Six Laps
- Walk Forward And Backwards With Black Band Twenty-Six Laps
- Hamstring Curls With Black Band Twenty-Six Repetitions (Holding Onto The Counter)
- Single Leg Heel And Toe Raises Fifty Repetitions (Holding Onto The Counter)
- Deep Lunges To Tolerance Twenty-Six Repetitions
- Step Lowering Forward On An Eight-Inch Step, Twenty-Six Repetitions Each Leg
- Step Lowering To The Side On An Eight-Inch Step, Twenty-Six Repetitions Each Leg
- Single Leg Stance On A Pillow, Eyes Open For Two Minutes Each Leg (Alternate Position Single Leg Stance On A Pillow, Eyes Open With Toe Touch)
- Single Leg Stance On The Floor With Eyes Closed For Two Minutes On Each Leg (Alternate Position: With Toe Touch)
- Standing With Feet Together On A Pillow With Eyes Closed For Three Minutes
- Recumbent Bike For Twenty Minutes (Resistance As Tolerated Per Protocol)

### **4. SUNDAYS:**

- Either Rest Or Recumbent Bike For Twenty Minutes Only (Resistance As Tolerated Per Protocol)

## Section Five -

# Phase Two Exercise Progressions

*“Only those who risk going too far can possibly find out how far they can go.”*

T.S. Eliot

### About Phase Two

#### **FOR THE PERSON WITH EDS:**

Congratulations! You are now ready for Phase Two of the Muldowney Exercise Protocol. It has been a long haul, but you made it. You should be considerably better than when you first began this protocol many months ago. Phase One gets you out of pain and allows you to perform activities of daily living with minimal pain. Phase Two allows you to live life to the fullest. Life is not about getting dressed, eating, driving your car or watching television without increased pain although, it is nice that you can do these activities now. Life is about going to cookouts, playing catch with your friend and picking strawberries with your child. These are the memories we cherish and that stay with us throughout life. This is what Phase Two is all about. Phase Two is divided into three exercise progressions working on functional activities that are important to all of us. The twisting progression allows for activities like strawberry picking, working in your office and petting your dog without increased pain. The throwing progression allows for activities such as playing catch with your child or tossing a frisbee with your friends. The balance progression focuses on preparing you for activities like walking on grass at a friend’s cookout or walking across a field to watch your child play soccer. Unlike Phase One, in Phase Two, you will begin all progressions together at the same time and will advance through each progression individually, as you tolerate. I suggest introducing each progression in Phase Two on separate days to ensure that you can handle this new activity. Once a progression is introduced, add it to your home exercise program. Once you reach the top level of this progression, go to the next level, even if you did not finish the other two progressions. For

example, you may be on Level Three twisting, Level Two balance and Level One throwing. Progress at your own pace. Good Luck! I Hope that by the end of Phase Two, you are living life to the fullest.

## **About Phase Two**

### **FOR THE PHYSICAL THERAPIST:**

Phase Two begins the functional activity phase. Phase Two has three exercise progressions that can be worked on and progressed individually by you as your patient tolerates. These progressions are: the twisting progression, the throwing progression and the balance progression. Unlike in Phase One, exercises in Phase Two will be progressed based on each patient's abilities. For example, a patient may reach the top level of the twisting progression, but may remain at the lowest level of the balance progression. Not all patients with EDS will reach the top level of Phase Two for each progression. The physical therapist will guide each patient individually through Phase Two and limit the progression of the exercises if a patient has increased pain or decreased stability in a joint when performing the exercises. During Phase Two, the physical therapist can continue performing manual therapy on any region of the body that needs it. Once the patient is performing the higher level exercises in Phase Two, the physical therapist will determine if bracing and taping certain joints may be needed during the physical therapy session while exercising and then removed once they have finished that particular treatment session. Once they have reached the top level of an exercise, I will explain where that exercise should be added to their final home exercise program. Keep in mind, that when progressing through Phase Two, they need to continue their final home exercise program from Phase One on their own. Phase Two is not a substitute for Phase One. When they complete Phase Two, the exercises will be added into their final home exercise program. At this point, they should feel much better than before they began the Muldowney Exercise Protocol. If they do not feel better, then you need to refer them to their primary care physician for further evaluation.

## Twisting Progression

### **FOR THE PHYSICAL THERAPIST:**

The Twisting Progression exercises have two goals. The first goal is to strengthen muscles in the transverse plane (twisting motion). The second goal is to teach proprioception on how far a person is able to twist without injury. Remember, this population is hypermobile and, therefore, our goal is to allow patients to understand where a safe range of motion of twisting can be performed without causing increased subluxations.

### **Level One Twisting:**

### **FOR THE PERSON WITH EDS AND THE PHYSICAL THERAPIST:**

There is only one exercise in this level: Standing Superman. This exercise is intended to teach the patient to twist leading with the hips and not with the lumbar or thoracic spine.

## 1. STANDING SUPERMAN



### **POSITION:**

- Stand in front of a mirror with your feet hip-width apart in pelvic neutral and with your hands resting on hips (do not arch your back). Keep your stomach tight.
- Twist to the right approximately forty-five degrees, leading with the hip joint. Once reaching forty-five degrees of rotation to the right, twist to the left forty-five degrees past center. Continue to twist alternating right and left forty-five degrees each way, moving in a slow and controlled speed, not stopping each time in the center.
- Use the mirror to monitor your range of motion, making sure you do not twist beyond forty-five degrees in either direction.
- Perform this exercise for one and a half minutes.

## **PROGRESSION**

-Begin this exercise at one and a half minutes, adding ten seconds per day until you reach three minutes. Once you reach three minutes, you are ready for Level Two of the twisting progression.

### **FOR THE PHYSICAL THERAPIST:**

-If the patient becomes dizzy when performing this exercise, stop immediately. Determine when it is appropriate for the patient to attempt this again, as this is an important functional exercise that patients should eventually be able to complete so they do not injure themselves during activities of daily living. If dizziness continues, have the patient see their cardiologist to check for POTS.

-Have the patient stay in the range of motion described above. Do not allow them to twist beyond forty-five degrees because this can cause increased stress on both knees and ankles.

-Have the patient maintain pelvic neutral throughout the entire exercise in order to stabilize the mid back and low back and allow twisting primarily from the hips.

-Have the patient keep their hands on their hips in order to lock out their lumbar and thoracic spine to avoid twisting from these areas. All twisting motion should come from the hips during this exercise.

### **Level Two Twisting**

### **FOR THE PERSON WITH EDS AND THE PHYSICAL THERAPIST:**

There is only one exercise in this level: The Matrix. This level now allows the patient to incorporate the thoracic spine along with the hips in twisting.

## 1. THE MATRIX



### **POSITION:**

- Stand in pelvic neutral six to eight inches away from a closed door, facing the center of the door with feet hip-width apart and hands down by your side.
- Twist to the right leading with the hips and reach with left hand at chest height, touching the back of your left hand to the outside of the doorframe on the right. Then twist to the left leading with the hips and reach with right hand at chest height, touching the back of your right hand to the outside of the doorframe on the left.
- Continue to twist alternating right and left, moving at a slow and controlled speed, not stopping each time in the center.
- Perform this exercise for one and a half minutes.

