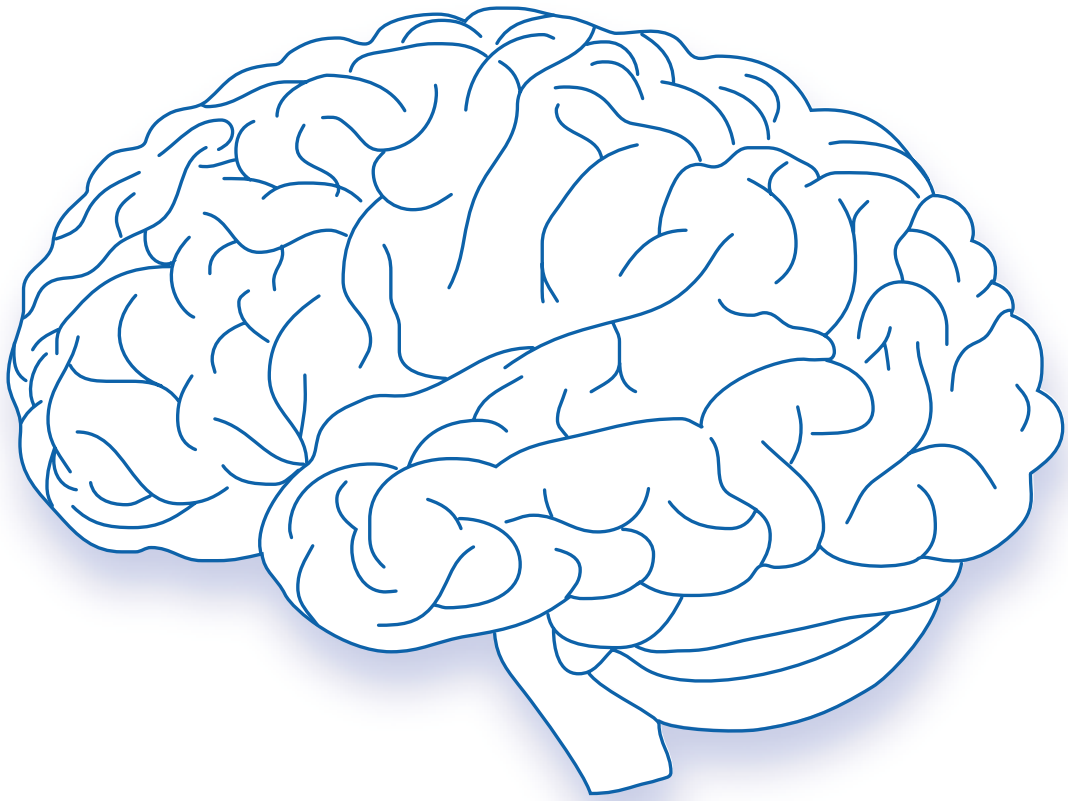
SHANDS

Neurological Center

at the University of Florida



Understanding Seizures and the Treatment Options

A Guide For You And Your Family

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Introduction

The University of Florida Comprehensive Epilepsy Program at Shands Neurological Center at UF offers a multidisciplinary approach to the diagnosis and treatment of patients with intractable epilepsy. A team of UF physicians, psychologists, and research scientists as well as Shands at UF neuroscience nurses, EEG technologists, and social workers staff the program. These professionals specialize in the treatment of patients with epilepsy who have not experienced significant relief with the use of standard medications. The program also offers a wide range of diagnostic and treatment services planned to meet the individual needs of each epilepsy patient.

Patient education is an important part of the program. This booklet will help you and your family learn about the UF Comprehensive Epilepsy Program at the Shands Neurological Center. An educational videotape also is available for patients who may be candidates for epilepsy surgery.

What is a Seizure?

A seizure is a temporary loss of awareness of, and/or control over, certain body functions. It happens as a result of abnormal electrical discharges in the brain. A seizure may cause a sudden change in alertness, behavior, muscular movements, or feeling in the body. Twenty-five million Americans (one in every 10) have had, or will have, a seizure at some point in their lives. Although seizures can develop at any time, they most commonly begin before the age of 25. Twenty percent of all seizures occur in children from age 5 and under.

Although scientists have not determined the exact cause of all seizures, some seizures can be related to brain injuries, infections, birth defects, brain tumors, or circulation disorders such as strokes. Some seizures may have a mild warning sign called an "aura." Examples of auras include a bad taste in the mouth, an unpleasant odor, spots in front of the eyes, or a feeling of anxiety or fear. Some patients describe a feeling of being cold or hot before a seizure.

What is Epilepsy?

Epilepsy is a particular type of seizure disorder characterized by recurrent seizures. Approximately 2.5 million people in the United States have some form of epilepsy. About 125,000 new cases are diagnosed each year. Thirty percent of epilepsy patients between the ages of 5 and 25 develop seizures related to illness or accidents involving an injury to the head. As many as 50 percent of epilepsies continue into adulthood. Epilepsy may be triggered in adulthood by head injuries, infectious diseases, slow-growing tumors, or from circulation problems. In approximately 70 percent of patients, there is no identifiable cause of seizures.

Seizures are classified as partial or generalized. Partial seizures occur in one side, or hemisphere, of the brain. This type of seizure also is referred to as a focal seizure. Generalized seizures involve abnormal activity on both sides of the brain. The following chart lists some of the most common types of seizures and their characteristics.

International Classification of Seizures

TYPE	LEVEL OF CONSCIOUSNESS	CHARACTERISTICS
	Partial	
Simple partial	No change in consciousness	Change in movement or behavior
Complex partial	Change in consciousness	Hallucinations, loss of awareness, "déjà vu," fear, confusion, wandering, change in movements such as lip smacking, picking at clothing
	Generalized	
Tonic-clonic	Loss of consciousness	Two types of muscle movement First, muscles in the arms, legs and torso become stiff. These muscles then exhibit uncontrollable jerking movements.
Absence (petit mal)	Brief loss of consciousness (less than 15 seconds)	Response to environment impaired; (less than 15 seconds) staring off, non-responsive eye blinking
Myoclonic	No change in consciousness	Uncontrollable jerking of the muscles of the arms, legs or torso

Non-surgical Treatment Options

Medical Management

Most seizure disorders are adequately controlled with anti-epileptic medication. A new medication or a change in the current medication may be all that is needed to bring seizures under control. Other seizures are difficult to control with medication and are termed "medically intractable." Adults and children with these difficult seizures may be potential candidates for other treatment options. Even with other treatments, anti-epileptic medications will be continued. These medications may be gradually decreased as your seizures respond to the new treatment.

Following current Food and Drug Administration (FDA) regulations for approved indications of anti-epileptic medications, some medications may be used alone and others are used only in combined treatment.

This information is meant to serve only as a guide and does not cover all the possible uses, actions, precautions, side effects, or interactions with other medications. All medication carries a potential risk of side effects and complications. You should discuss these possible risks with your doctor. Some side effects, such as drowsiness, will go away as the body adjusts to the medication or to the dosage of medication. *However, any side effects you experience while taking anti-epileptic medications should be reported to your doctor.* If you develop a rash or an unusual or unexpected reaction while taking these medications, your doctor should be notified immediately. Many of these medications are associated with birth defects, especially when the mother is taking anti-epileptic medication during the first three months of pregnancy. The risk for birth defects may increase with the number of medications taken. Patients should talk with their physician if they are planning to

become pregnant or as soon as they think they may be pregnant.

It is always important to strictly follow your doctor's instructions regarding your anti-epileptic medication. Generally speaking, you should continue to take your medication even though you may be feeling better and are no longer having seizures. You should not suddenly stop taking your medication or change the dosage without first speaking with your doctor. It is advisable to avoid activities that may cause injury to yourself and others until you know how a particular medication will affect you. You should avoid the use of alcohol and sleeping pills while taking these medications. Make sure to store your medication away from heat, direct sunlight and moisture. These environments may break down the medication and cause it not to work properly. Refill prescriptions approximately seven days before running out of your medication. This allows enough time to solve any problems or questions that may arise and ensures that you will not miss any doses. Throw away all outdated medication and always keep all medications out of the reach of children. Several medications used to control or prevent seizures are listed alphabetically below.

ACTH (ADRENOCORTICOTROPIC HORMONE)

This medicine is used to treat infants who have **infantile spasms**. Possible side effects may include high blood sugar and diabetic complications, high blood pressure and salt retention, decreased potassium levels, stomach or intestinal ulcers, irritability and sleep disturbance.

DEPAKENE® OR DEPAKOTE® (VALPROATE OR VALPROIC ACID)

This medicine is used to treat certain types of seizures. Possible side effects may include drowsiness, dizziness, blurred or double vision, headache, nausea, vomiting, an increase or decrease in appetite and/or weight, poor coordination, sore throat, fever, trembling of hands or arms, restlessness, irritability, hyperactivity, hair loss, unusual bruising or bleeding as well as possible changes in the menstrual cycle. Take this medication with food to reduce stomach upset. Avoid carbonated drinks and milk products. Potentially serious side effects include yellow skin or eyes and unusual tiredness and should be brought to your doctor's attention immediately.

DILANTIN® (PHENYTOIN)

This medicine is used to control certain types of seizures. Possible side effects may include sleepiness, poor balance, rapid eye movement, blurred vision, headaches, joint pain, tender or enlarged gums, excessive hair growth, coarse facial features, acne, fever, sore throat, mouth sores or skin rash. You may want to take this medication with food to avoid stomach upset. It also is important to brush your teeth and rinse out your mouth after each meal to reduce the side effects on your gums. Regular, daily dental flossing also is highly recommended.

GABITRIL® (TIAGABINE)

This medication is newly available in the United States. It is used to control certain types of seizures. Possible side effects may include dizziness, fatigue, tremors or confusion. This medication can be taken with food

to reduce the chance of stomach upset. You should avoid sedatives while taking this medication.

