

# Epilepsy Surgery

Guidebook



## Using Your Patient Education Handbook

You or your loved one have been referred to the AdventHealth Neuroscience Institute for surgery to treat epilepsy. We understand it is very difficult when one does not respond to anti-seizure medications, and that continued seizing can be very stressful. Families tend to worry about potential injury, changes in cognitive function and side effects from increasing doses of medication. In the pages that follow, we will explain how we can help.

A glossary has been included in the appendices to help explain epilepsy and surgical terms. Please refer to it as you read along to help you better understand the details of the epilepsy surgical process.

If you have any questions about the material in this guidebook, call 407-303-8127.

This epilepsy education guidebook belongs to

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# Welcome to AdventHealth



On behalf of our entire care team, I would like to welcome you to AdventHealth. For more than 100 years, we have dedicated ourselves to improving the lives of others by delivering advanced health care to the communities we serve. Our mission—to extend the healing ministry of Christ—has inspired us to build a unique health network dedicated to providing comfort, healing and the discovery of new treatments and cures.

We're honored that you have entrusted us with your health. We look forward to caring for you.

Sincerely,

**Daryl Tol**

President and CEO

AdventHealth Central Florida Region





## Introduction

### Who is referred to our epilepsy center?

Epilepsy is called “intractable” or “drug resistant” when a person has failed two anti-seizure medications that have been maximized by increasing doses to a therapeutic level. It does not include medications that may have been stopped due to drug reactions, allergies or intolerable side effects.

Research shows that people with intractable epilepsy will continue to break through other AED drug treatment regimens after a short or long honeymoon period. This means that a particular medication or combination of medicines may help a person’s seizure frequency or severity for a month to several months, or even a year or two, but that the benefits will not be long lasting.

When medical treatment with anti-seizure drugs fails, a comprehensive epilepsy evaluation may be necessary to find the causes of epilepsy and alternative treatment options such as brain surgery and diet. This is what a comprehensive epilepsy evaluation is all about.

## When is surgery a consideration?

We know that the thought of epilepsy surgery can be a scary and big decision. Our dedicated epilepsy team is here to help you through this process. The first step will be testing and gathering more information about you or your loved one's epilepsy. After results are returned and reviewed by our team of experts, you may then be considered as a surgical candidate in the second step of the process. The third step of epilepsy surgery consideration would be the determination of a specific surgical procedure to best help you. We realize that you may have thoughts, concerns and questions throughout this several-month process and are ready and willing to help you.

Surgery for intractable epilepsy is a voluntary or elective procedure. It can be considered when seizures are thought to be coming from one hemisphere of the brain, left or right, but not both. This is called seizure lateralization. The location of the seizure focus, or center, must also be identifiable in one or more lobes of that hemisphere.

Most people consider surgery when they have failed at least two anti-seizure medications (AEDs). The seizures are usually frequent enough or severe enough to greatly affect a person's ability to function at his/her best.

## What can epilepsy surgery do to help me or my loved one?

- May help reduce the number and severity of seizures
- May make you or your loved one seizure-free
- May reduce the risk of falls or injuries from seizures

## Who benefits from surgery?

Surgery may prove a beneficial option for people with:

- Simple partial seizures
- Complex partial seizures
- Partial seizures with secondary generalization
- "Drop" seizures

Usually the best surgical outcomes happen when the test results show seizure activity in only one hemisphere and in a specific lobe(s) or location(s) of the brain. The goal of the epilepsy surgery team is to remove the area(s) of seizure focus without creating any motor or language problems. By motor, we mean the movement of your arms, hands, legs and feet. Language refers to your understanding of what is said to you, as well as being able to speak in words.



## What if I am not a candidate for surgery?

There are still several options we can help with, including:

- Medication adjustment
- Ketogenic diet
- Clinical trials
- Other medical treatment depending on the causes of epilepsy

LEARN MORE [AdventHealthNeuroInstitute.com](https://www.adventhealthneuroinstitute.com)

# Program Overview

Our epilepsy center is located at AdventHealth Orlando. Our team works hard to stop or lessen your or your loved one's seizures with various innovative treatment options. We also hope to improve our patients' quality of life.

## How does our epilepsy center work?

Our expert team will create a step-by-step treatment plan designed specifically for you. The team will be there for you through all steps of the process.

We will handle your medication needs and seizure control following the initial visit. Throughout the evaluation, surgery and post-operative period, we will assist you with medication changes and refills, as well as problems with seizure control.

During these few months, we will also maintain contact with your neurologist. Three to six months following surgery and after your follow-up appointment at the clinic, you can arrange to resume care with your primary neurologist. If you need to find a neurologist, the team will make every effort to assist you.

If surgery is not an option for you, our team will meet with you and explain the test results. We will also offer you other possible treatment choices for your specific seizure disorder.

## Our Epilepsy Team

- Neurologists (Epileptologists)
- Neurosurgeons
- Neuroradiologists
- Neuropsychologists
- Pathologists
- Pharmacist
- Physician assistants, nurse practitioners, and registered nurses
- EEG/MEG technologists
- Patient care attendants
- Social workers
- Speech/physical/occupational therapists

The epilepsy team knows that having a loved one with intractable epilepsy affects the whole family. Each team member will treat your needs, and those of your family, with compassion and respect.

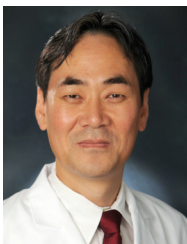
### THE GOALS OF OUR TEAM ARE TO:

- Provide the highest quality of care for you
- Coordinate your care
- Address your questions and concerns
- Attend to your scheduling needs
- Communicate with your school, place of employment and primary physicians, as needed

There are members of our team who will support you and your family through this process. Following is a list of support team members, along with a description of their roles and how you can reach them. They include social workers, holistic health specialists, massage therapists and pastoral care chaplains.



## Physicians



### **KI HYEONG LEE, MD, MS, MBA** Medical Director, Epileptologist

One of the leaders in epilepsy and seizure diagnosis and treatment in the country, Dr. Lee directs a team of specialists to treat a wide range of epilepsy and seizure-related diseases and conditions. Through his efforts and those of his colleagues, many of our patients are able to live a seizure-free life.

Dr. Lee is a renowned expert in epilepsy and has successfully treated thousands of patients, either reducing the incidences of seizures or eliminating them entirely through groundbreaking approaches to the diagnosis and treatment of these disorders. Many of these utilize highly advanced technologies, such as the 3T MRI, which can provide real-time feedback of the brain during surgery, greatly improving outcomes.

#### **Education and Experience**

Dr. Lee is a graduate of Seoul National University College of Medicine in Korea, where he earned his medical degree. He went on to serve his pediatrics internship and residency at the Medical College of Georgia in Augusta. Dr. Lee completed his epilepsy research fellowship at the prestigious Mayo Foundation and his clinical neurophysiology fellowship at the Medical College of Georgia. He also fulfilled a stroke fellowship at Seoul National University Hospital and was associate professor at the University of Cincinnati's Department of Neurology and Pediatrics before coming to AdventHealth.





**JAMES BAUMGARTNER, MD**  
Surgical Director, AdventHealth Neuroscience Institute

Specializing in minimally invasive and traditional surgery, Dr. Baumgartner is a leading expert on seizures, seizure-related conditions and epilepsy. As a board-certified neurosurgeon, he collaborates with other members of our team to treat people of all ages, reducing the frequency and severity of seizures, and in many cases, eliminating them entirely.

Dr. Baumgartner is highly regarded in the field of neurosurgery and has established a legacy of successfully treating his patients using the most recent advancements and proven treatments in medicine, including surgeries that leave little to no scarring. This includes the use of state-of-the-art diagnostic and surgical technologies, such as the Intraoperative 3T MRI that allows the brain to be scanned in real time during surgery, increasing the accuracy of procedures and positive patient outcomes.

Dr. Baumgartner treats a wide range of disorders and conditions, including petit mal, grand mal, tonic, myoclonic, atonic and partial seizures.

**Education and Experience**

After earning his medical degree from the University of Michigan in Ann Arbor, he served his surgery internship and neurosurgery residency at the University of California, San Francisco. He also completed his fellowship in pediatric neurosurgery there.

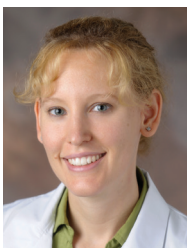


**JOO HEE SEO, MD, MSC**

Dr. Seo is a fellowship-trained epileptologist at AdventHealth. Through the AdventHealth Neuroscience Institute, Dr. Seo has implemented the Tuberous Sclerosis Complex Clinic and Ketogenic Diet Clinic to help accurately diagnose the source of neurological problems and develop individualized treatment plans for patients. She is committed to providing her patients with superior care, using some of the most advanced diagnostics, treatments and techniques available.

