

# a Parent's Guide to Pediatric *Epilepsy* Surgery



This guide is for parents and families thinking about pediatric epilepsy surgery at the Comprehensive Epilepsy Center of Children's Medical Center Dallas.

We know that the decisions involved in surgery are not easy ones for you to make, but we hope that this guide will help make the journey a little easier.

Whether or not your child goes all the way to surgery, we want you to be as informed as possible.

Our team of highly qualified doctors and nurses is here to support you throughout this journey and to make sure that your child has the best care possible.

## Steps of the Pediatric Epilepsy Surgery Journey





## What is a Surgery Journey?

The Pediatric Epilepsy Surgery Journey is the path that takes a child through all of the steps involved in surgery.

The journey is more than just the surgery. It also includes all of the pre-surgical tests and the checkups for a few years after surgery.

### Steps of the Pediatric Epilepsy Surgery Journey





### Important Things About the Journey

- Surgery is not right for all children with epilepsy.
- If the tests tell us that surgery would not help or is not safe, then we won't do it.
- The journey will take time and many appointments. We want as much information as possible before recommending surgery.
- Learning about epilepsy surgery is just the first step in the journey.

### Steps of the Pediatric Epilepsy Surgery Journey





### Important Things About the Journey

- You will always be the one to make the final decision about the surgery.
- The journey below is a general guide. The doctor may change the steps based on the individual needs of your child.
- Each child's journey may take a different amount of time.
- Please talk to the doctor or nurse about any questions you have about the journey.

### Steps of the Pediatric Epilepsy Surgery Journey



# a Parent's Guide to Pediatric *Epilepsy* Surgery

**Who You'll See:** The Neurologist (an epilepsy specialist) in the Neurology Clinic.

**What Will Happen:** History. Exam. Review of medical records. Talk about treatment options. Schedule testing if needed.

step

1

## Your First Visit



The Neurologist will go over your child's medical history and ask you questions about your child's:

- Birth
- Physical and social development
- Major illnesses or hospital visits
- Progress in school

The doctor will also ask you to describe your child's seizures in as much detail as possible. If you have taken a video of your child having a seizure on your phone or camera, be sure and show it to the doctor.

### Steps of the Pediatric Epilepsy Surgery Journey



# a Parent's Guide to Pediatric *Epilepsy* Surgery

**Who You'll See:** The Neurologist (an epilepsy specialist) in the Neurology Clinic.

**What Will Happen:** History. Exam. Review of medical records. Talk about treatment options. Schedule testing if needed.

step

1

## Your First Visit



The doctor will do a physical & neurological exam of your child to look for weakness or trouble with:

- Vision
- Sensation (touch and feeling)
- Talking
- Reflexes
- Walking
- Balance

The exam is similar to what your child's pediatrician does at checkups.

### Steps of the Pediatric Epilepsy Surgery Journey



# a Parent's Guide to Pediatric *Epilepsy* Surgery

**Who You'll See:** The Neurologist (an epilepsy specialist) in the Neurology Clinic.

**What Will Happen:** History. Exam. Review of medical records. Talk about treatment options. Schedule testing if needed.

step

1

## Your First Visit



The doctor will go over your child's:

- Medical records
- Antiepileptic medicines tried in the past
- Medicines currently used
- Results of any tests at other hospitals
- Walking
- Balance

If your child is taking medicine, please bring all bottles and directions to this first visit.

### Steps of the Pediatric Epilepsy Surgery Journey





# a Parent's Guide to Pediatric *Epilepsy* Surgery

**Who You'll See:** The Neurologist (an epilepsy specialist) in the Neurology Clinic.

**What Will Happen:** History. Exam. Review of medical records. Talk about treatment options. Schedule testing if needed.

step

1

## Your First Visit



The doctor will go over the treatment options that might help your child.

Treatments the doctor might talk about include:

- Antiepileptic medicines
- Vagus Nerve Stimulation
- Ketogenic Diet
- Epilepsy Surgery

Some are more helpful for treating partial seizures. Others are more helpful for treating generalized seizures.

### Steps of the Pediatric Epilepsy Surgery Journey





# a Parent's Guide<sup>to</sup> Pediatric *Epilepsy* Surgery

**Who You'll See:** The Neurologist (an epilepsy specialist) in the Neurology Clinic.

**What Will Happen:** History. Exam. Review of medical records. Talk about treatment options. Schedule testing if needed.

step

1

## Your First Visit



Medicines are usually the first treatment that we try because they are the safest.

However, some children have seizures that can't be controlled after trying two antiepileptic medicines. This is called intractable or refractory epilepsy.

If your child has tried two medicines without good results, then your child probably has intractable epilepsy.

It might be time to begin talking about other treatments.

### Steps of the Pediatric Epilepsy Surgery Journey



**Who You'll See:** The Neurologist (an epilepsy specialist) in the Neurology Clinic.

**What Will Happen:** History. Exam. Review of medical records. Talk about treatment options. Schedule testing if needed.

**step****1****Your First Visit**

Blood work may be done, but other testing is usually not done at this visit.

If the doctor isn't sure what kind of seizures your child has or where they are coming from, he or she might want to schedule an EEG or an MRI for your child.

**Steps of the Pediatric Epilepsy Surgery Journey**

**Who You'll See:** Technicians in the EEG laboratory and the Radiology Suite of the hospital.

**What Will Happen:** EEG and MRI testing.

step

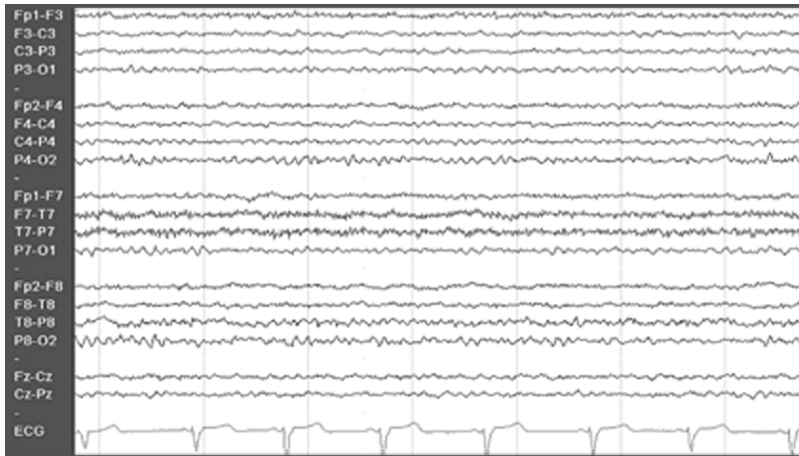
2

## Outpatient Testing - EEG

An EEG measures the normal and abnormal electrical bursts of the brain.

It is the basic test that we use to learn about:

- Your child's seizures
- What part of the brain might be causing the seizures
- How the seizures affect other parts of the brain



This is a normal EEG with a normal pattern of brain waves.

### Steps of the Pediatric Epilepsy Surgery Journey



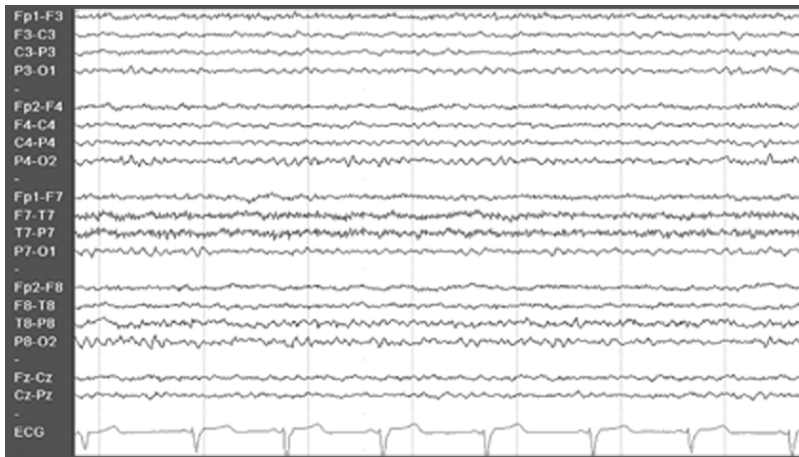
**Who You'll See:** Technicians in the EEG laboratory and the Radiology Suite of the hospital.

**What Will Happen:** EEG and MRI testing.

step

2

## Outpatient Testing - EEG



This is a normal EEG with a normal pattern of brain waves.

The EEG machine is like a language translator that "listens" to the electrical language of the brain as brain cells "talk."

The machine then translates that language into rows of wavy lines that we can see on a computer. Each line represents a different area of the brain.

