

Medical response dogs

Learn how they can detect a seizure before it happens

A mother's story

Susan Axelrod's relentless and heroic battle to stop seizures

Latest treatments

Hospitals leading the way with cutting-edge technology

**MEDIA
PLANET**

February 2011

EPILEPSY

YOUR
COMPLETE
GUIDE
TO UNDERSTANDING
EPILEPSY

RAISING AWARENESS, SAVING LIVES

Andrew Stevens and his best friend Alaya, a seizure response dog, share an inspirational battle against epilepsy

CHALLENGES

This supplement shows the exceptional progress made in the diagnosis and treatment of epilepsy in the last twenty years. We now have an abundance of new medications, surgical procedures that are safe and highly effective, developing new therapies called neurostimulation, and a growing appreciation that epilepsy is not just seizures.

The future of epilepsy treatment

Despite all this progress, the problem of epilepsy is far from being solved. About one-third of people with epilepsy continue to experience seizures even with available therapies. And, the gap in what we know about the burden of epilepsy is huge. Even our best estimates of how many people have this condition are just that—estimates.

The American Epilepsy Society (AES) is among sponsors of an Institute of Medicine study to document the public health burden of epilepsy. AES is the society of 3,000 professionals dedicated to education, research and patient care of people with seizures. When completed in about a year, the study will provide a plan to more precisely assess how many people have epilepsy, how

many have each form of the disorder, the nature and extent of associated patient and family issues, and much more.

(For more about this study go to www.iom.edu/Activities/Disease/Epilepsy.aspx)

The critical need for greater funding of epilepsy research is highlighted by an astonishing new report just published in the January issue of the journal *Neurology*. In the report, epidemiologists analyzing the best available data suggest that one in every 26 people in the United States will develop epilepsy at some point in their life. That is to say 11.5 million people alive in this country today have had, now have, or will have epilepsy. A major focus of today's epilepsy research is on finding therapeutic strategies to cure or prevent the disorder and reduce the suffering of those who de-

“The World Health Organization estimates that 50 million people around the globe have this neurological disorder.”



John M. Pellock, MD
President, American Epilepsy Society
Chairman, Division of Child Neurology, and Professor of Neurology, Pediatrics and Pharmaceuticals,
Virginia Commonwealth University

velop epilepsy.

In the meantime, as reported in this supplement, the lives of people with epilepsy can often be improved. Epileptologists, medical experts who specialize in the study and treatment of epilepsy, work with patients and families to achieve the best attainable outcomes. Epileptologists comprise the core membership of the American Epilepsy Society, which this year celebrates its 75th anniversary.

Also within these pages are suggestions on how to find a doctor who specializes in epilepsy. Readers interested in learning more about seizures and epilepsy are encouraged to visit the following online resources: aesnet.org, cureepilepsy.org, epilepsy.com, epilepsyfoundation.org, and www.ninds.nih.gov/disorders/epilepsy/epilepsy.



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FEBRUARY 2011

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Dedicated to John Daul

It's time we found a cure.

CURE
Citizens United for Research in
EPILEPSY

Join us on March 25th for the premiere San Francisco Benefit for CURE with David Axelrod
www.CUREepilepsy.org/sfgala



First and Second Seizures: What to Know and Do

Seizures in children are one of the most frightening events for a parent or family member to witness, and one of the most anxiety-provoking incidents for a child to experience. Understanding the different types of seizures and what a first or second seizure may mean for a child can be a comfort to children and parents, and help families and physicians know how to best support the child.

A few basic facts about seizures can be reassuring. Only about one-third of children who experience a first unprovoked seizure will have a second seizure. The cumulative incidence of a first seizure with or without a fever exceeds one in 20 children before age 18. However, few children with febrile (fever-induced) seizures ever develop epilepsy, which is defined as recurrent, unprovoked seizures. With a first nonfebrile seizure, testing may not be necessary. There is no known benefit to immediate treatment on the likelihood of further seizures.