**Education and Experience**

After earning her medical degree from Yonsei University in Korea, Dr. Seo completed a pediatrics internship at Cincinnati Children's Hospital, followed by a pediatrics residency at Arnold Palmer Hospital for Children and Women. Following, Dr. Seo pursued an epilepsy fellowship at Cincinnati Children's Hospital, as well as another pediatrics residency and pediatric neurology fellowship from Severance Children's Hospital/Yonsei University College of Medicine. She holds active memberships in the American Epilepsy Society, Korean Pediatric Association, Korean Child Neurology Society and Korean Epilepsy Society.



**HOLLY J. SKINNER, DO**

Dr. Skinner is an award-winning neurologist and neurophysiologist who is fellowship-trained in both sleep medicine and epilepsy. During her extensive training, Dr. Skinner provided inpatient care at AdventHealth East Orlando, as well as in the Epilepsy Division of the Department of Neurology at the University of Florida, Gainesville, all while being an avid clinical investigator. During her residency, Dr. Skinner was named chief resident and received the Best Neurology Presentation award. Her primary medical and research interests include epilepsy syndromes and sleep disorders, for which she has published multiple articles in peer-reviewed journals. She is a member of the American Epilepsy Society, American Academy of Neurology, American Osteopathic Association and American Academy of Sleep Medicine.

**Education and Experience**

Dr. Skinner earned her Doctorate of Osteopathic Medicine from Nova Southeastern University's College of Osteopathic Medicine. Following, she pursued a Master of Science degree in clinical and translational science from the University of Florida Clinical and Translational Science Institute as a member of the Advanced Post-graduate Program for Clinical Investigators. During her neurology residency at the Medical University of South Carolina, Dr. Skinner achieved chief resident status. She then completed a clinical neurophysiology fellowship at the University of Florida.



### **ELAKKAT D. GIREESH, MD**

Dr. Gireesh is an epileptologist with research interests including seizure localization and transcranial neurostimulation. His clinical focus has centered on epilepsy, long-term EEG monitoring in critically ill patients and intraoperative neuromonitoring. He has substantial experience in the use of intracranial EEG monitoring, NeuroPace RNS (responsive neurostimulation) and ketogenic diets for controlling seizures

#### **Education and Experience**

Dr. Gireesh received his subspecialty fellowship training at Johns Hopkins University following neurology residencies at New York University and Johns Hopkins. Dr. Gireesh was a post-doctoral fellow at the National Institutes of Health (NIH) in Bethesda, MD, and he holds an advanced degree in medical science and technology from the Indian Institute of Technology.

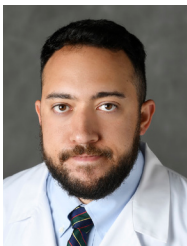


### **MICHAEL WESTERVELD, PHD, ABPP-CN**

Dr. Westerveld is board certified in clinical neuropsychology, working with other specialists at AdventHealth to diagnose and treat a range of developmental, medical, psychiatric and neurological conditions. Dr. Westerveld understands the importance of making an accurate diagnosis as early as possible, so an effective treatment plan can be implemented to achieve the best possible long-term outcome.

#### **Education and Experience**

Dr. Westerveld received his PhD in clinical psychology from Fairleigh Dickinson University in New Jersey and is highly respected in the field of pediatric neuropsychology, as well as a noted author, lecturer and panelist. He previously served as an associate clinical professor of neurosurgery at Yale University School of Medicine, New Haven, Connecticut.



### **ANGEL O. CLAUDIO, MD**

Dr. Claudio is a board-certified neurologist with additional training in epilepsy. He obtained his medical degree from UCC School of Medicine in Bayamón, Puerto Rico, and then completed his residency in neurology at Texas Tech University Health Sciences Center. He went on to complete fellowship training in epilepsy at the University of Miami Miller School of Medicine. He is a member of the American Epilepsy Society and the American Academy of Neurology. Dr. Claudio is fluent in English and Spanish.

## **Adult Nurse Practitioner**



### **CHRISTINA WOMBLES, APRN**

Christina Wombles, APRN, is an advanced practice registered nurse with more than 10 years of clinical experience. She is certified in advanced, cardiac life support and basic life support and was honored as a student with the President's Award for highest academic achievement in nursing. Christina earned her Bachelor of Science in Nursing at Pensacola Christian College and her Master of Science in Nursing at the University of South Alabama in Mobile.

Christina utilizes a personal, individualistic approach to each patient. She incorporates both nursing skills and medical knowledge to develop a unique plan of care for each of her patients.

## Epilepsy Care Coordinator



### MARITSA CASARES, BSN, RN, CNRN

Maritsa Casares, BSN, RN, CNRN, received her Bachelor of Science in Nursing from the University of Central Florida. She began her nursing career at AdventHealth in 2013. Her experience includes neurology and progressive care.

#### What is a care coordinator?

The epilepsy care coordinator is a specially trained registered nurse who provides expert clinical assistance and support to patients who are receiving health care related to epilepsy at AdventHealth.

Whether it's coordinating appointments, working with you and your physician to identify the right treatment plan, or just a heart-to-heart talk about your daily concerns, Maritsa is your advocate who ensures you receive the care you need when you need it. She is available Monday through Friday and will return your call within two business days. All calls are free and confidential, and no insurance is required to talk or meet with her.



### MICHELLE CURTIER Program Coordinator

With 18 years of experience at Advent Health, Michelle Curtier has a wide range of expertise in patient financial services, customer service and coordination of patient care. She leads a team of scheduling, insurance and authorization specialists that lends a unique approach to streamlining the patient experience.

## Clinical Social Worker



### JOSEPHINE SCHWEITZER, MSW

While we strive to make your stay as comfortable as possible, being in the hospital can be stressful for patients and their loved ones. Some of the questions we hear include:

- Will anyone be there to provide emotional support?
- Can someone help me with paperwork to allow for time off from work?

The team's social worker can help you with these and other issues that may arise during your hospital stay.

#### The social worker is trained to:

- Listen to your needs and concerns, and offer support
- Locate resources for you when you are in the hospital and also near your home after you are discharged
- Serve as an advocate for you and your family

Our social worker will first meet with you early on in the epilepsy surgery evaluation process. They will continue to support your family during your admission for testing, surgery and recovery.

## Pastoral Care

We believe prayer and spiritual guidance can have a profound impact on healing for patients and caregivers. To provide comfort and support, AdventHealth has chaplains on duty 24-hours-a-day, seven-days-a-week. Our chaplains understand the importance of faith and prayer for healing, and that spiritual interventions complement traditional medical treatment. As a result, AdventHealth is a leader in whole-person health — treating the body, mind and spirit.

Each of our compassionate and caring chaplains is a trained professional and an integral member of AdventHealth's healing team. They are not only sensitive to the medical, emotional and spiritual needs of our patients, but to the feelings of the patient's family and friends as well. Our chaplains invite meaningful and healthy use of an individual's spiritual beliefs and resources in the midst of an illness or crisis. Pastoral care is fully integrated into the treatment program at AdventHealth.

### OUR CHAPLAINS:

- Receive referrals from physicians and nurses
- Participate in interdisciplinary care conferences
- Enter their services into the medical record
- Provide support to patients, family and staff 24-hours-a-day, every day
- Provide a bridge to community clergy, as needed

At the core of pastoral care is our belief in a God who cares and wants to support us in our daily walk. As representatives of God, our chaplains stand ready to assist you in your walk. Just ask your nurse for assistance, or call the hospital operator and ask for the chaplain on call.



## Physical Rehabilitation

The physical rehabilitation (physical therapy) team will evaluate you at some point during your admission. They will discuss possible therapies, including physical, occupational, speech-language and/or recreational therapy. They can provide a realistic picture of what recovery will look like for you and your caregivers.

Following surgery, these specialists will help arrange for outpatient therapies to continue at home. In some instances, you may need to participate in an off-site inpatient rehabilitation program to help you gain strength and function in your motor, speech and/or functional abilities. A dedicated team of physical therapists, recreational therapists, occupational therapists, speech-language therapists, nurses, social workers and others will help you meet your goals. You will be part of a team meeting to create your care plan.



