

Hope in One Hemisphere



Age 5 Age 13

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Disclaimer

This lecture is simply the view from a parent's perspective and not the view of the Epilepsy Foundation or the Hemispherectomy Foundation. The lecture is for informational purposes only and it is not intended to be a substitute for professional medical advice, diagnosis or treatment. Always seek the advice of your physician or other qualified health provider with any questions you may have regarding a medical condition. Never disregard professional medical advice or delay in seeking it.

Objectives

- To share a first-hand account of various brain injuries of a child.
- To share various rehabilitation therapies utilized to help with neuroplasticity.
- To share various skills learned to help with independence.

Journey of Brain Trauma/Injuries

- Apnea/Blue Spells at Birth
- New onset seizures and epilepsy diagnosis
- Lesions in all lobes in right hemisphere
- Rasmussen's Encephalitis
- Atrophy in right hemisphere
- Hemispherectomy Brain Surgery
- Cortical Dysplasia
- Asymptomatic hydrocephalus
- Returned seizures/spells
- 2nd Brain Surgery (ETV)

Apnea at birth



- Twins born on time at 27 weeks
- Met milestones.
- 2nd of twins born with suction cup. Bruise on forehead
- Apnea/Blue spells
- 10 days in NICU

Life is good for almost 2 1/2 years.



New onset seizures and epilepsy diagnosis



05/16/06

First seizure in May 2006 at age 2 years and 4 months old.



06/17/2006


Four major seizures in one day on 6/16/06, including a tonic clonic in the ER. Overnight stay and inpatient MRI.

First Seizure

RMC Seizure History

May 22nd, 2006: Day of very first seizure. Mom was at her Grandma's funeral visitation. Back at home, around 2:30 p.m., she was standing on the platform of the Little Tikes slide in the backyard outside, she then kneeled down with face down on the platform drooling. She then "passed out". She laid herself down, her lips were a light purple. The babysitter said her name twice and she woke up, but was still dazed and disoriented. The babysitter took her to the house and laid her down on the living room floor. The babysitter went to get Dad, who was sleeping in the house. Dad picked her up and rocked her in the chair. She was passed out for less than a minute, and was lethargic and confused for a period of time after. No jerking, no shaking.

First MRI: Lesions in all lobes in white matter in right hemisphere



Subdural
abnormal
hyper and reduce
and lower sit-
ing (shrinkage) of
t side.

Subdural
Healthy tissue

Left Side

5 cm

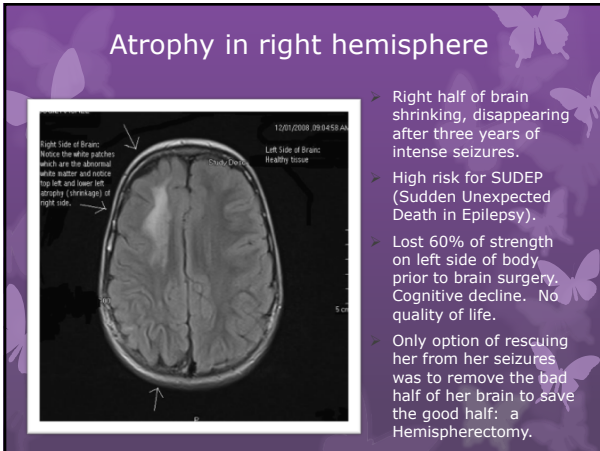
“White matter is a vast, intertwining system of neural connections that join all four lobes of the brain (frontal, temporal, parietal, and occipital), and the brain's emotion center in the limbic system, into the complex brain maps being worked out by neuroscientists.” 1

Seizures, seizures and more seizures



- Failed numerous seizure medications.
- Multiple seizure types. Harsh seizures. Turned blue, faint breathing during seizures.