### **PROGRESSION**

- Begin this exercise at one and a half minutes, adding ten seconds per day until you

reach three minutes. Once you reach three minutes, you are ready for Level Three of the twisting progression.

**FOR THE PHYSICAL THERAPIST:**

-If the patient becomes dizzy when performing this exercise, stop immediately. Determine when it is appropriate for the patient to attempt this again, as this is an important functional exercise that patients should eventually be able to complete so they do not injure themselves during activities of daily living. If dizziness continues, have the patient see their cardiologist to check for POTS.

-Limit the range of motion if the patient's knees, ankles or mid back have increased pain or if their ribs sublux.

-Have the patient maintain pelvic neutral throughout the entire exercise in order to stabilize the low back and allow twisting primarily from the hips and mid back.

**Level Three Twisting**

**FOR THE PERSON WITH EDS AND THE PHYSICAL THERAPIST:**

There is only one exercise in this level: Diagonal Twisting. Dizziness becomes a major limiting factor when performing this exercise with the EDS population. This level now allows the patient to incorporate the entire body in twisting in order to provide the maximum strength needed to complete all activities of daily living without causing injury. If the patient gets dizzy with this exercise, then have them attempt the alternate position. If the patient gets dizzy with the alternate position, have The Matrix be their final level of twisting.

## 1. DIAGONAL TWISTING



### **POSITION:**

- Stand with your feet hip-width apart.
- Take both of your hands and twist and bend and touch your right knee.
- After touching your right knee, take both of your hands and move them diagonally across your body and place them above your left ear. Then return to your right knee.
- Repeat this for **one minute** and then switch to moving your hands to your left knee and above your right ear for **one minute**.
- Perform this exercise for **one minute** on each side, adding ten seconds per day for each side until you reach **two minutes** on each side. Once you reach two minutes on each side, add this exercise to your Monday and Thursday schedule with the SIJ and Lumbar Spine progression.

### **FOR THE PHYSICAL THERAPIST:**

- If the patient gets dizzy with diagonal twisting, try the alternate position of Table Twisting.

## 1A. ALTERNATE POSITION TABLE TWISTING



-Stand at a table and twist and reach to the right. Touch the right hand to the table. **Stand up straight again.** Then twist your body forty-five degrees to the left and touch the table with the left hand.

-Do not remain slumped forward the entire time because it will place increased stress on your low back and sacrum.

-Repeat this process without stopping for **one minute**. Add ten seconds per day until you reach three minutes. Once you reach three minutes, attempt diagonal twisting again. If you get dizzy, with Diagonal Twisting again, then keep this alternate position of Table Twisting as your final home exercise program. If you get dizzy with Table Twisting, then The Matrix will be your final level and added to your Monday and Thursday home exercise program with the SIJ and Lumbar Spine progression.

**FOR THE PHYSICAL THERAPIST:**

- Make sure the patient does not twist their knee excessively.
- If the patient gets dizzy with both Diagonal Twisting and Table Twisting, then do not have them perform these exercises and use the Matrix as their final level of their home exercise progression.
- Make sure the patient twists from the hips and not the lumbar spine.
- Make sure the patient returns to the upright position after each reach toward the table.
- Add the twisting progression to the Monday and Thursday home exercise program with the SIJ and Lumbar Spine progression.

## Throwing Progression

### **For The Physical Therapist And The Person With EDS:**

The Throwing Progression was developed primarily for younger patients and parents who wanted to be able to throw a ball with their kids and friends, which usually caused increased shoulder pain. Even if your patient has no interest in throwing a ball, still have them go through this progression in order to provide strength to their shoulder girdle for activities requiring an overhead reach. The four exercises in this progression are: Touch Down, Throwing With Tubing, Shoulder Internal Rotation At Eighty Degrees of Abduction and Shoulder External Rotation At Eighty Degrees of Abduction. The four exercises will remain the same through each level and will be progressed by adding weight or resistance tubing. The Shoulder External Rotation At Eighty Degrees Of Abduction exercise needs to be progressed at the same level of resistance as the Shoulder Internal Rotation At Eighty Degrees of Abduction exercise in order to avoid muscle imbalance. So, if a patient is able to perform a higher band resistance for shoulder internal rotation at eighty degrees of abduction, but not for shoulder external rotation at eighty degrees of abduction, then they should remain at the lower band resistance for both to allow for muscle balance.

# 1. TOUCH DOWN

## **FOR THE PERSON WITH EDS AND THE PHYSICAL THERAPIST:**

-This exercise can be progressed independently from the other exercises in the Throwing Progression.



## **POSITION:**

- Stand in pelvic neutral with feet hip-width apart with hands crossed in front of your body.
- Then lift both arms up simultaneously, uncrossing arms, as if to say “touch down,” ending with arms overhead and palms facing forward (elbows should never go above shoulder height).
- Then return arms to starting position.
- Keep arms moving continuously at a slow and controlled pace, without holding.
- Perform this exercise for one and a half minutes.

## **PROGRESSION**

- Begin this exercise at one and a half minutes, adding ten seconds per day until you reach three minutes. Once you reach three minutes, you are ready to add weights.
- Once you complete this exercise for three minutes without weights, add a one pound weight in each hand. Begin performing this exercise at one and a half minutes with one pound weights, adding ten seconds per day until you reach three minutes. Once you reach three minutes using one pound weights, then add two pound weights in each hand.
- Begin performing this exercise at one and a half minutes with two pound weights, adding ten seconds per day until you reach three minutes. Once you reach three minutes using two pound weights, begin performing this exercise at one and a half minutes with three pound weights, adding ten seconds per day until you reach three minutes. Once you reach three minutes using three pound weights, you have reached the top level of this exercise and it will be added into your final home exercise program as part of the neck, mid back and upper extremity progression performed on Tuesdays and Fridays. Not all people with EDS will progress to using three pound weights for three minutes due to increased pain in the shoulder and/or neck region. In this case, whatever level you can perform for three minutes without increased pain, will become the final level incorporated into your final home exercise program.

## **FOR THE PHYSICAL THERAPIST:**

- Have the patient maintain pelvic neutral. Do not allow them to arch their back, especially when in the “touch down” arms overhead position.
- Do not allow the patient to hyperextend their knees.
- Patient’s elbows should be below shoulder height (about eighty degrees of shoulder abduction).
- Have the patient keep their elbows bent to ninety degrees in the overhead position.
- If there is shoulder pain during this exercise, limit the height at which you raise the arms overhead.

## 2. THROWING WITH TUBING



### **FOR THE PERSON WITH EDS AND THE PHYSICAL THERAPIST:**

-This exercise can be progressed independently from the other exercises in the Throwing Progression.

### **POSITION:**

-Stand in pelvic neutral in staggered stance with left leg forward, right leg back and with your back facing a door. Secure yellow tubing at the top of the door, holding it in your hand with the shoulder abducted to slightly below your shoulder, elbow bent to ninety degrees and your hand at the level of your head. If the left leg is forward in your staggered stance, then pull the tubing with the right hand across your body touching the left hip with right hand. Then return to the original position.

