

A different therapy
Creating art to
heal stigma

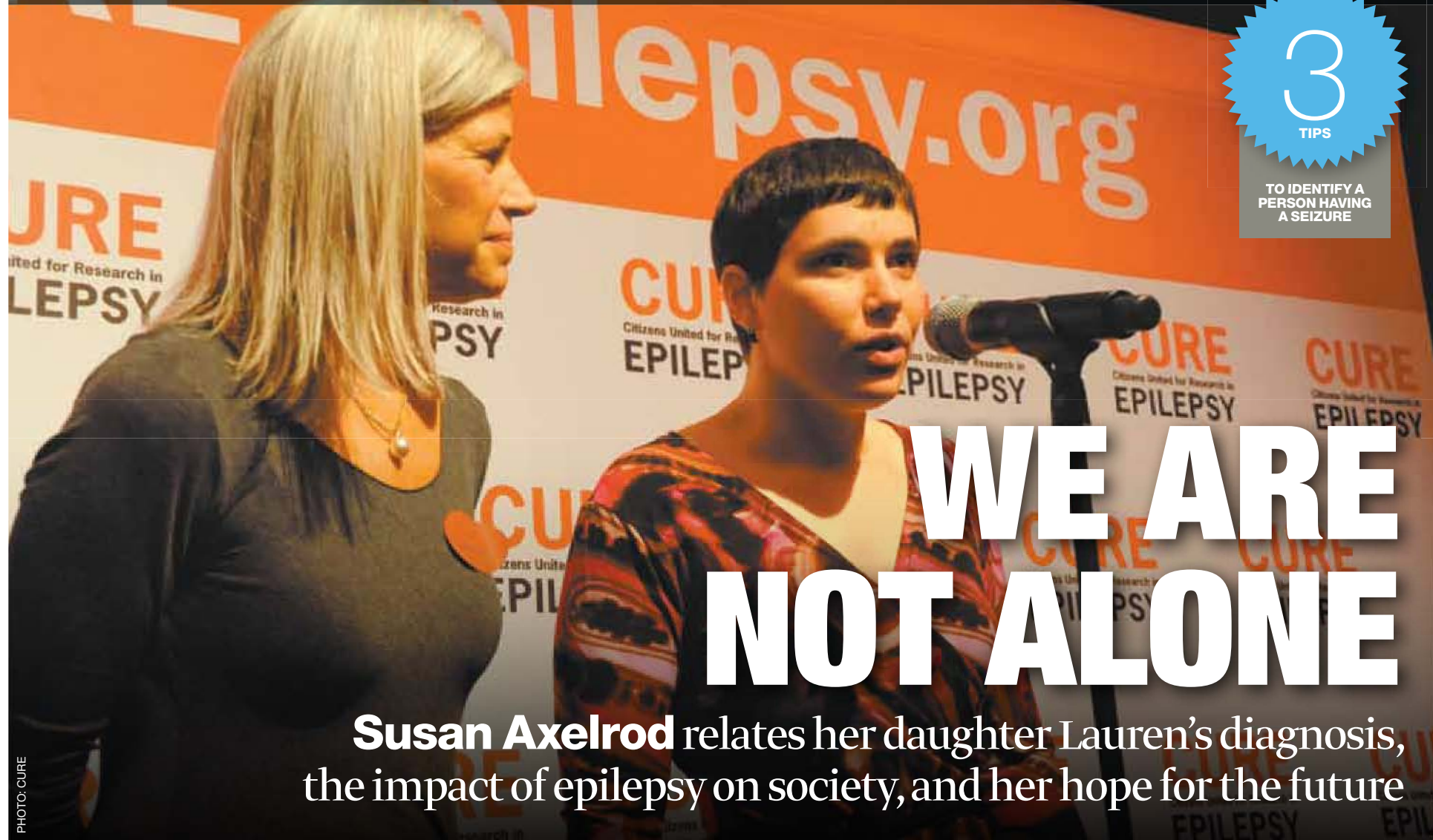
Scientific pursuits
The latest technology
advancements discussed

By the numbers
Vital epilepsy
statistics

**MEDIA
PLANET**

November 2011

EPILEPSY AWARENESS



Susan Axelrod relates her daughter Lauren's diagnosis, the impact of epilepsy on society, and her hope for the future

It's time we found a cure.

