



Beating Bad Seizures, Part 1 of 3

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If you are reading this article, I assume that you are having problems with seizures or problems with side effects of medication. Take heart. You may feel like you are at the end of your rope, but most likely you are only at the end of your knowledge. In epilepsy, knowledge is power – and seizure control.

I am Robert J. Mittan, Ph.D., an epilepsy neuropsychologist. For nearly 25 years I have been teaching patients and families how to cope with epilepsy through the Seizures & Epilepsy Education (S.E.E.) seminar program. Over the years I have had the privilege to meet thousands of parents of children with epilepsy. Most of them were struggling with difficult to control seizures. Most were afraid for their child. Many were frustrated with medical care. A lot of the children had more health problems than epilepsy. Few parents realized how some good information could make a profound difference in seizure control and in their daily lives.

In the first article (June) I am going to help you understand what epilepsy is and how it is diagnosed. The successful treatment of epilepsy depends upon an accurate diagnosis. You may be surprised to discover that for most children that diagnosis depends upon you.

The second article (July) explains the treatment options available to your child. Never before has there been so many ways to control seizures. Never before have parents needed to understand those treatment options so completely. There are four entirely different types of treatments for epilepsy. A fifth one is on the horizon. Each of these can be used when another one fails, and some of them can be combined. Thoughtful use of these strategies can be the key to seizure control.

In the final article (August), I will talk about the steps you can take when you are faced with difficult to control seizures. That article will pull together the knowledge you gained about diagnosis and treatment in the previous articles in order to give you the understanding you need to get the best results for your child.

I am sure you already know that epilepsy is more than just a medical diagnosis. Epilepsy affects the entire family. It affects the child's development, social skills, and school performance. In four future articles I will go on to discuss the psychological, family, social, school challenges of epilepsy along with some practical ways to overcome these problems. I only have the space to cover the basics, but you will find that understanding the basics can be very powerful in giving you more control and giving you back your family's life.

THE GOAL OF TREATMENT

The goal of epilepsy treatment is very simple: **NO SEIZURES** and **NO SIDE EFFECTS**. That's it. In recent years, I have heard more complaints about medication side effects than I have about seizures (though I do hear plenty about seizures.) Treatment should *not* be part of the problem. Unfortunately, I have also discovered parents often do not bring up problems with side effects to the physician – or they barely mention them. Remember the physician does not live with you. If you do not provide full and detailed reports of the problems you are having, even the most expert doctor can't make it better. Trust your own sense if you feel your child is overmedicated – and back it up with the clearest description your child's changed behaviors and appearance you can. If you feel the doctor is not listening to you, write your concerns down and hand it to the doctor. Keep a dated copy for yourself. You may discover written words get more response than spoken words.

The same is true for seizures. The physician needs to know in complete and accurate detail how many seizures your child has had and what type of seizures they were. Many children have more than one type of seizure, and it is important to know the time, date, number, and circumstances of each of them. Sometimes small changes in seizure patterns can give big clues to more effective treatment. If you go into the physician saying your daughter has “had about the same number as last time,” you aren't providing the doctor with much help. Keep a **seizure diary**. Write both seizures and side effects down. Be sure to bring it with you when you see the doctor! There are several pre-designed seizure diaries out there. The S.E.E. program Seizure Diary prompts you to record all the critical information. You don't have to buy one, you can create your own. The important part is “*do it.*”

WHAT IS EPILEPSY?

What is this thing we are dealing with called a seizure disorder or epilepsy? Epilepsy is the condition where a person has “recurrent, unprovoked” seizures. Recurrent means more than one. Unprovoked means that the seizures occur at a time when the body, and especially the brain are not clearly sick – there is no infection, stroke, or injury occurring moments before the seizure. The term “seizure disorder” is just another name for epilepsy.

What causes a seizure? Most people know seizures are due to an electrical disturbance in the brain. A lot of people have heard that a seizure is a “short circuit” or an “electrical storm” in the brain. I hate those explanations because they are wrong and they scare people. If you have ever seen a real short circuit in an appliance or wall plug, it is a frightening and destructive thing. POW! and a shower of sparks. The same with the example of lightning in a storm. Parents who hear those explanations are afraid seizures might be just as destructive to their child's brain cells, with each seizure causing further brain damage.