KEPPRA® (LEVETIRACETAM)

This medicine is used to control partial and generalized myoclonic seizures. Possible side effects may include drowsiness and dizziness. Keppra does not interfere with the body's metabolism of other epilepsy drugs and it is unlikely to cause interactions with other commonly used drugs such as oral contraceptives.

KLONOPIN® (CLONAZEPAM)

This medicine is used to control certain types of seizures. Possible side effects may include drowsiness, poor coordination, muscle weakness, slurred speech, drooling, behavioral changes, confusion, agitation, dizziness, unusual tiredness, bleeding, fever and sore throat. This medicine can cause stomach upset and should be taken with food. You should avoid sedatives while taking this medicine.

LAMICTAL® (LAMOTRIGINE)

This medicine is used to control certain types of seizures. Possible side effects may include drowsiness, dizziness, double or blurred vision, headache nausea, vomiting, hair loss and rapid eye movements. If necessary, take this medication with food to avoid stomach upset. You should avoid sedatives while taking this medication. Potentially serious side effects should be brought to your doctor's attention immediately and include a higher than usual chance of a rash, especially when used in combination with other medications. If left untreated, this rash has been known to become life threatening. If you experience a rash while taking this medication, you should notify your doctor immediately.

LUMINAL® (PHENOBARBITAL)

This medicine is used to control certain types of seizures. Possible side effects may include drowsiness, decreased alertness and attention span, poor coordination, slow breathing, skin rash, and hyperactivity. You should avoid sedatives while taking this medication. Potentially serious side effects may include physical and psychological dependence with prolonged usage of this medication.

MYSOLINE® (PRIMIDONE)

This medicine is used to control certain types of seizures. Possible side effects may include drowsiness, dizziness, decreased alertness, headache, hyperactivity, irritability, poor coordination, unsteady gait, joint pain, changes in vision, fever, decrease in appetite, nausea, vomiting, and skin rash. This medication may be taken with food to reduce stomach upset. You should avoid sedatives while taking this medication.

NEURONTIN® (GABAPENTIN)

This medicine has recently become available for epilepsy patients and is used to control certain types of seizures. Possible side effects may include drowsiness, dizziness, blurred or double vision, fatigue, weakness, muscle aches, trembling, dry mouth, diarrhea or constipation, nausea, vomiting, weight gain and behavior changes. This medication can be taken with or without food. You should avoid sedatives while

taking this medication. Potentially serious side effects should be brought to your doctor's attention immediately and may include uncontrollable eye movements, extreme mood changes, memory loss, fever or chills, cough or hoarseness, slurred speech, severe diarrhea, severe dizziness or drowsiness, lower back or side pain and difficult urination.

TEGRETOL® OR EPITOL® (CARBAMAZEPINE)

This medicine is used to control certain types of seizures. Possible side effects may include dizziness, uncontrollable eye movements, poor coordination, blurred or double vision, yellow skin or eyes, nausea, vomiting, constipation, diarrhea, abdominal pain, and behavioral changes. Take this medicine with food to reduce the chance of stomach upset. You should avoid the use of sedatives and erythromycin (an antibiotic medicine) while taking this medication. Avoid prolonged exposure to the sun while taking this medication and always apply sunscreen to any exposed area. Potentially serious side effects should be brought to your doctor's attention immediately and may include fever, sore throat, rash, ulcers in the mouth and unusual bleeding or easy bruising.

TOPAMAX® (TOPIRAMATE)

This medicine is one of the most recently approved anti-epileptic drugs and has been available in the United States since early 1997. It is used to control certain types of seizures. Possible side effects may include drowsiness, dizziness, poor coordination, uncontrollable eye movements, decreased appetite, weight loss, and decreased concentration, confusion, or word finding difficulties. This medication should be taken with food to reduce the chance of stomach upset. With continued use, the risk of developing kidney stones is two to four times greater than seen in the general population. Therefore, it is important to drink adequate amounts of fluids to keep hydrated.

TRILEPTAL® (OXCARBAZEPINE)

This medicine is used to control certain types of seizures. Possible side effects may include dizziness, uncontrollable eye movements, poor coordination, blurred or double vision, yellow skin or eyes, nausea, vomiting, constipation, diarrhea, abdominal pain, and behavioral changes. Take this medicine with food to reduce the chance of stomach upset. You should avoid the use of sedatives and erythromycin (an antibiotic medicine) while taking this medication. Avoid prolonged exposure to the sun while taking this medication and always apply sunscreen to any exposed area.

ZARONTIN® (ETHOSUXIMIDE)

This medicine is used to treat certain types of seizures. Possible side effects may include drowsiness, dizziness, blurred vision, decreased appetite, nausea, vomiting, weight loss, diarrhea or constipation, hiccups, headache, fatigue, difficulty sleeping and nervousness. Take this medication with food to reduce the chance of stomach upset. You should avoid sedatives while taking this medication. Potentially serious side effects should be immediately brought to your doctor's attention and may include extreme stomach upset, hallucinations, joint pain, swollen glands, rash, fever, mouth sores, sore

throat, swelling around the eyes, unusual bleeding or bruising and behavior and mood changes.

ZONEGRAN® (ZONISAMIDE)

This medicine is used to control partial and generalized myoclonic seizures. Possible side effects may include drowsiness, change in concentration, and kidney stones. You should drink 6–8 glasses of water a day to help prevent kidney stones. You should contact your doctor if you develop a skin rash.

New drugs are frequently being evaluated. You may be offered the opportunity to participate in trials of drug treatments or non-drug treatments.

KETOGENIC DIET PROGRAM

The ketogenic treatment diet is a special eating plan for children and rarely for some young adults who do not respond well to medication therapy. Initially studied in the 1920s and widely used through the 1940s, the diet was abandoned in favor of newly discovered anti-epileptic medications. Recently, however, there has been a resurgence of interest in the ketogenic diet as a treatment option for some children with medically intractable epilepsy.

The physician-monitored, dietitian-supervised diet begins in the hospital with a one- to two-day fast followed by meals consisting of heavy cream, butter and other fats, limited amounts of protein, fruits, vegetables, and no starch or sugar. The treatment diet simulates the effects of prolonged starvation, causing the body to burn fat as its main energy source instead of carbohydrates. This fat metabolism results in ketone bodies that the brain uses as energy. It is not known why this diet sometimes results in improved seizure control. However, its effectiveness is currently being evaluated through research sponsored by the National Institutes of Health.

To achieve this ketotic state, total calorie and fluid intake are controlled. High-fat, low-carbohydrate and low-protein foods must be carefully chosen and precisely weighed and measured. Individual dietary guidelines are calculated for each patient and modified depending upon the diet's effectiveness. Anti-epileptic medications are continued and are gradually decreased only if adequate seizure control is achieved. Vitamin and mineral supplements must be taken to ensure adequate and balanced nutrition. In the home, urine is tested daily for the presence of ketones to ensure fat metabolism, the desired effect of the diet. Patients are routinely monitored on an outpatient basis to evaluate changes in blood chemistry and the diet's effectiveness. If the diet has helped in seizure control, it must be continued for one to three years and then slowly discontinued.

Possible side effects of this eating plan include kidney stones, poor linear growth, poor weight gain, elevated cholesterol levels and gall stones. This diet only should be used under the proper medical supervision of a team of healthcare professionals who can monitor the patient and provide support to the family during the difficult period of adjustment once the treatment diet has begun.

The Ketogenic Diet Program at Shands Neurological Center is an important

Medications Used for the Treatment of Seizures*

TRADE NAME	GENERIC NAME	SEIZURE TYPE	SIDE EFFECTS
ACTHAR®	Adrenocorticotropic hormone (ACTH)	Infantile spasms; myoclonic	High blood sugar, high blood pressure, salt retention, decreased potassium, stomach or intestinal ulcers, diabetic complications, irritability, sleep disturbance
Depakene® or Depakote®	valproate or sodium divalproex	Myoclonic; absence (petit mal); generalized tonic-clonic; complex partial; mixed seizure types; infantile spasms	Hair loss, irregular periods, increased or decreased appetite, nausea, vomiting, upset stomach, weight gain
Dilantin®	phenytoin	Generalized tonic-clonic; simple partial; complex partial	Unsteady gait, blurred or double vision, skin rash, hair growth, tender or enlarged gums
Gabitril®	tiagabine	Combination therapy for complex partial seizures	Headache, fatigue, nausea, dizziness, tremors
Keppra®	levetiracetam	Partial; generalized myoclonic	Drowsiness
Klonopin®	clonazepam	Absence (petit mal); myoclonic	Drowsiness, slurred speech, double vision, behavioral changes, increased saliva production
Lamictal®	lamotrigine	Combination therapy for partial seizures with or without secondary generalization; for use above age 12	Rash, blurred or double vision, headache, nausea, dizziness
Luminal®	phenobarbital	Generalized tonic-clonic; myoclonic partial	Hyperactivity or drowsiness, depression, irritability, trouble thinking
Mysoline®	primidone	Generalized tonic-clonic; complex partial; simple partial	Drowsiness, hyperactivity in children, unsteady gait, behavioral changes
Neurontin®	gabapentin	Combination therapy for partial seizures with or without secondary generalization; for use above age 12	Headache, dizziness, fatigue, nausea, vomiting, muscle aches, abnormal vision
Tegretol® or Epitol®	carbamazepine	Simple partial; complex partial; secondary tonic-clonic	Fatigue, dizziness, unsteady gait, decreased sodium, behavioral changes, blurred or double vision
Topamax®	topiramate	Combination therapy for partial seizures with or without generalization; for use above age 16	Dizziness, drowsiness, decreased concentration, confusion, slurred speech, word-finding difficulties,depression, loss of appetite, kidney stones
Trileptal®	oxcarbazepine	Partial; generalized	Similar to Tegretol®
Zarontin®	ethosuximide	Absence (petit mal)	Loss of appetite, headache, fatigue, upset stomach, dizziness, behavioral changes
Zonegran®	zonisamide	Partial; generalized myoclonic	Drowsiness, kidney stone, change in concentration

*ALL INFORMATION IS BASED ON DATA AVAILABLE AS OF 12/99.

component of our comprehensive approach to the treatment of epilepsy. We have one of the few programs in the country that utilizes a full-time dietitian as well as a pediatric neurologist, nurse practitioner, social worker and research coordinator. With the addition of our home care treatment option, specially trained nurses carefully monitor each patient's progress and gradually phase in the diet at home, eliminating the need for an inpatient hospital admission. Together these professionals form our "Keto Team" and have currently treated more than 100 patients, making our program one of the most comprehensive in the southeastern United States.