A basic history and physical examination are essential to establishing the diagnosis of seizure. What were the circumstances before the episode? Was the child febrile? Was there a trigger, such as trauma or flashing lights? What did the child do during the event? How long was the spell and what happened afterwards?



Paul Fisher, MD, is Chief of Child Neurology at Lucile Packard Children's Hospital and the Beirne Family Professor of Pediatric Neuro-Oncology at Stanford University School of Medicine.

The child's complete history and physical will also help to determine the circumstances and characteristics of the event, including whether a provoking infection, trauma, toxin exposure, or vascular problem is present. Just what tests to pursue in a child with a suspected seizure depends largely on whether the child has a fever, and whether the seizure is the first for the child. The American Academy of Pediatrics (AAP) endorses certain lab tests, a lumbar puncture, or toxicology screen only in certain clinical circumstances. However, the AAP does endorse an EEG for the first unprovoked nonfebrile seizure, as it may help predict the risk of recurrence. In certain cases, a CT scan or MRI may be appropriate.

Referral to a neurologist is not always required. When it is, a neurologist can offer a systematic approach to the following five questions for patient evaluation and management:

- Was it a seizure?
- What, if any, investigations should be done?



About Lucile Packard Children's Hospital

Lucile Packard Children's Hospital is annually ranked as one of the nation's best pediatric hospitals by *U.S. News & World Report*, and is the only San Francisco Bay Area children's hospital with programs ranked in the *U.S. News Top Ten*. The 311-bed hospital is devoted to the care of children and expectant mothers, and provides pediatric and obstetric medical and surgical services in association with the Stanford University School of Medicine. Packard Children's offers patients locally, regionally and nationally a full range of health-care programs and services, from preventive and routine care to the diagnosis and treatment of serious illness and injury. **For more information, visit www.lpch.org.**

- When should the child be treated?
- Does status epilepticus (a single continuous seizure or cluster of seizures) change things?
- What precautions are necessary?

A physician's most important role is to educate and counsel parents and children about seizures.

Depending on the child's age, circumstances and diagnosis, different types of support will be needed. Although a child's future after a first or second seizure may be uncertain, assuring them of a normal and successful life is not only comforting, but well-proven. Even in cases when a child does develop epilepsy, there is little he or she cannot achieve.

INSPIRATION

TIP

1

ACCELERATE
RESEARCH
EFFORTS**Question:** What should I do if my current treatment isn't stopping my seizures?**Answer:** Don't give up! Seek out other treatments, doctors and medical centers.

A mother's battle to stop seizures

HOW WE MADE IT

Countless medications with horrific side effects, brain stimulation, special diets, hospitalizations... but still, seizure after seizure after seizure, sometimes more than twenty-five a day. This describes the first eighteen years of my daughter Lauren's life. At just seven months, she began having uncontrollable seizures for no known reason. I don't know how to describe what epilepsy has meant to her and my family.

All we have wanted, since that first

seizure, was to make them stop. But that goal remained elusive. Lauren would wake up after a seizure just long enough to feel the next one coming and scream out, "Mommy, make them stop!" And I couldn't do a thing.

Fight to find a cure

After a horrific seven-hour surgical procedure (where they bored holes into my then-fifteen year old daughter's skull in an attempt to find the area responsible for the seizures) proved inconclusive, I resolved to do something. What we needed was



"What we needed was a cure."

Lauren Axelrod
(as a child)

PHOTO: CURE

a cure. This is what compelled us to come together and found CURE, Citizens United for Research in Epilepsy. We are raising funds and awareness, and supporting critical, cutting-edge research to eradicate this devastating disease.

When Lauren was eighteen, a new drug turned out to be her magic bullet. Miraculously, she has been seizure-free for the past ten years. Despite the irreversible damage to her brain, we see steady improvement in her cognitive skills and her ability to function independently. No longer

haunted by recurrent seizures, she is able to live life fully and is a true joy to witness.