Our brains do operate using electricity, but in very, very tiny amounts. Not only that, these small electrical charges stay inside each brain cell. The charges are much too small to jump from one brain cell to the next. Brain cells “talk” with each other with chemicals, called “neurotransmitters,” not with electricity.

So what is a seizure in the brain? A seizure is like the “wave” you see in the stadium at a football game. Normally everyone in the crowd is doing their own thing – talking, eating a hotdog, or questioning the referee's eyesight. Then along comes a cheerleader who wants the crowd to do the “**wave**.” Suddenly, each person stops what he or she was doing. Whole groups suddenly stand up together and sit down again. The wave spreads from one group of people to the next until sometimes it goes around the entire stadium. That is what a seizure is. Normally brain cells are all doing their individual thing. Then something comes along that causes them to stop doing their individual thing and instead join with others to do the “wave.” Depending upon where this “wave” starts, how far it spreads, and how quickly the brain cells “stand up and

sit down,” you get different kinds of seizures. The brain’s electrical *and* chemical systems are required for the “wave” to occur.

DIAGNOSIS

Differences in seizure types are very important. The medications used to treat seizures often differ for different kinds of seizures. If the seizures are not correctly diagnosed, the wrong medication could be chosen. So, the starting point for effective treatment is an accurate diagnosis. However, there are several real challenges in coming up with an accurate diagnosis. The biggest one is what I call the “*First Cosmic Law of Epilepsy*.” This law is “Thou shalt never have thy seizure in the doctor’s office where he or she can see it!” Most children are very good at obeying this law (they should do so well with some other rules, right?) As a result, the doctor must depend on a description of the seizure from family members who are inevitably frightened at the time – and who have no training in seizure observation! Often the doctor can guess correctly, but this is not a formula for diagnostic accuracy. This is not the parents’ fault or the doctor’s fault. We find on average that about 40 percent of parents who go through the seizure observation training part of the S.E.E. program discover that their child has a different kind of epilepsy than they thought.

Seizure Observation

What should you look for when observing seizures? There are three important observations to make: What happened right as the seizure was *beginning*, what happened *during* the seizure, and finally, what happened *after* the seizure was over.

There are two main families of seizures. One of those families is *generalized* seizures. The electrical / chemical disturbance begins throughout the brain all at once. There are several different kinds of generalized seizures. (See the side panel, *Common Seizure Types*.) Because the whole brain participates in the “wave” from the start, there is *never* a warning that the seizure is about to occur. It just suddenly happens. The second family of seizures is *partial* seizures. These seizures are called “partial” because they start in a specific part of the brain, not in the whole brain. Unlike generalized seizures, partial seizures can have a warning before they occur. Sometimes this warning is called an “*aura*.” Auras are actually a kind of seizure (called “simple partial seizures.”)

What happens at the very beginning of a seizure is often the most important thing to observe. Carefully watching the beginning of a seizure can give important clues as to whether the seizure is a partial seizure or a generalized seizure. This is important because the medications used to treat generalized seizures tend to be different from the ones used to treat partial seizures. If the diagnosis is wrong, it is easy to choose the wrong medication. In true generalized seizures, there is never a warning before a seizure occurs. Partial seizures, however, may have a warning rarely, often, or all of the time. Another clue that a seizure is a partial seizure is it starts in a specific part of the body or begins with an unusual movement, sensation, smell, emotion, or thought at the start of the seizure. The spot in the brain where the partial seizure starts is called the seizure “*focus*.” Since different parts of our brain do different things, what happens at the beginning of the seizure depends upon where the seizure focus is located in the brain. This means the first movement or sensations that occur at the beginning of a partial seizure are important clues as to where in the brain the seizure focus is located (See the side panel, *Seizure Focus and the Brain*.)

