Re: [Child’s Name]

To whom it may concern:

[Patient] is a young [boy/gir]l with a history of drug-resistant seizures. S/He underwent a [hemispherectomy/hemispherotomy] - a procedure where half the brain is removed and/or completely disconnected to stop drug-resistant epilepsy.] Here, the [right/left] side of [Child’s] brain was [removed/disconnected] to stop [his/her] drug-resistant epilepsy as a result of [hemimegalencephaly/ cortical dysplasia/ stroke etc.].

[Child] is now seizure-free, but there are permanent, unavoidable side effects from the removal/disconnection of the [right/left] hemisphere of [his/her] brain. These are:

**Visual Impairment**

[Child] has a permanent cortical vision impairment known as homonymous hemianopsia. This vision loss is in half of [his/her] visual field. In other words, [he/she] 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. Please note that 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 the [Child’s] orientation and mobility in school in various static and dynamic environments, as well as [his/her] ability to view text and reading materials. In language read from left to right, right hemianopsia can have a profound affect on the child’s ability to read/learn to read.

**Hearing Impairment**

Cortical auditory impairment (also referred to as central hearing loss or central auditory processing disorder/CAPD) are known results 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**

[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 [left/right] side of the body even exists). This is part of the overall upper motor neuron syndrome caused by the surgery.

Please note that fine motor function in the “good hand” is affected as well. This may manifest as difficulty with writing, drawing, force production, and pressure sensitivity.

**Other Health Impairments**

**Fatigue** [Child] may have general fatigue, as well as decreased cognitive and physical stamina as a result of the surgery. Additionally, please note child may have have a return of seizures at any time. S/He should have a seizure action plan and a complex care plan in place.

**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 child already has a shunt, describe shunt and failure warning signs]. The risk of developing hydrocephalus is throughout the lifespan.

**ADHD** [Child] may also have challenges with higher executive function skills because one pre-frontal cortex has been removed or disconnected, regardless of auditory skills. We often see heightened auditory distractibility, attention concerns, or attention deficit hyperactivity or inattentive disorder (ADHD/ADID) post-operatively. Child may have hyperkinesis, perseverate, and/or self-stimulate.

**Thermoregulation** Some children after hemispherectomy surgery are unable to regulate their body temperature appropriately.

**Reduced sensitivity to heat, cold, and pain** Sensitivity to heat, cold, and pain is impaired in the hand, forearm, and upper arm opposite the removed hemisphere**.** The reduced sensitivity is most significant in the hand. Children are at risk of unknown broken bones after falls because their pain reaction is significantly reduced, or burns. After a fall or exposure to extremely hot or cold surfaces, they should be checked by the school nurse for broken bones or burns even if they are not complaining of pain. *Additionally*, sensitivity to hot and cold is impaired in the arm on the *same side* of the removed hemisphere in the upper arm.

Most, but not all, children after hemispherectomy surgery have the following challenges discussed below. Because my observation of [Child] is limited by the brief amount of time we have during clinic visits, I am unable to provide diagnosis of the following; however, if parents are concerned, proper assessments should be done to address these potential issues:

**Specific Learning Disability / Intellectual Disability**

Hemispherectomy surgery and removing anti-epileptic drug use is known to increase intellectual quotient 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.

**Autism**

Autism and epilepsy, even if seizures are controlled, are often co-morbid 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. If parents are concerned, 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 injury, 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. Again, if parents are concerned, 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.

If you have any questions, please do not hesitate to contact me.

Very truly yours,

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Neurologist or Neurosurgeon

***To the clinician - sources for the content of this letter include:***

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