SURGICAL EVALUATION AND SURGERY

FOR INFORMATION ONLY - DO NOT SUBMIT

The next several questions are about your child's journey to a surgical evaluation, whether your child has had brain surgery to stop seizures, and details of surgery. Answer to the best of your recollection, but please don't guess. If you don't know the answer to a question, it's OK to answer "I don't know".

Surgical Evaluation

When were you referred for a surgical evaluation for your child?

_____
(If you do not recall the exact date, enter an approximate date)

What type of medical insurance did your child have at the time of your child's surgical evaluation?

For health insurance outside of the USA, please select the categories that most closely describe the source of the child's health insurance.

(Please check all that apply)

- ☐ private health insurance - HMO
- ☐ private health insurance - PPO
- ☐ Medicare
- ☐ Medigap
- ☐ Medicaid
- ☐ State-sponsored health plan
- ☐ SCHIP (State Children's Health Insurance Program)
- ☐ Military health care (Tricare/VA, Champ/VA)
- ☐ Indian health service
- ☐ Other government program
- ☐ Single service plan (e.g. dental, vision, prescription)
- ☐ no insurance
- ☐ other
- ☐ I don't know

What anti-seizure pharmaceutical medications was your child taking AT THE TIME OF this surgical evaluation? Check all that apply.

- ☐ Rufinamide (Banzel, Inovelon)
- ☐ Primidone (Mysoline)
- ☐ Pregabalin (Lyrica)
- ☐ Phenytoin (Dilantin, Epanutin, Phenytek)
- ☐ Phenobarbital (Phenobarbital)
- ☐ Perampanel (Fycompa)
- ☐ Oxcarbazepine (Oxtellar, Oxtellar XR, Trileptal)
- ☐ Lorazepam (Ativan)
- ☐ Levetiracetam XR (Keppra XR)
- ☐ Levetiracetam (Keppra)
- ☐ Lamotrigine (Lamictal)
- ☐ Lacosamide (Vimpat)
- ☐ Gabapentin (Neurontin)
- ☐ Felbamate (Felbatol)
- ☐ Ezogabine (Potiga)
- ☐ Ethosuximide (Zarontin)
- ☐ Eslicarbazepine Acetate (Aptiom)
- ☐ Divalproex Sodium-ER (Depakote ER)
- ☐ Divalproex Sodium (Depacon, Depakote, Epival)
- ☐ Diazepam (Diastat, Diazepam, Valium)
- ☐ Clonazepam (Epitril, Klonopin, Rivotril)
- ☐ Clobazam (Frisium, Onfi)
- ☐ Carbamazepine-XR (Carbatrol, Tegretol XR)
- ☐ Carbamazepine (Atretol, Carbagen SR, Epitol, Mazepine, Tegretol, Tegrital,Teril, Timonil)
- ☐ ACTH
- ☐ Prednisolone
- ☐ Prednisone
- ☐ Synacthen
- ☐ Tiagabine Hydrochloride (Gabitril)
- ☐ Topiramate (Topamax)
- ☐ Topiramate XR (Qudexy XR, Trokendi XR)
- ☐ Valproic Acid (Convulex, Depakene, Depakine, Orfiril, Valporal, Valprosid)
- ☐ Vigabatrin (Sabril)
- ☐ Brivaracetam
- ☐ Epidiolex
- ☐ Other
- ☐ I don't know

Other (please describe):

_____

What non-pharmaceutical drugs, interventions, or therapies did your child use PRIOR to this surgical evaluation?

- ☐ ketogenic diet
- ☐ modified Atkins diet
- ☐ cannabidiol (CBD)
- ☐ Omega-3 oils (such as cod liver oil, fish oil, flaxseed oil, mustard oil, soybean oil, walnut oil)
- ☐ Other
- ☐ None of the above

Other (please describe):

_____

Please identify the types of seizures your child had at the time of his/her surgical evaluation. Check all that apply.

If you don't know or don't recall, that's okay. You can respond "I don't know" at the bottom of the list.