We must accelerate research efforts in the field and address this age-old problem with the urgency and intensity that it merits. Each and every seizure can cause brain damage, or even death. We must continue to fight to find a cure so all our children can live happy, healthy, seizure-free lives.

SUSAN AXELROD, CURE CHAIR

editorial@mediaplanet.com

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Thanks to the experts at Northern California's largest pediatric epilepsy center.



CHILDREN'S HOSPITAL
& RESEARCH CENTER OAKLAND

Neurosciences Center

www.childrenshospitaloakland.org/epilepsy.asp



Reighven, 5, suffered from multiple daily seizures before Children's Hospital Oakland neurosurgeons performed a temporal lobectomy. He has been seizure-free for more than a year.



INSPIRATION



RAISING AWARENESS
 Lauren Axelrod and Susan Axelrod at a CURE event.
 PHOTO: CURE

↓ DON'T MISS!



San Francisco Benefit for CURE

CURE is a volunteer-based organization founded by mothers of children with epilepsy who joined forces to spearhead the search for a cure. For tickets to the San Francisco event call (312) 255-1801.

Where

→ The Four Seasons Hotel, 57 Market Street, San Francisco, California, 94103.

When

→ Friday, March 25, 2011 at 5:30 pm: Sponsor Reception 6:00 pm: General Reception, dinner to follow.

What

→ Remarks by David Axelrod, former Senior Advisor to the President. Special Performance by Grammy Award-winner Peter Rowan.



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NEWS

NEW TECHNOLOGIES AND TREATMENTS

■ **Question:** Is surgery, neurostimulation, or responsive neurostimulation a good choice for you?

■ **Answer:** Talk to your doctor. If your current methods aren't working, consider seeking out other methods until your seizures are under control.

While brain surgery may seem a radical step, many procedures have decades of safety and outcomes data to attest to their benefits. For instance, temporal lobectomy carries a 60 percent chance of lifetime freedom from seizures. These are better odds than are seen with further medical therapy when several attempts at controlling seizures with properly chosen and dosed drugs are unsuccessful at achieving seizure freedom.

However, not everyone is a candidate for removal of the seizure focus area. For these people, neurostimu-

lation may be an option.

Vagus nerve stimulation (VNS) stimulates the brain indirectly by delivering an electrical current from a generator implanted in the chest to the vagus nerve in the left side of the neck. VNS is approved by the FDA for use in addition to anti-convulsant drugs for adults and adolescents over 12 years of age whose partial-onset seizures are not well controlled by their drug treatment.

Direct stimulation of the brain is also adjustable and reversible. Two approaches to this are currently being developed for consideration for FDA approval.

The affects of stimulation

Deep brain stimulation of the anterior nucleus of the thalamus is thought to interrupt one of the major pathways in the brain for the spread of seizures. This procedure involves placement of an electrode into the thalamus on each side

of the brain. In a recent large randomized trial, seizures remained reduced by about half after 2 years of stimulation in about half of the treated patients.

Responsive neurostimulation is another new technology. Electrodes are placed at the presumed origination point of the seizures (either on the surface or deep in the brain). A small area of skull is removed to make room for the battery. The device is taught to detect the patient's specific abnormal EEG patterns. It then delivers a burst of stimulation to the area to abort the seizure. A double blind study demonstrated that the stimulation group experienced a 41 percent reduction in seizures compared to a nine percent reduction in the group receiving no stimulation.

DR. JOSHUA ROSENOW, FACS
Director, Functional Neurosurgery,
Northwestern Memorial Hospital



UPCOMING COMMUNITY OPEN HOUSE EVENT: PEDIATRIC EPILEPSY PROGRAM AT CHILDREN'S HOSPITAL & RESEARCH CENTER OAKLAND



Epilepsy and your child: What every parent needs to know

Join the experts from the Pediatric Epilepsy Program at Children's Hospital & Research Center Oakland in a discussion about the latest in epilepsy care—including advancements in medications, sur-

gery, research, dietary treatment, and support options.