CURE
Citizens United for Research in
EPILEPSY

November is National Epilepsy Awareness Month.
Find out how you can help: www.CUREepilepsy.org



CHALLENGES

Epilepsy is a medical condition that produces seizures. When a person has two or more unprovoked seizures, they have epilepsy. Seizures happen when clusters of nerve cells in the brain signal abnormally, which briefly alter a person's consciousness, movements or actions.

TIP

1

CONVULSIONS
ARE A COMMON
SEIZURE
INDICATOR

WE RECOMMEND



Dr. Robert Gumnit, M.D.
urges families to visit
an epilepsy center
for optimal treatment

PAGE 6

MEDIA
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It's time to change our thinking

Most think a person living with epilepsy needs simply to take a pill and seizures will stop. That's true for about 50 percent of the 3 million Americans living with epilepsy. And what tremendous opportunities come with seizure freedom!

What happens to a person with uncontrolled epilepsy? When seizures persist, their whole world stops. The pain and the loneliness of intractable epilepsy can easily overtake the strongest among us. In children, uncontrolled epilepsy can prevent regular school attendance, and kids who have seizures in school often feel isolated by their peers.

In adults, uncontrolled seizures may mean losing the privilege to drive, the ability to be insured, and the loss of employment as a result of the impact of relentless seizures. Everyone living with uncontrolled epilepsy lives with the unpredictability of not knowing when and where their next seizure will happen. Multiple medications can impact day-to-

day thinking and memory, and then there is the unimaginable. 50,000 people die each year from epilepsy—more lives lost than breast cancer takes each year.

Chicago—My kind of town

Several successful epilepsy research, advocacy and supportive care organizations make Chicago their headquarters to impact lives in Illinois, across the country and around the world. Together we serve thousands of families with award-winning supportive care and awareness initiatives. Camp Blackhawk, our epilepsy clinic, and employment programs are all provided at no cost to individuals with epilepsy and their families.

Citizens United for Research in Epilepsy (CURE) (www.cureepilepsy.org) raises millions each year to provide promising researchers with seed money for innovative epilepsy research projects and raises awareness about the federal government's underfunding of epilepsy research. Epilepsy Services of Northeastern Illinois is a counseling and care organization serving northern Illinois (www.esniinfo.org).

The Danny Did Foundation (www.dannydid.org) has launched a powerful nationwide awareness organization to prevent deaths caused by epilepsy.

We feel privileged when celebrities like Greg Grunberg (who launched www.TalkAboutIt.org to help raise awareness of epilepsy), Hugh Laurie, Band From TV, and others visit Chicago to support our efforts.

Chicago is also home to the best clinicians and researchers in the world who work with us and support our efforts daily. Together, we align and collaborate in Chicago. We all believe epilepsy has taken too many lives, destroyed too many families and devastated too many people. Everyone should have the opportunity to live life free of seizures and side effects. We've chosen to replace isolation, despair and fear, with support, inspiration and hope.

You can help

Join me at a "meet-and-greet" event near you to learn more about our vision to make a difference in your community. To learn

more, contact the EFGC at (312) 939-8622, visit us online at www.epilepsyichicago.org, or email us at info@epilepsyichicago.org.

I sincerely hope you'll join us in the fight to end epilepsy.

Philip M Gattone, M.Ed.,
President and
CEO, Epilepsy
Foundation
of Greater
Chicago

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NEWS

Question: Do the results of surgery for epilepsy compensate for the risks?
Answer: And then some. The real risk is in avoiding treatment

Take control with epilepsy surgery

The idea of neurosurgery is understandably daunting, but for those with epilepsy that doesn't respond to medication, it should be considered an alluring treatment option.