-Keep arms moving continuously at a slow and controlled pace, without holding.

-Perform this exercise for **one minute** on the right arm and for **one minute** on the left arm with opposite staggered stance to avoid muscle imbalance.

### **PROGRESSION**

-Begin this exercise at **one minute** for each arm using yellow tubing, adding ten seconds

per day until you reach two minutes for each arm. Once you reach two minutes for each arm using yellow tubing, you are ready to increase to using red tubing.

-Begin this exercise at **one minute** for each arm using red tubing, adding ten seconds per day until you reach two minutes for each arm. Once you reach two minutes for each arm using the red tubing, increase to using green tubing.

-Begin this exercise at **one minute** for each arm using green tubing, adding ten seconds per day until you reach two minutes for each arm. Once you reach two minutes for each arm using the green tubing, increase to using blue tubing.

-Begin this exercise at **one minute** for each arm using blue tubing, adding ten seconds per day until you reach two minutes for each arm. Once you reach two minutes for each arm using the blue tubing, you have reached the top level of this exercise and it will be added into your final home exercise program as part of the neck, mid back and upper extremity progression performed on Tuesdays and Fridays. Not all people with EDS will progress to using blue tubing for two minutes due to increased pain in the shoulder and/or neck region. In this case, whatever color tubing you can perform for two minutes without increased pain, will become your final level incorporated into your final home exercise program.

### **FOR THE PHYSICAL THERAPIST:**

-Have the patient maintain pelvic neutral. Do not allow the patient to arch their back, especially when returning to the starting position.

-Do not allow the patient to hyperextend the knee that they are not stepping forward with.

**-Do not allow the patient to bring their arm into excessive external rotation when returning to the starting position. This can cause the shoulder to sublux.**

-When bringing the arm down toward opposite hip, if the band hits the patient's neck, have them side step away from the band and then perform the exercise.

-If there is shoulder pain during this exercise, limit the range of motion.

### 3. SHOULDER EXTERNAL ROTATION AND INTERNAL ROTATION WITH ABDUCTION TO EIGHTY DEGREES

#### **FOR THE PERSON WITH EDS AND THE PHYSICAL THERAPIST:**

These two exercises need to be progressed at the same resistance level to avoid muscle imbalance. For most patients with EDS, shoulder external rotation at eighty degrees of abduction will be the limiting factor. Regardless of whether or not you can progress shoulder internal rotation at eighty degrees of abduction, do not use different colored tubing for these two exercises to avoid muscle imbalance.

#### **External Rotation At Eighty Degrees Of Abduction**



#### **POSITION:**

-Stand in pelvic neutral six to eight inches away from a door, facing the door. Secure yellow tubing at the top of the door. Raise arm out to the side so elbow is slightly below shoulder height. Bend elbow to ninety degrees and move hand forward approximately forty-five degrees. While holding the tubing, move hand from the forward position backwards even with your head and then return to the original position. **Do not move your hand behind your head because this position can sublux your shoulder.**

-Perform this exercise for one and a half minutes on the right arm and for one and a half minutes on the left arm to avoid muscle imbalance.

## **PROGRESSION**

- Begin this exercise at one and a half minutes for each arm using yellow tubing, adding ten seconds per day until you reach three minutes for each arm. Once you reach three minutes for each arm using yellow tubing, you are ready to increase to using red tubing.
- Begin this exercise at one and a half minutes for each arm using red tubing, adding ten seconds per day until you reach three minutes for each arm. Once you reach three minutes for each arm using the red tubing, increase to using green tubing.
- Begin this exercise at one and a half minutes for each arm using green tubing, adding ten seconds per day until you reach three minutes for each arm. Once you reach three minutes for each arm using the green tubing, increase to using blue tubing.
- Begin this exercise at one and a half minutes for each arm using blue tubing, adding ten seconds per day until you reach three minutes for each arm. Once you reach three minutes for each arm using the blue tubing, you have reached the top level of this exercise and it will be added into your final home exercise program as part of the neck, mid back and upper extremity progression performed on Tuesdays and Fridays. Not all people with EDS will progress to using blue tubing for three minutes due to increased pain in the shoulder and/or neck region. **Never progress to a tubing that is a higher resistance than what you are doing for internal rotation at eighty degrees of abduction.** In this case, whatever color tubing you can perform for three minutes without increased pain for both exercises will become your final level incorporated into your final home exercise program on Tuesdays and Fridays.

## **FOR THE PHYSICAL THERAPIST:**

- Have the patient maintain pelvic neutral. Do not allow the patient to arch their back, especially when bringing their arm into external rotation.
- Do not allow the patient to rotate their neck during the exercise (keep in neutral looking straight ahead).
- Do not allow patient to raise shoulder above eighty degrees of abduction.
- Have the patient keep their wrist in neutral.

- Do not allow the patient to hyperextend their knees. Have them keep their feet hip-width apart.
- Have the patient perform this exercise in a pain-free range of motion.

## Shoulder Internal Rotation At Eighty Degrees Of Abduction



### POSITION:

-Stand in pelvic neutral six to eight inches away from a door, with your back facing the door. Secure yellow tubing at the top of the door. Raise arm out to the side so elbow is slightly below shoulder height. Bend elbow to ninety degrees and have hand pointing straight ahead at the level of the head. While holding the tubing, move hand forward to approximately forty-five to sixty degrees and then return to the original position (control the motion when returning to the original position).

**-Do not allow your hand to go behind your head when performing this exercise because it could sublux your shoulder.**

-Perform this exercise for one and a half minutes on the right arm and for one and a half minutes on the left arm to avoid muscle imbalance.

### PROGRESSION

-Begin this exercise at one and a half minutes for each arm using yellow tubing, adding ten seconds per day until you reach three minutes for each arm. Once you reach three minutes for each arm using yellow tubing, you are ready to increase to using red tubing.

-Begin this exercise at one and a half minutes for each arm using red tubing, adding ten seconds per day until you reach three minutes for each arm. Once you reach three

minutes for each arm using the red tubing, increase to using green tubing.

-Begin this exercise at one and a half minutes for each arm using green tubing, adding ten seconds per day until you reach three minutes for each arm. Once you reach three minutes for each arm using the green tubing, increase to using blue tubing.

-Begin this exercise at one and a half minutes for each arm using blue tubing, adding ten seconds per day until you reach three minutes for each arm. Once you reach three minutes for each arm using the blue tubing, you have reached the top level of this exercise and it will be added into your final home exercise program as part of the neck, mid back and upper extremity progression performed on Tuesdays and Fridays. Not all people with EDS will progress to using blue tubing for three minutes due to increased pain in the shoulder and/or neck region. **Never progress to a band that is a higher resistance than what you are doing for external rotation at eighty degrees of abduction.** In this case, whatever color tubing you can perform for three minutes without increased pain for this exercise and for shoulder external rotation at eighty degrees of abduction, will become your final level and incorporated into your final home exercise program.