Atrophy in right hemisphere



- Right half of brain shrinking, disappearing after three years of intense seizures.
- High risk for SUDEP (Sudden Unexpected Death in Epilepsy).
- Lost 60% of strength on left side of body prior to brain surgery. Cognitive decline. No quality of life.
- Only option of rescuing her from her seizures was to remove the bad half of her brain to save the good half: a Hemispherectomy.

Rasmussen's Encephalitis

"Rasmussen's encephalitis (RE) is a rare neurological disease that causes intractable epileptic seizures, cognitive deficits and paralysis of 1/2 of the body. The disease process typically runs its course over a 1 to 2 year period during which time one half of the body is rendered useless — hemiplegia — and epileptic seizures continue unabated.

- RE typically affects previously normal children aged between two and ten years. An unusual feature of the disease that sets it apart from other inflammatory diseases of the central nervous system, is that it is usually confined to one hemisphere of the brain. RE is resistant to standard anti-seizure medicines thus making possible the only known "cure" for the condition — **a surgical hemispherectomy** — the removal or disconnection of the affected side of the brain. The surgery in most cases stops the seizures, but at a high cost to the quality of life for the individual."


Hemispherectomy

What is a hemispherectomy?


"A hemispherectomy is a surgical procedure in which half of the brain is removed or disconnected. The deep structures of the brain (the thalamus, brain stem and basal ganglia) are left intact."³

When is a hemispherectomy indicated?

"A hemispherectomy is a radical operation. Most often, this surgery is considered in patients with severe seizure disorders coming from one side of the brain. Even then, the procedure is considered only when drugs cannot control the seizures and the patient is increasingly handicapped. Candidates may also show bi-hemispheric EEG abnormalities but be surgical candidates if a lesion is found in one hemisphere. While most have surgery for seizures, there are some unusual cases where patients may not have seizures. Cases such as mostly uni-hemispheric damage from viral or bacterial infections, trauma or tumors. Children with tuberous sclerosis may also be candidates for surgery."³



Inpatient at UCLA doing a video EEG for her pre-surgery testing. She is in a simple partial seizure. We did not know she was also having this kind of seizure until this trip.

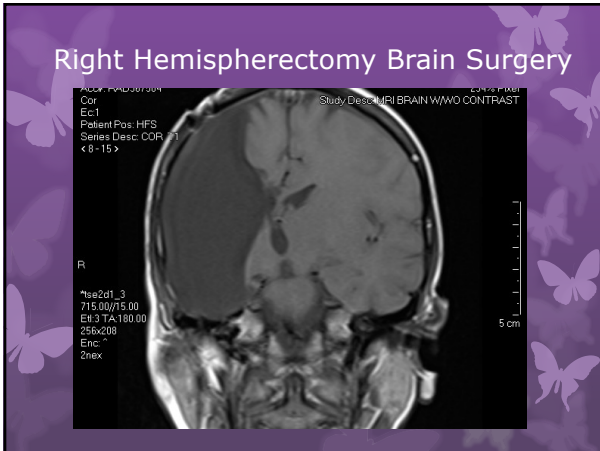


Disneyland Trip 2 days before surgery. She had 5 major seizures on this day, but was able to enjoy it, when she was alert. However, she doesn't remember any of it.



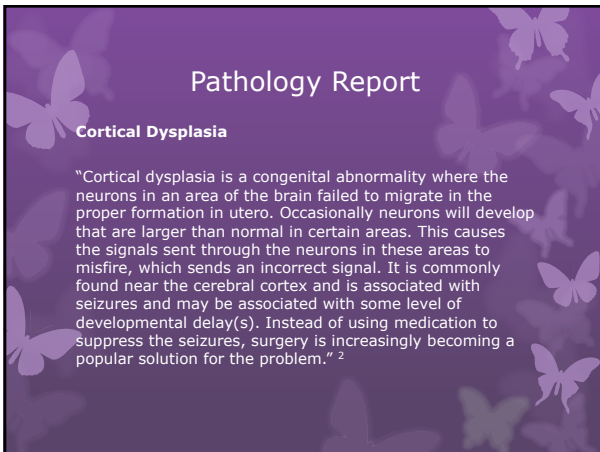
With her neurosurgeon on the morning of her surgery, right before they wheeled her in the operating room.....