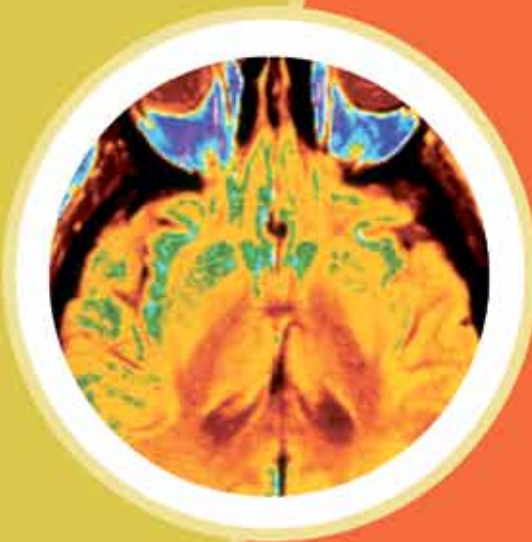
- Saturday, March 19, 2011
- 9:30 a.m. - Noon
- Children's Hospital & Research Center Oakland
- Outpatient Center Auditorium
74752nd Street, Oakland, CA 94611
Space is limited.

RSVP by March 16 to:
mstillwagon@mail.cho.org
For more information visit:
www.childrenshospitaloakland.org/epilepsy.asp



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Adult and Pediatric Epilepsy: (415) 353-2437

Adult Website: www.ucsfhealth.org/epilepsy

Pediatric Website: www.ucsfbenioffchildrens.org/epilepsy

UCSF Medical Center

UCSF Benioff Children's Hospital

NEWS

 MEET AN
EPILEPTOLOGIST


William W. Sutherland, MD
Medical Director of Epilepsy and
Brain Mapping Program, Level 4
Comprehensive Epilepsy Center

→ “If a seizure disorder is not controlled in two years or after two medications, the patient should be referred to an epileptologist.”

The Epilepsy and Brain Mapping Program is a comprehensive healthcare center for treating adult and pediatric epilepsy and other neurological disorders with seizures. We offer: medical management of seizures through established anti-epileptic medications and clinical drug trials, ketogenic diet, surgical treatment and cognitive and psychological assessment, counseling and rehabilitation.

For more information: www.epilepsyandbrainmapping.com.

What is the ketogenic diet?

The ketogenic diet is a special high-fat diet that is used for difficult-to-treat seizures. Heavy cream, butter and vegetable oils provide the necessary fat. The diet also completely eliminates sweets such as candy, cookies, and desserts. Other carbohydrate-rich foods such as bread, potatoes, rice, cereals, and pasta are not allowed on the strictest form of the diet, but are allowed on more liberal forms of the diet. All foods must be carefully prepared and weighed on a

gram scale. Each meal must be eaten in its entirety for the diet to be most effective.

■ **Who can be helped by the diet?** Children with seizures from infancy through the teenage years may be helped by the diet. There is no way to predict beforehand whether it will be successful. Traditionally the diet has been used for children with myoclonic, atonic and tonic-clonic seizures. In every decade since the 1920's, studies consistently show

that 50-75 percent of children with difficult to control seizures of all types are helped by the diet. Children over the age of five years may find the diet difficult to follow due to its strictness. New and creative recipes have helped to make the diet more palatable in the past few years.

■ **How effective is the diet at controlling or eliminating seizures?** The diet has never been evaluated in a controlled scientific study. Studies that have followed

children on the diet for long periods reveal that 1/3 of children treated with the ketogenic diet have greater than 90 percent seizure control with half of these children becoming seizure free. An additional 1/3 gain a 50 percent reduction in seizures. The remaining 1/3 discontinue the diet due to its ineffectiveness or its difficulty.