These rows and patterns of "brain waves" tell us if each part of the brain is working correctly.

Children that have many seizures can still have a normal EEG if they don't have a seizure during the test.

### Steps of the Pediatric Epilepsy Surgery Journey



© KRISTEN M. BAGNALL, 2010

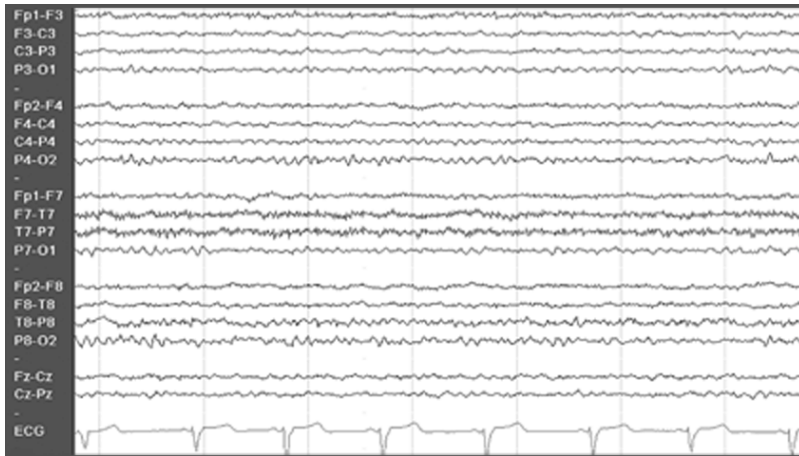
**Who You'll See:** Technicians in the EEG laboratory and the Radiology Suite of the hospital.

**What Will Happen:** EEG and MRI testing.

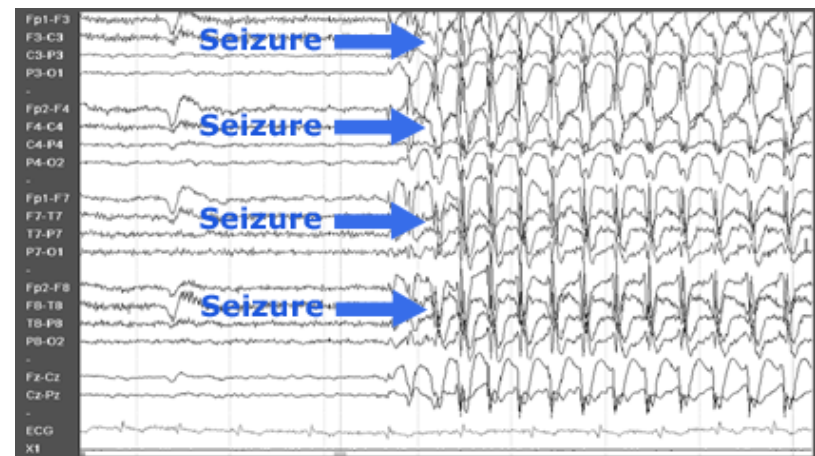
step

2

## Outpatient Testing - EEG



This is a normal EEG with a normal pattern of brain waves.



This child has generalized seizures. Surgery would not help.

### Steps of the Pediatric Epilepsy Surgery Journey



© KRISTEN M. BAGNALL, 2010

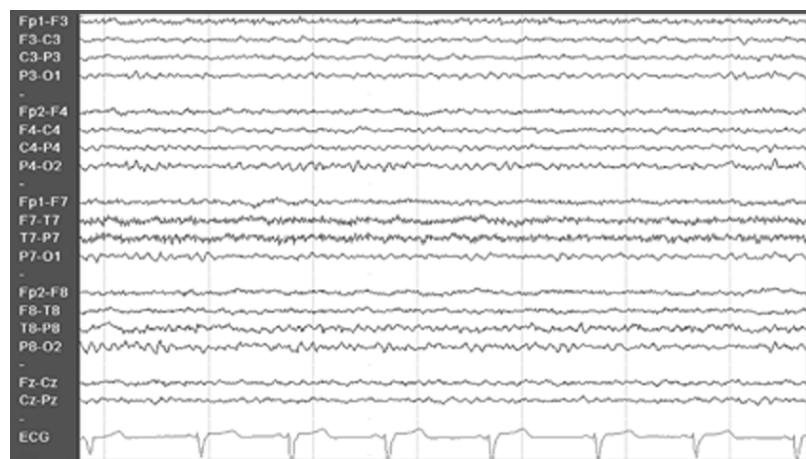
**Who You'll See:** Technicians in the EEG laboratory and the Radiology Suite of the hospital.

**What Will Happen:** EEG and MRI testing.

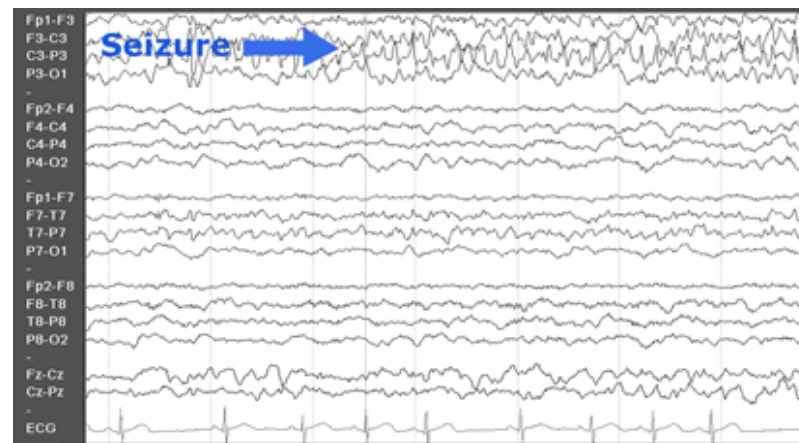
step

2

## Outpatient Testing - EEG



This is a normal EEG with a normal pattern of brain waves.



This EEG shows a partial seizure. Surgery might help.

### Steps of the Pediatric Epilepsy Surgery Journey





**Who You'll See:** Technicians in the EEG laboratory and the Radiology Suite of the hospital.

**What Will Happen:** EEG and MRI testing.

step

2

## Outpatient Testing - MRI



An MRI takes a picture of the brain. MRI scans do not expose a child to X-rays or radiation. Magnets are used to make pictures of the brain. It helps us look for:

- Brain dysplasia
- Tumors
- Medicines currently used
- Scarring or signs of a major head injury
- Signs of stroke
- Balance

During the scan, a shield is put around your child's head. It has a mirror in it and a screen for children to watch videos.

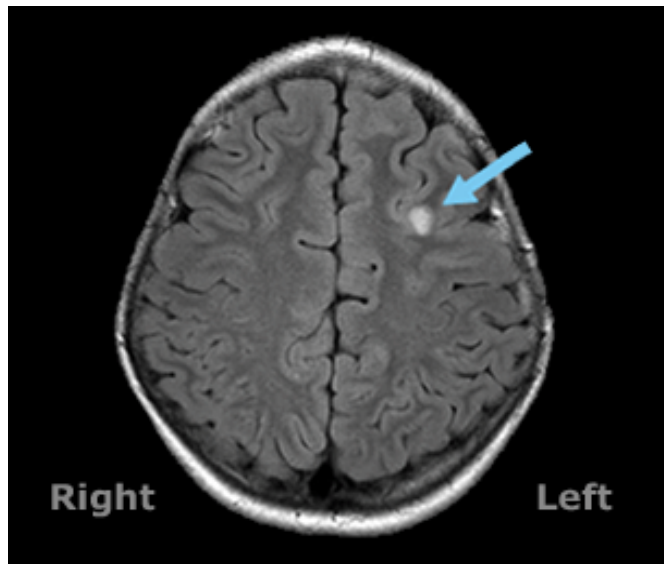
### Steps of the Pediatric Epilepsy Surgery Journey





**Who You'll See:** Technicians in the EEG laboratory and the Radiology Suite of the hospital.

**What Will Happen:** EEG and MRI testing.

**step****2****Outpatient Testing - MRI**

This is a pre-surgery MRI of a child with partial seizures.

The MRI picture shows a lesion in the left frontal lobe. It looks like a bright white spot against the gray of the brain.

The lesion is probably the cause of this child's partial seizures.

**Steps of the Pediatric Epilepsy Surgery Journey**

**Who You'll See:** The Neurologist in the Neurology Clinic.

**What Will Happen:** Go over EEG or MRI results. Talk about the option of surgery if needed. Schedule more testing.

**step****3**

### Follow-Up Appointment



The Neurologist will go over the results of your child's EEG or MRI tests.

If the tests show that your child's seizures are partial seizures, the doctor might talk with you about the option of surgery.