New research out of University College London has found that roughly half of epileptic adults treated with surgery remain seizure-free after ten years. The study, which followed 615 patients with refractory focal epilepsy, also found that about 40 percent of those patients experienced long-term, total freedom from seizures. Encouragingly, none of the patients' seizures became worse following the surgery.

These findings reinforce the opinion of myriad neurological authorities who assert that epilepsy surgery is vastly underutilized.

"Any patient who has a diagnosis of epilepsy whose seizures aren't being controlled by medication—we're talking even infants, the first few years of life, school-going kids, and obviously adults—can be a good surgical candidate," says **Dr. Ingrid**



Dr. Hans Lüders
Director, University Hospitals
Epilepsy Center



Dr. Ingrid Tuxhorn
Chief of Pediatric Epilepsy, Rainbow
Babies & Children's Hospital

Tuxhorn, Chief of Pediatric Epilepsy at Rainbow Babies & Children's Hospital. "People don't have surgery on their radar soon enough."

Worth the risk

As diagnosis and surgical procedures have progressed in accuracy and effectiveness, the risks of recurring seizures far outweigh those of undergoing surgery.

"These findings reinforce the opinion of myriad neurological authorities who assert that epilepsy surgery is vastly underutilized."

"People often forget that the chance of mortality for those with frequent seizures is not insignificant," says **Dr. Hans Lüders**, Director of the University Hospitals Epilepsy Center.

The most serious risks associated with recurring seizures include sudden unexpected death in epilepsy (SUDEP), trauma from seizure-related accidents, suicide resulting from depression, and status epilepticus.

Children are increasingly being considered for surgical treatment, and an experienced pediatric neurologist can readily identify whether or not a child is a strong candidate.

"It's relatively simple to tell within the first six months or year if you can treat a child with medication or if medication will not be effective," says Lüders.

With a good chance of evading prolonged suffering, surgery for epilepsy is a more than worthy option for patients to consider.

STEVE ETHERIDGE

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DON'T MISS!

Art therapy and epilepsy

Because I have suffered from epilepsy almost my whole life, I have always had a problem with depression. Epilepsy has kept me from doing so many things that I have wanted to do throughout my life. I tried joining the military, but Uncle Sam said "no." Then, when I tried getting into sports, my seizures went out of control and my dreams of becoming a fighter in the ring were gone.

I've had people see me as the guy with seizures my whole life. Whenever I would try to explain seizures to people, they would just ignore me and forget about me not only because of seizures, but because of side effects of medication.

I have tried many ways to cope so that I would still be able to enjoy life.

One way that I have learned to cope is

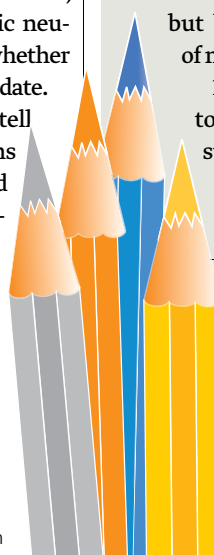
through art. Both admiring it and making it, so imagine how excited I was to hear that the Epilepsy Foundation of Greater Chicago had developed a program called Studio E: Art Therapy Program.

This program was managed by people who both enjoy working with people who have epilepsy and love making and admiring artwork. We would first make our own artwork then try to describe it for everyone in the program. That too was fun for me since I always enjoy showing my artwork to others.

I would definitely recommend that anyone who suffers from epilepsy should find a way cope with their emotions through artwork. You will not only have fun, but you will also make new friends.