### ADVENTHEALTH SPORTS MEDICINE AND REHAB FACILITIES

#### **Altamonte Springs**

711 East Altamonte Drive  
Suite 200  
Altamonte Springs, FL 32701  
407-303-5465

#### **Apopka**

2100 Ocoee-Apopka Road  
Suite 030  
Apopka, FL 32703  
407-609-7207

#### **Celebration**

400 Celebration Place  
Suite C200  
Celebration, FL 34747  
407-303-4003

#### **East Orlando**

7975 Lake Underhill Road  
Suite 345  
Orlando, FL 32822  
407-303-8626

#### **Kissimmee**

2400 North Orange Blossom Trail  
Suite 201  
Kissimmee, FL 34744  
407-933-6684

#### **Lake Mary**

100 Waymont Court  
Suite 120  
Lake Mary, FL 32746  
407-323-0399

#### **Maitland**

8701 Maitland Summit Boulevard  
Orlando, FL 32810  
407-916-4500

#### **Dr. Phillips**

5018 Dr. Phillips Boulevard  
Orlando, FL 32819  
407-532-6815

#### **Orlando**

5165 Adanson Street  
Orlando, FL 32804  
407-303-7600

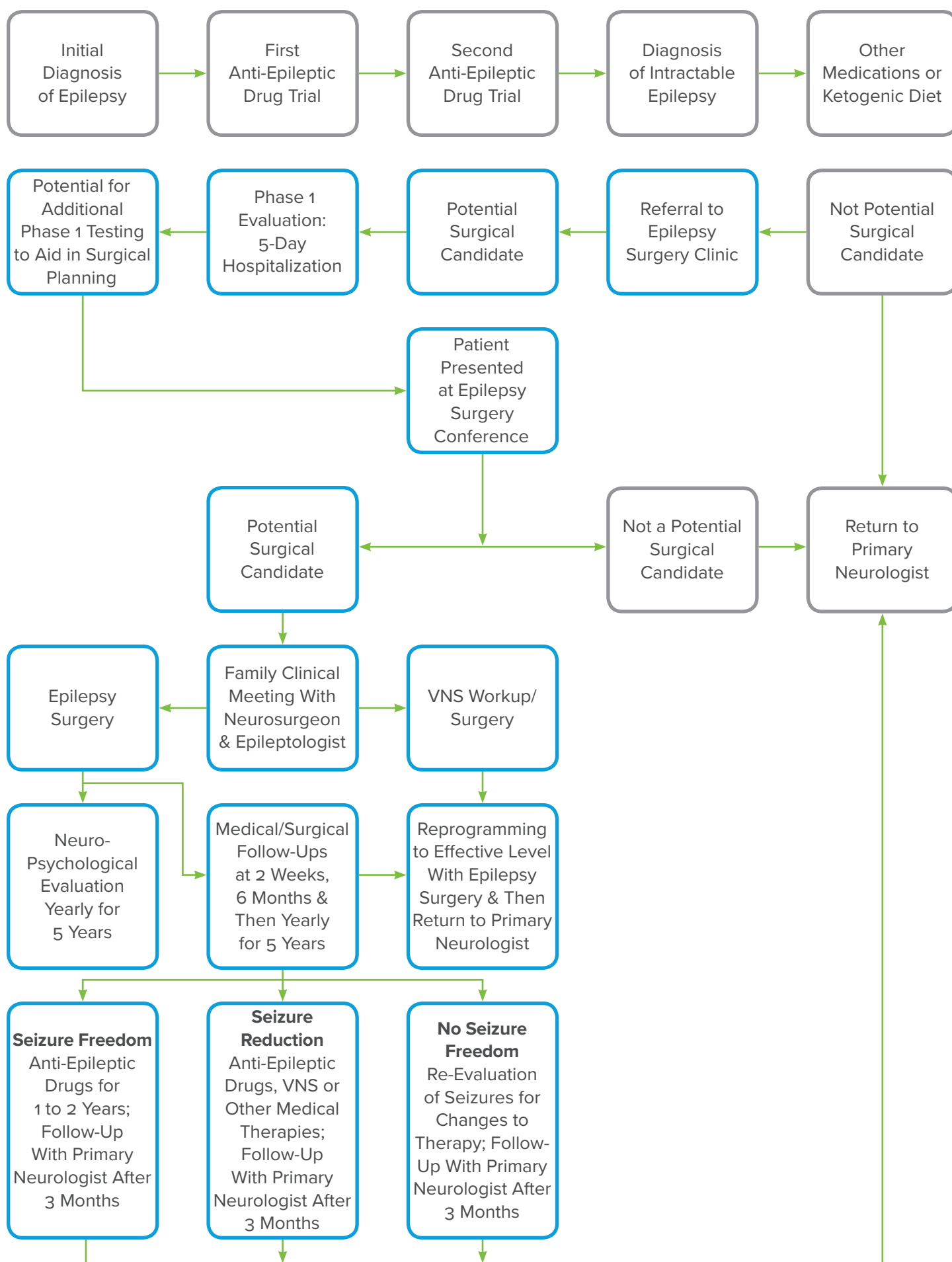
#### **Oviedo**

8000 Red Bug Lake Road  
Suite 140  
Oviedo, FL 32765  
407-359-5211

#### **Winter Park - Center for Health and Wellbeing**

2005 Mizell Avenue  
Winter Park, FL 32792  
407-646-7711

# A Patient's Journey to Epilepsy Surgery





## The First Step: Clinical Evaluation

### What will happen at the first office visit?

Prior to your clinical evaluation, a member of our nursing staff will get a detailed medical history. During the initial office visit, the epileptologist and/or nurse practitioners will ask you questions and examine you. We will:

- Compile a complete past medical, family and seizure history
- Review any testing you had done before, like EEGs, MRIs, genetic or metabolic testing

You may also meet some other members of the team, including our nurse and social worker. At the end of the visit, the team will talk with you about recommendations for testing and treatment.

### What if surgical evaluation is recommended?

If surgical evaluation is recommended, a five-day hospital stay will be scheduled in our Epilepsy Monitoring Unit (EMU). This admission is called a Phase One Evaluation. During this evaluation, you will have a series of tests. These tests will help the team:

- Identify the type(s) of seizures occurring
- Locate the seizure focus
- Find the cause of epilepsy
- Determine if surgery is a good option

Prior to the hospital stay, a member of the epilepsy team's nursing staff will call you to discuss your seizures and related AEDs. Depending on how frequent and severe your seizures are, the AEDs may be reduced or stopped altogether shortly before you come into the hospital. It is very important that you feel comfortable with any medication change suggested by the team. As soon as adequate seizures are captured during the monitoring, you will be restarted on your AEDs. If needed, you will also be given other anti-seizure medications to help prevent or stop seizures until your regular AEDs are working again.

## Phase One Evaluation: Neuropsychological Evaluation

Neuropsychological testing is ideally done during admission to the Epilepsy Monitoring Unit. Testing results are necessary before your case can be presented during an epilepsy surgery case conference. Testing is done by the epilepsy team's neuropsychologist(s) or the program technician.

**What to Expect:** A neuropsychological evaluation includes an interview about your history, observation and interview with you, and cognitive testing. Information is obtained through testing and questionnaires that you complete.

**Length of Evaluation:** The time required to complete testing depends on the patient's functional ability. Typically, it takes between three to six hours.

**How We Can Help:** We evaluate the patient's brain functioning by testing abilities such as IQ, language, visual-spatial skills, memory, problem-solving, motor skills and behavioral functioning. Understanding where the patient is functioning currently may help identify brain areas that are involved. The neuropsychologist will work with your physicians to combine results from medical tests, such as brain imaging or blood tests, to help diagnose the problem and help plan interventions. Test results will help you and potential therapists and doctors provide treatments and interventions for your unique needs.

Testing is done to obtain a baseline against which to measure the outcome of treatment (new medications and/or surgery). If you are determined to be an epilepsy surgical candidate, neuropsychological testing will be repeated at regular intervals to help monitor your progress.

The neuropsychologist will provide test results to you, your primary neurologist and our team. You will receive a copy of the report, as will your primary physicians and potential therapists.

**What to Bring:** If you have had a neuropsychological evaluation or academic testing in the past, please provide a copy of the results to our team. A copy of an Individualized Educational Plan (IEP), if appropriate, from recent years would also be helpful.





## Hospital Admission for Phase One Evaluation

### THE EPILEPSY MONITORING UNIT (EMU)

You will be admitted to the EMU for a varying period of time, dependent upon your individualized care plan. You will be in a private room.

### TESTING DURING THE PHASE ONE EVALUATION

You should expect to have any or all of the following procedures\* during your stay on the EMU:

### VIDEO ELECTROENCEPHALOGRAM (VIDEO EEG)



#### Purpose

A video EEG is a painless exam that records the electrical activity associated with seizures.

#### Description

- Our EEG technicians will place a set of electrodes on your scalp and then continuously monitor your wave patterns and seizures. They will work with the nurses and the epileptologist to capture seizures and regularly evaluate findings.
- A cap is placed over the electrodes after they are attached. The wires from the scalp electrodes make a rope that connects to a small backpack. Wires are also attached to the wall behind your bed. You can place the backpack on the bed or carry it around the room. The electrodes will not be disconnected unless you are leaving for testing. Please bring a zipper or button-up shirt to wear, so you can change.

- A small camera on the ceiling of your room allows us to record on video your behavior and movements during a seizure. Family members involved in your care should be aware that it is imperative they do not block this camera while you are having a seizure. Also, they should turn on the overhead light during a nighttime seizure and remove any blanket that may be covering you to allow our technicians and doctors to see clinical activity occurring during the seizure. The EEG technicians and epileptologists will review the recordings of wave patterns to see how your actions and behavior are related to the electrical activity seen on the EEG.
- The nurses and EEG technicians check the electrodes regularly to make sure none have come loose. If they do, the EEG technicians will replace the electrodes quickly so that the recording can continue.
- Nurses must be present when the patient is out of bed and within one arm's reach.
- The EEG technician removes the electrodes on the morning you go home. You can then wash your hair.