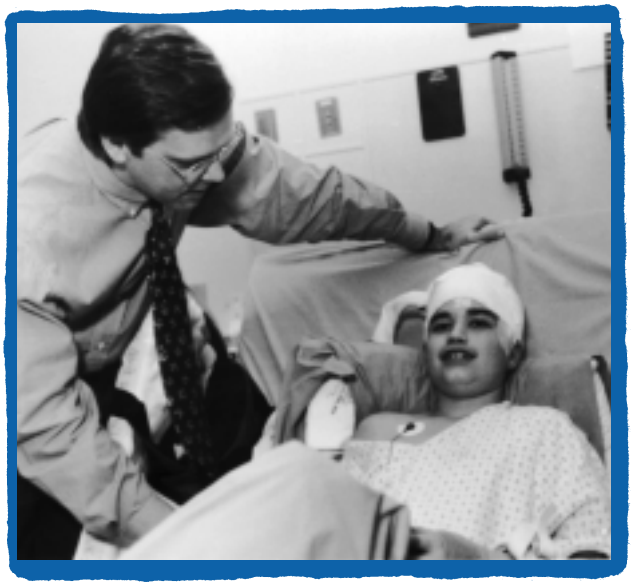
Although not for everyone, this treatment diet has had some real successes.

Surgical Treatment Options

The vast majority of epilepsy patients achieve adequate seizure control with the use of medication therapy. However, current estimates indicate that nearly 20 to 30 percent of patients suffer from medically intractable epilepsy and need to explore other treatment options.

The largest factor in determining if epilepsy surgery will be offered as a treatment option is careful seizure observation. This requires a series of inpatient hospital evaluations to characterize the seizure type, frequency, location of onset, the surrounding brain structures and their corresponding functions.

At Shands Neurological Center, we have divided this evaluation process into a series of four phases. These phases are briefly



outlined below to give a general overview of the entire selection process. Each phase of the program is then separately explained in detail. The combined results of these evaluations are essential in determining the most appropriate treatment from a variety of surgical options.

Phases of Epilepsy Surgical Treatment

Our Epilepsy surgical treatment includes several phases that provide guidelines for evaluation and treatment during the program. These phases are referred to as *Phase 1, 2, 3 and 4.*

Phase 1 includes a thorough inpatient evaluation in the hospital. A detailed history of your seizures, drug levels, brain scans, a neuropsychological examination, and video EEG telemetry monitoring are obtained. Older children and adults may undergo a Wada test for language and memory testing.

Phase 2 entails a second inpatient hospital admission and surgery for placement of recording electrodes called grids,

strips, and/or depths directly on or in the brain. This phase is necessary only when direct brain activity monitoring is required to adequately identify the seizure focus and its related functions.

Phase 3 may be completed during the second hospital admission or may require a third inpatient admission. It involves the surgical removal of the area in the brain causing seizures or a procedure to help decrease the symptoms and/or frequency of seizures.

Phase 4 represents the close follow-up you will require after your epilepsy surgery. This includes outpatient visits to your neurosurgeon and neurologist and at least one EEG, MRI and neuropsychological exam to monitor your progress.

Phase 1: Seizure Monitoring

Video EEG Telemetry

Adult patients are admitted to the Epilepsy Monitoring Unit (EMU), located on Unit 65 Surgery at Shands at UF medical center, for seizure monitoring. Children will be admitted to the EMU on Unit 45 Pediatrics in Shands Children's Hospital at UF. The rooms on 65 Surgery and 45 Pediatrics have special seizure-monitoring equipment and ceiling-mounted cameras. These rooms are assigned to patients having video EEG telemetry. A member of the staff — either a nurse, nursing assistant, or EEG technologist — will explain the use of the nurse-call system, seizure-monitoring equipment, and information about the

hospital routine. Side rails are padded to prevent injury during a seizure, and blue-colored sheets are placed on the bed to provide contrast for the camera. This color contrast allows the camera to better view the seizure. The room lights will be left on all night so that the camera can record seizures. A small tube, known as an intravenous (IV) medlock, will be placed in a vein in your arm so that nurses can administer fast-acting medications to control seizures.

The doctors, nurses, nurse practitioners, and EEG technologists will ask questions about your medical history and, specifically, about your seizures. Questions about seizures will provide the staff with information about the presence or absence of a seizure warning sign (aura), frequency of seizures, description of the seizures, and the use and effectiveness of different seizure medications.

We require that you have a family member or friend stay in the monitoring room during the monitoring period. This person is called the companion. The companion will need to recognize any changes in your behavior that may indicate a seizure. The companion will be shown how to use the emergency call light system in case emergency assistance is needed. A foldout bed will be provided for the companion. Members of the epilepsy team provide the companion with 15-minute breaks, usually three times a day.

Monitoring is continuous as scalp electrodes work constantly to measure results. Therefore, we provide you with sponge baths rather than tub baths or showers. While you are in the hospital, you are not permitted to smoke or chew gum. Shands at UF is a non-smoking institution.

How Long is the Hospital Stay?

The length of the hospital stay is determined by how long it takes to record enough seizures to provide information about your type of seizure and its source in the brain. This may range from two days to two weeks or may require more than one hospital admission.

The epilepsy team will study the recorded seizures to decide if monitoring should continue. Information will be available to the EEG technologists and the nurses to let them know what is required to either help bring on a seizure or stop the seizure activity that is occurring.

The seizure-monitoring period can be long and tedious for both you and your companion. You are encouraged to bring any items and activities that may make this time as enjoyable as possible. Please refer to pages 22–23 for helpful suggestions and necessary guidelines to assist you in your preparations.

Pediatric patients often have special concerns that need to be addressed before admission. Arrangements should be made with teachers so children will not fall behind in their schoolwork. One way for children to pass some time is on class assignments. Pediatric patients with an anticipated hospitalization of more than one week can be referred to our teacher for help with their classwork and other tutoring needs. To access this valuable service, available during the school year only, please ask to be referred by your nurse or social worker upon admission.

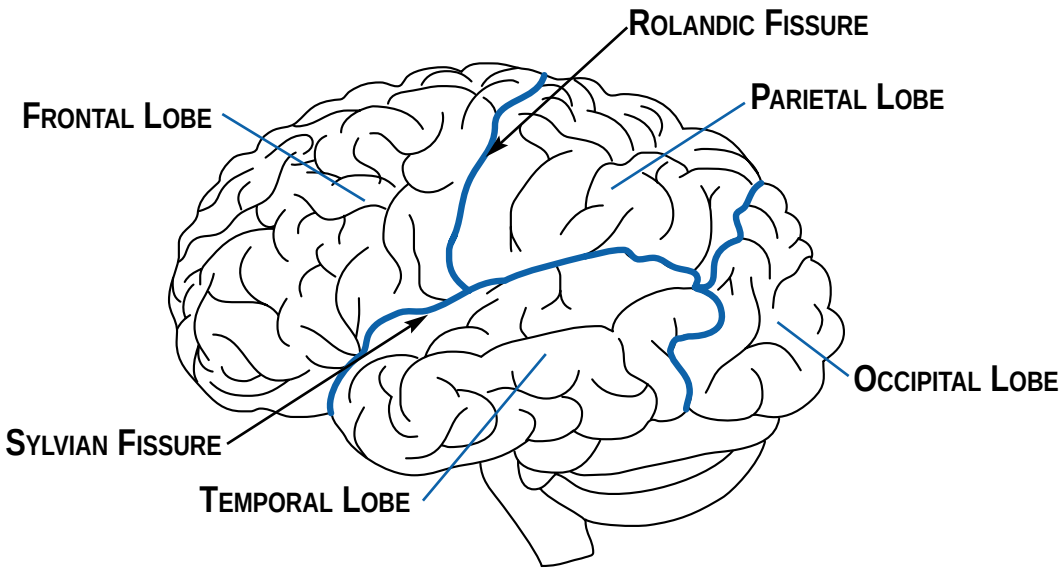
Surface Electrodes

Upon admission to the Epilepsy Monitoring Unit, EEG electrodes will be placed on your scalp. Many scalp electrodes may be used to help locate the origin of the seizure activity. It is important for your hair to be as clean as possible before the electrodes are attached so that they stick well. Do not use cream rinse or conditioner when washing your hair before you come to the hospital. A special glue called collodion will help hold the electrodes in place. Cream rinse may be used to help remove the electrode glue when you go home. Your head will be covered with a gauze wrap and the electrode wires will be placed in a zippered bag to prevent them from becoming tangled. When packing, avoid bringing clothes that pull over your head because this may detach or loosen the electrodes attached to your scalp.

Sphenoidal Electrodes

Sometimes seizures come from deep areas of the brain that may not be detected by EEG electrodes on the head's surface. Small wires called sphenoidal electrodes may be used to help find the part of the brain that is causing the seizure activity. Sphenoidal electrodes are placed through the skin, above the jaw, using a sterile technique at the bedside. These special electrodes give good pictures of the brain activity coming from the area of the brain called the temporal lobe. This is a common place for seizures to start.

The skin near the jaw joint will be numbed when the sphenoidal electrodes are inserted; however, you may feel pressure. Children will receive a sedative prior to insertion of these electrodes. There is some discomfort at first, but gradually the pain



goes away. Mild pain medication such as Tylenol® often helps ease the achy feeling in the jaw. Your diet will consist of soft foods for the first 24 hours after these electrodes are in place.