#### **FOR THE PHYSICAL THERAPIST:**

**-Do not allow patient's hand to go behind their head when performing this exercise, because it could sublux their shoulder.**

-Have the patient maintain pelvic neutral. Do not allow patient to arch their back, especially when returning to the starting position.

-Do not allow patient to rotate their neck during the exercise (keep in neutral looking straight ahead).

-Do not allow the patient to raise their shoulder above ninety degrees of abduction, in order to protect the shoulder.

-Have the patient keep their wrist in neutral.

-Do not allow patient to hyperextend their knees. Keep feet hip-width apart.

- Have the patient perform this exercise in a pain-free range of motion.
- Have the patient control the eccentric contraction and not go into excessive shoulder external rotation because that could cause the shoulder to sublux.

## Balance Progression

### **FOR THE PERSON WITH EDS AND THE PHYSICAL THERAPIST:**

This exercise progression was developed to work on dynamic balance (balance while moving) both on even and uneven surfaces and walking up and down stairs. Jumping is never addressed in this exercise protocol, due to the increased forces on the ankle, knee, hip and especially the SIJ. Therefore, jumping needs to be avoided for people with EDS. The exercises in this progression are: walking up and down stairs, star, tandem walking and walking on foam squares. Each exercise is progressed individually and is independent from each other.

## 1. WALKING UP THE STAIRS



**Two Railings**



**One Railing**



**No Railings**

## 2. WALKING DOWN THE STAIRS



**Two Railings**



**One Railing**



**No Railings**

### POSITION

-A standard set of stairs is thirteen steps. Begin up and down thirteen steps while using two handrails.

## **PROGRESSION**

- Once you are able to perform this exercise safely as determined by the physical therapist, then progress to walking up and down thirteen steps using one handrail.
- Finally, the physical therapist will progress you to walking up and down thirteen steps without holding onto railing. Once you can walk up and down a flight of stairs without holding on, add a second flight of stairs, beginning with two handrails for the second flight of steps. Then use one handrail for the second flight and progress to using no handrails for the second flight. Once you can walk two flights without holding on, this can be added to the final home exercise program with the Lower Extremity Progression performed on Wednesdays and Saturdays. Not all patients will progress to walking two flights without holding on, so whatever level you can safely perform will be the final level.

## **FOR THE PHYSICAL THERAPIST**

- Do not allow the patient's knee to move into valgus.
- Use close supervision with patient as they are going up and down the stairs to ensure their safety, especially when they progress to using no railings.
- Only once a physical therapist decides a patient is safe on the stairs can they progress this exercise to the final home exercise program.
- Have the patient perform this with you in the clinic until you determine that they are safe to perform this exercise at home.
- Ask the patient about stair height at home and stair width at home. Have them take pictures so you can assess safety before allowing them to perform this at home.

### 3. STAR



1



2



3



4

#### **POSITION:**

- Hold onto the counter and stand on your left foot and touch the floor with your right foot in front of you, to the side of you and to the back of you. Then return to starting position in front of you. Every time you touch forward, this is considered one repetition.
- Repeat this exercise for ten repetitions on the right leg and ten repetitions on the left leg.

#### **PROGRESSION**

- Hold onto counter to maintain balance for this exercise. Begin at ten repetitions on each leg, adding two repetitions per day until you reach twenty-six repetitions.

- Once you reach twenty-six repetitions, perform this same exercise without holding onto the counter, starting at ten repetitions. Then add two repetitions per day until you reach twenty-six repetitions.
- Once you reach twenty-six repetitions without holding onto the counter, you can perform the Star exercise while standing on a pillow and holding onto the counter, starting at ten repetitions. Add two repetitions per day until you reach twenty-six repetitions.
- Once you reach twenty-six repetitions, then perform the Star exercise on a pillow without holding on for ten repetitions, adding two repetitions per day until you reach twenty-six repetitions. This will be added to your final home exercise program.
- Not all patients will progress to standing on a pillow, so whatever level you can safely perform will be the final level.

#### **FOR THE PHYSICAL THERAPIST**

- Do not allow the patient's stance knee to move into valgus.
- Have the patient keep a slight bend in the knee that is moving at all times.
- When touching the toe backwards, make sure the toe is directly behind the stance leg and not out to the side.
- Make sure the patient touches the floor with only their toe, not the whole foot, so that most of the weight bearing is on the stance leg.

## 4. TANDEM WALKING



### **POSITION**

-Stand next to your kitchen counter, hold onto counter and place right foot in front of left foot with right heel touching left toes. Switch by placing left foot in front of right foot with left heel touching right toes and continue to walk this way the length of the counter. Turn around and walk forward the same way until you reach the original starting point on the counter. This is considered one lap.

-Perform this exercise for ten laps.

### **PROGRESSION**

-Hold onto the counter the entire time, then once you reach twenty-six laps, begin again at ten laps without holding onto the counter, adding two laps per day until you reach twenty-six laps. Once you have reached twenty-six laps, this can be added to

your final home exercise program with your lower extremity progression exercises on Wednesdays and Saturdays.

-Not every person will progress to twenty-six laps without holding onto the counter, so whatever level you can safely perform will be your final level.

### **FOR THE PHYSICAL THERAPIST**

-Have the patient maintain pelvic neutral throughout exercise.

-Do not allow the patient to hyperextend their knees.

-Do not allow the patient to have a Trendelenburg gait. If this occurs, have the patient spread their feet apart a little bit so that they are not heel-toe walking, and then move toward tandem walks as they get stronger.

-Do not allow the patient to cross their leg beyond midline (to avoid hip subluxations) while stepping forward into the tandem position.

-Make sure all patients first perform this exercise while holding onto the counter and then perform it a second time without holding onto the counter.

## 5. WALKING ON FOAM SQUARES



### **POSITION**

-Place five foam squares on the floor and walk across all five foam squares with holding onto the counter. Then turn around and walk back to original position. This is considered one lap. Then, once you reach twenty-six laps with holding onto a counter, perform this for ten laps without holding onto anything.

-Add two laps per day until you reach twenty-six laps. Make sure the physical therapist is guarding you with this exercise. Make sure the surface that the foam squares is on will not allow the foam squares to slip while you are walking on them.

### **PROGRESSION**

-Begin with ten laps with holding onto the counter, adding two laps per physical therapy session until you reach twenty-six laps. Once you reach twenty-six laps holding onto the counter, perform ten laps without holding onto the counter. Add two laps per day until you reach twenty-six laps. Once you reach twenty-six laps without holding onto the counter, you can begin to walk outside on grassy areas between 100 and 300 feet as part of the lower extremity progression. Have the physical therapist guard you the first time you walk on grass. Remember to watch for holes in the grass.

### **FOR THE PHYSICAL THERAPIST**

- Make sure patients ankles, knees and hips stay in neutral.
- Do not allow the patient to have a Trendelenburg gait.
- Properly guard patient in case of loss of balance.
- Make sure patient is independent with walking on grass before adding walking on grass to their home exercise program. Guard the patient the first time they walk on grass.
- Not all patients will progress to walking on uneven terrain.