Often the second most important part of the seizure to observe is what happens after the seizure. After certain types of seizures are over, the child is confused. It may take minutes and sometimes hours for the child to become completely himself or herself. This is called “*post-ictal confusion*.” “Post” means “after,” “ictal” is the medical term for a seizure or event, and “confusion” refers to the fact that the child may

temporarily not know where he or she is or what was happening right after the seizure. Post-ictal confusion is caused by a temporary memory disturbance. Even when the child has returned to full consciousness, the memory disturbance can last for hours after. This can make things like learning in school or test taking difficult, even though the child otherwise appears normal. There are two kinds of seizures that sometimes look alike, but are very different and require different medications. These are the **Absence** seizure and the **Complex Partial** seizure. Both can appear as little more than a momentary lapse of consciousness. However, after an Absence seizure there is an immediate and complete return to full consciousness with no post-ictal confusion. A hallmark of a Complex Partial seizure is the presence of post-ictal confusion after the seizure – at least for a few seconds, and usually longer.

Surprisingly, what happens during a seizure is sometimes the least important part of seizure observation. At other times it can be of great help. For example, Absence seizures usually last for several seconds, while Complex Partial seizures usually last a couple of minutes or more. On the other hand, Tonic-Clonic seizures and Partial Seizures that Secondarily Generalize look the same during the main part of the seizure and afterwards. Despite appearances, they are entirely different kinds of seizures that usually require different medications. Sometimes a seizure starts as a partial seizure, with the “wave” occurring in just part of the brain. In some children the “wave” continues to spread to involve the entire brain. This is what is meant by the term “**Partial Seizure Secondarily Generalized.**” When this happens, the behavior on the outside of the child looks the same as a **Tonic-Clonic** seizure: a **tonic** phase of stiffening all over the body and sometimes a throaty cry, then a **clonic** phase where the body and muscles appear to be jerking.

One of the most common errors in seizure observation is to confuse Tonic-Clonic and Secondarily Generalized seizures. The key to distinguishing these is to carefully observe what happened at the beginning of the seizures (notice the plural – you may have to see several seizures before you can get this right.) True generalized Tonic-Clonic seizures never, ever have an aura or warning before they occur. If the child can tell you he or she is about to have a seizure, or if you notice a particular behavior is sometimes present at the beginning of the seizure, such as the head turning to the side, an unusual arm movement, hand movement, sudden change in mood, or other odd behavior or sensation just before the seizure, then there is a good chance it is a Partial Seizure Secondarily Generalized rather than a Tonic-Clonic seizure. That difference changes the treatment strategy.

“Drop attacks” is a common name for **Atonic** seizures. With Atonic seizures, the child falls because he or she has a sudden loss of muscle tone – the body goes limp and drops straight down to the floor. **Tonic** seizures (stiffening of the entire body) can also cause a child to fall to the floor. In Tonic seizures the body gets stiff and falls like a tree rather than straight up to down. While both seizures may be brief, Tonic seizures tend to last longer. Partial seizures can also mimic these kinds of seizures, further complicating diagnosis. **Myoclonic** seizures, where there is a sudden muscle jerk that involves the entire body or part of the body, can also cause the child to lose balance and fall. It is another type of seizure that can be confused with Atonic seizures or “drop attacks.”

I hope you are getting the message that diagnosis can be difficult, yet a correct diagnosis is often essential to successful seizure control. Ideally parents should know about the many different kinds of seizures and the kinds of observations that are useful in distinguishing them from each other. Unfortunately parents seldom have the opportunity to learn about seizures and to practice seizure observation skills. In the S.E.E. program this training requires a couple of hours and includes a videotape of different kinds of seizures. If you do not have access to this kind of training, there is still something very useful you can do.

Take advantage of the greatest advancement in seizure observation in the 3,000-year history of epilepsy. **Videotape** your child’s seizures. You may have to set up the camera and run it for days or weeks before you catch a seizure. Just rewind the tape and use it again. *Be sure your child’s entire body fits in the picture frame.* If your child has seizures in her sleep, use a nightlight in the bedroom. Most video cameras will

record OK in low light. Turn up the thermostat so the child can sleep without a sheet or covers on top, and dress the child in pajamas that have trousers, not skirts, so that leg activity can be easily seen. Once you have the seizures on tape, the doctor can go over it frame by frame if necessary to come up with a more accurate diagnosis.

