Pediatric Epilepsy Surgery Alliance

In the event of an emergency (defined as: [*a seizure, a blow to the head, a hard fall, sudden change in behavior, etc.*]):

**CONTACT PARENTS**
Text both cell phones with '911 [*child's name*]
[*Parents names/phone numbers*]

**CALL 911**
Take to [*name of preferred*] Hospital
[*address*]
[*phone*]

Child's medical record #

Pediatrician:
[*name*]
[*phone number*]

Pediatric Neurologist:
[*name*]
[*phone number*]

Pediatric Neurosurgeon:
[*name*]
[*phone number*]

**Medical Information:**

- Massive stroke in utero *[year of event]; [or other underlying etiology]*
- **[left/right]** hemispherectomy surgery [*year of surgery*];
- [*ANY OTHER SURGERIES; e.g. aneurysm clipping surgery, VP shunt surgery[shunt setting], orthopedic surgery, etc. [side, year of surgery*]
- Epilepsy, currently in remission [*type, e.g. infantile spasms*]
- **[left/right]** hemiplegia/ Cerebral Palsy
- Multiple visual impairments, including:
    - complete **[left/right]** homonymous hemianopia (blindness) from the midline to the ear in both eyes affecting his **[left/right]** field of vision,
    - [*ANY OTHER VISION IMPAIRMENTS THE CHILD HAS SUCH AS: nystagmus, esophoria and convergence insufficiency (eyes come together with close reading), astigmatism, myopia (corrected with glasses), and visual processing disorder.*]
    - [*He wears glasses.*]

**Other relevant conditions:**
Due to the massive brain injuries he has suffered, [Child] has [*list what applies to the child and add other if needed*]

- *central auditory processing disorder (CAPD)*
- *autism and social communication disorder (SCD)*
- *learning disabilities*
- *ADHD, slow processing speed, working memory challenges*
- *significant memory challenges (neurocognitive disorder)*

**© Pediatric Epilepsy Surgery Alliance 2024**

# CLINICAL HISTORY AND DIAGNOSES:

[Child] underwent a hemispherectomy – the **[left/right]** side of his brain was disconnected to stop drug-resistant epilepsy as a result of a stroke in utero.

There are permanent, unavoidable side effects from the removal/disconnection of the **[left/right]** hemisphere of his brain:

- **Visual Impairment**: [Child] has a permanent cortical vision impairment known as homonymous hemianopia (loss of vision in **[left/right]** half of his visual field). He is totally blind beginning from approximately the nose (midline) all the way to the ear opposite from the side of surgery. This includes loss of half the central (foveal) vision as well. This visual field loss affects both eyes and is a result of surgical disconnection of the occipital lobe of the brain. This vision loss is not correctable using glasses because it is unrelated to focusing of the lens of the eye. Homonymous hemianopsia can severely affect [Child]'s orientation and mobility in school in various static and dynamic environments, as well as his ability to view text and reading materials. He will not see anything approaching him from the **[left/right]** side and needs verbal reminders for safety.

- **Hearing Impairment**: [Child] has a cortical auditory impairment (or central auditory processing disorder/CAPD) which results in significant **[left/right]** ear deficit on dichotic listening tasks, significant difficulty understanding speech in the presence of noise or reverberation, reduced sound blending and sound recognition skills, and listening fatigue. *[if the child has not yet been assessed for CAPD, central auditory processing disorder/CAPD is a known result of hemispherectomy. The extent and severity of the impairment and perceived communication handicap can vary from child to child, but typically results in mild-to-severe dichotic listening deficits, poor sound lateralization, difficulty understanding speech in the presence of noise, and sound localization challenges. For example, because there is massive suppression of auditory input into the ear on the same side of the removed hemisphere, children may neglect conversational partners of the side of the missing hemisphere when experiencing different types of speech inputs to both sides simultaneously. Please note that cortical auditory impairment cannot be detected by a pure-tone hearing test which mainly assesses detection of sounds as a peripheral hearing function.*]

- **Orthopedic Impairment (cerebral palsy)**: [Child] has significant loss of gross motor function on his/her **[left/right]** side known as hemiparesis. This also manifests as a loss/limitation of fine motor skills essential for highly coordinated movements of the **[left/right]** hand and fingers, as well as a complete hemispatial neglect in most children (a lack of awareness that the right side of the body even exists). This is part of the overall upper motor neuron syndrome caused by the surgery. Fine motor function

**© Pediatric Epilepsy Surgery Alliance 2024**

in the "good hand" is affected as well. This may manifest as difficulty with writing, drawing, force production, and pressure sensitivity. He uses orthotics to provide stability and support (can be removed for short periods of time as needed). [Child] has scoliosis, he needs to maintain good posture to prevent worsening scoliosis and he requires frequent stretching for tightness.