## FINAL HOME EXERCISE PROGRAM INCLUDING PHASE TWO

### **FOR THE PERSON WITH EDS:**

This final home exercise program is broken up into a three day schedule. The first day is the lumbar spine progression with the twisting progression, the second day is neck, mid back and upper extremity progression with the throwing progression and the third day is the lower extremity progression with the balance progression. Perform only the exercises for that specific day in order not to over work your muscular system. One day a week, you will not perform any exercises (“rest day”) except for the recumbent bike for cardiovascular exercise if you choose. This will allow your body to recover from the week’s workout. If you miss a day, begin the next day with the exercises for the day you missed. For example, if you miss Monday’s lumbar stabilization progression exercises, then on Tuesday, proceed with the lumbar stabilization progression. Then, each successive day follow the outlined progression and your “rest day” will have become the day you originally missed (Monday in this example). When you reach Sunday, you will be caught up and back on schedule to begin as directed the following Monday. The physical therapist should circle what level of Phase Two you reached, and you should perform only the exercises in Phase Two that the physical therapist circled. **CONGRATULATIONS!**

## **1. MONDAYS AND THURSDAYS:**

***\* All Exercises Should Be Performed For Three Minutes Each Unless Otherwise Stated***

-SIJ And Lumbar Spine Progression:

-Dying Bug (Alternate Position With Heel Touches)

-Prone Swimmer (Alternate Position Leaning Over Ball)

-Bridges With Kickouts (Alternate Position Bridges With Heel Raises)

-Seated On The Ball Kickouts

-Ball Roll Outs With Heel Ups (Alternate Position Ball Roll Outs With Toe Ups)

-Bridging With Legs On Ball Arms Across Chest

-Hugging The Ball With Kickouts (Alternate Position Hugging The Ball With Hands On The Mat )

-Clam With Black Tubing

-Ball Squeezes

-Phase Two Twisting (Physical Therapist Should Circle One)

-Standing Superman Or Matrix Or Diagonal Twisting (Two Minutes Each Way) Or Table Twisting

## **2. TUESDAYS AND FRIDAYS:**

***\* All Exercises Should Be Performed For Three Minutes Each Unless Otherwise Stated***

-Neck, Mid Back And Upper Extremity Progression:

-T,Y,I's With Chin Tucks With Three Pounds (Alternate Positions Kneeling On Mat Leaning Over Ball Or Standing Leaning Over Ball)

-Shoulder Internal Rotation With Black Tubing

-Shoulder External Rotation With Black Tubing

-Full Can With Five Pounds

-Shoulder Abduction With Four Pounds

-Hand Ball Squeezes

-Four Way Wrist With Three Pounds

-Bicep Curl With Five Pounds

-Triceps Push Downs With Black Tubing

-Criss-Cross Eyes

-Eyebrow Raise

-Ear Wiggle

-TMJ Isometrics One Minute Each Way

-Phase Two Throwing (Physical Therapist Should Circle One For Each)

-Touch Down With: No Weight Or One Pound Or Two Pounds  
Or Three Pounds

-Throwing With: Yellow Or Red Or Green Or Blue Tubing

-Shoulder Internal Rotation At Eighty Degrees Of Abduction  
With: Yellow Or Red Or Green Or Blue Tubing

-Shoulder External Rotation At Eighty Degrees Of Abduction  
With: Yellow Or Red Or Green Or Blue Tubing

### **3. WEDNESDAYS AND SATURDAYS**

***\* All Exercises Should Be Performed For Twenty-Six Repetitions Or Laps Each Unless Otherwise Stated***

-Lower Extremity Progression

-Side Stepping With Black Band

-Walk Forward And Backwards With Black Band

-Hamstring Curls With Black Band (Hold Onto The Counter)

-Single Leg Heel And Toe Raises Fifty Repetitions Each Leg (Hold Onto The Counter)

-Deep Lunges To Tolerance

-Step Lowering Forward On An Eight-Inch Step

-Step Lowering To The Side On An Eight-Inch Step

-Single Leg Stance On A Pillow, Eyes Open For Two Minutes Each Leg (Alternate Position Single Leg Stance On A Pillow, Eyes Open With Toe Touch)

- Single Leg Stance On The Floor, Eyes Closed For Two Minutes Each Leg (Alternate Position Single Leg Stance On The Floor, Eyes Closed With Toe Touch)

-Stand Feet Together On A Pillow, Eyes Closed

-Recumbent Bike For Twenty Minutes (Resistance As Tolerated Per Protocol)

-Phase Two Balance (Physical Therapist Should Circle One For Each)

-Walking Up And Down Stairs:

First Flight, Two Railings Or One Railing Or No Railings;

Second Flight, Two Railings Or One Railing Or No Railings

-Star On Floor: Holding Onto Counter Or Not Holding Onto Counter

-Star On A Pillow: Holding Onto Counter Or Not Holding Onto Counter

-Tandem Walking: 300 Feet, Holding Onto Counter Or Not Holding Onto Counter

-Walking On Foam Squares: Holding Onto Counter OR Not Holding Onto Counter

-Walking On Grass 100 To 300 Feet

**4. SUNDAYS:**

-Either Rest Or Recumbent Bike For Twenty Minutes Only (Resistance As Tolerated Per Protocol)

## FINAL GOODBYE:

***“Congratulations! Today is your day. You’re off to Great Places! You’re off and away.” Dr. Seuss***

**Congratulations!** You have made it through the Muldowney Exercise Protocol! There have been some bumps along the way, but you persevered and now, your hard work has paid off. You are in control of your body and living life with less pain than you ever thought possible. Your physical therapist and this book have been your guide, but you are the one who stuck with it and pushed through when things were difficult. This was not an easy journey and you should be proud of what you have accomplished. Now that you have completed this demanding program, reach out to other patients who are just beginning their program and be a mentor to them. My wish for you is to continue with the maintenance phase of this protocol and live your life to the fullest. Be proud and carry on!

***“You have brains in your head. You have feet in your shoes. You can steer yourself any direction you choose. You’re on your own. And you know what you know. And YOU are the one who’ll decide where to go...”***

**Dr. Seuss**

## **Appendix A – SIJ And Lumbar Spine Exercise Progression At A Glance**

### **Level One Mat For One And A Half To Three Minutes**

- Supine Marches (Alternate Positions: Either Supine Toe Raises Or Supine Heel Raises)
- Prone Alternating Hip Extension (Alternate Position: Leaning Over Ball)
- Bridges
- Ball Squeezes
- Clam With Yellow Tubing

### **Level Two Mat For One And A Half To Three Minutes**

- Supine Kickouts (Alternate Position: Supine Heel Touches)
- Prone Swimmer (Alternate Position: Leaning Over Ball)
- Bridges With Ball Squeezes
- Ball Squeezes For Three Minutes
- Clam With Green Tubing
- Sit On The Ball For Three To Five Minutes

### **Level One Ball For One And A Half To Three Minutes**

- (Add This Next Session After Level Two Mat For One And Half To Three Minutes)
- D/C Sitting On Ball (After Beginning Level One Ball)
  - Seated Alternating Heel Ups (Alternate Position: Seated Alternating Toe Ups)
  - Bridging With Legs On Ball
  - Ball Multifidus (Alternate Position: With Hands On Mat)