#### Length of Test

During your hospital stay, generally from Monday to Friday, the video EEG will take place in your room. You will be able to move about the room and go to the bathroom, but will not leave your room, except for scheduled tests.

#### Other Information

You may be sleep-deprived one or two nights during the hospital stay in order to capture clinical seizures. This may be especially valuable if fatigue or being overtired can bring on your seizures. With sleep deprivation, the epilepsy team will encourage you to stay awake during the day. Nursing staff and EEG technicians will work together to help you stay awake for the determined time period at night, if needed, to obtain seizure activity.

Medications may be held or even reduced during your stay. Other medications may also be held if they are felt to affect the EEG recording (examples include gabapentin and Fiorcet). This will make it more likely to have a seizure. There is a risk for larger or longer seizures since we will taper or hold your medications. Nurses will have a rescue medication to control seizures in case they become prolonged.

*\*Depending on insurance, some of the testing may need to be completed as an outpatient. We will work with you and your insurance company to provide the most efficient care for you.*

## 3T MAGNETIC RESONANCE IMAGING (MRI)



### Purpose

A MRI test scans for any irregularity in your brain structure that may help explain your seizures. It can be very helpful in locating area(s) of the brain that include the seizure focus or origin of your seizures. The MRI can also identify any evidence of tissue scarring, birth malformations, past infections, lesions or tumors.



### Description

A MRI scan is a painless test that uses large magnets, radio waves and a computer to make a detailed picture of structures inside the brain. The team typically uses a special MRI, called a 3T MRI, to increase detail and better define structures. A common comparison would be a high-definition television compared to a regular television.



### Length of Test

MRI testing will take approximately 60 minutes.



### Other Information

Because the MRI creates a strong magnetic field, please inform us if you have any health-related metal devices (pacemaker, vagal nerve stimulator (VNS), metal plates, oral or body braces). You will also need to remove any of your jewelry or other metal objects—such as barrettes, eyeglasses, dental pieces, hearing aids or body piercings—before the test.

During the MRI, it is important that you lie very still. The nurse may give you a sedative if you are unable to lie still on your own. This may be given intravenously (through a needle inserted in the arm) or orally (by mouth).

## SINGLE PHOTON EMISSION COMPUTED TOMOGRAPHY (SPECT)



### Purpose

Ictal/interictal SPECT scans can show areas of increased brain activity (seizures) related to increased blood flow to these area(s). These scans show a bright white or red flare, highlighting area(s) responsible for causing seizures.



### Description

This test is completed in two individual parts: the ictal scan and the interictal scan. These scans are combined to give one final image and result.

*Ictal SPECT is done while a seizure is occurring.*



### Preparation

You will need sedation, including holding food for several hours prior to the test. Occasionally, each part of the test may be done two days in row. This will be discussed ahead of time to determine what is best for you.

If there is something that triggers a seizure, our nursing/EEG staff can try to provide that stimuli during this test (i.e., flashing lights, sounds, physical activity or lack of sleep).

A nurse from the EMU will start an intravenous line in your arm prior to the test. A nuclear medicine technologist will sit bedside in your room during the entire test. You should expect minor to moderate discomfort while the IV is being inserted.

At the beginning of your seizure, the technologist will inject a radioisotope called technetium into your vein through the intravenous line. This radioisotope will not cause seizures. It will travel to the area of your brain that has the most blood flow. The area of increased blood flow is often related to the seizure focus area. After your seizure is controlled, you will have an ictal SPECT scan.



### Length of Test

The ictal SPECT test usually takes five to six hours to complete. Most of this time, you are in your room on the EMU, waiting for the seizure to occur. You can sleep or do quiet activities in bed. You will then be taken to another hospital floor for one of the SPECT scans (ictal or interictal), which will take less than 60 minutes to complete.

*Interictal SPECT is a baseline study done between seizures while in the hospital.*



### Preparation

You will be lying comfortably on a table with your head held in a headrest. There is no pain during the scanning. Between seizures, the radioisotope, technetium, is injected into your vein through the intravenous line. This procedure may be done during the week of testing after the Phase One evaluation.

If no seizure occurs during the testing time for the ictal SPECT, you will be sent to get the interictal SPECT scan. In this case, you may need to return to the hospital for another admission to attempt a second ictal SPECT. If this is necessary, our scheduler will help arrange this retest for you.



### Length of Test

The interictal SPECT scan typically lasts 30 to 40 minutes. You will be temporarily transferred to our post-anesthesia care unit (PACU) for recovery as this test requires anesthesia.

## POSITRON EMISSION TOMOGRAPHY (PET)



### Purpose

PET is a test that measures how the body uses blood sugar (glucose) within brain cells. Blood sugar acts like food for our brain. This test can help our epileptologist see chemical changes taking place in the brain and highlight areas in which seizures may be active.

### **Description**

You will have EEG leads attached to your scalp prior to the scan to monitor for seizure activity.

During the test, a nurse will place a small amount of sugary liquid into your vein through an intravenous line.

You may need medicine to help you lie still on the scanning table.

The PET scanner maps an image of the brain, showing where chemical activity (with the blood sugar) is taking place.

### **Length of Test**

The PET scan takes approximately one hour. You will need to stay totally still during this time.

### **Getting Results**

The PET scan will be reviewed by the epileptologist and a physician who specializes in reading PET scans.

Final results of the PET scan will not be available until all Phase One testing is completed. The data from the PET scan and all the other tests must be compiled and reviewed by the epileptologist and epilepsy team during the epilepsy surgery conference approximately two to three weeks after all tests have been completed.

## **MAGNETOENCEPHALOGRAPHY (MEG)**

### **Purpose**

MEG is one of the newest, non-invasive tests available for studying epilepsy and recording brain activity. MEG provides additional accurate and reliable information about the location of the brain's motor, sensory and language areas. It also can be very helpful in locating area(s) of seizure activity.

### **Description**

The MEG provides an accurate picture of brain activity by measuring small magnetic fields produced by small electrical currents starting inside the brain cells. These magnetic signals cause much less distortion than electrical signals, which can be affected by skull and tissue overlying the brain.

### **Length of Test**

It may take up to two hours.

### **Other Information**

For this test, it is important that you do not wear any metal objects, such as watches, necklaces or earrings. If possible, wear clothing that has no metal snaps or zippers.

If you have any health-related metal devices (pacemaker, VNS, metal plates, oral or body braces), please let a nurse know prior to or at the start of your hospital stay. In cases where metal cannot be removed, the MEG may not be an option.

The room where the MEG test is performed will be quiet. During the procedure, it is important that you lie very still. If you are unable to lie still on your own, you may be given a slight sedative.

At the beginning of the test, you will be drowsy or asleep. Later in the test, you will be awake and asked to perform tasks, such as reading from a book, looking at pictures or watching videos.

### **Getting Results**

The epileptologist will review the MEG recordings with the specialists who perform this test.

Final results of the MEG scan will not be available until all Phase One testing is completed. The data from the MEG scan and all the other tests must be compiled and reviewed by the epileptologist and epilepsy team during the epilepsy surgery conference approximately two to three weeks after all tests have been completed.

## **FUNCTIONAL MAGNETIC RESONANCE IMAGING (fMRI)**

### **Purpose**

The fMRI is an additional test that can be done as an outpatient after the Phase One evaluation hospital admission. A member of the epilepsy team will let you know if this test is needed to complete your evaluation.

If your seizure focus, from the results of the Phase One testing, indicates that it may be near your motor or sensory area, the fMRI may be an important test to consider. It can help determine if brain tissue, in the area of seizure focus, can be removed safely without affecting your ability to move your limbs, use language or obtain sensory input.

### **Description**

To do the fMRI, you will be asked to follow instructions, identify pictures and read, if you are able to do so.

### **Length of Test**

The test may take two to four hours, but it can vary, depending on how well you can answer questions and follow directions.

### **Getting Results**

The fMRI will be read by a trained radiologist who specializes in helping adults with intractable epilepsy.

Final results of the fMRI scan will not be available until all Phase One testing is completed. The data from the fMRI scan and all the other tests must be compiled and reviewed by the epileptologist and epilepsy team during the epilepsy surgery conference approximately two to three weeks after all tests have been completed.

## THE WADA TEST



### Purpose

The Wada test — also known as the intracarotid sodium amobarbital (ISAP) procedure — is used for similar purposes as the fMRI. This test is used to provide information regarding seizure focus proximity to key language or memory areas. It may be ordered when you cannot perform the fMRI.



### Description

Similar to the fMRI, the Wada test requires patients to be able to follow simple directions and read. It requires meeting with the interventional radiology team prior to administering the test. This appointment will also involve discussion of the Wada's risks and benefits.



