Expressions of Courage:
Award-winning artwork by people with epilepsy

The State of Epilepsy Treatment Today
It Takes a Village: Parental Advocacy and Involvement
message from the chair

Every day I am inspired by amazing people. While I have met and worked with many dignitaries during my days on Capitol Hill and at other times in my life, I have found much of my inspiration comes from people who do not appear in newspapers or on television. I look up to people who spend the moments of each day living happy and fulfilled lives with family, friends and colleagues. It is those people who form passionate and caring communities. I am proud to be part of such a community—made up of people with epilepsy and their caregivers.

That is why I am so excited about the inaugural National Walk for Epilepsy on March 31st. With one voice we can emphasize the goals of the Walk, which are to increase awareness about epilepsy, end stigma and discrimination and continue to raise funds in order to improve treatment and work toward finding a cure.

At www.walkforepilepsy.org you can register for the Walk—the actual walk or the virtual walk—join a team or support other participants. You can also learn more about epilepsy and this historic event. Many of you have already made a commitment to participate. For those of you who haven’t, please consider spending a beautiful spring Saturday with us. However, if you are unable to join us on the Mall, you can still be a part of the Walk in your own hometown! Virtual walkers may participate by walking in their own communities, as a team or by themselves. Once all walkers have reached the finish line, the total distance covered and the total amount raised will be displayed on the www.walkforepilepsy.org Web site.

The Foundation continues to lower barriers created by stigma and misunderstanding; fund research leading to new discoveries about what causes epilepsy and new treatments toward a cure; advocate on all levels of government for improving the lives of people with epilepsy; and provide programs and services in communities around America.

We are just getting started.

The Epilepsy Foundation is a proud part of your community of caring people with epilepsy and caregivers. On the National Mall in Washington, DC on March 31st we can celebrate our accomplishments and—as one community—rededicate ourselves to doing everything we can to make sure not another moment is lost to seizures.

I look forward to seeing you there—in person or online!

Tony Coelho
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“When I have seizures, my eyes go foggy and my body goes still,” says Veronica, age 5, artist of “A Caterpillar to Butterfly,” a submission in the Expressions of Courage® contest. She feels like she is sleeping, a caterpillar in a cocoon waiting to become a butterfly. “After my seizures are over, I can see better and then I go tell my mom and dad. I’m free to move just like the butterfly.”

COVER ART, “THE COOL CHORUS,” BY KATHLEEN GOLDSTEIN,
EXPRESSONS OF COURAGE® CONTEST WINNER.

www.epilepsyfoundation.org
1-888-886-EPILEPSY
My diagnosis was the most vigorous obstacle I have had to overcome in my life. It also was the most rewarding. I have epilepsy. But, it doesn’t stop me. It motivates me.

Almost a year had been lost following my diagnosis, as I struggled to confront reality. I was surprised and would not accept that this condition would be a part of my life. Unable to develop tolerance and acceptance of the situation I would have to live with; I coped by keeping emotions inside. Smiling and flaunting the fact that I had epilepsy was my way of suppressing screams and cries from within. My formerly content soul disappeared into a world of unknowns. I was unsure of my future. Friendships were being tested. Every day I wondered if I could make it to ninth period without having another seizure.

Before my diagnosis, everything was running smoothly. Starting at the end of sixth grade, seizures interrupted my attendance at school. Side effects of medications slowed my thinking, weakened my memory and depleted my overall energy. My social life was diminishing and my whole demeanor changed. My life was changing, spinning out of control. Gradually, I realized that seizures and medication side effects were my life. There simply was no rewind button, and I would just have to make the best of it. I confronted the fact that epilepsy is not who I am—it is what I have. I eventually came to understand that the number of hospital bracelets I’ve amassed cannot compare to the number of great accomplishments I’ve achieved since my diagnosis. I believe my acceptance and confrontation of my disability has helped me consider it a guide through my journey, pointing me in a direction in life.

After I became tolerant, knowledgeable and accepting of my own diagnosis, I promised myself to educate others about this condition. Through my membership and leadership on the Epilepsy Foundation’s Youth Council, my high school Key Club recognized and celebrated Epilepsy Awareness Month in November 2004 by raising funds for the Epilepsy Foundation of Long Island. I helped bring the Epilepsy Foundation of Long Island to my school to present informative programs to the faculty and health classes. I am proud to say that this program continues each year with the current ninth-grade health classes. My involvement with the local and national Epilepsy Foundations has given me the opportunity to participate in the Epilepsy Foundation’s Public Policy Institute. In 2005, I lobbied on Capitol Hill for increased funding for education and research programs.