Having Seizures

To find out the type of seizure and to determine which part of your brain the seizure comes from, it is necessary to record several seizures in a controlled environment. Several things may be done to bring on a seizure. Medications may be reduced or you may be asked to breathe fast (hyperventilate) for a three- to four-minute period to trigger a seizure. Physical exertion also may increase seizure activity, so you may be asked to ride an exercise bicycle several times a day. We will supervise you while you are using the bicycle to make sure you avoid injury. A physical therapist will show you how to do this exercise.

Lack of sleep will sometimes bring on a seizure, so you may be kept awake all night if you have not had a seizure by the third hospital day. Also, you and your family may be asked if there are specific circumstances that trigger seizures. These triggers may be used to help bring on a seizure so that we can monitor you.

The epilepsy team will record and evaluate approximately three to six typical seizures. Throughout your hospital stay, your seizures may become more frequent and/or severe. During any seizure activity, whether at home or in the hospital, there is always a risk of injury. The hospital staff and doctors will make every attempt to minimize this risk.

Neuropsychological Testing

A neuropsychologist will administer testing that examines hand-eye coordination, memory, and IQ. This testing is called neuropsychological testing and determines how well the brain performs certain functions. It is very helpful in locating the part of the brain that may not be performing its functions well and that also may be causing the seizure activity. This evaluation may include questions about you and your family, testing of memory and learning, attention and concentration, language, spatial abilities, motor skills and general problem solving abilities. The evaluation typically takes about five hours and is usually performed during Phase 1 or afterwards during an outpatient visit.

Other Tests

Before, during or after your Phase 1 admission, a special scan of the brain called Magnetic Resonance Imaging (MRI) will be done. You also may have a test called spectroscopy MRI, diffusion imaging MRI or

a Single Photon Emission Computerized Tomography (SPECT) scan. Occasionally, a Computerized Axial Tomography (CT) scan is needed. In rare cases, a Positron Emission Tomography (PET) scan may be useful in your evaluation. The special equipment needed to do this test is available at Emory University in Atlanta, Ga.

Wada Testing

The right and left hemispheres of the brain are responsible for different functions. A Wada test is done to help determine the side of the brain that controls language and memory. During this test, one-half of the brain will be put to sleep for about two minutes using a short-acting drug called Brevital®. This medication will be given through a soft catheter inserted through the femoral artery in your groin. The awake half of the brain will be tested for language, memory and learning functions. You will be asked to remember pictures, name items, and squeeze a small bulb that measures your strength. The other side of the brain will then be put to sleep and the tests repeated. EEG monitoring also is done to observe brain activity during Wada testing.

Research

During your evaluation, you may be asked to participate in research. The knowledge that is gathered from these studies will be used to develop future epilepsy treatment options. You are under no obligation to participate in these studies and your decision will not affect your epilepsy evaluation or treatment.

Epilepsy Management Conference

Patients who are considered potential candidates for epilepsy surgery, will have their case presented by the medical team at an Epilepsy Management Conference. At this conference, the epilepsy team makes several decisions. The first decision is whether or not the patient is a good candidate for epilepsy surgery. The second decision is whether or not the origin of the seizures has been exactly determined from the available information.

If enough information is available for the team to determine that you are a good candidate for epilepsy surgery, the epilepsy team will explain to you the type of surgery, along with its benefits and risks. You and your family play an important and active role in this decision-making process.

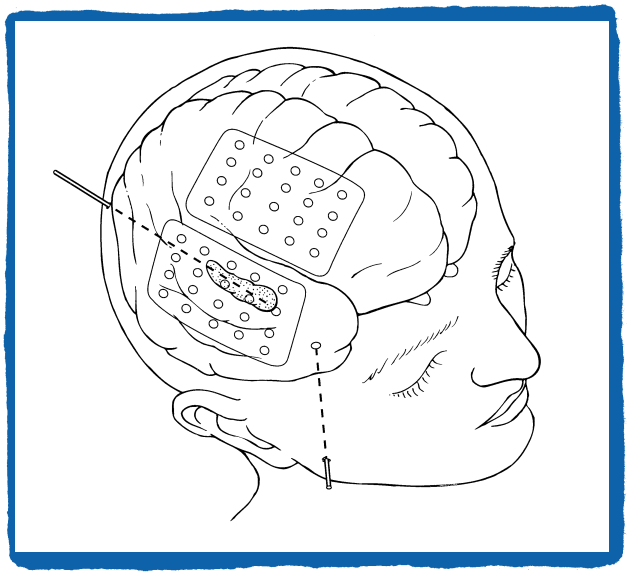
If we need more information, we may plan an additional inpatient hospitalization (Phase 2). In this stage of the monitoring process, we use more direct methods to locate the area of the brain responsible for your seizures. This area of the brain is called the epileptogenic focus. After the focus is identified, we complete additional testing to determine that the part of the brain to be

removed is not essential for language, motor, sensory, or memory skills.

Phase 2: Craniotomy for Placement of Intracranial Electrodes

Some patients will require an additional period of continuous video EEG monitoring similar to Phase 1 except that electrodes are placed directly on or in the brain. This is referred to as Phase 2. In Phase 2, surgery called a craniotomy will be performed by the epilepsy team neurosurgeon to place these special electrodes. A craniotomy is a surgery where an incision is made through the skull. Prior to surgery, you will be prepared for general anesthesia. This pre-operative work-up may include blood tests, a chest X-ray, an EKG and other additional studies your neurosurgeon might order. A craniotomy requires that all or some of your scalp hair be shaved.

In the operating room, a portion of your skull will be removed and your brain tissue exposed. A very thin plastic plate of electrodes called a grid or strip is placed directly on the surface of your brain, or depth electrodes are placed within your brain and then the portion of the skull will be replaced. After surgery, you will be in the recovery room for a few hours until the effects of the general anesthesia begin to wear off. Adult patients will then be transported to the Surgical Intensive Care Unit (SICU). Pediatric patients will be taken to the Pediatric Intensive Care Unit (PICU). You can expect to spend at least one night in these units before being transported to the EMU. Once in the EMU, you will again need your companion to stay with you at all times just as you did during Phase 1.



While you have these special electrodes in place, members of the epilepsy team will be able to monitor your brain's activity more directly and accurately during seizures. This process is called **electrocorticography**. Also in this phase, stimulation of these special electrodes may be done while you are asked to perform simple tasks. This is called **functional mapping**. This will help the team locate the areas of your brain that are important to the activities of daily living. Functional mapping helps to define the areas of the brain that should not be removed or injured during the surgery to extract the seizure focus. Phase 2 usually requires a two- to three-week hospital stay. During this stay, you are usually restricted to bed for safety reasons. It is very important that these special electrodes are not pulled out during or after a seizure. For your protection, you must wear a safety jacket (Posey®) and loose wrist restraints to prevent injury.

Phase 3: Surgical Treatment

Surgery for the removal of the seizure focus is referred to as Phase 3. During Phase 3 surgery, further EEG recordings may be done in the operating room, especially after taking out the seizure focus, to determine whether any abnormal brain activity remains.

The length of the hospital stay depends on the type of epilepsy surgery and your rate of recovery, but is generally four to seven days. After surgery, you will be in the recovery room for a few hours until the effects of the general anesthesia begin to wear off. Adult patients will then be transported to SICU and pediatric patients to PICU. You can expect to spend at least one night in these units before being transported to 65 Surgery (for adults) or 45 Pediatrics (for children).

Types of Surgery for the Treatment of Epilepsy

Many surgical techniques are available for the patient with epilepsy. The most common operation in adults is called an **anterior temporal lobectomy**. Other procedures include **hemispherectomy, extratemporal focal resections**, and **corpus callostomy**. (A brief description of these surgical procedures is contained in the Glossary on pages 33–34.) The goal of all these surgeries is to remove the smallest amount of brain tissue that will result in a significant decrease in the frequency or severity of seizures or to cure the seizures completely.

It is important for you to know that the occurrence of seizures right after surgery does not mean that surgery was unsuccessful. Often, the brain is irritated by the surgery and this condition will slowly improve with time. Also, anti-epileptic medications will be continued after surgery. The dosages of these medications may be gradually decreased or discontinued one to two years after surgery.

Complications of surgical treatment depend greatly upon the type of epilepsy surgery performed. Possible side effects of an anterior temporal lobectomy, the most common type of epilepsy surgery, are usually mild and can include minor impairment of peripheral vision and potential memory changes. Your neurosurgeon will explain in detail the particular type of epilepsy surgery recommended and its associated risks and complications.

Approximately 60,000 people in the United States are good candidates for epilepsy surgery. Proper patient selection has proven to be the best indicator of success. Of patients who have had an anterior temporal lobectomy, 90 percent are either seizure-free or experience a greater than 90 percent reduction in their seizure frequency.

Phases

PHASE 1	PHASE 2	PHASE 3	PHASE 4
Seizure Monitoring	**Craniotomy for Placement of Intracranial Electrodes**	**Surgical Treatment**	**Follow-up after Surgery**
History & Physical Exam	Intracranial Electrodes (grids, strips, depth electrodes)	Surgery to remove the seizure focus or special procedures to decrease the frequency or severity of seizures.	Neurologist and/or neurosurgeon clinic visit at two weeks, one month, three months, six months, 12 months, and 24 months after surgery.
Video EEG Telemetry	Electrocorticography		At least one EEG, MRI, and neuropsychological exam within first 12 months after surgery.
Sphenoidal Electrodes	Functional Mapping		
Neuropsychological Testing			
Visual Field Exam			
Brain Scans (CT, MRI, SPECT, Ictal SPECT, PET)			
Wada test			

Phase 4: Follow-up After Surgery

After surgery, you will require close follow-up, which will include outpatient visits to the neurologist and neurosurgeon. You will visit the neurologist and/or neurosurgeon at two weeks, one month, three months, six months, 12 months, and 24 months after surgery. You will have at least one EEG, MRI, and neuropsychological exam during the first year after surgery. The following chart summarizes the treatment, evaluation, and follow-up period for all phases of the Comprehensive Epilepsy Program. This is a general guideline and the schedule may change based on individual patient needs.