### Length of Test

This test may take four or more hours. It can vary, depending on how well you can answer questions and follow directions. Some patients may need to stay for almost a full day for completion.



### Getting Results

The Wada test will be reviewed by a trained radiologist who specializes in interventional radiology.

Final results of the Wada test will not be available until all Phase One testing is completed. The data from the Wada and all the other tests must be compiled and reviewed by the epileptologist and epilepsy team during the epilepsy surgery conference approximately two to three weeks after all tests have been completed.

All of the Phase One tests are necessary for complete assessment of your seizures and very precise determination of the seizure focus. If the epilepsy team is unable to get the needed results on any of these tests, this may require your return to the EMU for an additional hospital stay or for outpatient testing. If you must return to the EMU, expect these hospitalizations to be between three and five days. We attempt to keep these return stays as brief as possible.

As research and technology progress in regards to epilepsy surgery, it may be found that only a few tests are needed to identify the seizure focus. At present, however, the redundancy from each of the tests as described is vital to accurately identify the seizure focus and to develop an exact, personalized plan for you.

## Laboratory Tests

Some patients may undergo blood testing for metabolic or genetic work-up to either exclude a diagnosis or find the underlying cause of the seizures. Oftentimes, the blood draw can be completed during the hospital stay or office visit.

## Epilepsy Surgery Conference

Once you have completed all of the necessary tests of the Phase One evaluation, the epilepsy surgery team will carefully and completely review the data collected. Within a few weeks after completing this extensive evaluation, your history and test results are presented at the epilepsy surgery conference. Approximately 20 to 25 medical professionals, including epileptologists, neurosurgeons, nurse practitioners, nurses, radiologists, neuropsychologists and social workers, gather at this conference to discuss patients with intractable epilepsy and your specific case. The goal of this conference is to provide you with the most accurate, specific and individualized plan for you.

You will receive a phone call from a member of the epilepsy team following the conference to schedule an appointment to obtain or to explain any additional testing needed prior to seeing the physician. Specifics of the testing, notification of the surgical candidacy or discussion of the results will not be discussed over the phone in order to minimize any chance of miscommunication or misunderstanding.

During this appointment, you and any family members will meet with members of the epilepsy team to discuss your:

- Complete Phase One evaluation results
- Recommendations from the epilepsy surgery conference
- Surgical procedure, details, risks and benefits

The epilepsy team and other specialists will have time during your meeting to address any questions or concerns you may have. You are encouraged to talk with the epilepsy team nurses, email them or set up an additional clinic appointment. We will be happy to answer your questions or discuss specifics regarding the surgical recommendations.



## Surgical Options and Evaluations: Explanation and Considerations

The following sections contain information about the different types of epilepsy surgery. If you are a surgical candidate, epilepsy surgery may involve a multi-step procedure or a one-step procedure. The physicians will explain details and rationale for a particular type of surgery. Due to the complex nature of the test results and plan, specifics will not be discussed prior to your clinic visit following the epilepsy surgery conference.

### Phase Two Evaluation: Multi-Step Epilepsy Surgical Procedures

A Phase Two evaluation may be suggested as your best surgical option for seizure freedom or reduction. Unlike Phase One evaluation, Phase Two evaluation does involve surgery. You may expect to be in the hospital for seven to 10 or more days. The neurosurgery team will be able to give you a more specific approximation.

#### **STEP ONE OF PHASE TWO EVALUATION: ELECTRODE GRID PLACEMENT**

The first part of a Phase Two evaluation involves a detailed surgical procedure in the operating room. The neurosurgeon and the epileptologist work together to place electrodes on the brain surface, close to where the seizure focus is suspected, based on the Phase One test results.

Invasive testing, during surgery, may be necessary to confirm the seizure focus and identify seizures prior to any surgical resection. Results from Phase Two testing will be compared with the results of those compiled from Phase One. You can expect the electrode grids that were placed on your brain during surgery to remain in place for several days or more. This helps to monitor electrical activity on your brain. Following the grid placement, you will go to the Intensive Care Unit (ICU). The epilepsy team will then start to monitor electrical activity received from the electrode grids. They will also monitor your clinical seizures to specifically define and confirm the area of the seizure focus.

The implanted electrodes will remain in place until they are surgically removed during a second surgery, as described below. The goal of the second surgery is to remove the electrode grids and to remove your seizure focus. You will not go home with the electrode grids in place. Depending on the frequency of your seizures, while waiting to capture several seizures, the electrodes may be in place for a few days to a few weeks before you will return to the operating room to have them removed.

## Hospital Stay Following Step One

- You will be in the ICU to be monitored closely by the medical teams.
- Following your stay in the ICU, you may be moved to the EMU for the next few days. Your seizure activity will be closely monitored by the EEG technicians, nurses and epileptologists.
- Following grid placement, cortical mapping may be performed. This will help the team relate seizure location to your key motor, speech or sensory areas. This will take place in your room.
- From seizure and mapping data, a very accurate and individualized surgical plan can be constructed. Once this is created, you will have a conference with the epileptologist and neurosurgeon to review the plan. You will have the final decision regarding surgical resection for your epilepsy.

## STEP TWO OF PHASE TWO EVALUATION: RESECTIVE SURGERY

### Resective Surgical Treatment Following Electrode Grid Placement and VEEG Monitoring

Surgical removal of the seizure focus is the final surgery of a Phase Two evaluation. This surgery involves the surgical treatment for your intractable epilepsy, with the goal of removing brain tissue housing the seizure focus. From the video EEG monitoring of seizures and any mapping needed, the surgical margins for recommended brain tissue removal will have been identified.

During the second surgery, the electrode strips or grids will be carefully removed, and the neurosurgeon will resect the brain cortex that is causing the seizures. This tissue being removed is not functioning normally and has been causing the seizures.

Resective surgery can last five to seven hours, similar to the length of the first surgery. Families will get several progress reports during this time from the surgery team in the operating room.

### Stereotactic EEG (sEEG)

Stereotactic EEG (sEEG) is another tool for intracranial EEG monitoring. It may be utilized in place of the traditional open method for electrode placement or as an extra step prior to this method. This option may be offered if you have intractable focal epilepsy but the location of seizure onset is uncertain—either the side of seizure onset cannot be identified or the location of seizure onset within a hemisphere cannot be identified.

Similar to step one of Phase Two, the neurosurgeon and the epileptologist work together to place thin electrodes into the seizure area using ROSA™ (Robot Surgical Assistant). ROSA acts as a GPS for the doctors to use during surgery. Utilizing data from the testing during Phase One, a detailed plan is made tailored to your case for ROSA to follow.

Guided by ROSA, the neurosurgeon will make 10 to 20 small burr holes in the scalp. Each electrode is passed through a separate hole in the bone and deep into the brain tissue. Much like grid placement, the epilepsy team can monitor electrical activity received from the electrodes.



The length of time from electrode placement to the next surgery is typically five to seven days, the same as if you had an open craniotomy. You will go back to the operating room for electrode removal after seizures have been captured. However, unlike the traditional open electrode placement where the resection surgery is done at the same time as electrode removal, you may not have a procedure done for seizure control at this time. If there is no need to gather additional data prior to your final surgery, laser ablation or a resection surgery can be performed in most cases at the time of electrode removal.

If additional seizure monitoring is required through placement of electrodes along the brain surface (and possibly deep to the brain surface as well), there will be around a four-week rest period between sEEG and the traditional open surgery to minimize the risk of complications and to allow for the doctors to plan for the next phase of your seizure evaluation.

### **Hospital Stay Following Step Two**

- You will be in the ICU for at least 24 hours after surgery to be monitored closely by the medical teams.
- You will then be moved to the Step-down Unit and will spend several days on this unit prior to going home.
- You will continue to be monitored for pain, return of appetite and activity, seizures and infection.
- The sterile head dressing will be removed by the neurosurgery team one to three days after surgery.
- Additional services may be involved in your care while on the Step-down Unit. These services may include nutrition, occupational therapy, physical therapy, speech therapy and rehabilitative medicine. Some of these therapies may require additional time in the hospital.

### **NeuroPace RNS® System**

The RNS System is a proven treatment option for adults who have disabling seizures that are not controlled by medication. Unlike most epilepsy treatments that deliver therapy continuously, this smart device responds only when seizure activity is detected. The system offers an ideal alternative for patients who are not surgical candidates.

The RNS System is for individuals 18 and older who have tried at least two anti-seizure medications, but still suffer from frequent and disabling partial-onset seizures that come from one or two areas of the brain. Your doctor can help you determine if the RNS System is right for you.