Your child is not committed to surgery at this point.

More testing must be done before the Epilepsy Team can recommend surgery.

#### Steps of the Pediatric Epilepsy Surgery Journey



© KRISTEN M. BAGNALL, 2010

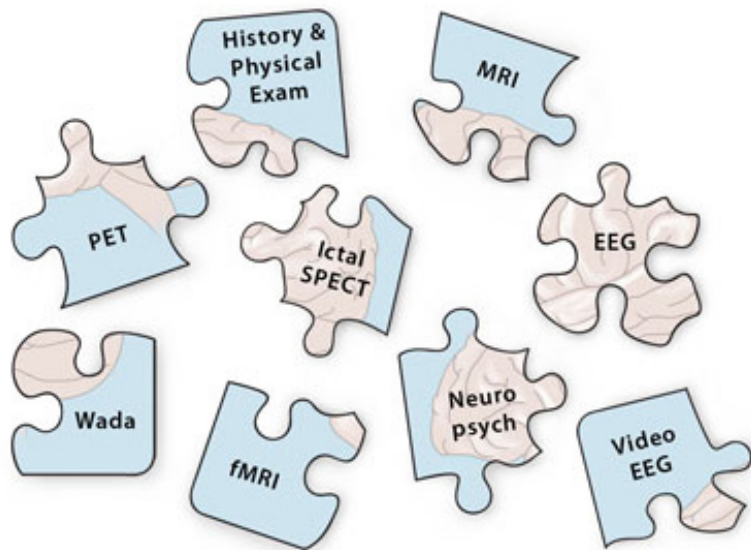
**Who You'll See:** The Neurologist in the Neurology Clinic.

**What Will Happen:** Go over EEG or MRI results. Talk about the option of surgery if needed. Schedule more testing.

step

3

## Follow-Up Appointment



Parents often ask why we need to do so many tests.

We like to say that finding the cause of a child's seizures is like putting a puzzle together.

Each pre-surgical test is a piece of the puzzle. We need all of the pieces before we can clearly see what is causing seizures.

The next pieces of the puzzle are usually a Video EEG and an appointment with the team Neuropsychologist.

### Steps of the Pediatric Epilepsy Surgery Journey



**Who You'll See:** Technicians, nurses, and the Neuropsychologist in the EMU of the hospital during a two to five day stay.

**What Will Happen:** Video EEG. Neuropsychological testing. Ictal SPECT scan (if needed). PET scan (if needed).

step

4

## Inpatient Testing - Video EEG



A Video EEG is a long EEG that is done while videotaping your child. The test usually takes two to five days.

We look at the video recording and the EEG results on a computer screen at the same time. It can help us see patterns that may point to the area of the brain causing seizures.

When you arrive at the hospital, a nurse will put electrodes on your child's head. Bandages will be wrapped around his or her head to keep the electrodes from moving. This is not painful but can be itchy.

### Steps of the Pediatric Epilepsy Surgery Journey



**Who You'll See:** Technicians, nurses, and the Neuropsychologist in the EMU of the hospital during a two to five day stay.

**What Will Happen:** Video EEG. Neuropsychological testing. Ictal SPECT scan (if needed). PET scan (if needed).

step

4

## Inpatient Testing - Video EEG



Your child will stay in the EMU of the hospital for the Video EEG. Children may bring their favorite toys or pillows. The room also has some video games for children to play.

We may use safe techniques to “catch a seizure” if your child does not have one on his or her own.

Please be aware that the rooms are not extra-large. Family members can visit, but the room is usually only comfortable for one family member to stay the night. One family member must stay in the room at all times for your child's safety.

### Steps of the Pediatric Epilepsy Surgery Journey



**Who You'll See:** Technicians, nurses, and the Neuropsychologist in the EMU of the hospital during a two to five day stay.

**What Will Happen:** Video EEG. Neuropsychological testing. Ictal SPECT scan (if needed). PET scan (if needed).

**step****4****Neuropsychological Testing**

Neuropsychological testing is a way to learn more about a child's thinking skills and behavior.

It also helps us learn if some parts of your child's brain aren't working as well as they could be.

These areas may be the areas that are causing seizures.

Neuropsychological testing includes:

- Parent interviews about development and school progress
- Parent ratings of behavior
- Tests and "puzzles" done by the child

**Steps of the Pediatric Epilepsy Surgery Journey**



# a Parent's Guide to Pediatric *Epilepsy* Surgery

**Who You'll See:** Technicians, nurses, and the Neuropsychologist in the EMU of the hospital during a two to five day stay.

**What Will Happen:** Video EEG. Neuropsychological testing. Ictal SPECT scan (if needed). PET scan (if needed).

step

4

## Neuropsychological Testing



The child then answers questions, does “puzzles,” and writes.

These tests tell us more about a child's:

- Intelligence (also known as IQ)
- Language
- Visual-spatial skills
- Memory and attention
- Problem-solving speed
- Hand speed

### Steps of the Pediatric Epilepsy Surgery Journey



# a Parent's Guide to Pediatric Epilepsy Surgery

**Who You'll See:** Technicians, nurses, and the Neuropsychologist in the EMU of the hospital during a two to five day stay.

**What Will Happen:** Video EEG. Neuropsychological testing. Ictal SPECT scan (if needed). PET scan (if needed).

step

4

## Neuropsychological Testing



Neuropsychological testing is not painful. However, it can make children feel tired or bored, so they are given many breaks.

Parents are later mailed a short report that they can share with schools.

This report often helps teachers better understand how seizures can affect a child's learning.

The doctor might want to do Neuropsychological testing again after surgery.

Post-surgical testing can help you and your child's teachers understand how your child's learning has improved.

### Steps of the Pediatric Epilepsy Surgery Journey



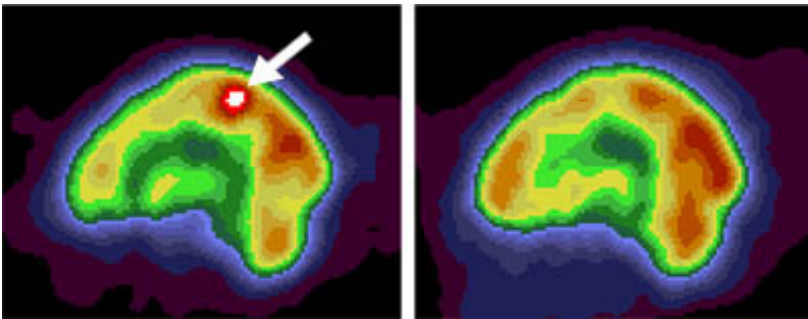
**Who You'll See:** Technicians, nurses, and the Neuropsychologist in the EMU of the hospital during a two to five day stay.

**What Will Happen:** Video EEG. Neuropsychological testing. Ictal SPECT scan (if needed). PET scan (if needed).

## step

## 4

## Inpatient Testing - Ictal SPECT



Brain during a seizure.

Brain between seizures.

An Ictal SPECT scan is only done for some children.

Sometimes seizures start in one part of the brain and then cause seizures in other parts of the brain.

The Ictal SPECT scan shows us where your child's seizures are really starting.

The scan lights up parts of the brain with more blood flow during a seizure, almost like a highlighter.

### Steps of the Pediatric Epilepsy Surgery Journey



# a Parent's Guide to Pediatric Epilepsy Surgery

© KRISTEN M. BAGNALL, 2010

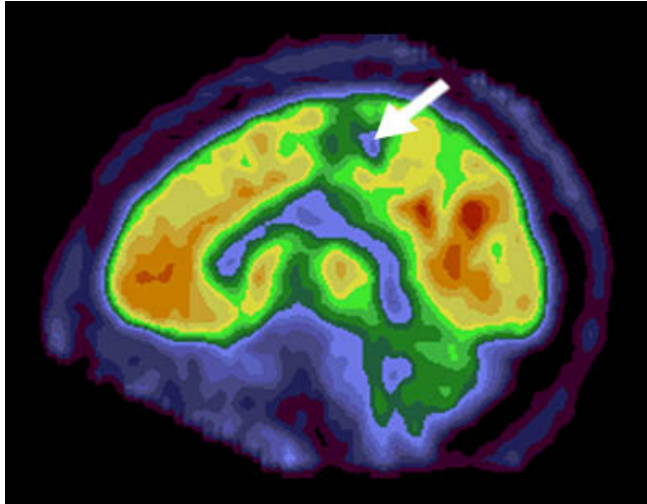
**Who You'll See:** Technicians, nurses, and the Neuropsychologist in the EMU of the hospital during a two to five day stay.