EEG

Sometimes the doctor can get around observation problems with an EEG (electroencephalogram.) The EEG can detect the tiny electrical activity of the brain that is a part of the “wave.” If the doctor is lucky enough to catch a seizure while the child is hooked up to the EEG machine, she may be able to tell what kind of seizure it is by seeing where the “wave” starts, where it spreads, and how fast it goes “up and down.” Notice I said “lucky.” When the child is not having seizure activity in the brain, the EEG will find only normal electrical activity. Guess what is happening most of the time for most children with epilepsy? No seizures. This is why your child can have epilepsy even though he or she has had many EEGs that all failed to find any seizure activity.

If diagnosis is a real issue for your child, a special kind of EEG can be performed. It is commonly called “**intensive monitoring**” or “**video monitoring**.” This is done in the hospital. The child is hooked up to an EEG machine in a special hospital room that contains a video camera. The video and EEG run 24 hours a day, usually for one to five days until seizures are recorded. In addition to being able to wait for the child to have a seizure, this procedure allows the doctor to see what is happening on the outside of the child (the video) and at the same moment see what is happening on the inside (the EEG.) Intensive monitoring is also an important step when considering surgery for the treatment of epilepsy (more about that later.)

SEIZURES & BRAIN DISORDERS

Seizures are like sneezes – they are the symptom of another disorder. Seizures are a symptom of some kind of brain disorder. The fact that your child has seizures does not tell you what the brain disorder is. It could be slight tissue damage from a brain infection or stroke, a small abnormality in brain development, or a genetic variation in brain function – any of a hundred different things. In about 75% of children this disorder is so small or so subtle it can’t be found, even with the most up-to-date brain scans. The only way we know something is there is because the child is having seizures. Many children will have what I call the “million dollar workup” of medical tests, only to find nothing. That is actually the best news you can have. As a rule of thumb, the larger and more detectable the brain disorder the seizures are a symptom of, the more difficult the seizures will be to control. There are exceptions to this rule, but this sometimes inaccurate rule of thumb can alert you to what you might expect.

Another rule of thumb is seizures that start in the first year of life tend to be troublesome. Again there are exceptions. While seizures that start in the first year of life may be particularly difficult to control, it is usually the underlying brain disturbance that is the biggest problem. Some of these get worse over time and some don’t. Much of the attention in treatment may be focused on the brain disorder rather than the symptom of “seizures.” Many of the genetic and developmental abnormalities that lead to severe seizures and brain disturbances occur in the first year. Fortunately these are rare. Knowing if your child has one of these types of epilepsy (usually called an “**epilepsy syndrome**” because they include several kinds of seizures and/or other important symptoms) is important for understanding what you and your child may face in the coming years. (See side panel on **Epilepsy Syndromes**.) Seizures that begin in childhood after the first year of life tend to be easier to control.

Be sure to get the diagnosis from your doctor. Have him or her write down the full medical name of the type of seizures or epilepsy syndrome your child has. You will need this in order to do your own research

into the treatment and possible outcomes of your child's seizures. Diagnoses such as "grand mal" or "petit mal" are not adequate. There is an "International Classification of Epileptic Seizures" and an "International Classification of Epilepsies and Epileptic Syndromes" that provides medical names used in books and articles on diagnosis and treatment, including those on the Internet. In addition there are other names for certain kinds of epilepsy that are generally used and accepted. These types of epilepsy are often named after the person(s) who first reported their discovery.

While seizures may appear frightening, there is not much evidence "regular" seizures in and of themselves cause noticeable brain damage. Researchers have recently been able to show seizures do affect the "wiring" of the brain in subtle ways. Epilepsy scientists argue about how important this is to thinking, memory, and intelligence. Psychological testing shows epilepsy can result in memory disturbances, but good research has only been able to show decreases in intelligence after 20 – 30 years of poorly controlled seizures. Again there are arguments about whether and how often these changes are enough to impair the quality of the person's life. This issue is made all the more confusing because epilepsy goes away with a surprising frequency. If seizures changed the brain so much, how could epilepsy go away so often?