### **Level Three Mat For One To Three Minutes**

- Dying Bug (Alternate Position: With Heel Touch)
- Prone Swimmer For Three Minutes (Alternate Position: Leaning Over Ball)
- Bridges With Kickouts (Alternate Position: Bridges With Heel Raises)
- Clam With Blue Tubing (Once You Have Reached Three Minutes, Progress To Clam With Black Tubing For One To Three Minutes)
- Ball Squeezes For Three Minutes

### **Level Two Ball For One And A Half To Three Minutes**

- Seated On Ball Marches
- Roll Out On The Ball In A Bridge Position
- Bridging With Legs On Ball And Arms Across Chest
- Hug Ball Kickout Toe Touching (Alternate Position: With Hands Touching Mat)

### **Level Three Ball For One To Three Minutes**

- Seated On The Ball Kickouts
- Ball Roll Outs With Heel Ups (Alternate Position: Ball Roll Outs With Toe Ups)
- Bridging With Legs On Ball Arms Across Chest For Three Minutes
- Hugging The Ball With Kickouts (Alternate Position: With Hands On The Mat)

### **Level One Neck For One To Three Minutes**

**(Given At The Same Time As Level Three Ball)**

- Supine Chin Tucks
- Supine Shoulder Extensions

### **Phase Two For One To Three Minutes**

- Superman Progressing To Matrix Progressing To Diagonal Twisting (Alternate Position: Table Twisting)

## **Appendix B – Neck, Mid Back And Upper Extremity Progression Phase One At A Glance**

### **Level One** (See Appendix A)

### **Level Two For One And A Half To Three Minutes (Except For Isometric Neck)**

- Isometric Neck For Four To Eight Minutes
- T,Y,I's With No Weights (If Patient Cannot Lie On Stomach, Do Not Perform This Exercise Until Level Three Alternate Position)
- Shoulder Internal And External Rotation With No Weights
- Full Can With No Weights
- Chicken Dance
- Hand Ball Squeezes
- Four Way Wrist With No Weights

### **Level Three For One And A Half To Three Minutes**

- Prone Chin Tucks (Alternate Positions Either Standing Leaning Over Ball On Couch Or Kneeling Over Ball On Mat)
- T,Y,I's With One Pound (Alternate Positions: Either Standing Or Leaning Over Ball With Chin Tuck With No Weight For Thirty Seconds To One Minute To Three Minutes Or Kneeling Over Ball With Chin Tuck With No Weight For Thirty Seconds To One Minute To Three Minutes)
- Shoulder Internal With Yellow Tubing
- Shoulder External Rotation With Yellow Tubing
- Full Can With One Pound
- Shoulder Abduction With No Weight

- Hand Ball Squeezes For Three Minutes (Tuesdays And Fridays Only)
- Four Way Wrist With One Pound
- Bicep Curl With One Pound
- Triceps Push Downs With Yellow Tubing

#### **Level Four For One And A Half To Three Minutes**

- T,Y,I's With Chin Tucks With One Pound (Alternate Position T,Y,I's With Chin Tucks With One Pound Either Standing Leaning Over Ball On Couch Or Kneeling Over Ball On Mat)
- Shoulder Internal With Red Tubing
- Shoulder External Rotation With Red Tubing
- Full Can With Two Pounds
- Shoulder Abduction With One Pound
- Hand Ball Squeezes For Three Minutes (Tuesdays And Fridays Only)
- Four Way Wrist With Two Pounds
- Bicep Curl With Two Pounds
- Triceps Push Downs With Red Tubing

#### **Level Five For One And A Half To Three Minutes**

- T,Y,I's With Chin Tucks With Two Pounds (Alternate Position: Either Kneeling On Mat Leaning Over Ball Or Standing Leaning Over Ball On Couch)
- Shoulder Internal Rotation With Green Tubing
- Shoulder External Rotation With Green Tubing
- Full Can With Three Pounds
- Shoulder Abduction With Two Pounds
- Hand Ball Squeezes For Three Minutes (Tuesdays And Fridays Only)
- Four Way Wrist With Three Pounds

- Bicep Curl With Three Pounds
- Triceps Push Downs With Green Tubing
- Criss-Cross Eyes
- Eyebrow Raises
- Ear Wiggles
- TMJ Isometrics One Minute Each Way

### **Level Six For One And A Half To Three Minutes**

- T,Y,I's With Chin Tucks With Three Pounds (Alternate Position: Either Kneeling On Mat Leaning Over Ball Or Standing Leaning Over Ball On Couch)
- Shoulder Internal Rotation With Blue Tubing
- Shoulder External Rotation With Blue Tubing
- Full Can With Four Pounds
- Shoulder Abduction With Three Pounds
- Hand Ball Squeezes For Three Minutes (Tuesdays And Fridays Only)
- Four Way Wrist With Three Pounds For Three Minutes (Tuesdays And Fridays Only)
- Bicep Curl With Four Pounds
- Triceps Push Downs With Blue Tubing
- Criss-Cross Eyes For Three Minutes (Tuesdays And Fridays Only)
- Eyebrow Raises For Three Minutes (Tuesdays And Fridays Only)
- Ear Wiggles For Three Minutes (Tuesdays And Fridays Only)
- TMJ Isometrics For One Minute Each Way (Tuesdays And Fridays Only)

### **Level Seven For One To Three Minutes**

- At Three Minutes, Perform Exercises On Tuesdays And Fridays Only**

- T,Y,I's With Chin Tucks With Three Pounds For Three Minutes (Tuesdays And Fridays Only) (Alternate Position: Either Kneeling On Mat Leaning Over Ball Or Standing Leaning Over Ball On Couch)
- Shoulder Internal Rotation With Black Tubing
- Shoulder External Rotation With Black Tubing
- Full Can With Five Pounds
- Shoulder Abduction With Four Pounds
- Hand Ball Squeezes For Three Minutes (Tuesdays And Fridays Only)
- Four Way Wrist With Three Pounds For Three Minutes (Tuesdays And Fridays Only)
- Bicep Curl With Five Pounds
- Triceps Push Downs With Black Tubing
- Criss-Cross Eyes For Three Minutes (Tuesdays And Fridays Only)
- Eyebrow Raises For Three Minutes (Tuesdays And Fridays Only)
- Ear Wiggles For Three Minutes (Tuesdays And Fridays Only)
- TMJ Isometrics For One Minute Each Way (Tuesdays And Fridays Only)

## **Phase Two**

### **All Exercises Are Progressed From One To Three Minutes**

- Touch Down (Progressing From No Weight To One Pound To Two Pounds To Three Pounds)
- Throwing With Tubing (Progressing From Yellow Tubing To Red Tubing To Green Tubing To Blue Tubing)
- Shoulder Internal Rotation With Abduction To Eighty Degrees (Progressing From Yellow Tubing To Red Tubing To Green Tubing To Blue Tubing) (Has To Be Progressed At Same Rate As Shoulder External Rotation With Abduction To Eighty Degrees)
- Shoulder External Rotation With Abduction To Eighty Degrees (Progressing