**What Will Happen:** Video EEG. Neuropsychological testing. Ictal SPECT scan (if needed). PET scan (if needed).

step

4

## Outpatient Testing - PET scan



A PET scan looks like an Ictal SPECT scan.

However, the PET scan tells us how much energy each part of the brain is using.

An area causing seizures may use less energy than the rest of the brain in between seizures. During a seizure, it will use more energy than the rest of the brain.

Seizure areas will appear blue on an abnormal PET scan when they should be yellow, orange, or red.

Other parts of the brain may be blue, but blue in those parts is normal.

### Steps of the Pediatric Epilepsy Surgery Journey



**Who You'll See:** You and your child will not be there.

**What Will Happen:** All of the doctors on our Epilepsy Team will talk about surgery for your child.

step

5

## Epilepsy Team Conference



The doctors on our Epilepsy Team will meet to talk about surgery for your child. Our team of doctors is highly trained in specialties such as:

- Neurology
- Neurosurgery
- Neuropsychology
- Neuroradiology

Many different kinds of doctors are involved in the surgery decision. We put all of our heads together so that we can give your child the best possible care.

### Steps of the Pediatric Epilepsy Surgery Journey



© KRISTEN M. BAGNALL, 2010

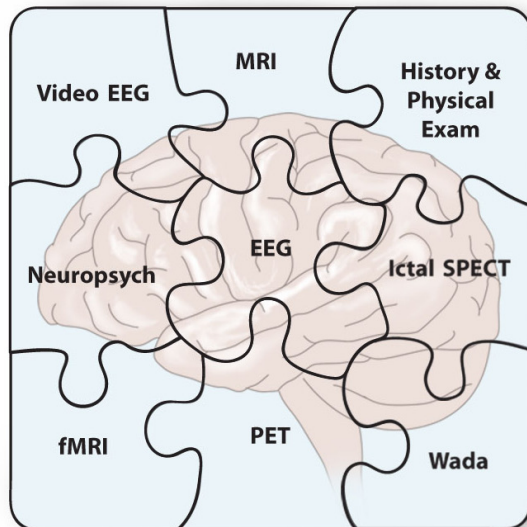
**Who You'll See:** You and your child will not be there.

**What Will Happen:** The Epilepsy Team will either recommend surgery or recommend another treatment for your child.

step

6

## Team Recommendation



During the meeting we put together all the “puzzle pieces” of testing.

Hopefully all of the pieces give us a clear picture of your child’s brain.

We also want to make sure that all of the seizures are coming from the same part of the brain.

We will recommend surgery if we all agree that it could help your child.

### Steps of the Pediatric Epilepsy Surgery Journey





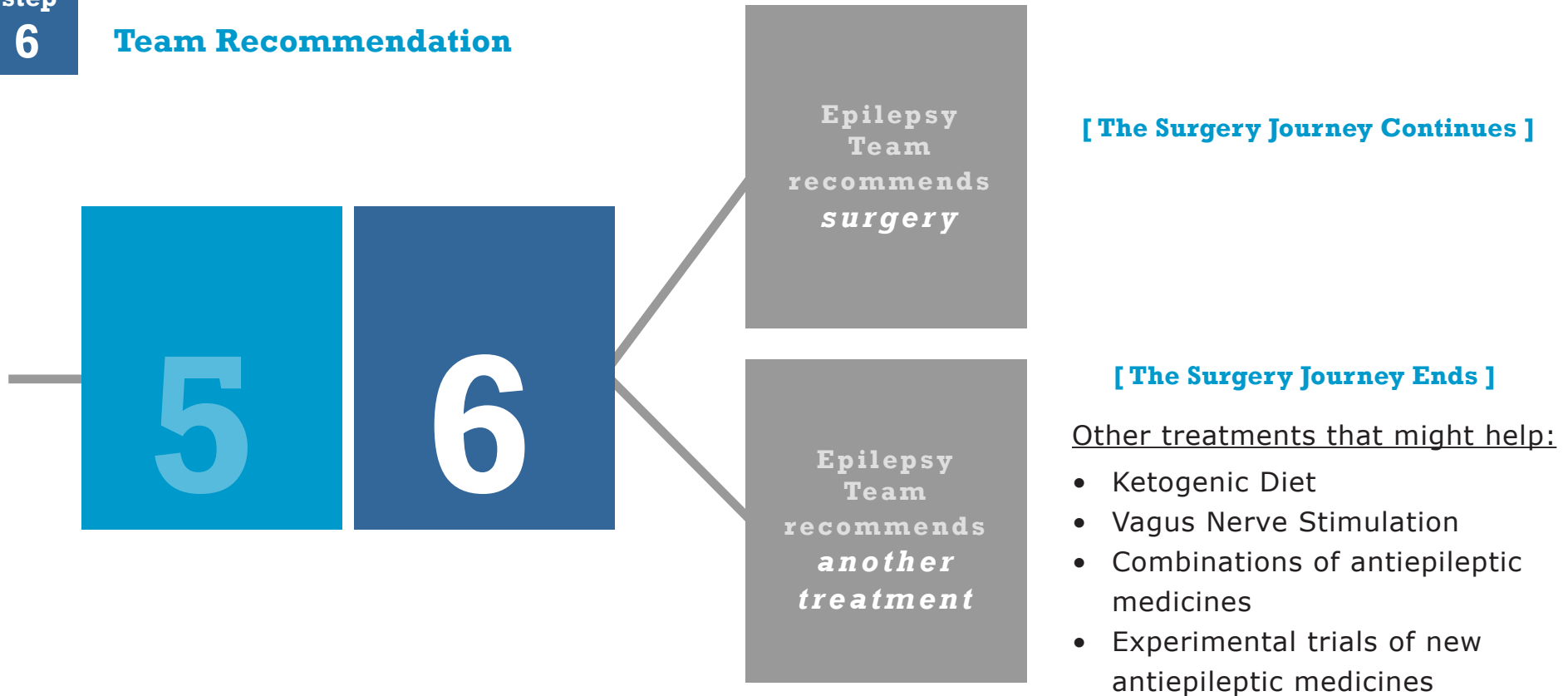
**Who You'll See:** You and your child will not be there.

**What Will Happen:** The Epilepsy Team will either recommend surgery or recommend another treatment for your child.

step

6

## Team Recommendation



### Steps of the Pediatric Epilepsy Surgery Journey



# a Parent's Guide<sup>to</sup> Pediatric *Epilepsy* Surgery

**Who You'll See:** You will talk to a member of the Epilepsy Team over the phone.

**What Will Happen:** We will call you with our recommendation for surgery..

step

7

## Phone Call



We will call you if we think that surgery could help your child.

We will suggest that you meet with our Neurosurgeon as the next step in the journey.

However, you are still not committed to surgery.

### Steps of the Pediatric Epilepsy Surgery Journey



**Who You'll See:** The Neurosurgeon in the neurosurgery clinic.

**What Will Happen:** Review testing and history. Exam. Talk about surgical benefits and risks. Schedule more testing if needed.

step

8

## Neurosurgery Appointment



The Neurosurgeon will meet with you to go over:

- Your child's medical history
- All pre-surgical testing already done
- Possible medical, social, and developmental benefits of surgery
- Your questions about the surgery
- Possibility of more testing before surgery

The Neurosurgeon will also do another physical & neurological exam of your child.

### Steps of the Pediatric Epilepsy Surgery Journey



**Who You'll See:** The Neurosurgeon in the neurosurgery clinic.

**What Will Happen:** Review testing and history. Exam. Talk about surgical benefits and risks. Schedule more testing if needed.

step

8

## Neurosurgery Appointment



Your child will be scheduled for more testing if the surgeon thinks that it is needed to plan the surgery.

However, you are still not committed to surgery at this point in the journey.

You are just getting information about the next step.

### Steps of the Pediatric Epilepsy Surgery Journey



# a Parent's Guide<sup>to</sup> Pediatric *Epilepsy* Surgery

**Who You'll See:** This is a decision for you and your family.

**What Will Happen:** You decide if your child is going to continue along the Pediatric Epilepsy Surgery Journey.

step

9

## Your Decision



Some families are ready to say “yes” to surgery in the Neurosurgeon’s office in step eight.

Other families need to go home and talk about the surgery with each other.