Other Surgical Treatment Options

Vagus Nerve Stimulator

This innovative therapy is an option for a select group of patients who suffer from complex partial seizures that are not well controlled with the use of medications or other treatments. Approved by the FDA in July 1997 for use along with anti-epileptic medication, this treatment uses a small device to interrupt seizures by sending an electrical impulse to the brain. Many patients find this device shortens the duration of their seizures, lessens the intensity, or both.

The Vagus Nerve Stimulator (VNS) is a small, battery-operated device resembling a thin stopwatch. It is implanted through a small incision in the chest during an outpatient surgical procedure under general anesthesia, which usually lasts two hours. A painless electrical impulse is emitted by the VNS through a threadlike wire that winds around the vagus nerve on the left side of the neck.

The vagus nerve, often called the wandering nerve, is very long and sends messages to many organs, including the heart, lung, stomach and voice box. It also communicates with a part of the brain stem linked to certain types of seizures. Physicians believe stimulation of the vagus nerve prevents seizures either by returning brain activity to normal or by interfering with the abnormal brain activity that leads to seizures.

The VNS is programmed to emit an electrical pulse for 30 seconds, then remain inactive for five minutes. Patients who feel the onset of a seizure can manually trigger the device by the use of a magnet. This magnet, when taped over the device, also can be used to stop stimulation if it becomes uncomfortable.

Possible side effects of VNS are few and usually decrease over time. These include coughing for a short period after the device is first implanted, a mild tingling in the neck or a vibrating voice during stimulation. The advantages with this type of treatment are substantial. The VNS device can be easily removed with surgery and is not associated with the common side effects of traditional medication therapy such as drowsiness, dizziness, blurred vision, rashes, lack of coordination or concentration.

Clinical Trials

Neurologists and neurosurgeons sometimes participate in scientific studies to determine the effectiveness of new

therapies. It may be very helpful for patients to have the opportunity to try the newest medications, devices, and technologies under investigation. Since these studies change with time, you should ask your neurologist or neurosurgeon if any current studies would be of potential benefit in managing your particular type of seizure disorder.

Complementary Services

Patients suffering from epilepsy often have additional problems related to their seizure disorder. Some of these varied problems can include sleep disorders, low self-esteem, language and communication problems, anxiety and mood disorders, as well as learning and conduct disorders. These conditions can be caused or influenced by the type of initial brain injury, side effects of anti-epileptic medications, recurrent seizures, and/or difficulty adjusting to the seizure disorder.

The UF Comprehensive Epilepsy Program at Shands Neurological Center has a number of adult and pediatric neurological services that complement the care of our epilepsy patients. These include a Sleep Disorders Center for adults as well as a similar pediatric clinic that is currently under development. Our new Attention Deficit Hyperactivity Disorder Clinic effectively addresses many of the conditions listed above, including problems in concentration and school performance.

The UF Comprehensive Epilepsy Team understands the complexity of epilepsy and other seizure disorders and provides access to a continuum of care to treat all of the related needs of the patient and family. Emotional support is often provided by our devoted team of epilepsy care providers and can be supplemented when necessary by psychiatric evaluations, psychological counseling, and local support agencies. Included in this patient guide is a listing of epilepsy-related organizations, support groups and a reading list to help you locate additional resources and extend education and understanding to those around you.

Summary

Epilepsy and other seizure disorders currently affect more than two million people in the United States. Many of these individuals are plagued by uncertainty, a restrictive lifestyle and the misconceptions of family, friends, employers and co-workers about this prevalent but treatable condition. Because they never know exactly when a seizure will strike, they are denied simple pleasures that others may take for granted, like the opportunity to drive a car.

At Shands Neurological Center, our focus is to break through those barriers by advancing the treatment of epilepsy on all fronts. New technology, medications and surgical techniques have made available a diverse range of treatment options. Our Comprehensive Epilepsy Program employs the latest therapeutic and diagnostic disciplines to ensure that each patient is thoroughly evaluated and given his or her best opportunity for a cure. We feel that all epilepsy patients deserve the most comprehensive care, by an outstanding team of healthcare professionals in the safest and most comfortable environment possible.

The UF Comprehensive Epilepsy Team

Each highly skilled member of the UF Comprehensive Epilepsy Team plays a very specific role. Patients may see some team members daily and may only meet with others once. A specific plan of care will be customized for each patient by the epilepsy team. A brief explanation of their roles and contribution to your care is alphabetically listed below:

Appointment Coordinator

The appointment coordinators in the University of Florida College of Medicine Department of Neurology and Division of Pediatric Neurology schedule appointments and procedures. Patients and families may often be in contact with other staff members in the Neurology Department. These individuals can help with questions regarding the hospital stay or financial arrangements. If a decision for surgery is made, the secretary in the UF College of Medicine Department of Neurosurgery will schedule the inpatient hospital admission(s), surgical procedure(s), and follow-up appointments.

Clinical Psychologist

The UF clinical psychologist specializes in evaluating the impact of epilepsy on the emotional and psychological functioning of the patient. This healthcare professional performs psychological testing, which may be done while in the Epilepsy Monitoring Unit or as an outpatient.

Clinical Social Worker

The clinical social worker provides counseling to help with the adjustment to an illness or hospitalization. The clinical social worker can also help you find necessary support services and financial aid information.

Epilepsy Monitoring Unit (EMU) Staff

The Epilepsy Monitoring Unit staff consists of EEG technologists who perform specialized EEGs as well as help make patients and families become more comfortable with the operation of the electrodes and monitoring equipment. Other specially trained staff members, located in the EMU Control Room, monitor the recording of all patient activity which will then be reviewed by your doctors and other members of the epilepsy team.

NEURO-ANESTHESIOLOGIST

The neuro-anesthesiologist is a UF physician who specializes in administering medications that produce a loss of consciousness and/or sensation of pain. This team member will be responsible for your anesthesia used during the Phase 2 and 3 surgeries.

NEUROLOGIST

A neurologist is a UF physician who specializes in the treatment of nervous system disorders such as epilepsy. Although the epilepsy team is composed of several adult and pediatric neurologists, one neurologist will be your primary doctor.

NEURO-OPHTHALMOLOGIST

The neuro-ophthalmologist is a UF physician who specializes in the structures, functions and diseases of the eyes. This team member will administer the visual field exam, if one is required for your diagnosis and treatment.

NEUROPSYCHOLOGIST

The neuropsychologist is a UF psychologist specially trained in neurologic disorders. This healthcare professional performs neuro-psychological testing; behavioral tests which examine the functioning of specific brain areas such as language, speech, motor skills, and memory in each patient.

NEURO-RADIOLOGIST

The neuro-radiologist is a UF physician who specializes in the evaluation of diagnostic imaging studies of the nervous system such as X-rays, CT scans, and MRIs, as well as other procedures which serve to aid your diagnosis and treatment. As a member of the epilepsy team, the neuro-radiologist performs the Wada testing during Phase 2.

NEUROSURGEON

The neurosurgeon is a UF physician who participates in the decision-making process regarding surgical treatment and performs surgeries for the implantation of special monitoring electrodes and/or the removal of the part of the brain causing the seizures.

NURSE PRACTITIONER

The epilepsy nurse practitioner is an advanced practice nurse with special training and expertise in epilepsy. The epilepsy nurse practitioner coordinates your care throughout the treatment process and will answer questions you may have about any of the phases of epilepsy treatment.

NURSING STAFF

Nurses are health professionals with special expertise in the diagnosis and treatment of physical and emotional responses to health problems. During your hospitalization, nurses provide care and support for you and your family. They also provide teaching related to seizure disorders, medications, the epilepsy monitoring process, and your care requirements after surgery.

PSYCHIATRIST

The psychiatrist is a UF physician who specializes in the evaluation of a patient's emotional problems and in the treatment of these problems. As a part of the team, the psychiatrist also evaluates the patient's potential responses to the surgical treatment

of epilepsy and recommends appropriate therapy when indicated.

Registered Dietitian

The registered dietitian is a healthcare professional who specializes in setting nutritional and dietary guidelines to aid in the care of patients and the treatment of their health conditions. This team member will set the patient-specific dietary guidelines for participants in the ketogenic treatment diet.

Preparing for Your Epilepsy Surgical Treatment Program Hospital Admissions

Medication

You and your companion must each bring all medications you are currently taking with you for your stay in the hospital.

Food

In the EMU patient room, a small, private refrigerator is available to store drinks and snacks. You may wish to bring items from home for this purpose. A microwave oven is available on the nursing unit.

Clothing

You may only bring clothes that button up the front. Otherwise, a hospital gown will be provided. Socks, slippers or other footwear must be brought from home.

Your companion should pack several days worth of comfortable clothes. If an extended hospital stay is required, laundry facilities are available and located on the 4th floor. However, you must provide your own laundry detergent and supplies. (Laundry detergent may be purchased in the gift shop on the first floor by the main entrance.)

Jewelry

You may not wear earrings or necklaces during your epilepsy monitoring, so these items should be left at home prior to this admission. However, you may wear bracelets, watches and rings.

For Phases 2 and 3 admissions, all jewelry must be removed before surgery and should be left at home.

Personal Items

You and your companion will each need to bring your own shampoo, toothbrush, toothpaste and other personal items or toiletries.

You and your companion may wish to bring your own pillows and blankets from home. Otherwise, these items are provided by the hospital. Feel free to bring stuffed animals, family photos or other articles from home to add to your comfort.

Entertainment

Your room is equipped with a VCR. Various videotapes are available, although you may wish to bring your favorite tapes from home.