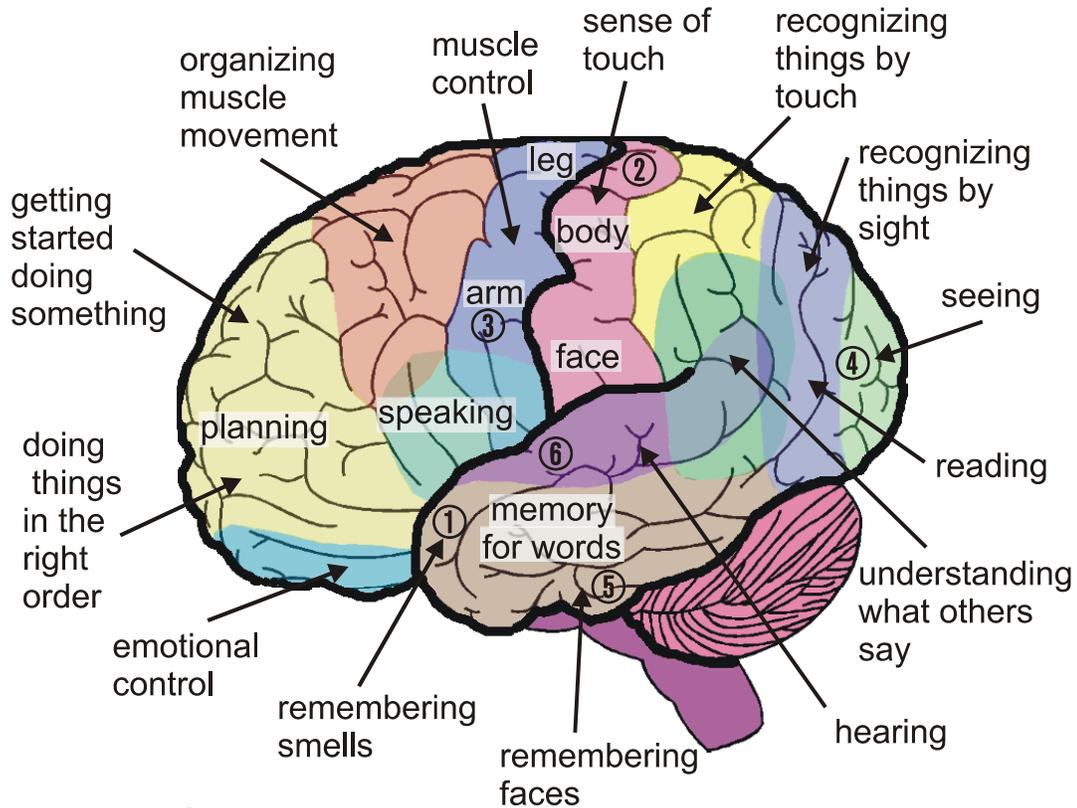
The brain disorder for which the seizures are just a symptom can play the major role in life outcomes. If the brain disorder also left the child mentally or developmentally challenged, this can limit adult success. In such cases, treatment and rehabilitation of the brain disturbance is often much more important to long-term outcomes than are the seizures. There is a minority of children with epilepsy whose seizures are so frequent or so severe that epilepsy is the major problem. These seizures need to be treated as aggressively as possible.

For most children it is the emotional and social reactions people have to seizures and epilepsy (especially in the family) that may have more to do with how the person turns out. Studies have found seizure types and number of seizures have little to do with how successful a person with epilepsy might be in adult life. Some people with frequent seizures are great social and financial successes. Some people who have had only a couple seizures in their life become disabled. Obviously, there is a lot of opportunity to change these reactions and improve outcomes. This will be the topic of future articles. For now we will stick with the medical aspects. In next month's article I will discuss the incredible range of treatment options available to you and your child – and how to get the most out of each.