### Steps of the Pediatric Epilepsy Surgery Journey



© KRISTEN M. BAGNALL, 2010

**Who You'll See:** This is a decision for you and your family.

**What Will Happen:** You decide if your child is going to continue along the Pediatric Epilepsy Surgery Journey.

step

9

## Your Decision



[ The Surgery Journey Continues ]

[ The Surgery Journey Ends ]

Other treatments that might help:

- Ketogenic Diet
- Vagus Nerve Stimulation
- Combinations of antiepileptic medicines
- Experimental trials of new antiepileptic medicines

### Steps of the Pediatric Epilepsy Surgery Journey





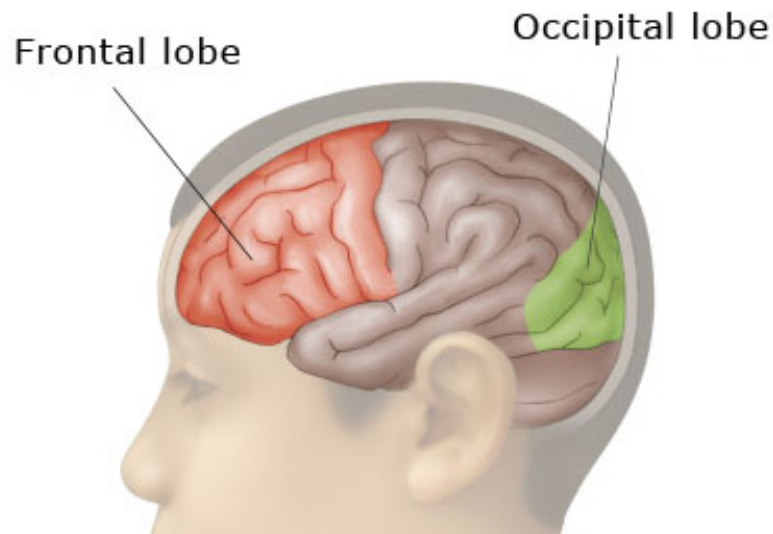
**Who You'll See:** For Visual Field Testing: Ophthalmologist. For an fMRI: technicians in the Radiology Suite.

**What Will Happen:** Visual Field Testing (if needed). fMRI (if needed).

step

10

## Possible Outpatient Testing



Your child might need more testing in order to better plan the surgery.

During your appointment with the Neurosurgeon in step eight, he or she will tell you if any of these tests are needed.

An fMRI tests the frontal lobe. It is done if your child's seizures are in or near the areas controlling movement, spoken language, or impulse control.

Visual Field Testing tests the occipital lobe. It is done if your child's seizures are in or near the area controlling vision.

### Steps of the Pediatric Epilepsy Surgery Journey



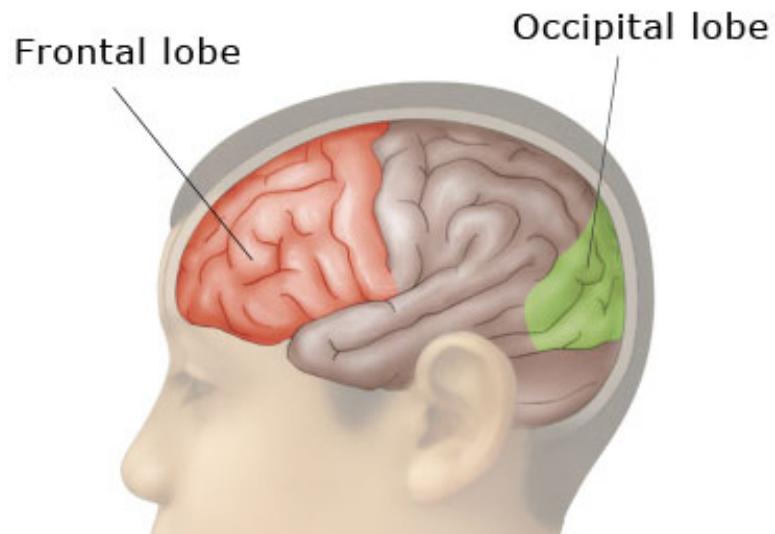
**Who You'll See:** For Visual Field Testing: Ophthalmologist. For an fMRI: technicians in the Radiology Suite.

**What Will Happen:** Visual Field Testing (if needed). fMRI (if needed).

step

10

## Possible Outpatient Testing



The goal of these tests is to better understand exactly what part of your child's brain controls these basic functions since they vary slightly from child to child.

We also want to know if your child's seizures have affected these critical areas.

This information helps the Neurosurgeon plan your child's surgery for the best possible results.

### Steps of the Pediatric Epilepsy Surgery Journey



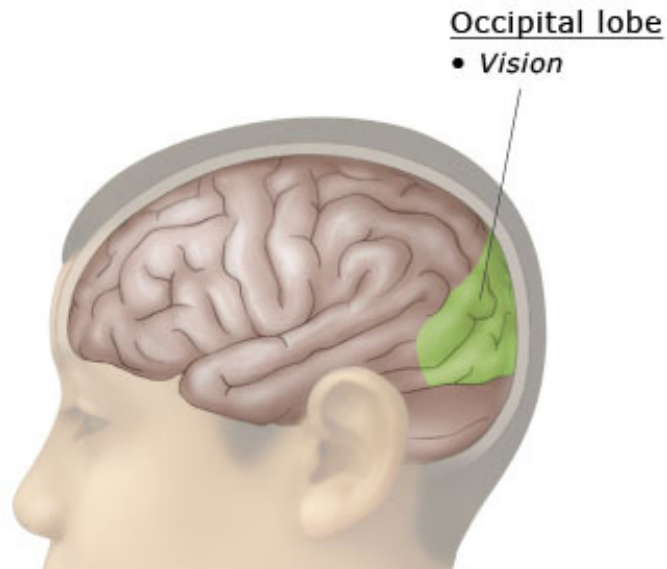
**Who You'll See:** For Visual Field Testing: Ophthalmologist. For an fMRI: technicians in the Radiology Suite.

**What Will Happen:** Visual Field Testing (if needed). fMRI (if needed).

step

10

## Visual Field Testing (Outpatient)



If we think that your child's seizures might be coming from an area near the brain's vision center (in the occipital lobe), we will test your child's vision before and after surgery.

This test will help us to understand what your child can and can't see.

It also gives us a baseline understanding that we compare with post-surgical results.

During your appointment with the Neurosurgeon in step eight, he or she will tell you if loss of vision is a possible side effect for your child's surgery.

### Steps of the Pediatric Epilepsy Surgery Journey



**Who You'll See:** For Visual Field Testing: Ophthalmologist. For an fMRI: technicians in the Radiology Suite.

**What Will Happen:** Visual Field Testing (if needed). fMRI (if needed).

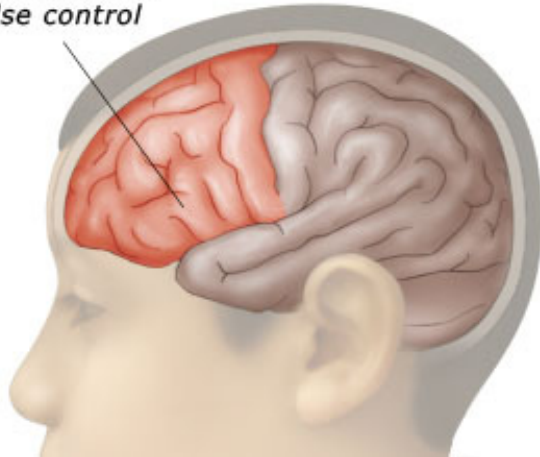
step

10

## fMRI (Outpatient)

### Frontal lobe

- Movement
- Spoken language
- Impulse control



A Functional MRI (fMRI) is a special kind of MRI scan that is only done for some children with partial seizures coming from their frontal lobe.

Children must also be old enough to have an MRI scan while fully awake.

The frontal lobe controls movement, spoken language, and impulse control.

So, before doing surgery in the frontal lobe, we want to know if your child's seizures are coming from an area in or near these critical areas.

### Steps of the Pediatric Epilepsy Surgery Journey



**Who You'll See:** For Visual Field Testing: Ophthalmologist. For an fMRI: technicians in the Radiology Suite.

**What Will Happen:** Visual Field Testing (if needed). fMRI (if needed).

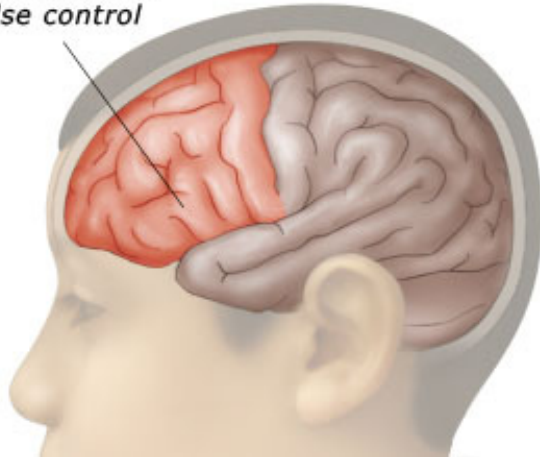
step

10

## fMRI (Outpatient)

### Frontal lobe

- Movement
- Spoken language
- Impulse control



During your appointment with the Neurosurgeon in Step 8, he or she will tell you if we are worried about the risks of surgery near your child's speech or motor areas.