Nintendo and Super Nintendo units and games are shared between the adult and pediatric EMU rooms. You may wish to bring games from home that can be played on these units.

Other items such as a radio, CD player, laptop computer, hand-held arcade games, etc., are permitted only if they are battery operated. Any type of appliance that needs

to be plugged into a wall socket will not be allowed (NO EXCEPTIONS).

Other items that you may want to bring include books, puzzles, cards, board games, crossword puzzles, etc.

Other Items

A recent picture of yourself is required and will be placed inside your hospital chart. You are encouraged to bring one from home or the hospital staff will take one upon admission.

Restrictions

Shands at UF is a smoke-free environment and no smoking is permitted except in clearly designated smoking areas outside the hospital. Additionally, you may not chew tobacco or gum during the monitoring process. If necessary, nicotine patches may be worn to help curb your desire to smoke or chew tobacco and should be obtained prior to your admission.

Suggestions

Your companion will be given short breaks by hospital staff when not in conflict with other staffing needs. The support of other family members and/or friends has been found to be very helpful to companions. These individuals can assist your companion by providing additional and consistent breaks during the course of your hospital stay. Obtaining the support of these individuals prior to admission is highly recommended.

Available Resources during Your Stay at Shands at UF

Patient and Family Resources

Patient and Family Resources provides you and your family with a variety of supportive services. One service includes informing you of federal, state, and/or community resources that may be of assistance to you. They also will help you apply for these services, if applicable. In addition, social workers are often called upon to listen and respond to the various concerns expressed by you and your family. To request a visit by a social worker during your hospital stay, please call the Department of Patient and Family Resources at (352) 265-0224.

Child Life Services

The Child Life program provides individual and group recreational, therapeutic, and educational activities for pediatric patients during their hospital stay. Child Life staff understand child development and can assist children to make their hospital experience more positive. A Child Life specialist can be called upon to help children understand medical procedures and surgery, provide an opportunity for patients to express their feelings through activities and play, and provide supportive counseling for family members. To request the services of a Child Life specialist, please call the Department of Patient and Family Resources at (352) 265-0224.

Pastoral Services

Pastoral Services seeks to provide spiritual support for you and your family members by providing spiritual counseling, the sharing of sacraments and other rituals of faith, and supportive persons who will listen objectively to your concerns. There are three full-time chaplains available to assist you — a part-time Catholic priest and a Rabbi are available on-call. If you are in need of a spiritual leader from a different faith, they can help locate one for you. To request any of these services, please ask your nurse to notify Pastoral Services at (352) 265-0123. An interfaith chapel, located on the first floor, is available 24 hours a day for prayer and meditation.

Shands Arts In Medicine Program at UF

The Shands Arts in Medicine program combines the ideas of healing and art by providing a variety of experiences designed to engage and entertain you and your family during your hospital stay. For example, you may request the use of a walkman and headphones for various kinds of musical enjoyment or books on a variety of topics. In addition, other activities include journal and poetry writing, bedside storytelling and interactive theater, bedside art projects, and bedside dance and music performances on Wednesday evenings and Friday afternoons when possible. One example of such a project is the Healing Ceiling project where patients, families and caregivers paint ceiling tiles, which are then placed throughout Shands Children's Hospital at UF. To request the services of Shands Arts in Medicine, please call (352) 265-0151.

Volunteer Services

Volunteer Services provides a vehicle by which members of area communities can donate their time and talents. Volunteers participate in a wide variety of activities. Some of these services that may be of special interest to you are the circulation of a mobile book cart, and the ability to run in-house errands and to provide short breaks to your companion when volunteers are available. The Volunteer Services office is open Monday through Friday from 8 am to 5 pm. To request any of these services, please call the office at (352) 265-0360.

The Gift Stop

The Gift Stop is a gift shop located near the main entrance on the first floor. It is open 7:15 am to 8 pm Monday through Friday, 10 am to 5 pm Saturday, and 1 pm to 5 pm Sunday. Items for sale include personal products and toiletries, magazines and books, cards, flowers, candy, toys and stuffed animals, as well as a special selection of seasonal, occasional, and personal gifts. You can call (352) 265-0121 to check on the availability and price of an item, place an order, and/or request delivery to your room.

About Shands Neurological Center at the University of Florida

Shands Neurological Center is a Center of Excellence within the Shands at the University of Florida medical center. Shands at UF is a 576-bed private, not-for-profit, referral center serving the Southeastern United States. Located in Gainesville on the

campus of the University of Florida, Shands at UF is the primary teaching facility for the UF Health Science Center. Faculty members in the Health Science Center's College of Medicine are members of the medical staff at Shands at UF. Faculty members, each distinguished in their field, are involved in research and teaching activities to support state-of-the-art medical care for their patients.

Shands at UF is part of the Shands HealthCare system, which offers the most comprehensive range of health services in northern Florida. The not-for-profit enterprise encompasses eight community and specialty hospitals in north Florida and includes Shands Jacksonville, another teaching facility affiliated with UF.

Questions and Answers

Q: Are there seizure disorder support groups?

A: Yes, you are not alone. There are several national and state support organizations for people with seizure disorders. The Epilepsy Foundation can help you identify the support group closest to you. You can contact the Foundation at 4351 Garden City Drive, Landover, MD, 20785, or by phone at (800) 332-1000. Gainesville-area residents can contact the Epilepsy Foundation of Northeast Florida, located in Jacksonville, at (904) 731-3752.

In Florida, the Advocacy Center for Persons with Disabilities is an organization that deals with the rights of people with disabilities. If you are disabled, this group can help with questions or problems you might have on the services to which you are entitled. The Advocacy Center can be reached at 2371 Executive Center Circle, W., Suite 100, Tallahassee, FL, 32301, or by phone at (800) 342-0823.

Q: Which activities will be restricted?

A: A common-sense rule is to make certain that if you should lose consciousness, what you are doing will not put you or someone else at risk of injury. These restrictions depend on the type and frequency of seizures you have.

Children with epilepsy should be supervised closely during all activities that may become potentially harmful for them or others if they have a seizure. We suggest wearing a helmet when riding bicycles and when climbing slides and jungle gyms.

You should never swim alone and there should always be adult supervision. You can participate in most team sports, including basketball and baseball, provided you wear a mask to protect your face. We do not recommend football or boxing. Most individual sports are okay, except for scuba diving, parachuting, or any activity involving a car, truck, or motorcycle.

Q: What effects can my medication have on thinking?

A: All anti-epileptic medications can have undesirable effects on your thinking. These vary from patient to patient. If your child has a seizure disorder and is already hyperactive, phenobarbital or barbiturates may make the condition worse. Some medications also may cause physical side effects including a hairy overgrowth, increase in bony development, coarseness of

facial features, and gum overgrowth. It is best to discuss with your doctor the type of medication you are taking and their side effects.

Q: Will I be able to drive?

A: In Florida, if you are not under a doctor's care, you must be seizure-free for two years before you can drive. In certain circumstances, with your doctor's approval, you can drive after being seizure-free for a shorter period of time. The laws in other states vary. It is advisable to contact the state government or ask your doctor regarding the laws in the state where you live.

Q: Will my seizure disorder change with age?

A: A seizure disorder may change with age, but not necessarily in a predictable manner. Some patients may be seizure-free for five to 10 years and then have a relapse of seizure activity. Others may outgrow the seizures altogether. If you have a seizure disorder caused by trauma, you may see some improvement over time. If you have frequent seizures, you may notice that over time these seizures can affect your thinking and, in particular, your memory.

Q: Should I wear a medical-alert bracelet?

A: This is a good idea. The bracelet should include information about your medication(s). This provides medical personnel information about your condition should you have a seizure when you are not accompanied by someone familiar with your condition. Most companies charge a small fee for the bracelets. Contact your local pharmacy to see if it carries these bracelets, call Medic Alert at (800) 432-5378, or visit their website at www.medicalert.org.

Q: If I have children, are they susceptible to seizures?

A: That depends on the type of seizure disorder you have. Some types of epilepsy occur more frequently in families. Parents, siblings, and children may be more likely to have epilepsy than the general population. In other cases, there is little risk of your children developing seizure disorders.

Women should discuss their situation with their doctor before becoming pregnant. Genetic counseling may be advised before planning a family.

Q: Will my child outgrow the seizure disorder?

A: This depends on the type of epilepsy. If your child has absence or Rolandic epilepsy, the answer is probably yes. If it's an epilepsy such as complex partial seizures, probably not. Some people with epilepsies such as complex partial seizures may have a period of five to 10 seizure-free years.

Q: What can I do to make it easier for my child to function in social situations?

A: There is a delicate balance between letting your child participate in social activities and ensuring your child's safety. The first thing you can do is alert adults (teacher, coach, scout leader) that your child is prone to seizures and educate them about what to do if a seizure occurs. This should include first aid information as well as facts about how to make certain your child does not

become injured during a seizure. If appropriate, the other children in the activity can be told that your child is prone to seizures. Several books and organizations are listed in the Resource section of this guide. Those resources can help you and your child in this process.

The best thing for your child is for you to allow participation in activities appropriate for your child's age group. By involving your child in social situations, you can promote healthy physical and emotional growth, dispel myths, and help people to understand epilepsy and seizure disorders.

Financial Aid Assistance

There are several government-sponsored financial aid opportunities available for people with seizure disorders. If you meet the qualifications for these programs, you often can receive help meeting medical financial obligations and also may be eligible for food stamps, rehabilitation, and other services.

Although it is often frustrating waiting for approval from these programs, the potential benefits still make it worthwhile to apply. You must be persistent through the application process. Remember, you and your family are your own best advocates. Usually, it is best to apply for these programs in person. In your county, contact the agency in advance to find out if appointments are necessary and what documents you need to bring. We suggest that you keep a record of your contacts, including names and telephone numbers. Some agencies, such as Social Security, will do a telephone interview.

Below is a brief outline of some of these programs. Since the information on these programs is subject to change, it is best to contact a clinical social worker for assistance. At Shands at UF, contact Patient and Family Resources at (352) 265-0224.