SEAN KELLY

editorial@mediaplanet.com



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NEWS



NEWS IN BRIEF

"Shark Tank" encourages innovation in epilepsy care

Epilepsy Therapy Project (ETP)/epilepsy.com is hosting the 3rd Epilepsy Pipeline Update Conference in San Francisco, February 2-4. New to this year's event is a "Shark Tank" competition. ETP is inviting entries through December 15th that represent the most innovative ideas in epilepsy treatment and care. Five projects selected to present will be judged at the conference; the winner will be announced and receive a \$50,000 grant to accelerate the idea towards improving the quality of life for people with epilepsy.

EPILEPSY THERAPY PROJECT

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New technology for epilepsy

Anti-epileptic drugs (AEDs) will control seizures in most people with epilepsy. However, for up to a quarter of patients, seizures continue despite trials of several AEDs. For these individuals, surgery to remove the epileptic focus is often the best alternative therapy, if the seizures consistently originate from one brain area, if that focus can be identified, and if that region can be removed without causing neurological deficits. All three of these criteria depend on pinpointing the brain location of abnormal epileptic cortex relative to important nearby cortex that may control movement, sensation, or language. Several of the new technologies for epilepsy evaluation involve improved localization of brain function, sometimes called "brain mapping."

Mapping the brain

Radiological procedures, such as CTs and MRIs, show brain structure, but this may not be abnormal in seizures disorders. Only two diagnostic tests measure brain activity, normal and abnormal, both directly and in real time. These are electroencephalography (EEG) and magnetoencephalography (MEG). EEG, the recording of electrical brain waves, is an established technology, but new methods for analyzing these data with computer models, such as dipoles, are providing neurologists with the ability to visualize the location of epileptic foci within the brain in 3D. Perhaps more amazing technologically is MEG, the recording of magnetic fields coming out of the head generated by brain activity. These magnetic fields are extremely weak, in fact far less than the earth's own gravity. In order to

"With these new technologies and advanced analysis methods, neurologists can better determine non-invasively if a patient is a candidate for epilepsy surgery..."

**John S. Ebersole, M.D.**

Professor and Director, Adult Epilepsy Center, The University of Chicago; Medical Director, Illinois MEG Center, Alexian Brothers Medical Center

see such tiny signals, the array of sensors in the recording helmet of an MEG machine must be cooled in liquid helium to make them superconductive. The reason for employing such high tech methods is because magnetic fields from the brain pass through the skull and scalp without any attenuation or distortion. MEG sees brain activity, including that of epileptic foci, as clearly as though the skull was absent. This allows for even more accurate 3D localization of epileptic and essential normal cortex.

With these new technologies and advanced analysis methods, neurologists can better determine non-invasively if a patient is a candidate for epilepsy surgery, where the epileptic focus is within the brain, and whether it can be safely removed.

JOHN S. EBERSOLE, M.D.

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INSPIRATION

Susan Axelrod shares the first terrifying moments when she discovered her infant daughter, Lauren, having a seizure. Lauren's **epilepsy** was uncontrolled for years, placing her with millions of other Americans who seek a cure.



Our lives had changed forever

HOW WE MADE IT

Imagine walking into your first-born child's bedroom when she is just seven months old, finding her lying gray and limp in her crib; thinking she has died. But then one arm stiffens over her head. Her eyes roll back into her head. She froths at the mouth, and makes strange guttural noises. And then it is over.

That's what we thought, anyway, when Lauren suffered that first seizure. It was actually the first of thousands we would come to witness over the next 18 years. Our lives had changed forever. We were totally at the mercy of uncontrollable seizures, scores of medications

with horrific side effects, brain stimulation and surgery, special diets, lengthy hospitalizations and innumerable emergency room visits.

To this day, 30 years later, we have no idea why Lauren's seizures ever began, and why they were so relentless and resistant to treatment... why she sometimes had more than 25 seizures a day, that wreaked havoc on her developing brain.

What we do know is that we are not alone. Lauren's experience is but one story of epilepsy that represents a third of patients for whom answers do not exist. That's over one million individuals in this country alone. The public



"Misperceptions about how serious and devastating epilepsy can be have left us in the dark ages."