An fMRI tells us important areas to avoid during your child's surgery.

### Steps of the Pediatric Epilepsy Surgery Journey



**Who You'll See:** For Visual Field Testing: Ophthalmologist. For an fMRI: technicians in the Radiology Suite.

**What Will Happen:** Visual Field Testing (if needed). fMRI (if needed).

step

10

## fMRI (Outpatient)



This is an fMRI scan showing this child's spoken language area in the left frontal lobe.

The specific location may be slightly different in each child.

### Steps of the Pediatric Epilepsy Surgery Journey





# <sup>a</sup> Parent's Guide<sup>to</sup> Pediatric *Epilepsy* Surgery

© KRISTEN M. BAGNALL, 2010

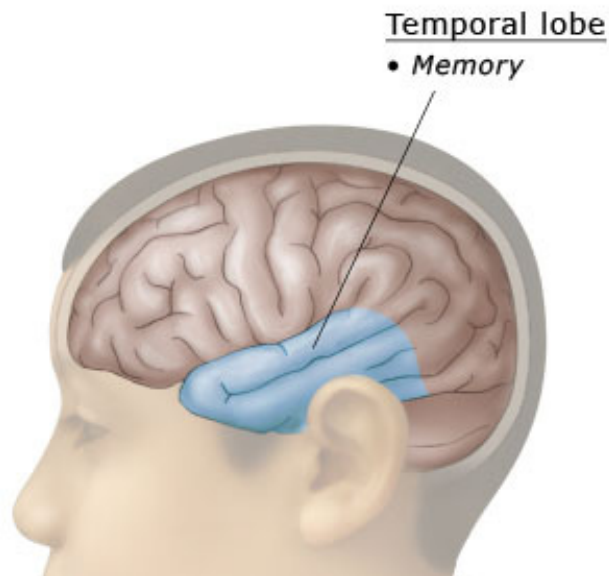
**Who You'll See:** Technicians in the EMU of the hospital.

**What Will Happen:** Wada test (if needed).

step

**11**

## Wada test (Inpatient)



A Wada test is only recommended for children with partial seizures coming from the temporal lobe. Children must also be old enough to cooperate during the testing.

The main concern when operating on the abnormal temporal lobe is to avoid the area controlling memory.

This test looks at each temporal lobe separately. This tells us if your child's non-epileptic temporal lobe is strong enough to handle memory on its own.

### Steps of the Pediatric Epilepsy Surgery Journey



**Who You'll See:** Technicians in the EMU of the hospital.

**What Will Happen:** Wada test (if needed).

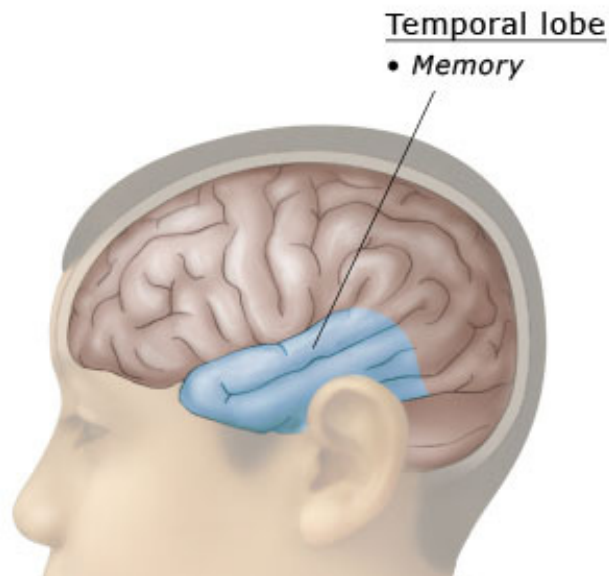
step

11

## Wada test (Inpatient)

If both the left and the right temporal lobes are needed for memory, then we won't suggest epilepsy surgery in that area.

However, if your child's seizures are coming from the temporal lobe that is not needed for memory, then we can safely do surgery in that area.



### Steps of the Pediatric Epilepsy Surgery Journey



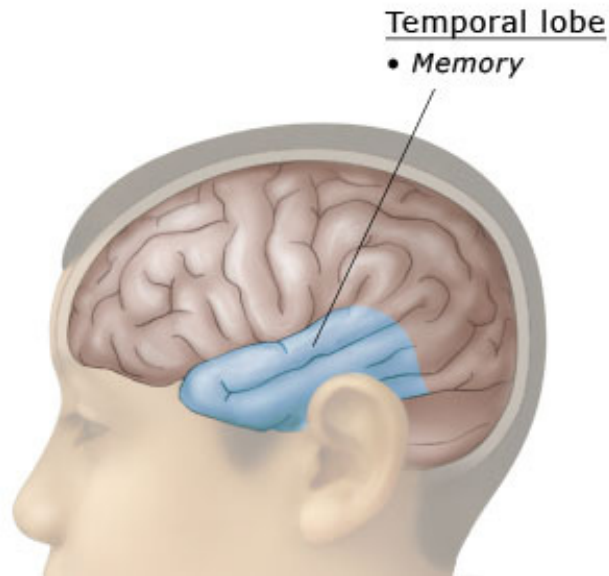
**Who You'll See:** Technicians in the EMU of the hospital.

**What Will Happen:** Wada test (if needed).

step

**11**

## Wada test (Inpatient)



For this test, a catheter (a small, flexible tube) is placed in the groin. It is threaded up through the arteries of the body to the neck. Technicians use an x-ray machine to follow the location of the catheter in the body.

A small amount of anesthesia is used to put half of the brain to sleep for five minutes.

During this time, the memory in the other half of the brain can be tested by talking to the child and showing pictures.

### Steps of the Pediatric Epilepsy Surgery Journey



© KRISTEN M. BAGNALL, 2010

**Who You'll See:** Technicians in the EMU of the hospital.

**What Will Happen:** Wada test (if needed).

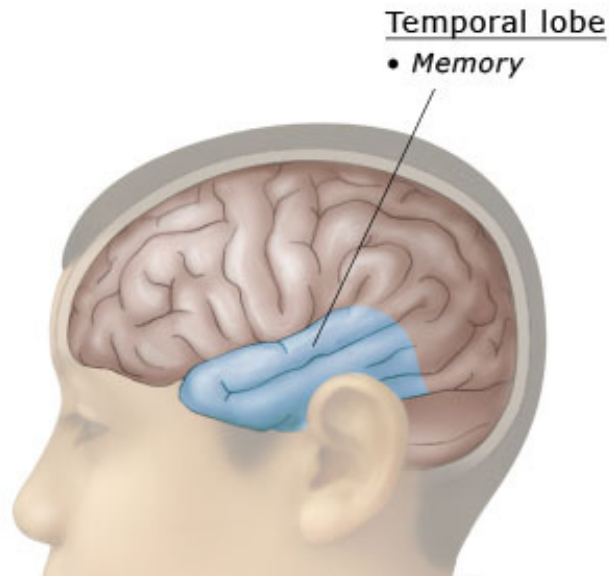
step

11

## Wada test (Inpatient)

If the catheter is in the left carotid artery, the left side of the brain is put to sleep.

After testing one side, the catheter is placed in the other carotid artery. Then the memory of the other temporal lobe is tested.



### Steps of the Pediatric Epilepsy Surgery Journey



# a Parent's Guide<sup>to</sup> Pediatric *Epilepsy* Surgery

**Who You'll See:** You can make another appointment with the Neurologist or Neurosurgeon or talk to a team nurse on the phone.

**What Will Happen:** You will make your final decision about the surgery, and the surgery will be scheduled.

step

12

## Final Decision



The Neurosurgeon and the Neurologist will make sure that any additional test results still show that surgery could help your child.

If all the pieces are falling into place, you will be contacted to schedule the surgery.

In some cases, the surgery may have already been scheduled at the appointment with the Neurosurgeon in step eight.

The last step before surgery is for you to make your final decision about the surgery.