## One-Step Epilepsy Surgery Procedures

One-step epilepsy surgeries are different from the Phase Two evaluation surgeries previously outlined. These procedures may be recommended as your best option for seizure control and reduction, as determined by your medical history and Phase One evaluation. Common one-step surgical procedures for seizure control include:

- Corpus callosotomy
- Functional hemispherotomy
- Vagal nerve stimulator (VNS)

### CORPUS CALLOSOTOMY

A corpus callosotomy is a surgical procedure that may be warranted if your seizures are disabling, if they cause dangerous and frequent falls, or if they begin on one side of the brain and spread quickly to the other side. This procedure involves disconnection of nerve fibers along the brain structure between the right and left hemispheres, interrupting the spread of seizures. This surgery typically doesn't result in full seizure freedom, but a reduction of seizures. It takes approximately four to five hours.

You will be in the ICU for approximately 24 hours after surgery, so that the medical teams can closely monitor your progress and offer medical support. The neurosurgery team and the ICU team will create a treatment plan to assist with problem prevention, pain, nausea or vomiting and fluid intake/output.

### LASER ABLATION

Laser ablation is a surgical option for select adults with intractable epilepsy. Candidates are patients with abnormal brain tissue focus that is relatively small and generates seizures. These include patients with mesial temporal sclerosis (MTS) or deep brain tumors.

The small size of the laser allows the neurosurgeon to ablate seizure-producing tissue while leaving the healthy surrounding tissue untouched. Using MRI guidance and stereotactic navigation, a 2mm probe is passed through a small hole in the skull (burr hole) to the area causing the seizures. Once the probe reaches the target area and is confirmed to be in the correct location via MRI, the laser is turned on to 130 degrees Fahrenheit, and ablates (destroys) the affected area.

You will be in the ICU for 24 to 48 hours after surgery so the medical team can closely monitor your progress and offer medical support. Hospital stays are minimized to a couple of days with minimal scarring and hair removal.

### FUNCTIONAL HEMISPHEROTOMY

Adults with severe, intractable epilepsy due to more widespread brain abnormalities may be candidates for functional hemispherotomy. In functional hemispherotomy, all connections between the left and right brain will be disconnected surgically. Seizures, as a result, cannot generalize or spread to the other hemisphere. Surgical disconnection of the abnormal hemisphere causing seizures can have up to a 75 percent chance of stopping seizures. An additional 20 percent of patients will have improvement in lessening seizure frequency or severity. Quality of life may significantly improve for you and your family. This surgical procedure can last six to eight hours.

You will be in the ICU for approximately 24 hours after surgery, so that the medical teams can closely monitor your progress and offer medical support. The neurosurgery team and the ICU team will create a treatment plan to assist with problem prevention, pain, nausea or vomiting and fluid intake/output.

Adults who have this procedure will lose significant function in one arm and leg following surgery, unless they have an existing weakness. Additionally, they will have some loss of peripheral vision in each eye, but no loss of central vision. Because of these unique considerations for families, the epilepsy team will recommend that families consult with several specialists to assist you in your decision-making process concerning epilepsy surgery.



## Physical Rehabilitation

The rehabilitation staff can talk to you about efforts that can be taken following a functional hemispherotomy to help you regain strength and function to your greatest potential. They will discuss possible therapies, including physical therapy, occupational therapy, speech-language therapy and recreational therapy. They can give you a realistic picture of what the loss of function will mean for you and your family. Following surgery, these specialists can help you arrange outpatient therapies that would continue at home. In some instances, you may need to participate in an off-site, inpatient rehabilitation program. It may be needed to help you gain strength and function in your motor, speech and/or functional abilities. A dedicated team of physical therapists, recreational therapists, occupational therapists, nurses, social workers and others will help you meet your goals. You will be part of a team meeting to create your care plan.

## Ophthalmology

These specialists can help to determine if you have had any loss in peripheral field vision prior to surgery. This may occur in adults who have had significant seizures near the part of the brain that controls vision. These specialists can also provide data about loss of peripheral vision related to the procedure. Ophthalmology would then follow you regularly after surgery.

## Ethics

Experts from this group can join you during the conference with the epilepsy surgery and neurosurgery teams. They will provide unbiased help to clarify issues and determine the pros and cons of having a functional hemispherotomy.

## Psychology

Having you talk with a counselor may be beneficial to express your feelings and concerns.

## VAGAL NERVE STIMULATOR (VNS)

Placement of a VNS in the front of your left chest may be a surgical option when resective surgery is not an option for partial or generalized seizures. The VNS is a small electronic device, much like a heart pacemaker. When surgically placed in the left chest and connected to the vagal nerve in the left side of the neck, it will send electrical impulses to the brain to help prevent seizures. The device can be programmed to send the right amount and timing of electrical current to help control your seizures. Placement of the VNS is done in a few hours in the operating room.

## Returning Home

The epilepsy team will discuss care of the scalp incision, general pain and activity concerns or restrictions, epilepsy medications, follow-up care and anticipated school/work return during this time. Before discharge, you will receive specific written information and prescriptions for any changes in seizure medications. You will also schedule a post-operative visit with the epilepsy surgery team before leaving the hospital. At this visit you and your family will typically see the neurosurgeon, epileptologist and/or a nurse practitioner.

You may have many questions for the epilepsy team prior to your discharge home. Be assured that the epilepsy, neurosurgery and rehabilitative medicine teams will be available to help you get the answers you need. We will also be available post-surgery and at follow-up visits.

## TYPICAL SCHEDULE OF RETURN VISITS AFTER SURGERY:

Scheduled Visit After Surgery	Description of Visit
Two weeks	<ul style="list-style-type: none"><li>Neurosurgeon and epileptologist will see you</li></ul>
Six months	<ul style="list-style-type: none"><li>Epileptologist</li><li>You will gradually transition back to your primary neurologist, based on your needs</li></ul>
Yearly (for five years)	<ul style="list-style-type: none"><li>Epileptologist and neuropsychological testing to evaluate progress made since surgery</li></ul>



## Frequently Asked Questions: Epilepsy Monitoring Unit and Epilepsy Surgery

### Stay on the EMU

#### WHAT SHOULD I BRING TO THE EMU?

- All of your medications: Please bring along all of your prescriptions and non-prescription medications in their original containers for nursing staff's review.
- Button-down tops and comfortable clothes without zippers or snaps
- Slippers
- Bandana or hat for going home
- DVDs, CDs, music and books
- Blanket and pillow from home
- Computer or electronics
- Money for snacks and vending machines
- A sweater, jacket or extra blanket, in case the room feels cool

#### WHAT IS MY ROOM LIKE ON THE EMU?

- Private room
- In-room thermostat control
- Television
- Internet access
- Small storage space for personal belongings

#### WHAT HAPPENS FOR MEALS AND SNACKS?

- Food, snacks and drinks are provided for the patient via menu ordering.
- Food trays can be requested during your stay. One family member is allowed to have a guest tray brought to the room for three meals on the EMU.
- Visitors can go to the cafeteria for meals.
- Visitors can use hospital vending machines.
- If you are NPO (cannot eat or drink) for testing, you will not be allowed to have food or drink in the room.

## WHAT HAPPENS WHEN I HAVE A SEIZURE IN THE EMU?

- Nursing and EEG technologists will work together to identify your seizure from video monitoring and/or your input from observations.
- Padding on bed rails, use of oxygen and turning you on your side will also help.
- Another team member (i.e., physicians) and medications will be available, if warranted.
- Physicians will review the VEEG to delineate seizure activity on the EEG, compared with what was captured on the video in the room.
- We want you to be aware that your seizures may present differently in the EMU compared to at home, especially when you are off your medication.

## WHAT HAPPENS WITH PHASE ONE TESTING DURING THE WEEK?

- Some patients may need sedation or general anesthesia for certain tests. If you need this, you may not be able to eat for several hours prior to the test.
- Individual tests will be discussed with you prior to each day. There will not be more than one major test per day.

## Following Phase One Evaluation

### WHAT HAPPENS TO MY MEDICATION AFTER DISCHARGE POST-PHASE ONE EVALUATION?

- If you had to stop or reduce your medication during hospitalization, the medication and regular dose schedule will start as soon as possible once testing is complete.
- Decisions may be made, during the hospital stay, to change your seizure medication in anticipation of surgery or in an effort to improve your seizure control. Your primary neurologist will be made aware of any changes in medication, as well as results from hospitalization.

### CAN I RETURN TO SCHOOL OR WORK UPON RETURNING HOME?

- We encourage you to do what is best for you. Since you will likely have a weekend ahead after discharge, we recommend a low-key weekend for your family. Most patients will be able to return to their normal routine the following week.
- Some patients may be tired for a few days upon returning home, especially if they have missed some sleep with testing.
- Please let us know if you have any questions or need any doctor's notes for work or school.

## WHEN DO WE LEARN OF RESULTS FROM PHASE ONE EVALUATION AFTER THE HOSPITALIZATIONS?

- Following hospitalization, your test results will be carefully reviewed by the epilepsy team.
- Results will then be compiled for presentation at an interdisciplinary epilepsy surgery conference, where your history and test results will be presented and individualized recommendations will be developed.
- An appointment will be scheduled for you to return to our center to review and discuss the results and plan for treatment of your epilepsy. Usually this meeting occurs within a few weeks after you complete the Phase One evaluation.