Susan Axelrod with daughter Lauren and husband, David Axelrod.

health impact of epilepsy is enormous.

And, we also know that epilepsy is a disease which, if given its fair share of resources, can be conquered. Historically, the investment in epilepsy research has paled by comparison to the burden of the disease. Misperceptions about how serious and devastating epilepsy can be have left us in the dark ages.

This is what compelled us to come together to found CURE—Citizens United for Research in Epilepsy. We raise funds and awareness, and support cutting-edge research aimed at curing this disease.

Miraculously, Lauren has been free

of seizures for the last 11 years, having responded to a brand new medication. No longer haunted by relentless seizures, she is making amazing strides—but she will never be able to live independently.

Each and every seizure can cause brain damage, or even death. You can help by joining us in our efforts to tackle this age-old problem by accelerating research efforts that will, once and for all, put an end to epilepsy and seizures.

SUSAN AXELROD

editorial@mediaplanet.com

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INSIGHT



TIPS

Convulsive seizure first aid**Do:**

- Remain calm
- Protect from any sharp or dangerous objects nearby
- Put something soft under the head
- Gently roll person on his/her side to prevent choking
- Let seizure take its course
- Stay with person until fully conscious
- Offer assistance when seizure is over
- Call for medical assistance if seizure lasts more than five minutes

Do not:

- Put anything in the mouth (you cannot swallow your tongue)
- Restrain person or try to stop the seizure

AMERICAN EPILEPSY SOCIETY

editorial@mediaplanet.com

Question: If someone I know or my child has a seizure, should we make an appointment to see a family doctor or neurologist?

Answer: For optimal treatment, find an epilepsy center.

How to stop seizures right away

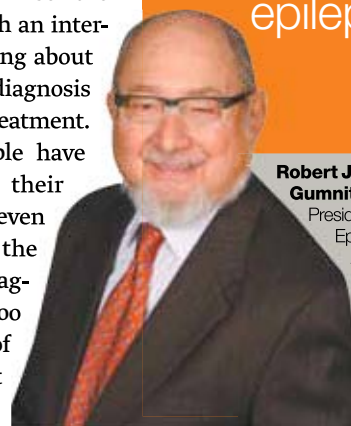
Seizures are common. One out of every ten Americans will have a seizure some time in their life. Three percent of the population will have more than one seizure on more than one occasion.

Seizures are scary, because people are afraid of the word epilepsy, because they are hard to diagnose and poorly understood by most doctors, seizures are not well treated in the United States today. This is a serious matter. The more seizures a person has, the more they are likely to get. The longer a person has uncontrolled seizures, the harder they are to treat. National recommendations state that if someone

has seizures that haven't been controlled in three months by a family doctor or within one year by a neurologist, they should be referred to an epilepsy center. Epilepsy centers are groups of neurologists with advanced training in seizure disorders who work with an interdisciplinary team to bring about a precise and accurate diagnosis and prescribe the right treatment.

Now that most people have large deductibles for their health insurance, it is even more important that the seizures be properly diagnosed and treated early. Too many people spend a lot of money on tests that don't answer the question

"Seizures are scary, because people are afraid of the word epilepsy..."



Robert J. Gumnit, M.D.
President, MINCEP
Epilepsy Care,
American
Epilepsy Society
President, 1980-
81, National
Association of
Epilepsy Centers
President, 1988
to present

when they see a family doctor or a neurologist. It doesn't cost more to go straight to an epilepsy center and get it done right the first time. Not all neurologists are specialists in epilepsy. This really becomes clear when you think there are about 50 flavors of seizure types, over a hundred causes, and over 22 distinctly different antiepileptic medications. Add to that the fact that one third of people with uncontrolled seizures are being treated with antiepileptic drugs and don't have epilepsy at all (because of a misdiagnosis) and it is easy to see why early intervention by the most expert group makes sense.