A lot can change in 10 years, or in 1 day. That’s why I live my life to the fullest and help others accomplish the same. My personal motto is that life may change at any given moment, as mine did on that fateful day in June 2001, but you have to make the best of what may come your way. I don’t have to love the hand I was dealt, but I do have to make the most of it, since I only get one life to live.

In My Own Words is a column featuring the voices of people affected with epilepsy.

Jennie is 18 years old and a senior at Great Neck South High School in New York. She hopes to be an educational lawyer or a special education teacher. She currently serves on the Foundation’s Youth Council.
Do the Right Thing

On January 3, 2007, at about 12:45 p.m., Wesley Autrey risked his own life to save another’s. He saw 20-year-old Cameron Hollopeter, of Littleton, MA, experiencing a medical problem in a New York City subway station and took action when he saw the film student fall onto the subway tracks just as the train was approaching.

Autrey said, “I don’t feel like I did something spectacular; I just saw someone who needed help. I did what I felt was right.”

Autrey is a 50-year-old Harlem construction worker, a Navy veteran, and father of two young girls (Syshe, 4, and Shuqui, 6). Since the incident, he’s been on David Letterman’s “Late Show,” honored by New York City mayor Michael Bloomberg, appeared on The Ellen DeGeneres Show and, most recently, was introduced by President Bush during the State of the Union address. He’s received checks and trips, scholarships for his daughters and calls from total strangers who want to tell him what an inspiration he is.

Autrey remembers thinking, “If I let him stay there by himself, he’s going to be dismembered.”

“What I did was something that any and every New Yorker should do,” Autrey said.

Five cars went over them—with just inches to spare—before the train operator, who had seen someone on the tracks, was able to engage the emergency brakes and stop. People screamed and Autrey and Hollopeter were so close to the bottom of the train, Autrey’s blue knit cap was streaked with grease.

According to Autrey, after the train stopped Hollopeter asked if he was dead. Autrey replied, “You are very much alive, but if you move you’ll kill the both of us.” He then yelled to bystanders, “We’re OK down here, but I’ve got two daughters up there. Let them know their father’s OK.”

Both men survived the incident with only bruises and police said it appeared that Hollopeter and Autrey had experienced a seizure. Hollopeter was taken to St. Luke’s-Roosevelt Hospital Center after the power was cut and workers got them out from under the train. Autrey refused medical treatment and went to work the nightshift at his job after visiting Hollopeter in the hospital.

Cameron Hollopeter’s father, Larry, said, “There are no words to properly express our gratitude and feelings for his actions. May God’s blessings be with Mr. Autrey and his family.”

“Good things happen when you do good,” Autrey said.

The Epilepsy Foundation periodically reports on selected new research findings that may be interesting to people with epilepsy. People who read these reports should be aware that one study generally is not considered to be adequate scientific evidence on which results can be relied upon. Usually many studies are necessary to confirm the results and/or to base treatment decisions or recommendations thereon. Most importantly, individuals should not make personal treatment changes based on research results on their own. Instead, personal treatment choices should be made with the advice and guidance of a licensed medical professional.

KEPPRA MAY HOLD PROMISE FOR NEW ONSET EPILEPSY PATIENTS

New research indicates that treatment with low doses of levetiracetam (Keppra) is effective for newly diagnosed epilepsy patients with partial seizures, according to a study published in Neurology. Levetiracetam is currently approved as an add-on therapy, however new evidence shows it might provide effective seizure control on its own (monotherapy).

Researchers assigned nearly 600 adults who had at least two seizures in the previous year to either levetiracetam or to controlled-release carbamazepine, a common epilepsy treatment. Study author Martin Brodie, MD, and his colleagues found that the seizure-freedom rates were nearly identical in each group—approximately 73 percent. Of the patients who were seizure-free at 6 months, 80 percent who took levetiracetam and 85 percent of those who took the carbamazepine were still at the lowest dose level. Withdrawal rates for adverse events were higher in the carbamazepine group (19.2 percent) vs. 14.4 percent for levetiracetam, although this difference was not statistically significant.

Brodie commented, “the fast and sustained efficacy and good tolerability of levetiracetam in adults and children with partial-onset seizures, together with its favorable pharmacokinetic profile, lack of enzyme-inducing properties and low potential for pharmacokinetic interactions, make it a promising AED for use as initial monotherapy in newly diagnosed epilepsy.”

ARE EPILEPSY PATIENTS ABLE TO PREDICT SEIZURES?

A new study reported in Neurology reveals that some epilepsy patients can reliably predict when some of their seizures are likely to occur, a finding that may lead to better seizure prevention.

To determine how accurate patient predictions were, researchers examined 71 patients who had at least one seizure during the past year, but not more than one per day. Patients were asked to keep a daily log in which they predicted how likely they were to experience a seizure in the coming 24 hours.