From Yellow Tubing To Red Tubing To Green Tubing To Blue Tubing) (Has To Be Progressed At Same Rate As Shoulder Internal Rotation With Abduction To Eighty Degrees)

## **Appendix C – Lower Extremity Exercise Progression, Phase One At A Glance**

### **Level One (Make Sure Patient Wears Custom Orthotics) (If Patient Has Subluxing Hips Or Balance Issues, Perform All Exercises Once With Holding Onto Counter And Once Without Holding Onto The Counter)**

- Side Stepping Ten To Twenty-Six Laps
- Walk Forward And Backwards Ten To Twenty-Six Laps
- Hamstring Curl Ten To Twenty-Six Repetitions (Always Hold Onto Counter For This Exercise)
- Heel And Toe Raises Ten To Twenty-Six Repetitions

### **Level Two (Make Sure Patient Wears Custom Orthotics) (If Patient Has Subluxing Hips Or Balance Issues, Perform All Exercises Once With Holding Onto Counter And Once Without Holding Onto The Counter)**

- Side Stepping With Yellow Band Ten To Twenty-Six Laps
- Walk Forward And Backwards With Yellow Band Ten To Twenty-Six Laps
- Hamstring Curl With Yellow Band Ten To Twenty-Six Repetitions (Always Hold Onto Counter For This Exercise)
- Heel And Toe Raises Twenty-Six To Fifty Repetitions
- Quarter Squats Ten To Twenty-Six Repetitions

### **Level Three (Make Sure Patient Wears Custom Orthotics) (If Patient Has Subluxing Hips Or Balance Issues, Perform All Exercises Once With Holding Onto Counter And Once Without Holding Onto The Counter)**

- Side Stepping With Green Band Ten To Twenty-Six Laps
- Walk Forward And Backwards With Green Band Ten To Twenty-Six Laps
- Hamstring Curl With Green Band Ten To Twenty-Six Repetitions (Always Hold Onto

Counter For This Exercise)

-Single Leg Heel And Toe Raises Ten To Twenty-Six Repetitions (Always Hold Onto Counter For This Exercise)

-Partial Lunges Ten To Twenty-Six Repetitions

-Stand Feet Together On The Floor (For One And A Half To Three Minutes, No Holding Onto Counter)

**Level Four (Make Sure Patient Wears Custom Orthotics) (If Patient Has Subluxing Hips Or Balance Issues, Perform All Exercises Once With Holding Onto Counter And Once Without Holding Onto The Counter)**

-Side Stepping With Blue Band Ten To Twenty-Six Laps

-Walk Forward And Backwards With Blue Band Ten To Twenty-Six Laps

-Hamstring Curl With Blue Band Ten To Twenty-Six Repetitions (Always Hold Onto Counter For This Exercise)

-Single Leg Heel And Toe Raises Twenty-Six To Fifty Repetitions (Always Hold Onto Counter For This Exercise)

-Deeper Lunges Ten To Twenty-Six Repetitions

-Step Ups Forward On A Four-Inch Step Ten To Twenty-Six Repetitions Each Leg

-Step Ups To The Side On A Four-Inch Step Ten To Twenty-Six Repetitions Each Leg

-Standing On Floor, Feet Together Eyes Closed (One And A Half To Three Minutes, Not Holding Onto Counter)

-Stand On A Pillow, Feet Together, Eyes Open (One And A Half To Three Minutes, Not Holding Onto Counter)

**Level Five (Make Sure Patient Wears Custom Orthotics) (If Patient Has Subluxing Hips Or Balance Issues, Perform All Exercises Once With Holding Onto Counter And Once Without Holding Onto The Counter)**

-Side Stepping With Black Band Ten To Twenty-Six Laps

- Walk Forward And Backwards With Black Band Ten To Twenty-Six Laps
- Hamstring Curl With Black Band Ten To Twenty-Six Repetitions (Always Hold Onto Counter For This Exercise)
- Single Leg Heel And Toe Raises Fifty Repetitions On Wednesdays And Saturdays Only (Always Hold Onto Counter For This Exercise)
- Deeper Lunges Twenty-Six Repetitions On Wednesdays And Saturdays Only
- Step Ups Forward On An Eight-Inch Step Ten To Twenty-Six Repetitions Each Leg
- Step Ups To The Side On An Eight-Inch Step Ten To Twenty-Six Repetitions Each Leg
- Standing On Pillow, Feet Together, Eyes Closed For One And A Half To Three Minutes
- Single Leg Stance On The Floor, Eyes Open For One To Two Minutes Each Leg (Alternate Position: With Toe Touch)
- Recumbent Bike Five To Twenty Minutes

**Level Six (Make Sure Patient Wears Custom Orthotics) (If Patient Has Subluxing Hips Or Balance Issues, Perform All Exercises Once With Holding Onto Counter And Once Without Holding Onto The Counter)**

- Side Stepping With Black Band Twenty-Six Laps On Wednesdays And Saturdays Only
- Walk Forward And Backwards With Black Band Twenty-Six Laps On Wednesdays And Saturdays Only
- Hamstring Curl With Black Band Twenty-Six Repetitions On Wednesdays And Saturdays Only (Always Hold Onto Counter For This Exercise)
- Single Leg Heel And Toe Raises Fifty Repetitions Each Leg On Wednesdays And Saturdays Only (Always Hold Onto Counter For This Exercise)
- Deep Lunges Twenty-Six Repetitions On Wednesdays And Saturdays Only
- Step Lowering Forward On A Four-Inch Step Ten To Twenty-Six Repetitions Each Leg
- Step Lowering To The Side On A Four-Inch Step Ten To Twenty-Six Repetitions Each Leg

- Single Leg Stance On Floor, Eyes Closed For One To Two Minutes Each Leg (Alternate Position: With Toe Touch)
- Single Leg Stance Standing On A Pillow, Eyes Open For One Two Minutes Each Leg (Alternate Position: With Toe Touch)
- Standing Feet Together On A Pillow, Eyes Closed For Three Minutes On Wednesdays And Saturdays Only
- Recumbent Bike Twenty Minutes On Wednesdays, Saturdays And Sundays Only (Resistance To Tolerance Per Protocol)

**Level Seven (Make Sure Patient Wears Custom Orthotics) (If Patient Has Subluxing Hips Or Balance Issues, Perform All Exercises Once With Holding Onto Counter And Once Without Holding Onto The Counter)**

- Once You Reach Maximum Repetitions And Time For Each Exercise, Perform Them On Wednesdays And Saturdays Only**
- Once You Have Completed This Level, You Are Ready For Phase Two**
- Side Stepping With Black Band Twenty-Six Laps On Wednesdays And Saturdays Only
- Walk Forward And Backwards With Black Band Twenty-Six Laps On Wednesdays And Saturdays Only
- Hamstring Curl With Black Band Twenty-Six Repetitions On Wednesdays And Saturdays Only (Always Hold Onto Counter For This Exercise)
- Single Leg Heel And Toe Raises Fifty Repetitions On Wednesdays And Saturdays Only
- Deep Lunges To Tolerance Twenty-Six Repetitions On Wednesdays And Saturdays Only
- Step Lowering Forward On An Eight-Inch Step Ten To Twenty-Six Repetitions Each Leg
- Step Lowering To The Side On An Eight-Inch Step Ten To Twenty-Six Repetitions Each Leg
- Single Leg Stance On Floor, Eyes Closed For Two Minutes Each Leg On Wednesdays And Saturdays Only (Alternate Position: With Toe Touch)

- Single Leg Stance Standing On A Pillow, Eyes Open For Two Minutes Each Leg On Wednesdays And Saturdays Only (Alternate Position: With Toe Touch)
- Standing Feet Together On A Pillow, Eyes Closed For Three Minutes
- Recumbent Bike Twenty Minutes (Resistance As Tolerated, Progressing Per Protocol.