Supplemental Security Income (SSI)

Available through the Social Security Administration, Supplemental Security Income (SSI) provides financial assistance for income-eligible persons. To be eligible, patients must have limited financial resources and income. In addition, Florida's Disability Determination Services, consisting of a physician and an evaluation specialist, must determine if it is likely the patient will be disabled for at least 365 consecutive days or permanently. If the patient is eligible for Supplemental Security Income, then Medicaid benefits also will apply. If approved, patients receive a monthly income and also may be eligible for other programs, such as food stamps. Contact your local Social Security Administration office to apply.

Social Security Disability Insurance (SSDI)

Also available through the Social Security Administration, Social Security Disability Insurance (SSDI) provides financial assistance if the claimant is found to be disabled and meets the currently insured status. Benefits begin five full months after the date of disability onset. Eligibility for benefits is based on the patient's work history and the

amount of benefit is based on earnings. A team from Florida's Disability Determination Services, consisting of a physician and an evaluation specialist, must determine there will be permanent or extended disability for at least 365 days. Although this program can take longer before payments begin, it may provide the disabled person better benefits. Patients also may be eligible for Medicare benefits after two years. If approved, patients receive a monthly income and also may be eligible for Medicaid and food stamps. Contact your local Social Security Administration office to apply.

Medicaid

Even if patients don't qualify for Medicaid through the Supplemental Security Income program, Medicaid may still provide financial assistance for medical services. Patients may qualify for the Medically Needy Program or Temporary Assistance for Needy Families (TANF) [see page 29]. The Medically Needy Program provides healthcare assistance to families and individuals. To see if you are eligible for Medicaid through the Medically Needy Program, contact your local Department of Children and Families office at 1000 NE 16th Ave., Gainesville, FL 32601. In Florida's District 3, the 11-county area surrounding Gainesville, the phone number is (352) 955-5339.

Temporary Assistance for Needy Families (TANF)

As mentioned earlier, if patients have dependent children under the age of 18 and have a limited income, they may be eligible for Temporary Assistance for Needy Families (TANF). Benefits from this program can include Medicaid and a monthly income. Patients also may meet the financial criteria for food stamp eligibility. Contact your local Department of Children and Families office to apply for this program. In District 3, call (352) 955-5339 or (352) 955-5176.

Children's Medical Services

Children's Medical Services (CMS), a program offered through the Department of Health, provides medical care to some children under 21 who have a chronic medical condition. To apply for this program, contact your local CMS office.
In District 3, the phone number is (800) 523-7545, or in the Gainesville area, call (352) 334-1400.

Vocational Rehabilitation

This federal program is administered by the Florida Department of Labor and may provide patients with financial assistance for rehabilitation services. These services are provided with an emphasis on returning the patient back to work and may include medical services, counseling, work evaluation, retraining, and educational expenses. For information, contact your local Department of Labor office, Division of Vocational Rehabilitation. In the Gainesville area, call (352) 955-3200.

The Epilepsy Services Program

The Epilepsy Services Program, a support agency funded by the Florida Department of Health and administered by the University of Florida's Department of Neurology, helps seizure disorder patients locate services. Although primarily serving the patients in Florida's District 3, the professionals in this office also can help patients from outside the district find assistance in their areas. The office is located in Gainesville and offers educational programs as well as support groups for area residents. For more information, call (352) 392-6449.

Directory of Resources

This directory provides possible resources for epilepsy patients and their families. The listing of an organization, website or publication does not necessarily imply endorsement. You are encouraged to contact these resources and ask for a complete listing of services offered, publications available and fees charged. Many of these organizations offer their services and educational materials at no cost. It is important to recognize that while information about various treatment options and experiences can be helpful, only candid discussions between individual patients, their physicians and families can yield the most appropriate treatment option.

Advocacy Center of Florida
2671 Executive Center Circle, W., Suite 100
Tallahassee, FL 32301
(800) 342-0823
(850) 488-9071
website: http://www.advocacycenter.org
Advocates for the rights of individuals with disabilities.

American Academy of Neurology
1080 Montreal Ave.
St. Paul, MN 55116
(800) 879-1960
(651) 695-1940
website: http://www.aan.com
Educational materials and referrals to other resources.

American Epilepsy Society
342 N. Main St.
West Hartford, CT 06117-2507
(860) 586-7505
website: http://www.aesnet.org
e-mail: info@aesnet.org

Centers for Disease Control and Prevention
National Center for Chronic Disease Prevention and Health Promotion
4770 Buford Highway, NE, Mailstop K13
Atlanta, GA 30341-3717
(770) 488-5080
website: http://www.cdc.gov/nccdphp/nccdhome.htm
Educational materials available.

The Charlie Foundation to Help Cure Pediatric Epilepsy
1223 Wilshire Blvd.
Santa Monica, CA 90403
(800) FOR-KETO (367-5386)
website: http://www.geocities.com/Hollywood/Hills/2844/mso_charlie.html
Free video on the ketogenic diet.

Shands Neurological Center at the University of Florida
Comprehensive Epilepsy Program
P.O. Box 100236
Gainesville, FL 32610-0236
(352) 265-8404 Neurology
(352) 392-4331 for Neurosurgery
website: http://neurology.ufl.edu/divisions-2/epilepsy/
e-mail: epilepsy@neurosurgery.ufl.edu

Epilepsy Foundation of America
4351 Garden City Drive
Landover, MD 20785-2267
(800) EFA-1000 (332-1000)
(301) 459-3700
website: http://www.efa.org
e-mail: webmaster@efa.org
Educational materials, referrals, and support groups.

Epilepsy Foundation of Northeast Florida
6028 Chester Ave., Suite 106
Jacksonville, FL 32217
(904) 731-3752
website: http://www.efnet.org
Case management services for the uninsured, educational materials, support groups and referrals to other resources.

Epilepsy Services of North Central Florida
1010 NW 8th Ave., Suite B
Gainesville, FL 32601
(800) 330-9746
(352) 392-6449
website: http://www.floridaepilepsy.org/northcentral.htm
e-mail: jlyons@college.med.ufl.edu
Case management services and social and educational programs.

Federation for Children with Special Needs
Director of Health Issues
95 Berkeley St., Suite 104
Boston, MA 02116
(617) 482-2915
website: http://www.fcsn.org
e-mail: fcsninfo@fcsn.org
Educational materials and referrals to other resources including special education programs and support groups.

Keto Klub, Inc.
Elaine Huffman, President
61557 Miami Meadows Court
South Bend, IN 46614
(219) 299-3438
website: http://www.ctel.net/~lynzac/ketoklub
e-mail: ketoklub@aol.com
Newsletter focusing on the ketogenic diet.

Lennox Gastaut Syndrome Support Group
website: http://www.wssg.org.uk/lgssg
e-mail: wssg@foden.net
An on-line resource for patients with this severe form of epilepsy and their families.

MedicAlert Foundation
2323 Colorado Ave.
Turlock, CA 95382
(800) 432-5378
(209) 668-3333
website: http://www.medicalert.org
Free catalogue.

National Institutes of Health
National Institute of Neurological Disorders and Stroke
P.O. Box 5801
Bethesda, MD 20824
(301) 496-5751
website: http://www.ninds.nih.gov
Educational materials and research study updates.

Parents Helping Parents (PHP)
3041 Olcott St.
Santa Clara, CA 95054-3222
(408) 727-5775
website: http://www.php.com
Directory of resources, educational materials and support groups.

Reading List

Adults

Brainstorms — Epilepsy in Our Own Words Steven C. Schachter, MD, et al, Pub: Raven Press, January 1993. Paperback and Hardcover. Personal accounts of living with seizures.

The Brainstorms Companion — Epilepsy in Our View Steven C. Schachter, MD, et al, Pub: Raven Press, January 1994. Paperback. Family members, co-workers and friends of people with epilepsy speak candidly about witnessing seizures.

The Brainstorms Family: Epilepsy on Our Terms Steven C. Schachter, MD, et al, Pub: Raven Press, June 1996. Paperback. An enlightening book that presents firsthand personal accounts of children with seizure disorders and their parents.

Epilepsy: A New Approach Adrienne Richard, Joel Reiter, Pub: Walker and Co., 1996. Paperback. An uplifting book that combines conventional medical treatments with innovative and natural stress-reducing strategies and self-help techniques.

The Epilepsy Diet Treatment: An Introduction to the Ketogenic Diet (2nd Ed.) John M. Freeman, MD, Pub: Demos Publications, January 1996. Paperback. An introduction to the facts on the ketogenic diet.

The Ketogenic Cookbook Dennis Brake, Cynthia Brake, Pub: Pennycorner Press, December 1997. Paperback. The ketogenic diet is presented in an appetizing and interesting collection of recipes in this innovative cookbook.

Legal Rights of Persons with Epilepsy: An Overview of Legal Issues and Laws Pub: Epilepsy Foundation of America, January 1992. Paperback. An in-depth overview of the issues that persons with epilepsy, their families and advocates may face.

Living Well with Epilepsy (2nd Ed.) Robert J. Gumnit, Pub: Demos Publications, 1997. Paperback. Offers information on all aspects of diagnosis and management of epilepsy, with an emphasis on active participation in the process.

Epilepsy and the Family: A New Guide Richard Lechtenberg, 1999. Paperback. A comprehensive book for parents and health professionals dealing with the effects of epilepsy on families.

Seizures and Epilepsy in Childhood: A Guide for Parents John M. Freeman, MD, Eileen P.G. Vining, MD, and Diana J. Pillas, Pub: The Johns Hopkins University Press. The facts and resources you need to keep your child's seizures from becoming a handicap.

For Young People

Dotty the Dalmatian Has Epilepsy Dr. Wellbook, Pub: Tim Peters and Co., May 1996. Paperback. Dotty the Dalmatian has epilepsy, but learns to accept her seizures and get back to helping her fire fighting friends.