- **Joint instability in [left/right] arm and shoulder**: due to atrophy, [Child]'s **[left/right]** arm is not fully developed. NEVER PULL ON HIS **[left/right]** ARM or it may dislocate and/or tear the tendons.

- **Fatigue**: [Child] has general fatigue, as well as decreased cognitive and physical stamina as a result of the surgery.

- **Cognitive overload** happens due to one hemisphere working beyond capacity, with the added load of significant sensory and motor deficits; this requires so much effort. [Child] needs encouragement to take breaks, he might not notice overload happening.

- **Seizures**: [*Child may have a return of seizures at any time. S/He should have a seizure action plan and a complex care plan or Individualized Healthcare Plan in place.*]
    - e.g.: [Child] is now seizure-free but at higher risk of seizure recurrence which may present as absence seizures (staring spells), jerks/spasms, or any other type of seizure. He may have an aura beforehand or a period of agitation/fatigue afterward (a little 'out of it'). Fever and illness may lower his seizure threshold; shunt failure may cause seizures. See seizure action plan.

- **Hydrocephalus**: [Child] is at an increased risk of hydrocephalus [or presently has shunt and concerns about shunt failure]. The warning signs of hydrocephalus [or shunt failure] include, but are not limited to, headache, vomiting, sleepiness, cognitive decline, blurry vision, seizures, and/or behavioral changes. [*or if the child already has a shunt, describe shunt and failure warning signs*]. The risk of developing hydrocephalus is throughout the lifespan.
    - *e.g.: [Child] suffered hydrocephalus and had a VP shunt placed in [year]. See shunt failure warning signs and emergency protocol.*

- **ADHD**: [Child] has challenges with higher executive function skills because one prefrontal cortex has been disconnected. He/she also displays heightened auditory distractibility, attention concerns, and attention deficit inattentive disorder (ADHD/ADID).

- Child may have hyperkinesis, perseverate, and/or self-stimulate.

**© Pediatric Epilepsy Surgery Alliance 2024**

- **Thermoregulation**: [Child] is unable to regulate his body temperature appropriately and may require reminders to add/remove layers of clothing or cooling garments on hot days.

- **Reduced sensitivity to heat, cold, and pain**: [Child] has reduced sensitivity to heat, cold, and pain in his **[left/right]** hand, forearm, and upper arm (most significant in the hand). [Child] is at risk of unknown burns or broken bones after falls because his pain reaction is significantly reduced. After a fall or exposure to extremely hot or cold surfaces, he should be checked for broken bones or burns, even if not complaining of pain.

- **Specific Learning Disability / Intellectual Disability** [*Hemispherectomy surgery and removing anti-epileptic drug use is known to increase IQ by approximately ten points over time; however, most children after hemispherectomy surgery will have specific learning disabilities or intellectual disability. Specific learning disabilities postoperatively often affect reading, mathematics, visual and auditory processing, and other areas. A neuropsychological evaluation is recommended to fully understand these challenges as respects [Child] and to see if he/she is a child identified as having specific learning disability or intellectual disability and to recommend appropriate educational interventions.*]

- **Autism** [Child] also has **AUTISM** [*Autism and epilepsy, even if seizures are controlled, are often comorbid conditions. If parents are concerned, [Child] should be evaluated to see if he/she is a child identified as having autism.*]

- **Behavior** [*Approximately 27% of children after hemispherectomy have significant behavior problems affecting school or social life. 10% require constant supervision due to behavior problems. Proper evaluations should be conducted to determine if the child's behaviors affect his/her ability to access the educational environment or present safety concerns.*]

- Finally, like a **traumatic brain injur**y, epilepsy surgery is often associated with impairments in the following areas: cognition; language; memory; attention; reasoning; abstract thinking; judgment; problem-solving; sensory, perceptual, and motor abilities; psychosocial behavior; physical functions; information processing; and speech.



**© Pediatric Epilepsy Surgery Alliance 2024**