ROBERT J. GUMNIT, M.D.

editorial@mediaplanet.com

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INSIGHT



Kathy Abbott & Diane Wilson

WHO: Kathy Abbott, Psy. D., Clinical Psychologist, and Diane Wilson, LCPC, Licensed Clinical Professional Counselor, are both Board Certified in Neurofeedback by the Biofeedback Certification International Alliance (BCIA)

CHANGE

Improve control of epilepsy

Many people who suffer from epilepsy find their medications are not as effective as they expect. One non-medication strategy to improve control of epilepsy is neurofeedback.

The unexpected finding

Like many important discoveries, the power of brainwave feedback (neurofeedback) was stumbled upon by accident—one of special significance for treating epilepsy.

In the mid-1960's Barry Sterman at UCLA rewarded cats with food every time they produced a brainwave pattern called SMR (sensorimotor rhythm). These cats were later grouped with another set of

cats. All were exposed to jet fuel to determine how long and how much of this neurotoxin would produce seizures that would kill the cats. The researchers were surprised to find the cats with the extra SMR had twice the life expectancy of those did not. Thus, the neurofeedback training provided protection against seizures in cats.

Sterman's own secretary had long struggled with epilepsy and then did neurofeedback SMR training. Through it, she became seizure free. Sterman's findings initiated a body of research which solidly supports SMR training for seizure resistance in humans. Most of the research is with clients who had a poor response to medications.

An analysis of all these studies showed that 80 percent of the clients "displayed significant clinical improvement" from neurofeedback (Egner & Sterman, 2006).

There is an increase in promotion of the use of neurofeedback by physicians. According to Dr. Daniel Hoch, a neurologist at Massachusetts General Hospital, "if [epileptics] spend some time every week trying to learn to generate certain frequencies of brain waves, they can reduce the likelihood of having a seizure."

Long-time neurofeedback practitioner Dr. Elsa Baehr at Neuroquest in Skokie says: "We have had a number of clients with epilepsy I have treated with neurofeedback with a positive result."



FACTS

What's wrong with these numbers?

- Epilepsy affects about 3 million people in the U.S. That's about 1 in 100.
- Epilepsy affects more than 300,000 children under the age of 15 in the U.S.
- More than 90,000 struggle with uncontrolled seizures.
- One in ten people will experience a seizure at some point in his or her lifetime.
- One in 100 people will develop epilepsy in the U.S.
- More than 570,000 adults over the age of 65 in the U.S. have epilepsy.
- Epilepsy affects more than 50,000,000 people worldwide!
- Epilepsy is the third most common neurological disorder.
- It's only behind stroke and Alzheimer's disease!
- More people have epilepsy

than Parkinson's disease, Cerebral Palsy, Muscular Dystrophy and Multiple Sclerosis combined.

■ It is estimated that 50,000 deaths occur annually in the US alone due to prolonged seizures.

■ Epilepsy results in an estimated annual cost of \$15.5 billion in medical costs as well as unemployment and underemployment.

The Anita Kaufmann Foundation is solely dedicated to educating the public about epilepsy and seizures. They provide seizure first aid trainings and seizure first aid material. They are the global sponsors of Purple Day, the largest grassroots epilepsy awareness initiative in the world. For more information, please visit www.akfus.org and www.purpledayer.org.

20%

■ It is estimated that 20 percent of our returning soldiers who sustained a traumatic brain injury will develop epilepsy and seizures.

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Others Have Eliminated Their Seizures. So Can You.

At the Epilepsy Center of University Hospitals Neurological Institute and the Division of Pediatric Epilepsy at University Hospitals Rainbow Babies & Children's Hospital, we believe that the key to effectively treating children and adults with seizures starts with an accurate diagnosis.

By using state-of-the-art technologies and the latest brain mapping techniques, we can pinpoint the source of seizure activity. This allows us to treat the needs of each patient using a variety of treatment options – including minimally invasive surgery.

The results?

We are now able to not only reduce seizures but possibly eliminate them altogether.

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To learn more about how you can eliminate seizures,
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