Mom, I have a Staring Problem: A True Story of Petit Mal Seizures and the Hidden Problem it may Cause Marian Carla Buckel, Tiffany Buckel, March 1992. Paperback.

Lee, the Rabbit with Epilepsy Deborah M. Moss, Pub: Woodbine House, October 1989. Hardcover. A brightly illustrated picture book that follows the adventures of a small rabbit who has seizures.

Issues and Answers: Exploring Your Possibilities: A Guide for Teens and Young Adults with Epilepsy Pub: Epilepsy Foundation of America, June 1992. Paperback.

Julia, Mungo, and the Earthquake: A Story for Young People About Epilepsy Saxby Pridmore, et al, Pub: Imagination Press, December 1991. Paperback. Tells the story of a young girl with epilepsy who becomes the school heroine.

My Friend Emily Susanne M. Swanson, Pub: Writer's Press Service, September 1994. Paperback. A heart-warming tale of Kathy and her friend, Emily, who has epilepsy. Child-to-child explanations of what seizures are and how to best deal with them when they occur.

Taking Seizure Disorders to School Kim Gosselin, Moss Friedman, Pub: Jayjo Books, January 1998. Paperback. Written to educate the classmates of a child with epilepsy. This book helps create a supportive school environment.

GLOSSARY

anterior temporal lobectomy: surgery to remove a seizure focus located within the temporal lobe

aura: the first manifestation of a seizure (sensory, auditory, olfactory, visual, and/or autonomic); sometimes the word aura is used to mean a warning; occurs before clinically observable signs

automatism: any involuntary activity; unconscious acts for which the patient has no recollection, frequently seen during complex partial seizures: lip smacking, eye fluttering, purposeless movements, excessive swallowing, and unintelligible speech

cerebrum: a cerebral hemisphere of the brain

collodion: a glue-like substance used to secure electrodes to the scalp

corpus callostomy: surgery where the fibers connecting the two cerebral hemispheres of the brain are severed

corpus callosum: a large band of white matter that connects the right and left sides of the brain

craniotomy: a surgical opening of the skull

deja vu: strange objects or people may be perceived as familiar

electroencephalogram (EEG): the process of recording electrical brain activity and the resulting wave-like tracing

electrocorticography (ECOG): the process of recording electrical brain activity using electrodes that have been placed directly on or in the brain

electrode: a device that conducts and measures electrical activity

epilepsy: a condition characterized by recurrent seizures

epileptic cry: a sound made during a seizure; usually occurs at the onset of a generalized tonic-clonic seizure

epileptogenic focus: a limited region of the brain displaying a given EEG pattern, either normal or abnormal. If abnormal, it is called an epileptoform focus.

extratemporal focal resection: surgery to remove any seizure focus not located within the temporal lobe

frontal lobe: one of the four lobes of each cerebral hemisphere

functional mapping: the process of stimulating several areas of the brain using small amounts of electrical current to identify areas related to the performance of activities vital to daily living

generalized seizures: abnormal brain activity (seizure) involving both sides of the brain

gliosis: an increase in neuroglial tissue within the central nervous system

hemispherectomy: surgery to remove one of the two cerebral hemispheres

hemisphere: one of the two sides of the cerebrum (brain); each hemisphere is composed of four lobes, namely frontal, temporal, parietal and occipital

hypotonia: decreased tone in the skeletal muscles

ictal: relating to or happening during a seizure

infantile spasms: a serious seizure disorder in young children

interictal: between seizures; referring to the patient's behavior when not having a seizure

intracranial: situated or occurring within the cranium (skull)

intractable: not easily managed, controlled or cured

Jacksonian March: the spread of a seizure from one motor area to the next or from one sensory area to the next

jamais vu: familiar objects or people are perceived as strange

neuropsychological testing: a combination of studies that help determine how well the brain is performing various functions

occipital lobe: one of the four lobes of each hemisphere

parietal lobe: one of the four lobes of each hemisphere

partial seizures: abnormal brain activity (seizure) which begins in one side of the brain

postictal: relating to or happening after a seizure; period of confusion and/or fatigue

preictal: relating to or happening before the seizure

Rolandic epilepsy: a seizure disorder that originates from the Rolandic fissure, the fissure between the parietal and frontal lobes of the brain ***(see diagram on page 13)***

Rolandic fissure: a crease or fold that separates the frontal and parietal lobes of each hemisphere of the brain

seizure: sudden change in normal brain activity that causes distinctive changes in behavior and body function

sphenoidal electrode: small wire-like electrodes inserted above the jawbone to measure temporal lobe brain activity

status epilepticus: continuous seizure activity lasting for 20 minutes or longer in duration, or recurrent seizures occurring with impairment of consciousness that are not associated with return of normal consciousness between seizure activity. It is considered a medical emergency that requires immediate treatment.

Sylvian epilepsy: a seizure disorder in which the focus involves the areas of the brain that surround the Sylvian fissure. This fissure separates the temporal lobe from the frontal and parietal lobes of the brain ***(see diagram on page 13)***.

Sylvian fissure: a crease or fold that separates the frontal and temporal lobes of each hemisphere of the brain

telemetry: the process of electrically recording information and transmitting it to a distant location

temporal lobe: one of the four lobes of each hemisphere

Todd's paralysis: a focal weakness in an arm or leg after a generalized tonic-clonic seizure

visual field testing: special vision tests that map the range of sight at a given instant without moving the eyes

Wada test: a test used to determine which side of an individual's brain controls language and memory skills. This test is named after Dr. Wada who developed the test.

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The information in this booklet is furnished to you by the Shands Neurological Center at the University of Florida in cooperation with the University of Florida College of Medicine and the Departments of Neurology and Neurological Surgery. This material is selective and does not cover all the information about this topic. If you have any questions or need clarification on this material, consult your physician. This information is not a substitute for the recommendations of your physician.

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Meet the Experts

The UF Comprehensive Epilepsy Program team is composed of many highly skilled physicians and healthcare professionals, each an expert in his or her field. To better acquaint you with some of the physicians you may meet during your treatment, below is a brief description of the standard of excellence they bring to your care.

Robin Gilmore, MD
Dr. Gilmore is a professor of Neurology in UF's College of Medicine and is the medical director of the Epilepsy Monitoring Unit at Shands Neurological Center. She is certified by the American Board of Psychiatry and Neurology, and the American Board of Clinical Neurophysiology. Dr. Gilmore has subspecialties in Clinical Neurophysiology, Epilepsy, and Pediatric Neurology. Dr. Gilmore has a keen interest in the treatment of epilepsy and has worked with both adult and pediatric patients for more than 20 years.

Stephan Eisenschenk, MD
Dr. Eisenschenk is an assistant professor of Neurology in UF's College of Medicine. He has subspecialties in Clinical Neurophysiology, Epilepsy, and Sleep Medicine. In clinical epilepsy, his main interests include localization of the seizure origin for surgical resection and intraoperative and extraoperative mapping of brain function to minimize the risk of secondary loss of motor, language, and visual function following epilepsy surgery. Dr. Eisenschenk's research interests include intracranial propagation patterns of seizures and the cellular and biochemical processes involved in epilepsy.

Basim Uthman, MD
Dr. Uthman is an associate professor of Neurology in UF's College of Medicine. He also serves as the assistant chief of Neurology and as director of the Clinical Neurophysiology Laboratory at the Veteran Affairs Medical Center in Gainesville. Dr. Uthman has subspecialties in Epilepsy, Clinical Neurophysiology, and Neuropharmacology and is certified by the American Board of Psychiatry and Neurology and the American Board of Clinical Neurophysiology. He has extensive post-doctoral training in epilepsy, including surgical evaluation, and has been widely published on a large variety of epilepsy-related topics. He conducts investigational trials to study new medications and procedures for the treatment of epilepsy and other neurological disorders.

Paul R. Carney, MD
Dr. Carney is an assistant professor of Pediatrics in UF's College of Medicine who specializes in Neurology, Epilepsy, Sleep Disorders, and Clinical Neurophysiology at Shands

Meet the Experts

Children's Hospital. Dr. Carney has a special interest in seizures in children and adolescents and continues to conduct extensive research in this area. He has expertise in a range of pediatric neurological problems and therapies including epilepsy surgery, anticonvulsant investigational trials, ketogenic diet, and sleep disorders.

Ronald G. Quisling, MD
Dr. Quisling is a professor and chief of Neuroradiology in UF's College of Medicine. He has clinical interests in Interventional Embolization, head and neck magnetic resonance imaging, computerized tomography, Cerebral Angiography, and Interventional Neuroradiology. Dr. Quisling has research interests in Interventional Neuroinvasive techniques for AV malformation treatment, functional imaging in Pediatric Neuro-oncology patients, and evaluation of seizure patients for hippocampal injury.

J. Chris Sackellares, MD
Dr. Sackellares is a professor of Neurology and Neuroscience in UF's College of Medicine. He has subspecialties in Epilepsy and Electroencephalography and is certified by the American Board of Psychiatry and Neurology and the American Board of Clinical Neurophysiology. Dr. Sackellares has served as principal investigator in numerous NIH-NINCDS and other research grants involving the pathophysiology of human epilepsy and the clinical evaluation of antiepileptic drugs.

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Dr. Roper is an associate professor of Neurological Surgery in UF's College of Medicine. He has had extensive training in neurological surgery for epilepsy at UCLA and directs the Surgical Epilepsy Program at the Shands Neurological Center at UF. He is certified by the American Board of Neurological Surgery and has a subspecialty in Adult and Pediatric Epilepsy Surgery. Dr. Roper has received several honors and awards including an Individual National Research Service Award for his research on epilepsy.

Lorna S. Williams, MD
Dr. Williams is an assistant professor of Radiology in UF's College of Medicine. She is board certified in Diagnostic Radiology. Dr. Williams has clinical interests in Neuroradiology, Interventional Radiology, magnetic resonance imaging and computed tomography.

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