JIM ABRAHAMS

Co-Founder & Executive Director,
The Charlie Foundation
editorial@mediaplanet.com

INCREDIBLE CHOCOLATE KETOGENIC BROWNIES



This is a soft, cake-like brownie that is mildly sweet. After baking, cut brownies into 10 pieces which results in a final weight of 21gm each containing 100 Calories with 1gm carbohydrate and a 3:1 ratio. You will find the precise values listed in KetoCalculator as a food item under the Fat Category.

Ingredients

- 1gm Baking Powder
- 3gm No Calorie Sweetener, Granular
- 6gm Cocoa (unsweetened)

- 50gm Egg—raw, mixed well
- 14gm Chocolate, Unsweetened
- 17gm Butter
- 16gm Coconut Oil
- 34gm Flaxseed Meal (whole ground flax seed)
- 45gm Macadamia Nuts (dry roasted with salt)—ground
- 30gm Sour Cream

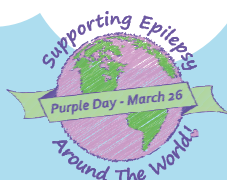
Directions

1. Melt the butter, Unsweetened Chocolate and coconut oil in a small pan (or microwave). Cool for 2 minutes then stir in mixed

- egg.
2. Mix together dry ingredients.
 3. Stir melted mixture into dry ingredients, then mix in sour cream until well blended.
 4. Make a foil pan with a 12 inch piece of foil, fold foil in half (shortwise) then create a small pan with approximately 1 inch sides.
 5. Spread mixture into foil pan; you do not need to grease the foil pan.
 6. Bake for 12-15 minutes in a pre-heated 325 degree oven.

PURPLE DAY For Epilepsy

Join us March 26 and wear purple to promote epilepsy awareness worldwide.



The Anita Kaufmann Foundation
Educating The Public Not To Fear Epilepsy

For more information:
201-655-0420
purpleday.org akfus.org



Cassidy Megan, 12 years old
Founder of Purple Day

INSIGHT

Substantial progress has been made over the last 15 years in the healthcare community's ability to diagnose and treat epilepsy and its complications. Yet this progress in epilepsy management has not reached most of the 50 million people around the world, including many of the nearly three million people in the United States who have the disorder.

Closing the gap in care

There is an enormous gap between what is currently being done and what is possible today to lessen the burden of epilepsy around the world.

According to the World Health Organization, an astonishing three-quarters of the global population with epilepsy get no treatment whatsoever for their seizures. The consequences are not insignificant, as uncontrolled epilepsy leads to a diminished quality of life, and a greater risk of disability and death.

Most patients here in the U.S. receive some form of therapy, but nonetheless there are problems with misdiagnosis, under-diagnosis, incorrect choice of therapy, and limited evaluation and treatment of associated complications affecting



Steven C. Schachter, MD
Professor of Neurology, Harvard Medical School; Chief Academic Officer, Center for Integration of Medicine and Innovative Technology

mood, memory and cognition.

Even with the plethora of epilepsy therapies now available, the Centers for Disease Control (CDC) estimates that at least 45 percent of people with epilepsy here in the U.S. continue to experience seizures. In a CDC survey, 1 in 3 people with recent seizures had not seen a neurologist or epileptologist in the previous year. Complete freedom from seizures is not a possibility for everyone who has epilepsy. But it is important for healthcare providers to make every effort toward that goal and to empower their pa-

tients with the necessary tools and healthcare practices.