Fifty-seven patients experienced seizures during the study. Of these patients, the study found they correctly predicted about 32 percent of their seizures, and 83 percent of their seizure-free days. Seizures were twice as likely to happen in the 24 hours following a positive prediction.

Some people were much better able to predict seizures than others. If these results are confirmed in future studies, the ability to predict seizures could have significant implications for treatment of epilepsy. “Patients who can accurately predict an increased risk of seizure might be able to take medications to pre-empt a seizure before it starts,” said Haut. “Accurate prediction of a reduced risk is also important since it might provide reassurance and improve quality of life for people with epilepsy.”

In addition, researchers say identifying periods of time when the probability of seizures is increased also offers patients an opportunity to institute precautionary measures.

In an editorial appearing in the same issue of Neurology, Dr. Brian Litt expressed concern that there were potential drawbacks to the study that could make the results difficult to interpret. However, overall, he concluded that if the results are validated, their findings help prove the concept that it is possible to develop tools and devices that can identify periods of time during which seizures are more likely to occur, giving patients warning and opening up opportunities for novel therapies to stop seizures before they start.
Expressions of Courage

Artwork from a variety of winners from the Expressions of Courage® art contest for people with epilepsy.

Watercolors, pencil sketches, sculptures or abstract paintings – whatever medium they choose, artists have the unique ability to express personal experiences and philosophies. When adding fear, hope and courage that stems from facing a serious neurological condition, artwork can bring a condition alive in imaginative ways.

The Epilepsy Foundation and Ortho-McNeil Neurologics, Inc. sponsored the Expressions of Courage® art contest, encouraging people with epilepsy to submit original artwork that expresses their feelings of living with a debilitating condition. More than 200 people submitted artwork for this year’s contest. Entries ranged in form and style, including such pieces as abstract drawings, traditional paintings and computer-generated art.

“The Expressions of Courage contest is a way to celebrate the accomplishments of everyone living with epilepsy,” said Eric R. Hargis, president and chief executive officer, Epilepsy Foundation. “People who enter the contest have varying experiences with epilepsy – some have well-controlled seizures, others have seizures that are difficult to manage. They all wish to share their feelings with us through their art. We appreciate their efforts and are proud to recognize their talents and courage.”

Contest entries were categorized into three age groups: children ages 12 years old and younger; teens ages 13 to 17 years old; and adults 18 years of age and older. Winners were chosen based on the entrant’s creativity and ability to demonstrate feelings of living with epilepsy through art.

Winning artwork is on display in an online gallery at www.expressionsofcourage.com. In addition, several winning entries are featured in calendars, greeting cards and coffee table books.

ARTIST: Kathleen G.
AGE: 50
TITLE: The Cool Chorus
MEDIA: Acrylics and Pencil

Art, music, and a love of nature drive Kathleen, who has had seizures since the age of 14. She has had surgery to control her seizures. “With the love and support of my husband, family, and doctor,” Kathleen says, “I have been able to deal with my seizure disorder and remain a free spirit and enjoy life”—just like her penguins.
**ARTIST:** Brianna D.  
**AGE:** 12  
**TITLE:** Summer Birds  
**MEDIA:** Paper Bag, Sharpie and Paint

Briana paints birds that are beautiful and graceful in flight. Perhaps they come from her dreams. Waking is often an abrupt experience for Briana. “My experience with epilepsy is when I wake up, I am crying in my bed. Sometimes I sleepwalk and fall on the floor,” says Briana.

**ARTIST:** David D.  
**AGE:** 45  
**TITLE:** Tower at the Point  
**MEDIA:** Watercolors

“Artwork is a graceful experience for me,” says David. “I do it to relax when I have the opportunity. Perseverance keeps me trying to improve.” David has suffered from epilepsy since 1975, more than two-thirds of his life. He has tried to control his seizures with medication, surgery (which reduced his seizures but did not eliminate them) and a VNS implant.
ARTIST: Braeden M.

AGE: 4

TITLE: Me and My Dog, Godiva, on a Sunny Day

MEDIA: Markers

Braeden was diagnosed with epilepsy when he was two. Playing outside with his dog, Godiva, makes him happy.

ARTIST: Dotti P.

AGE: 41

TITLE: Face to Face

MEDIA: Ink

Dotti had brain surgery for her epilepsy in 1998. “Drawing helps take my mind off my condition,” she says. Dotti likes to draw faces, and there is a world of faces waiting to be drawn, eager to distract Dotti from the ugly face of epilepsy.
ARTIST: Cicily M.
AGE: 32
TITLE: Untitled
MEDIA: Markers and Ink

“Epilepsy isn’t an easy thing to deal with,” says Cicily. “I enjoy doing art because it relaxes me and keeps my mind off the negative and stressful stuff in my life. I feel that I might as well use my talent, which is a blessed gift.”