### Steps of the Pediatric Epilepsy Surgery Journey



# <sup>a</sup> Parent's Guide<sup>to</sup> Pediatric *Epilepsy* Surgery

© KRISTEN M. BAGNALL, 2010

**Who You'll See:** MRI technician. Nurses of the pre-op team. Anesthesiologist.

**What Will Happen:** MRI. Pre-op appointment and exam. Blood drawn.

step

## 13a Pre-Op MRI



Your child will have another MRI that will help the Neurosurgeon during the surgery. This may be done on a different day than the pre-op appointment.

Some children have an MRI with fiducials. Fiducials are like little stickers that are put on a child's head.

They tell the Neurosurgeon where he or she is operating relative to your child's seizure area. Once the nurse places the fiducials, do not move them or take them off for any reason.

### Steps of the Pediatric Epilepsy Surgery Journey



**Who You'll See:** MRI technician. Nurses of the pre-op team. Anesthesiologist.

**What Will Happen:** MRI. Pre-op appointment and exam. Blood drawn.

step

13a

## Pre-Op Appointment



The pre-op appointment is usually scheduled for one to two days before surgery. A nurse will put a wrist band on your child that has important information for the surgery. It can not be taken off before surgery.

The pre-op nurses will:

- Take your child's height, weight, and blood pressure
- Do a physical exam
- Give you special instructions about food and drink before surgery
- Answer questions
- Send your child to the hospital lab to get blood drawn

### Steps of the Pediatric Epilepsy Surgery Journey





# <sup>a</sup> Parent's Guide<sup>to</sup> Pediatric *Epilepsy* Surgery

© KRISTEN M. BAGNALL, 2010

**Who You'll See:** MRI technician. Nurses of the pre-op team. Anesthesiologist.

**What Will Happen:** MRI. Pre-op appointment and exam. Blood drawn.

step

**13a**

## Pre-Op Appointment



A nurse will also give you special sponges to wash your child's hair. You will use one the night before surgery and another one the morning of surgery. Do not use shampoo on your child's hair.

We do not recommend that you shave your child's hair before coming to surgery. This can move bacteria around and increase the risk of infection during surgery.

Nurses in the operating room will carefully shave the area before surgery begins. They will not shave all of your child's hair.

### Steps of the Pediatric Epilepsy Surgery Journey



© KRISTEN M. BAGNALL, 2010

**Who You'll See:** MRI technician. Nurses of the pre-op team. Anesthesiologist.

**What Will Happen:** MRI. Pre-op appointment and exam. Blood drawn.

step

## 13a Pre-Op Appointment



You will also meet with a pediatric Anesthesiologist. This may or may not be the same Anesthesiologist who will be at the surgery.

He or she will ask you questions about your child's medical history such as:

- Any heart or lung problems
- Recent sickness or fever
- Past surgeries
- Past experiences or reactions to anesthesia
- Allergies or drug reactions
- Medicines your child is currently taking

### Steps of the Pediatric Epilepsy Surgery Journey



© KRISTEN M. BAGNALL, 2010

**Who You'll See:** The surgical team. Anesthesiologist. Neurosurgeon.

**What Will Happen:** The surgical team will prepare your child for surgery. Meeting with Anesthesiologist and Neurosurgeon.

step

13b

## Morning of Surgery

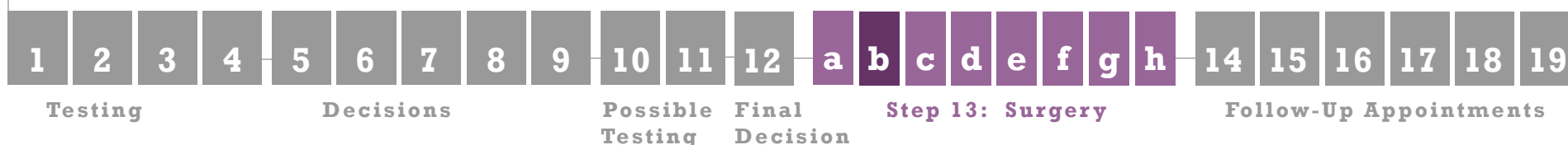


On the morning of surgery, your child will be cared for by the surgical team. The Anesthesiologist will give your child a medicine by mouth that helps children relax before the surgery. Sometimes it helps if children bring a favorite toy, doll, or book for comfort.

You will meet with your child's Anesthesiologist and Neurosurgeon to go over any last-minute questions. We encourage you to come with a list of questions that you might have thought of since the pre-op appointment. You will also sign the consent forms for the surgery.

You and your family may then wait in the Surgical Family Waiting area.

### Steps of the Pediatric Epilepsy Surgery Journey



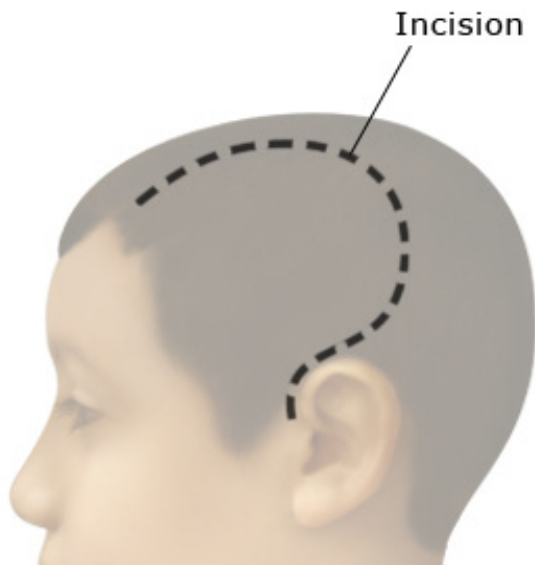
**Who You'll See:** You and other family members may sit in the Surgical Family Waiting room.

**What Will Happen:** Your child will have his or her surgery.

step

13c

## Hemispherectomy Surgery



In the operating room, the Anesthesiologist will put your child to sleep as gently as possible.

Throughout the surgery, the Anesthesiologist will closely watch your child's heart-rate, blood pressure, breathing, and temperature to make sure that your child is safe.

Nurses will also shave the part of your child's head that will be operated on during surgery. Your child's whole head will not be shaved.

### Steps of the Pediatric Epilepsy Surgery Journey



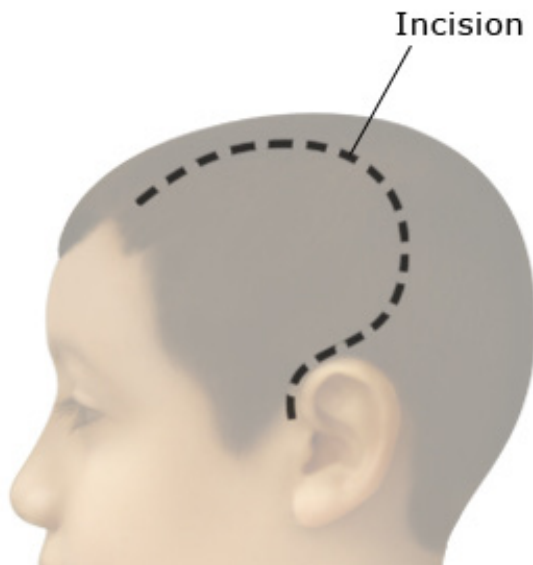
**Who You'll See:** You and other family members may sit in the Surgical Family Waiting room.

**What Will Happen:** Your child will have his or her surgery.

step

13c

## Hemispherectomy Surgery



The goal of a Hemispherectomy is to disconnect the hemisphere causing seizures from the rest of the brain.

During the Hemispherectomy:

- The Neurosurgeon will carefully cut a piece of your child's skull away and set it aside for later.
- The hemisphere causing seizures will be disconnected from the rest of the brain.
- The piece of skull is put back in place.
- Antibiotic ointment is put on the incision.

### Steps of the Pediatric Epilepsy Surgery Journey



**Who You'll See:** Your child. The Anesthesiologist. The Neurosurgeon.

**What Will Happen:** Anesthesiologist closely monitors your child. Neurosurgeon talks to you about how the surgery went.

**step**  
**13d** **Recovery Room**



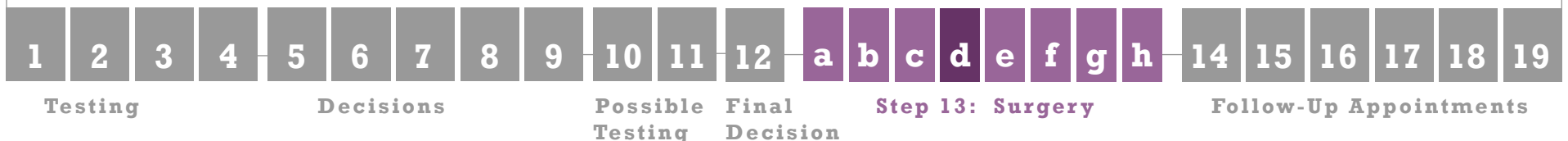
Your child will be moved to a recovery room immediately after surgery. This is also called the Post Anesthesia Care Unit.