Side Panel 1: Common Seizure Types

Seizure Type	Seizure Family	Age of Onset	Description	Ease of Control
Tonic-Clonic (Grand Mal)	Generalized (means the wave starts out all over the brain at once)	1-20, rarely adults	Child's entire body stiffens all at once. Will fall to floor if standing. Stays stiff without shaking for several seconds (tonic phase), then begins to shake, slightly at first, then becoming more pronounced and slower (clonic phase). During clonic phase muscles are actually contracting and relaxing, giving the appearance of convulsions. Shaking stops. The child is usually not arousable up to a few minutes after the seizure stops, breathing sounds labored and slowly calms down. The child usually wants to sleep, sometimes for several hours. Once conscious, the person may be temporarily confused after the seizure.	Usually easy
Absence (Petit Mal)	Generalized	4-20, very rare in adults	The child appears to stare into space for a few seconds. Does not fall. There may be slight rhythmic movements of the eyelids, hands, head, or other body part. Recovery is instant after the seizure, with no lingering confusion.	Usually easy
Myoclonic	Generalized	Any age	Sudden, brief, uncontrolled muscle jerk involving the entire body or part of the body (usually the upper half.) May cause the child to fall or to appear to throw something they were holding in their hand at the time of the seizure. These seizures may occur in groups of many, particularly after waking. No impairment of consciousness or very quick return to consciousness after seizure.	Difficult
Tonic	Generalized	Mostly children	Stiffening of the entire body, lasting a few seconds up to a minute or so. Many "drop attacks" are actually tonic seizures.	Difficult
Clonic	Generalized	Mostly children	Stiffening and relaxing of muscles, usually including the entire body. Gives the appearance of "convulsions."	Usually easy
Atonic (drop attacks)	Generalized	Mostly children	Sudden, brief loss of muscle control. The child goes limp. Often falls, with risk of injury from fall. No impairment of consciousness or very quick return to consciousness after seizure.	Very difficult
Infantile Spasm	Generalized	3 to 7(+) months	Looks like a brief muscle spasm. Arms and legs extend for a moment. Head and chin may move toward chest.	Very difficult
Complex Partial	Partial (means the wave starts from just one part of the brain)	Any age	Most common kind of epilepsy. Many different presentations, always with loss or impairment of consciousness. Often starts with a stare. The child may then make chewing movements, pick at their clothing, or wander around. Eyes are open, but the child does not respond to other people. Can last several minutes. The child is confused for moments or several minutes or more after the seizure ends. Memory disturbance after seizure can last minutes to hours.	Often difficult
Simple Partial	Partial	Any age	Varied presentation, all with no loss of consciousness. Could be a body part shaking or a change of sensation in a body part. Can also be a feeling or a thought that suddenly appears, always the same one.	Sometimes difficult
Secondarily Generalized (Grand Mal)	Partial	Any age	Looks like a tonic-clonic seizure, except something else happens before the stiffening phase. This seizure starts as either a simple partial or complex partial seizure (see above for possible symptoms) before the "wave" spreads to involve the entire brain, at which point the seizure looks like a tonic-clonic. Aura before seizure also a clue. Important to recognize the difference from tonic-clonic as the treatment is usually different than for tonic-clonic.	Sometimes difficult

Left Side of the Brain



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- ① If the seizure focus were located here, the beginning of the seizure (aura) would likely be a strong smell. Some people smell something like burnt rubber, rotten eggs, or a rose at the beginning of their seizure. This location is the front tip of the temporal lobe of the brain.
- ② If the seizure focus were located here, the beginning of a seizure (aura) would be some change in sensation (sense of touch) in the right leg. The sensation could be numbness, tingling, pins and needles, or some other unusual feeling. This location is in the “sensory strip” located in the parietal lobe of the brain.
- ③ If the seizure focus were located here, the symptom would be some sort of muscle twitching, movement, or contraction in the right arm. This location is in the “motor strip” of the frontal lobe of the brain.
- ④ If the seizure focus were located here, the beginning of the seizure (aura) would likely be some strange change in vision. Bright lights might suddenly appear, or colors, darkness, or some other change in vision. This location is in the “visual field” of the occipital lobe of the brain.
- ⑤ If the seizure focus were located here, the beginning of the seizure (aura) would likely be the appearance of someone’s face or image. This location is in the temporal lobe of the brain.
- ⑥ This spot is actually on the inside surface of the temporal lobe. If the seizure focus were located here, the beginning of the seizure (aura) would likely be a strong feeling, such as anger, fear, or depression, or a thought or memory.