## WHAT HAPPENS IF TESTING WAS INCOMPLETE DURING THE HOSPITAL STAY?

- If a test was not completed, for any reason, you will be asked to return to the hospital for re-testing. All Phase One testing, including neuropsychological testing, needs to be completed before your case can be presented at the epilepsy surgery conference.
- Repeat tests can sometimes be done on an outpatient basis (i.e., PET scan, MRI, fMRI or interictal SPECT scan). Some tests will require a short hospital stay (two to four days, i.e., ictal SPECT scan).
- If you come from out of state, every effort will be made to minimize inconvenience to you and your family.

## HOW DOES RESPONSIVE NEUROSTIMULATION (RNS) WORK?

Placement of a RNS® device involves the implantation of a small neurostimulator connected to leads (tiny wires) that are placed in one or two seizure onset areas. During placement, the surgeon positions the leads at the seizure zone and places the neurostimulator in your skull under your scalp. The device will be unnoticeable by eye or touch. Most patients will spend one night in the ICU and go home the next day. While the device is turned on in the operating room, it will only record for the first few months, depending on your seizure frequency. Once the doctor has seen enough of the EEG recordings, you will go to the clinic for it to be programmed to detect seizures and deliver stimulation. You should never feel the stimulation.

# Coping as a Family with Upcoming Epilepsy Surgery

While families have coped through various stages of the patient's journey with seizures, epilepsy surgery serves as a crucial milestone for the patient and family. For patients, spouses, parents and siblings alike, surgery can present as a new and unique challenge.

## Preparing as Parents or Caregivers

### KNOWLEDGE IS POWER.

Do not be afraid to ask questions of the epilepsy team at any time in the process. You can also seek reliable resources, such as research articles, books and accredited online sites. The National Epilepsy Foundation offers information and resources at [EpilepsyFoundation.org](http://EpilepsyFoundation.org).

### SEEK SUPPORT.

Whether you are in the decision-making process or holding your loved one's hand in the hospital, you can best help when you have ample support for yourself. Ask for and rely on the assistance and encouragement of family, friends, co-workers and neighbors. The Epilepsy Surgery Program also has a Patient-to-Patient Network to connect families who have experienced a similar surgical treatment journey. Professional counseling can also be very helpful for those needing extra support coping with their own or a loved one's condition. The epilepsy surgery social worker is available to help with any referrals.

### HAVE A PLAN.

Making arrangements prior to hospitalization will relieve any additional stress, so that you can remain focused on the journey ahead. Try to plan ahead for issues like child care, visitor schedules, lodging and employment leaves. If assistance is needed, our epilepsy team is happy to help however possible.

### COPING TOOLS CAN MAKE A DIFFERENCE.

Everyone has activities that help them during challenging or stressful times. For some, it is reading novels; for others, it is knitting or taking walks. Make a list of your coping skills and plan to bring some of your coping tools to the hospital. Maybe you have an item like a blanket from home that brings you reassurance. Just like a child benefits from his or her teddy bear, you need your own comfort items.



## Searching for a Cause: Surgical Biopsies and Cortical Dysplasia

Intractable seizures frequently have a poorly defined or unknown cause. Some adults, as a result of encephalitis, tuberous sclerosis, stroke, brain tumor, or severe head injury, may have an area of the brain that is more susceptible to seizures. In such cases, these specific health problems may have contributed to the development of intractable seizures. These seizures may be treated with medication and/or surgery.

For many other adults, however, the cause of their intractable seizures is not apparent from an injury or specific health problem. In these cases, the neurosurgeon may be able to take brain biopsies during your one- or two-step epilepsy surgeries. The small sample of brain tissue is then evaluated by a pathologist to identify a possible cause of intractable seizures. A disorder, commonly found in patients who have hard-to-treat seizures, is called cortical dysplasia. This dysplasia can be identified from the biopsied tissue.

Cortical dysplasia is a disorder of cellular migration. This malformation occurs, for unknown reasons, during the first three months of pregnancy. There is no correlation between cortical dysplasia and how a mom cared for herself and the baby during this first trimester of pregnancy.

What we do know is that the neurons, or brain cells, typically migrate to the gray matter in the developing brain in an orderly fashion and line up in one of six specific layers in the brain tissue. For some unknown reason, in cortical dysplasia, neurons go to the wrong layer in the brain or do not line up in an organized fashion. It is as though these neurons missed their marching orders. Sometimes, these neurons also have different shapes from the other normal brain cells. Pathologists can see these changes under the microscope.

Cortical dysplasia can occur in very small parts of the brain or involve a more widespread area. If it involves an entire hemisphere, it is called hemimegacephaly.

Symptoms that lead toward a diagnosis of cortical dysplasia include recurrent intractable seizures in childhood. Not all areas of cortical dysplasia cause seizures, but intractable seizure focus is commonly in an area of cortical dysplasia.

Suggestion of cortical dysplasia may be found with diagnostic tools like a high-definition 3T MRI. True confirmation of this disorder, however, can only be done through tissue biopsy, which can be collected during a one- or two-step epilepsy surgery. Our pathologists review the tissue and discuss their findings with the epilepsy team. Results will then be shared with you at one of your follow-up clinic visits.



# Epilepsy Resources

## Local Epilepsy Resources

### **Epilepsy Association, Inc.**

109 North Kirkman Road  
Orlando, FL 32811  
407-422-1416, ext. 101  
EpilepsyAssociation.com

## National Epilepsy Resources

### **Epilepsy Foundation**

8301 Professional Place  
Landover, MD 20785  
301-459-3700  
800-332-1000 toll free  
EpilepsyFoundation.org

### **Citizens United for Research in Epilepsy (CURE)**

730 North Franklin Street,  
Suite 404  
Chicago, IL 60654  
312-255-1801  
CUREEpilepsy.org

### **Epilepsy Institute**

257 Park Avenue South  
New York, NY 10010  
212-677-8550  
EpilepsyInstitute.org

### **People against Childhood Epilepsy (PACE)**

7 East 85th Street  
Suite A3  
New York, NY 10028  
212-665-7223  
PACEUSA.org

### **Charlie Foundation to Help Cure Pediatric Epilepsy (Ketogenic Diet Information)**

1223 Wilshire Boulevard  
Suite 815  
Santa Monica, CA 90403  
310-393-2347  
CharlieFoundation.org

### **American Epilepsy Society**

342 North Main Street  
West Hartford, CT 06117  
860-586-7505  
AESNet.org

## Websites

### **Epilepsy.com**

Offers a comprehensive overview of epilepsy and a special section for children, teens and families.

### **Epilepsy-Navigator.com**

This comprehensive site has many links and resources, as well as interesting facts about the brain. It includes a great section for children and teens with fun learning links.

### **Coping-With-Epilepsy.com**

Offers medical news updates, forums and message boards for patients and families.

### **HealingWell.com/Epilepsy**

This site offers resources, medical updates and forums for anyone coping with epilepsy.

### **EpilepsyClassroom.com**

Created for teachers to implement epilepsy into their classrooms with lesson plans and helpful tips. Site has a section for parents.

### **EpilepsyAdvocate.com**

This site includes updated information about the disease with an e-community support component.

### **Epilepsymoms.com**

This site provides podcasts, blogs and chat forums for parents coping with their child's epilepsy diagnosis.

### **SeizureTracker.com**

This site has downloadable logs and spreadsheets to help track seizure activity and medications. It also provides links to various epilepsy resources.

*Please note that information on these websites does not necessarily reflect your epilepsy team's recommendations. Always consult with your epilepsy team about medical treatments, medications and other surgical options first.*

## Patient-to-Patient Network

**Who?** The Patient-to-Patient Network is designed for families of epilepsy surgical candidates and for families of post-surgical patients.

**What?** Shared communication via telephone, email or in person for support through the surgical process and beyond.

**When?** A time convenient for both sets of patients/families and scheduled by the patients/families involved.

**Where?** It is not necessary for patients to meet in person. Phone and email communication are usually preferred. However, if patients decide to meet, a public location is encouraged for optimal safety.

**Why?** While talking with the medical team can provide many answers, there is no substitute for talking with someone who has journeyed through the same process with their loved one.

**How?** If a patient/family is interested in talking with someone whose loved one has had a similar surgery, the epilepsy surgery nurse coordinator can connect you with another patient/family. Ask for an authorization form to connect with a family soon.

### GOALS

- To provide a forum for people who share a common experience to exchange ideas, hope and support while managing their loved one's health condition.
- To increase one's ability to cope with challenges by providing:
  - A positive climate for sharing knowledge, feelings and encouragement
  - An opportunity for problem solving
- By talking with someone who shares a similar experience, we increase our personal awareness about:
  - The non-medical aspects of living with a person with a new medical condition
  - Resources in the community

### MATCHING

Once a request is made, we will attempt to match a family with similar experiences. Matching may take time and is dependent on availability.