10 hour surgery. In the PACU recovery room.



Right Hemispherectomy Brain Surgery

Accession: 15050304
 Cor
 E:1
 Patient Pos: HFS
 Series Desc: COR T1
 < 0 - 15 >
 R
 15e2d1_3
 715.00/15.00
 E: 3 TA: 180.00
 256x208
 Etc: 2
 2hex
 Study Desc: MRI BRAIN W/WO CONTRAST
 5 cm



Pathology Report

Cortical Dysplasia

"Cortical dysplasia is a congenital abnormality where the neurons in an area of the brain failed to migrate in the proper formation in utero. Occasionally neurons will develop that are larger than normal in certain areas. This causes the signals sent through the neurons in these areas to misfire, which sends an incorrect signal. It is commonly found near the cerebral cortex and is associated with seizures and may be associated with some level of developmental delay(s). Instead of using medication to suppress the seizures, surgery is increasingly becoming a popular solution for the problem." 2



Swollen eye at 4 days post op. At 5 months post op, we learned that her vision in her right eye was 20/4000. No one knows if it was related to her previous optic nerve issues or from her eye being swollen for an extended period of time.



External Drainage and Monitoring System

BECKER EXTERNAL DRAINAGE AND MONITORING SYSTEM
The first fully-assembled, disposable external ventricle drainage system on the market.

ABOUT BECKER EDMS

"The Becker® External Drainage and Monitoring System is used to drain and monitor CSF flow from the patient's lateral ventricles or the lumbar subarachnoid space to reduce intracranial pressure. The system can be used preoperatively, intraoperatively and postoperatively to monitor CSF chemistry, cytology and physiology, and to provide temporary CSF drainage."⁴



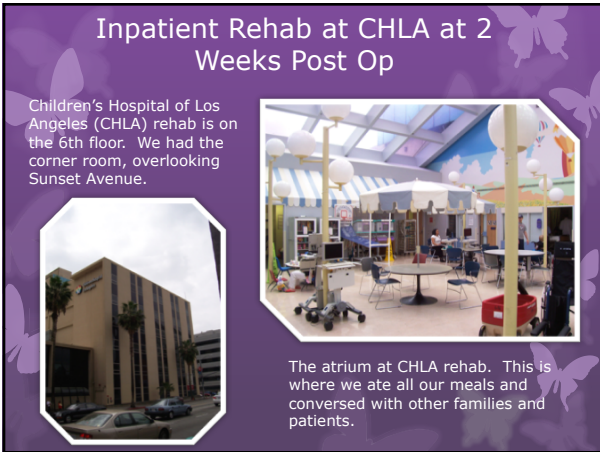
She would often get "hot" and so she would request icepacks and wet washcloths on her forehead around the clock.



Out of bed for the very first time and sitting in a chair. 8 days post op.



















Speech Therapy

Interactive Play



Big Mac Switch to activate a video for an incentive. Using communication with multiple modes of input.

Occupational Therapy



She is with her O.T. at ChildServe's TCU. Notice how she is grasping the rope with her left hand. It takes a lot of focusing and effort for her to squeeze her left hand, but she can do it.



She is using her left hand to put toys away.



Upper body bike to help build strength on weak side. Assistance or resistance to use it. Adjustable power on each side.



Core strengthening, push to one side to help with balance reactions to help activate her left trunk muscles to pull herself up.

Physical Therapy



She walks for the very first time all by herself in ChildServe's pool with her physical therapist. Neuroplasticity. The left brain is telling her left leg to walk, as she is learning to walk all over again. The water has helped strengthen her muscles effortlessly.



She gets her first leg brace – an AFO (Ankle Foot Orthotic) which helps support her weak ankle and her hyperextension of her knee. Learning how to walk again.