Side Panel 3: Epilepsy Syndromes

Syndrome Name	Age of Onset	Description	Ease of Seizure Control
West Syndrome (Infantile Spasms)	3 mos – 2 years	Sudden flexing of body (child looks like it is curling up) or less common sudden extension (arms and legs thrust out.) Spasms occur in clusters and can range from very mild to strong. As high as one-fifth may die in early life, usually due to aspiration pneumonia – greatest risk is in children with a known cause for the spasms. About 90% show mental deterioration. Spasms usually stop by age 5, but half or more go on to have other epilepsy, 30% - 40% get Lennox-Gastaut.	Difficult
Tuberous Sclerosis	3 mos – 20 years	Over 80% develop epilepsy. TS can result in several kinds of seizures. Up to 70% have Infantile Spasms, with about 25% having partial or secondarily generalized seizures. Mental retardation 40% - 60%. One quarter to one half have infantile autism. Most problems caused by tubers, not epilepsy. Surgical treatment becoming an option.	Difficult
Sturge-Weber Syndrome	Usually before 2 years	Up to 90% develop epilepsy. Usually Partial or Secondarily Generalized seizures. Seizures can stop for a while, then return. About half are controlled. Surgery is an option for refractory seizures.	Easy to difficult
Severe Myoclonic Epilepsy of Infancy (Dravet Syndrome)	Before 3 years	Often starts with febrile convulsion. Myoclonic seizures eventually follow, may cause falls. Absences in 40% - 90%, partial seizures 50%. Mental retardation always, sometimes severe, becomes stable.	Never controlled
Myoclonic Astatic Epilepsy of Infancy (Doose Syndrome)	1-5 years	Strong Myoclonic or Atonic seizures resulting in falls. 50% have Absences with myoclonic jerks. 75% have Tonic-Clonic at some time. About half get seizure control. Hyperactivity, poor attention, moodiness may be present.	Easy to difficult
Lennox-Gastaut Syndrome	1-8 years	Generalized seizures usually including two or more of the following: Tonic, Atonic, Myoclonic, Absence, more rarely other types. Seizures often daily. Non-convulsive status epilepticus common, sometimes subtle, and can be made worse with overmedication. Behavioral, cognitive, and social impairment common.	Very difficult
Epilepsy with Continuous Spikes and Waves During Slow Sleep	1-11 years	Often starts as a Clonic seizure, then evolves into Simple Partial, Complex Partial or Tonic-Clonic types. Absence status can occur in nearly half. Seizures stop near puberty, however mental development is usually impaired at time of onset, severe in half. Severe behavioral problems may occur with various degrees of hyperactivity and aggressiveness. Memory poor.	Usually easy, seizures go away
Landau-Kleffner Syndrome	3-8 years	The main symptom is loss of oral language abilities over the course of days. Behavioral disturbances and hyperactivity are common. Seizures in 70%, though abnormal EEG in 100%. Partial, Absence, and/or Tonic-Clonic seizures may be present and do not affect outcome. Intelligence usually maintained.	Usually easy
Childhood Absence Epilepsy	4-8 years	Usually very frequent Absence seizures throughout the day. Tonic-Clonic seizures in 40%. Good prognosis. Most become seizure free.	Usually easy
Juvenile Absence Epilepsy	10-17 years	Usually only one or a few Absence seizures per day. Absences can sometimes be triggered by doing math or spatial tasks. Tonic-Clonic seizures occur in 80%. Long-term outcomes not well known.	Usually easy
Juvenile Myoclonic Epilepsy	12-18 years	Usually mild to moderate myoclonic jerks of shoulders, typically after awakening. 90% have Tonic-Clonic seizures. One third have Absences. Sleep deprivation, fatigue, and alcohol are often triggers. Normal intelligence. Lifetime medication often required.	Usually easy