### **Phase Two (Make Sure Patient Wears Custom Orthotics)**

***\*Perform all exercises first while holding onto the counter, then again without holding onto the counter for all patients regardless of subluxed hips or balance issues.***

#### **-All Exercises Are Progressed Ten To Twenty-Six Repetitions**

- Walking Up And Down Stairs (One To Two Flights, Two Railings, One Railing Or No Railings)
- Star On Floor, Progressing To Star On Pillow, Ten To Twenty-Six Repetitions (Begin With Holding Onto The Counter And Progress To No Upper Extremity Support For Each Level)
- Tandem Walking, Ten To Twenty-Six Laps
- Walking On Foam Squares Progressing To Walking On Grass, 100-300 Feet

## **Appendix D – Beighton Scale**

A Beighton Scale is a nine-point scale used to determine if a person has hypermobility. A score of five or greater indicates that the patient should be referred to a geneticist for further testing for Ehlers-Danlos Syndrome.

1. Patient stands with knees straight and is able to bend forward placing palms of hands on the floor (one point)
2. Hyperextension of the elbow greater than ten degrees (one point for each elbow)
3. Standing hyperextension of each knee greater than ten degrees (one point for each knee)
4. Extension of the fifth digit's MP joint greater than ninety degrees (one point for each digit)
5. Able to touch thumb to the ventral side of the forearm (one point for each thumb)

## Appendix E

1. Postural Orthostatic Tachycardia Syndrome (POTS): This occurs when there is an increase in heart rate of 30 beats per minute (bpm) or more, or over 120bpm, within the first ten minutes of standing, in the absence of orthostatic hypotension. Many POTS patients experience fatigue, lightheadedness, headaches, heart palpitations, exercise intolerance, nausea, diminished concentration, shaking, syncope (fainting), coldness or pain in extremities, chest pain and shortness of breath. Symptoms among patients vary greatly, allowing some patients to continue with their normal daily activities, while others are extremely limited. Patients are monitored by a cardiologist for their symptom of POTS and usually are treated by increasing their fluid and salt intake, wearing compression stockings, performing exercises in a reclined position, altering their diet and taking medication. ([www.dysautonomiainternaional.org](http://www.dysautonomiainternaional.org))
2. Mast Cell Activation Syndrome (MCAS): This is characterized by the accumulation of genetically altered mast cells and/or abnormal release of mast cell mediators, affecting functions in potentially every organ system, particularly the skin, gastrointestinal tract, cardiovascular system and nervous system ([www.patient.co.uk](http://www.patient.co.uk)). This condition is usually managed by hematologists. There is a wide variety of symptoms including: rashes, abdominal pain, nausea, vomiting and diarrhea.
3. Mitochondrial Myopathies: This is a group of diseases caused by damage to the mitochondria, small, energy-producing structures that serve as the “power plants” for the cells. Symptoms include loss of muscle coordination, muscle weakness, exercise intolerance, vision and hearing problems, liver and kidney disease, gastrointestinal and respiratory disorders and neurological problems ([www.ninds.nih.gov](http://www.ninds.nih.gov)). There are no specific treatments for this mitochondrial disorders, but physical therapy can improve mobility.
4. Tethered Cord: Tethered spinal cord syndrome is a neurological disorder caused by tissue attachments that limit the movement of the spinal cord within the spinal column. Attachments may occur congenitally at the base of the spinal cord (conus

medullaris) or they may develop near the site of an injury to the spinal cord. These attachments cause an abnormal stretching of the spinal cord. The course of the disorder is progressive. In children, symptoms may include lesions, hairy patches, dimples, or fatty tumors on the lower back; foot and spinal deformities; weakness in the legs; low back pain; scoliosis; and incontinence ([www.ninds.nih.gov](http://www.ninds.nih.gov)). Surgery is usually the treatment used for this.

5. Chiari Malformation: This is a condition in which brain tissue extends into the spinal canal. It occurs when part of the skull is abnormally small or misshapen, pressing on the brain and forcing it downward. Treatment of Chiari malformation depends on the form, severity and associated symptoms. Regular monitoring, medications and surgery are treatment options. In some cases, no treatment is needed ([www.mayoclinic.org](http://www.mayoclinic.org)).
6. Syringomyelia: This is a disorder in which a cyst forms within the spinal cord. This cyst, called a syrinx, expands and elongates over time, destroying the center of the spinal cord. Since the spinal cord connects the brain to nerves in the extremities, this damage results in pain, weakness, and stiffness in the back, shoulders, arms, or legs. Other symptoms may include headaches and a loss of the ability to feel extremes of hot or cold, especially in the hands. Each patient experiences a different combination of symptoms ([www.ninds.nih.gov](http://www.ninds.nih.gov)). Surgery is usually recommended for syringomyelia patients or it may go untreated if there are no significant symptoms. Whether treated or not, many patients will be told to avoid activities that involve straining.
7. Cervico-Cranial Instability: This is a complex disorder emanating from the upper vertebra of the neck, including the related pain in the forehead, eyes and vertex of the head ([www.ednf.org](http://www.ednf.org)). The patient may have limited neck rotation, trouble swallowing, forward head posture, thoracic pain, headaches and weak neck muscles. Physical therapy, medication and surgery are all possible treatments.
8. Leaky Gut Syndrome: Symptoms of this include bloating, gas, cramps, food sensitivities, and aches and pains. It is a term used to describe an altered or damaged bowel lining or gut wall that results from poor diet, parasites, infection,

or medications, and that allows substances such as toxins, microbes, undigested food, or waste to leak through. It is thought that this prompts the body to initiate an immune reaction leading to potentially severe health conditions. The term “leaky gut” is not a recognized medical diagnosis, but rather is a proposed condition. Nutritional supplements and altered diets have been used to treat this, but there is no concrete evidence supporting this disorder or its treatment ([www.en.wikipedia.org](http://www.en.wikipedia.org)).

9. Gastroparesis: This is a condition in which the spontaneous movement of the muscles (motility) in the stomach does not function normally. Gastroparesis can interfere with normal digestion, cause nausea and vomiting, and cause problems with blood sugar levels and nutrition. Altered diet and medication are used to treat this disorder ([www.mayoclinic.org](http://www.mayoclinic.org)).