Children often feel sleepy and have nausea or vomiting after surgery.

Children may also have eye or head swelling for two to three days after surgery.

The Anesthesiologist will continue to watch your child as he or she wakes up. The Neurosurgeon will also talk with you about the surgery.

**Steps of the Pediatric Epilepsy Surgery Journey**



**Who You'll See:** Nurses in the ICU.

**What Will Happen:** Your child will stay in the ICU - usually overnight.

step

**13e**

## ICU - Intensive Care Unit

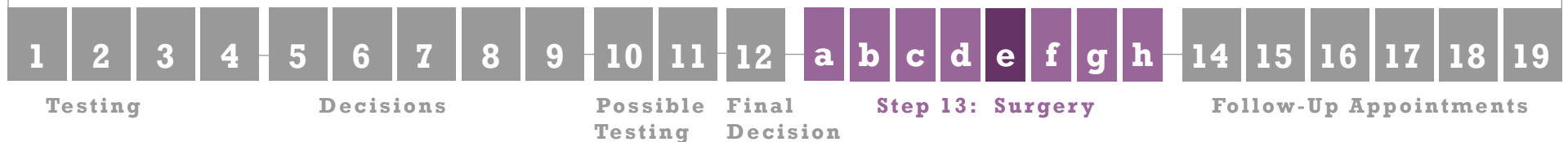


After recovering from the anesthesia, your child will be moved to the ICU for close care by nurses.

Most children stay in the ICU overnight.

A family member may stay overnight in the room.

### Steps of the Pediatric Epilepsy Surgery Journey





# a Parent's Guide<sup>to</sup> Pediatric *Epilepsy* Surgery

© KRISTEN M. BAGNALL, 2010

**Who You'll See:** Neurosurgery nurses. Neurosurgeon. Therapy Services.

**What Will Happen:** Close care of your child after surgery.

step

13f

## Neurosurgery Floor



The Neurosurgeon will check in to make sure that your child is recovering well.

Nurses will teach you how to care for the incision.

Therapy Services will also come to see if your child will need any new therapy after going home.

### Steps of the Pediatric Epilepsy Surgery Journey



# a Parent's Guide<sup>to</sup> Pediatric *Epilepsy* Surgery

© KRISTEN M. BAGNALL, 2010

**Who You'll See:** Therapy Services. Nurses.

**What Will Happen:** Your child will stay in the hospital for extra rehabilitation therapy if needed.

step

13g

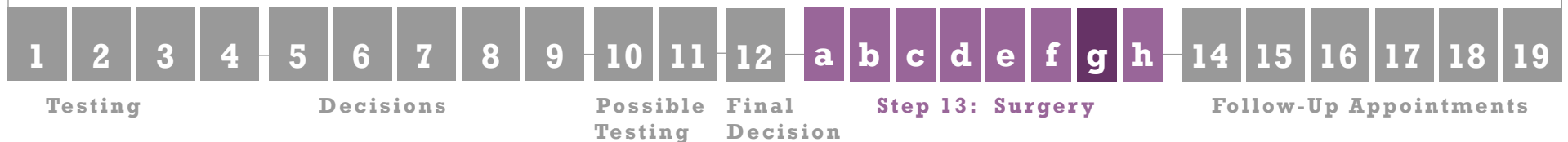
## Possible Post-surgical Therapy



Sometimes children who have hemispherectomies need rehabilitation therapy before going home.

Therapy is very important for hemispherectomy patients. It helps children's brains adjust to life after surgery so that they can continue to grow and develop.

### Steps of the Pediatric Epilepsy Surgery Journey



© KRISTEN M. BAGNALL, 2010

**Who You'll See:** Nurses.

**What Will Happen:** You will take your child home.

step

13h

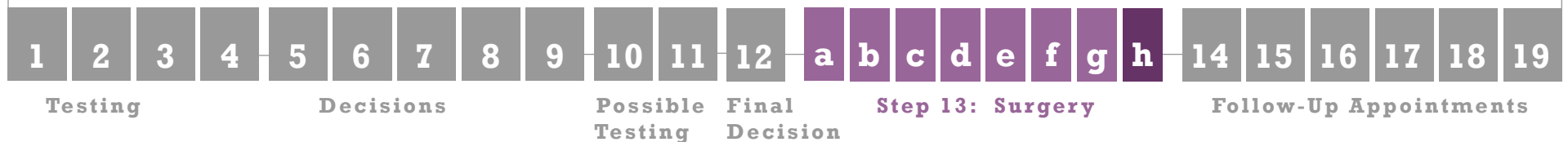
## Go Home.



Your child will be released from the hospital.

You will need to schedule the first follow-up appointment.

### Steps of the Pediatric Epilepsy Surgery Journey



# a Parent's Guide<sup>to</sup> Pediatric *Epilepsy* Surgery

**Who You'll See:** The Neurosurgeon in the neurosurgery clinic.

**What Will Happen:** A post-op wound check and exam.

step

14

## Post-op Appointment



At the post-op appointment, the Neurosurgeon will:

- Check your child's incision for infection
- Do a physical exam
- Make sure your child is recovering well
- Answer any questions you have

Your child's stitches will be removed if needed. Some types of stitches dissolve on their own.

Your child will continue to take normal doses of antiepileptic medicines.

### Steps of the Pediatric Epilepsy Surgery Journey



© KRISTEN M. BAGNALL, 2010

**Who You'll See:** The Neurologist in the neurology clinic.

**What Will Happen:** Surgery follow-up care and epilepsy monitoring begins.

step

15

## Follow-up Appointment



A few weeks later, your child will return to the clinic to begin follow-up care with the Neurologist.

Most children are ready to return to school two to four weeks after surgery.

Future visits depend on each child's needs. However, follow-up appointments are usually every three to six months for the next year.

Your child will continue to take antiepileptic medicines.

### Steps of the Pediatric Epilepsy Surgery Journey



# a Parent's Guide<sup>to</sup> Pediatric *Epilepsy* Surgery

© KRISTEN M. BAGNALL, 2010

**Who You'll See:** The Neurologist and the Neurosurgeon at separate appointments - usually on the same day.

**What Will Happen:** Epilepsy monitoring continues. Follow-up EEG test. Continue at least one antiepileptic medicine.

step

16

## Follow-up Appointment



About six months after surgery, your child will see the Neurologist and the Neurosurgeon. The two appointments are usually on the same day.

Your child will also have an EEG to look for seizure activity.

If your child has been seizure-free since the surgery, the Neurologist might lower the dosage of his or her antiepileptic medicines.

Your child will continue to take at least one antiepileptic medicine.

### Steps of the Pediatric Epilepsy Surgery Journey





# a Parent's Guide<sup>to</sup> Pediatric *Epilepsy* Surgery

**Who You'll See:** The Neurologist, the Neurosurgeon, and the Neuropsychologist in separate appointments.

**What Will Happen:** Epilepsy monitoring continues. Neuropsychological testing. Continue at least one antiepileptic medicine.

step

17

## Follow-up Appointment



About one year after surgery, your child will see the Neurologist and the Neurosurgeon. The two appointments are usually on the same day.

Your child will also see the Neuropsychologist to learn how your child's thinking skills and behavior have changed since the surgery.

If your child has been seizure-free since the surgery, the Neurologist might lower the dosage of his or her antiepileptic medicines.

Your child will continue to take at least one antiepileptic medicine.

### Steps of the Pediatric Epilepsy Surgery Journey





# a Parent's Guide<sup>to</sup> Pediatric *Epilepsy* Surgery

© KRISTEN M. BAGNALL, 2010

**Who You'll See:** The Neurologist and the Neurosurgeon at separate appointments.

**What Will Happen:** Epilepsy monitoring continues.

step

18

## Follow-up Appointment



About two years after surgery, your child will see the Neurologist and the Neurosurgeon. The two appointments are usually on the same day.

Some children stay seizure-free without antiepileptic medicines.

Other children need to continue antiepileptic medicines for best seizure control.

### Steps of the Pediatric Epilepsy Surgery Journey



## step

## 19

## The Surgery Journey is Over



Congratulations! You and your child have finished the Pediatric Epilepsy Surgery Journey.

Some of our past surgery patients are now doing things they could not do before, such as:

- Making A's in school
- Swimming and horseback riding
- Driving
- Going to college
- Getting a job

## Steps of the Pediatric Epilepsy Surgery Journey