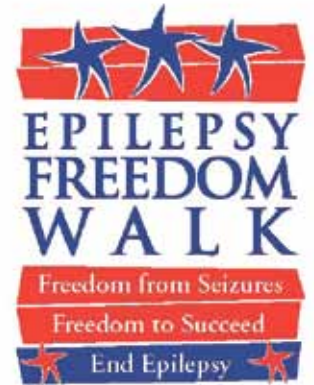
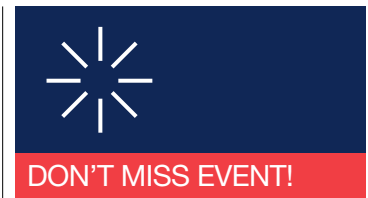
Too often people with epilepsy are led to believe by their physician that their treatment is 'as-good-as-it-gets'. Therefore, an important step toward the goal of freedom from seizures and related complications is for people living with epilepsy who have not achieved these goals to consider seeing a specialist such as an epileptologist

An epileptologist is a general neurologist who has taken at least an additional 2 years of specialized training in epilepsy and focuses on the treatment of epilepsy. Epileptologists, especially those at academic health centers, typically work in care teams who are responsible for evaluating the patient's condition, prescribing treatment and working to find the best possible treatment for the seizures while minimizing

side effects of therapy. To help in the search for epilepsy doctors, the Epilepsy Foundation has a "Find a Doctor" function on its website at epilepsyfoundation.org.

People living with epilepsy need to be very active in their own treatment and in reporting any side effects or impact on daily activities to their care teams. To help in this conversation with care providers, people with epilepsy are encouraged to keep a diary. A diary tool can be found at the epilepsy.com website. The diary allows patients to record a wide range of information from each seizure occurrence to drug side effects, mood changes, etc.

Too many people in the U.S. and around the globe are caught in the treatment gap close the gap and work toward better care for people with epilepsy.



■ Join The Epilepsy Foundation of Northern California on Saturday, May 21st at Six Flags Discovery Kingdom for the annual Epilepsy Freedom Walk to continue the fight for Freedom from Seizures, Freedom to Succeed, and help put an end to Epilepsy. For questions please call 800-632-3532 or go to www.norcalfreedomwalk.org.

SHOWCASE



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www.GiantMedical.com

INSPIRATION

TIP

3

REACH OUT
TO YOUR
COMMUNITY

**A BOY'S
BEST FRIEND**
Andrew Stevens
with his parents
Nancy and Andrew
Stevens, and his
dog Alaya.

PHOTO: NORA TOTH

A boy and his dog

■ **Question:** How can seizure response dogs help people with epilepsy?

■ **Answer:** They can detect seizures before they happen.

CHANGE

A boy and his dog is a precious image. In this scenario, the dog is more than a trusted companion; Alaya is a rescue dog trained to assist 12-year-old Andrew Stevens with seizures—a symptom of his Lennox-Gastaut syndrome, a severe form of epilepsy.

Alaya was taught to recognize the signs of seizures (even before a human) and swipe Stevens' chest with

a magnet secured in her collar that sends a signal to an implanted stimulator in his chest that can stop or ease the seizures. Stevens can experience up to 15-20 per day so reducing the impact is critical.

Officials in Fairfax County, Virginia banned the German Shepherd from Stevens' classroom suggesting teachers could respond to Stevens' needs. His dad, Army Sgt. Angelo Stevens, with the help of the Epilepsy Foundation of Virginia, kicked into gear to fight for Andrew's rights under the Americans With Disabilities Act. A petition was created called "Let Andrew bring his dog to school" that built support and even netted the story attention



"I grew up a selfish person... You have to stand up and be an advocate for others. Don't remain quiet."

Army Sgt. Angelo Stevens
Father of Andrew Stevens

on the TODAY show. Alaya has been allowed in school on a trial basis with Angelo accompanying them to ensure a smooth transition.

Galvanized by the support he and

his wife Nancy have received, Stevens created the Andrew Gordon Stevens Foundation with a goal to raise money to enable a company to train rescue dogs for service mem-

bers, veterans and families. They are costly—as much as \$10,000 for the animal and another \$10,000 in training and upkeep.

"Even if 100,000 people gave one dollar, think of all the dogs we could provide," says Stevens who adds his son has made him more compassionate. "I grew up a selfish person," admits Steven. "You have to stand up and be an advocate for others. Don't remain quiet."

For more information and how to help, go to www.theandrewgordonstevensfoundation.org for more information.