### GUIDELINES

- Share only what you feel comfortable revealing. One may choose to share concerns, feelings, experiences, strengths, wisdom or simply what has worked for them.
- What is shared is confidential and should not be discussed with anyone without permission of the disclosing party.
- Discussions are designed to foster support and are directed toward hope and solutions. They are not for the purpose of discussing medical treatment.
- Participants should avoid discussing medical issues because everyone's treatment is different. If participants have questions regarding medical treatment, the participant should contact his/her loved one's health care provider.
- Strive for a caring atmosphere and leave prescribing and diagnosing to the professionals.
- Avoid judgment and criticism.
- Remember, the support family has been there but are not health care professionals.



- Everyone's experience is unique; therefore, not all information shared will be applicable to you. Simply use what interests you and disregard what does not.
- Show courtesy by actively listening when someone is talking. Try not to interrupt.
- Avoid generalities by using "I" statements, such as "I had a similar situation and tried..."
- Remember that we cannot solve all problems; providing support is the goal. Make every effort to leave others' problems with them and not take them home with you.
- Ask for help if impacted or stressed by supporting a parent. If you have any concerns, contact your social worker.
- Phone contact will probably work best, considering families' caregiving commitments.
- If you plan to meet in person, meetings should be in a public place to ensure your safety.
- The AdventHealth Neuroscience Institute is grateful for the families participating in this program, and although we get to know many families through treatment of their loved ones, we certainly do not fully know their backgrounds or their personalities. We hope that all families will, at all times, act appropriately when participating in this program. However, we are not responsible for any unacceptable behavior or any injury that may result from any parent, patient or other family member participating in this program.

**If you are interested in participating in the Patient-to-Patient Network, please call Josephine Schweitzer, MSW, Program Social Worker at 407- 303-8127.**





# Glossary of Terms

## Non-Surgical Terms

**Absence seizure:** A generalized seizure that occurs without warning and includes brief periods of staring for less than 20 seconds. May be accompanied by rapid eye blinking or movements of the mouth.

**Anticonvulsant:** Medication that prevents or stops seizures

**Apnea:** Cessation of breathing.

**Aura:** A sensation you may have before a seizure

**Breakthrough seizures:** Seizures that occur despite drug therapy; they typically follow a honeymoon period.

**Chronic:** Affecting a person for a long period of time

**Clonic:** Seizure involving muscle contractions and relaxations

**Drop seizures:** With brief, but dramatic, disruption of normal brain signals that control posture, these patients slump to the ground, fall forward or drop to the ground. Drop attacks are caused by myoclonic, tonic or atonic seizures and may result in falls and significant injuries.

**Eloquent cortex:** Referring to the language, motor and speech areas of the brain that the team needs to spare with any surgical consideration

**Clusters of seizures:** Repeated seizures occurring over a short period of time, following periods of no seizure activity

**Complex partial seizure:** A staring episode during which a person is unable to respond to questions or commands. These seizures usually last from 30 seconds to two minutes. When the seizure is over, the patient may have confusion and may have no memory of what happened during the seizure.

**Cortex:** The thin outer layer of the brain that controls movement and senses

**Cortisectomy:** Surgical removal of tissue in the cerebral cortex

**Family Medical Leave Act (FMLA):** Provides certain employees with up to 12 weeks of unpaid, job-protected leave per year. It also requires that their group health care benefits be maintained during the leave. FMLA is designed to help employees balance their work and family responsibilities by allowing them to take reasonable unpaid leave for certain family and medical reasons, such as caring for an immediate family member (spouse, child or parent) with a serious health condition.

**Febrile seizure:** An epileptic seizure that involves one side of the brain

**Generalized seizure:** A seizure that affects both sides of the brain and includes a brief loss of consciousness

**Honeymoon period:** This is a period of seizure freedom, usually following the start of a new antiseizure medication or combination of medications. It can be a few days to a few years in length.

**Ictal:** Referring to the period during a seizure

**Idiopathic:** Of unknown start or cause

**Inter-ictal:** The period between one seizure ending and another seizure starting

**Involuntary muscle movement:** Contractions of muscles without full control

**Ketogenic diet:** A strict, high-fat, low-carbohydrate diet that can aid in the control of seizures

**Lateralization:** Identifying the seizure focus as centering in the right side of the brain (right hemisphere) or in the left side of the brain (left hemisphere)

**Localization:** Pinpointing very precisely that the seizure focus is a specific part of the brain within one hemisphere, such as the temporal lobe

**Post-ictal confusion:** Temporary confusion, inability to respond to contact or to the surrounding environment after a seizure

**Rasmussen's encephalitis:** This is a rare, chronically inflammatory disease that presents most often in children under 10 years of age. Seizures typically increase in frequency and severity over a period of eight to 12 months. They do not respond well to anti-seizure medications, and thus, the seizures are medically intractable. A child may also experience loss of speech, ability to move his/her arms/legs or experience mental deterioration. Rasmussen's typically involves usually one hemisphere of the brain, but it can spread to the other hemisphere. The cause of Rasmussen's encephalitis is unknown. It may be an autoimmune disease in which immune system cells enter the brain and cause inflammation, seizures and damage. A child's history of seizures, deficits on his/her physical exam, response to antiseizure medications and tissue biopsy may be used to determine this diagnosis.

**Sedation:** Use of medication to reduce your anxiety and/or irritability before a medical or diagnostic procedure. It will lessen consciousness. These medications are commonly given by mouth, through an intravenous (IV) line or inhaled as a gas.

**Seizure:** An abnormal electrical discharge in the brain

**Simple partial seizure:** Seizure activity in one part of the brain resulting in tingling, jerking or weakness of one or more body parts. The patient is alert, can respond to commands or questions and remembers what happened during the seizure.

**Status epilepticus:** Severe, non-stop seizures lasting longer than five minutes

**Techneium:** Tc-99m is a silvery gray, radioactive metal found in small amounts in our soils, food and water and is used for nuclear medicine testing. In epilepsy surgery, it is used for the ictal SPECT test. Once in the body, it concentrates in the thyroid gland and gastrointestinal tract. Half of it is excreted in 60 hours, with almost all of it gone within a month. There is a risk of cancer with exposure to any radioactivity.

**Tonic-clonic (grand mal) seizure:** Seizures that cause you to stiffen, lose consciousness and fall. This is followed by a period of jerking of the arms and legs, usually lasting one to three minutes, but at times longer. After the seizure, you may be tired and confused and may fall asleep.

## Surgical Terms

**Amygdalo-hippocampectomy:** Removal of the mesial brain structures, which generally accompanies the temporal lobectomy procedure

**Anesthesia:** Medication used to block sensations, creating loss of responsiveness and awareness, in order to decrease the pain or distress associated with a surgical or medical procedure. One or more medications may be used. These medications are usually given via an intravenous (IV) line or inhaled as a gas.

**Corticectomy:** Removal of an area of the cerebral cortex; may be frontal, temporal, parietal or occipital

**Craniotomy:** An opening in the skull that is made to place the electrodes and to remove the seizure focus

**Lesionectomy:** Removal of an anatomic abnormality of the brain, such as a tumor, vascular malformation or scarring related to a stroke that is causing seizures

**Lobectomy:** Removal of a whole or partial section of the brain (lobectomy versus partial lobectomy); may be frontal, temporal, parietal or occipital and related to the focus of the seizures

**Stereotactic methods:** The use of image-guided MRI technology in the operating room that assists the surgical team to identify specific brain structures

**Subdural strip and grid electrodes:** Array of electrodes of different shapes and sizes that are placed on the surface of the brain to collect information via EEG monitoring and identify seizure areas in the brain

**Vagal nerve stimulator:** Surgical placement of a device around the vagus nerve in the neck that helps to control seizures



# Our Health Equity Promise

## Patient Protection and Affordable Care Act: Section 1557

AdventHealth complies with applicable federal civil rights laws and does not discriminate on the basis of race, color, national origin, age, disability or sex. This facility does not exclude people or treat them differently because of race, color, national origin, age, disability or sex.

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- Written information in other formats (large print, audio, accessible electronic formats, other formats)

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### If you need these services, please call 407-303-5600 x1106707

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You can also file a civil rights complaint with the U.S. Department of Health and Human Services, Office for Civil Rights, electronically, through the Office for Civil Rights Complaint Portal, available at [ocrportal.hhs.gov/ocr/portal/lobby.jsf](http://ocrportal.hhs.gov/ocr/portal/lobby.jsf), or by mail or phone at:

### U.S. Department of Health and Human Services

200 Independence Avenue, SW

Room 509F, HHH Building Washington, D.C. 20201

1-800-368-1019, 800-537-7697 (TDD)

Complaint forms are available at [hhs.gov/ocr/office/file/index.html](http://hhs.gov/ocr/office/file/index.html).

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