- ☐ automatisms (such as lip smacking, finger rubbing, chewing)
- ☐ atonic (sudden loss of muscle tone often causing child to go limp and fall down)
- ☐ clonic (sustained, rhythmic jerking of part or the whole body)
- ☐ infantile spasms (also known as epileptic spasms)
- ☐ hyperkinetic (such as thrashing legs, pedaling, or rocking back and forth)
- ☐ myoclonic (brief, shock-like jerks)
- ☐ tonic (body, arms, or legs suddenly stiff or tense)
- ☐ autonomic (such as increased heart rate or blood pressure, sweating, facial flushing)
- ☐ behavior arrest (movement stops, sometimes called a freeze or pause)
- ☐ cognitive (such as impaired language, confusion, feeling of deja vu, illusions, or hallucinations)
- ☐ emotional (such as sudden fear or joy)
- ☐ sensory (such as tingling or numbness, visual symptoms, smells, sounds)
- ☐ typical absence (very brief lapse in awareness, sometimes with staring)
- ☐ atypical absence (some or no lapse in awareness, sometimes with staring. Child may be able to respond a bit)
- ☐ eyelid myoclonia (rapid blinking or jerks of one or both eyelids, sometimes with eyeball movements)
- ☐ I don't know

When did you first witness movements which were eventually diagnosed as infantile spasms?

_____
(If you do not recall the exact date, enter an approximate date)

Which professional did you first see when you were concerned about movements that were later diagnosed as infantile spasms?

- ◯ pediatrician
- ◯ emergency room physician
- ◯ neurologist
- ◯ neonatologist (doctor in the NICU)
- ◯ other

Other (please describe):

What condition or diagnosis did this doctor suggest? Please answer all that apply.

- ☐ reflux
- ☐ constipation
- ☐ colic
- ☐ irritability
- ☐ possible formula or other allergy
- ☐ normal baby movements
- ☐ overly worried parent
- ☐ did not make a diagnosis
- ☐ requested or performed an EEG
- ☐ recognized the movements to be infantile spasms
- ☐ Sandifer syndrome
- ☐ other
- ☐ I don't know

Other (please describe):

_____

When was your child diagnosed as having infantile spasms?

_____
(If you do not recall the exact date, enter an approximate date)

Do you believe there was a delay to diagnosing your child with infantile spasms?

◯ Yes
◯ No

Please describe the delay:

Which statement BEST describes the number of seizures your child was having at the time he/she was first evaluated for brain surgery to stop seizures?

◯ several seizures per year
◯ several seizures per month
◯ several seizures per day
◯ several seizures per hour

Which assessments and tests were performed to determine whether your child could have brain surgery to stop seizures? Include all assessments and tests performed, even if they occurred in phases or at different hospitals.

☐ EEG with video
☐ EEG without video
☐ Magnetic Resonance Imaging (MRI)
☐ Subdural electrodes (also known as grids)
☐ Depth electrodes
☐ Stereotactic EEG
☐ Magnetoencephalography (MEG)
☐ Positron emission tomography (PET)
☐ Intracarotid sodium amobarbital procedure (known as Wada test)
☐ Other
☐ I don't know

Other (please describe)

How soon after your child's first seizure did he/she have MRI?

◯ less than one month
◯ 1 - 3 months
◯ 4 - 6 months
◯ 7 or more months

Did this MRI show any abnormalities in the child's brain?

◯ yes
◯ no
◯ I don't know/I'm not sure

Was it determined that your child was a surgical candidate after the tests and assessments noted above?

◯ Yes
◯ No

Which statement BEST describes why your child was not considered a candidate for brain surgery to stop seizures?

☐ Seizures could not be localized
☐ Seizures were coming from both sides of the brain
☐ Child was considered too young for surgery.
☐ Child was considered too old for surgery.
☐ Child was considered too cognitively impaired for surgery.
☐ Child was considered too physically disabled for surgery.
☐ Child was considered too medically fragile for surgery.

You may use this box to describe your child's surgical evaluation process in detail. This may include how many different hospitals you visited, any satisfaction or frustration with the process, or other comments or concerns you have about your child's journey to a surgical evaluation:

Has your child had one or more surgeries to stop seizures?

◯ Yes
◯ Not yet because we are waiting for a surgery date
◯ Not yet, but we have a surgery date scheduled
◯ No, but we are in the process of getting surgical evaluations
◯ No because I/we declined brain surgery
◯ No, we were told that my child is not a surgical candidate at this time

Which statement BEST describes why you declined brain surgery to stop seizures for your child:

◯ It is a drastic solution.
◯ I'm not ready to make the decision yet.
◯ I want to try other pharmaceutical anti-epileptic drugs first.
◯ I want to try non-pharmaceutical anti-epileptic therapies first (such as the ketogenic diet, CBD oil, etc.)
◯ I believe that my child would lose too much cognitive function (intelligence).
◯ I believe that my child will lose too much motor function (such as the ability to walk or use his/her hands).
◯ I believe that my child might lose the ability to speak or understand language.
◯ I prefer not to answer.
◯ Other

Other (please describe):

25% Complete