FAYE BROOKMAN
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PANEL OF EXPERTS



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Question 1:
What are some of the latest advancements in pediatric epilepsy treatment?

While there is still no "miracle drug" to treat epilepsy, more effective anti-convulsive medications have emerged that have fewer side effects than previous options. There is also a better understanding of epilepsy's impact on a child's life, including the long term neuro-cognitive and social impacts. If medication therapies fail, surgical treatment options are explored to treat seizures and help decrease epilepsy's impact on a child's development. While it isn't new, the ketogenic diet - a high-fat, low-carbohydrate diet - can help improve the condition of children whose seizures have not responded to medications.

New medications are available that control seizures with fewer side effects. For patients who don't respond to medications, surgery may be an option. Modern neuroimaging can now detect subtle brain abnormalities that may explain why a patient is having seizures, and together with neuro-navigation technology, enables highly precise, targeted surgery.

In the last few years several novel anti-seizure drugs have been released. More are "in the pipeline." New seizure medications offer more treatment options with generally fewer side effects. They complement long available treatments like epilepsy surgery and the ketogenic diet.

New medications have evolved so our patients have fewer side effects from the medications and fewer seizures. But to me the most exciting advances are new imaging modalities like high field strength MRI scanners and the new therapies like responsive brain stimulation. With these tools we can better select and better treat surgical candidates.

Question 2:
Do children with epilepsy require different treatment than adults?

Children with epilepsy do require different treatment than adults, and it's important to understand that children aren't simply small adults. They're at a different developmental stage than adults, and can present with different types of epilepsy than adults. Pediatric neurologists are trained to diagnose and treat the forms of epilepsy that affect children. The care team for a child with epilepsy usually includes neurologists, neuropsychologists, dieticians and social workers.

These patients require a modified approach because epilepsy may profoundly affect the developing brain more than an adult brain. Children may require more frequent developmental follow-up and more frequent EEGs, because abnormal electrical activity detected between seizures may have as much of an impact on development as the seizures themselves.

A big goal for us who treat children with epilepsy is to help parents let their affected child grow up as normally as possible. Issues range from little kids moving back to sleeping in their own beds to teenagers gaining independence by going out with friends and driving.

Children with epilepsy do require different techniques than adults to maximize seizure control. The medications may differ, the doses of the medications differ, and even the surgeries differ. The brain of a developing child presents special challenges when trying to balance our treatment options with the desire to maximize their potential.

Question 3:
What other conditions do children with epilepsy frequently experience?

Children with epilepsy might also experience learning difficulties, depression, anxiety, social isolation and ADHD. It's not unusual for a child with epilepsy to experience some of these issues prior to ever having a seizure. These are all thought to be symptoms of the underlying neurological problem that causes epilepsy.

Many children with epilepsy have ADHD, depression, anxiety, and learning disabilities. These conditions may be present prior to an epilepsy diagnosis, with one-third of patients seeking mental health assistance before seizure onset. It's important to recognize these conditions and consider how epilepsy medications may potentially improve or exacerbate them.

Epilepsy is an abnormality of brain wiring and brain chemistry. Even when individual seizures are controlled, kids with seizures may have behavior challenges such as ADD and depression; they may have a harder time with certain types of learning and memory. Early recognition and proper treatment is the goal.

Many children with epilepsy look like normal children except when they are having seizures. Seizures in children can interfere with learning and development. We strive, in every case, to achieve freedom from seizures to maximize their potential. Some children need surgery to help them become seizure free.



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Sunovion Pharmaceuticals Inc. was created through the merger of Sepracor Inc. and the U.S. operations of its parent company, Dainippon Sumitomo Pharmaceuticals Co., Ltd. We've come together in the ongoing drive to improve the lives of people with central nervous system diseases.

Sunovion is a proud sponsor of this supplement and is dedicated to raising the awareness of epilepsy

Visit us at www.sunovion.com