ARTIST: Betty G.
AGE: 27
TITLE: The Pressure of Epilepsy
MEDIA: Pencils and Crayola Markers

Betty has felt like she has had an elephant on her back since the age of two when she was diagnosed with epilepsy. The pressures of epilepsy are huge for children and adults alike. Betty misses the simple pleasures of life like riding a bike or driving a car. “I hope that in time there will be newer and newer medications to control this neurological disorder and get this elephant off my back,” Betty says.
Recent data has validated what many of us believed, which is that if an individual has seizures that are uncontrolled, despite at least two good trials of antiepileptic drugs, the chances that a person will become seizure-free trying the third, the fourth, or the fifth drug are very slim.
“Stimulating certain parts of the brain, for example, a deep structure of the brain called the thalamus, may have potential benefits in stopping seizures from developing or stopping the progression of a seizure.”

EpilepsyUSA: So it’s helpful to have both the EEG results and also the visual of what’s happening to the patient?

Dr. Ettinger: Exactly. And even if the specific episode has not been captured, with very prolonged EEG testing, one can often find important abnormalities in the EEG background, which would not be likely to appear in the much briefer routine EEG.

I think the expansion of video EEG monitoring units—very ubiquitously now—across the country has helped improve diagnosis. Being able to capture the seizures for study also helps the clinician to better understand the nature of the seizure disorder; this can lead to a better treatment plan.

EpilepsyUSA: In what other ways has the diagnosis of epilepsy improved?

Dr. Ettinger: I think clinicians are becoming much more sophisticated about the terminology, diagnosis and treatment of epilepsy. The devoted efforts of foundations like the Epilepsy Foundation and the American Epilepsy Society have heightened awareness of neurologists and non-neurologists to the complexities of epilepsy.

EpilepsyUSA: Has heightened awareness also helped healthcare providers to know when they need to refer a patient to an even more specialized physician?

Dr. Ettinger: That’s an excellent question; timely referrals to specialized epilepsy centers remain a bit of a concern. Recent data has validated what many of us believed, which is that if an individual has seizures that are uncontrolled, despite at least two good trials of antiepileptic drugs, the chances that a person will become seizure free trying the third, the fourth, or the fifth drug are very slim. So unfortunately, we still see many clinicians spending many years trying one medication after another before considering referral to specialized centers. This is unfortunate since many valuable years can be lost and potential curative interventions like epilepsy surgery may be delayed. Worse yet, some clinicians may tell their patients that there’s frankly nothing else that can be done, or that the patient will have to endure unpleasant medication side effects, rather than seeking alternatives with a consultation by the specialist. By educating the public, however, these kinds of problems are less likely to occur.

EpilepsyUSA: What promising new treatments do you see on the horizon, say in 5 to 10 years?

Dr. Ettinger: I think some of the exciting work that’s being performed in epilepsy treatment research concerns the topic of neural or electrical stimulation in the attempt to stop seizures. While many individuals will have their seizures well controlled by medications, for those individuals who continue to have seizures, an epilepsy surgery evaluation is often advised. The most common type of epilepsy surgery is designed to locate where the seizures are coming from in the brain and, if possible, to remove that dysfunctional area.

However, there are still many individuals who will not be good candidates for surgery because their seizures may not occur from one specific area of the brain that can be removed. Sometimes we have difficulty pinpointing exactly where those seizures are coming from.

“...A third category that we need to explore further is the development of agents that reduce the chances of developing epilepsy in the first place, after a person incurs an insult to the brain.”

It has been noted for a long time now that stimulating certain parts of the brain, for example, a deep structure of the brain called the thalamus, may have potential benefits in stopping seizures from developing or stopping the progression of a seizure. There are many different strategies currently being tested. Some stimulators give small currents of electrical stimulation at regular intervals—whether a person is or isn’t having a seizure at that very time—trying to prevent more seizures from occurring. Other strategies being tested are more “reactive” in that electrodes are able to pick up that a certain abnormal electrical activity is developing; the device then respond by sending an electrical signal that may stop the seizure from progressing.

There are many unknowns in this area, in that we need to refine our understanding of what are the best...
I also believe that we are making progress in removing the stigma of having depression with epilepsy, in part because clinicians and patients are beginning to understand that depression is strongly related to the biological underpinnings of epilepsy.

Another promising area is medications. There are two main categories. Some of the medications “in the pipeline” are those that are new and improved “sons” of currently available drugs. For example, some drugs may be potentially very helpful against seizures, but when you raise the dosage, intolerable side effects develop. One strategy therefore, is to develop a derivative of that drug, one that is more potent and yet has less severe side effects.

Another strategy is to look for compounds that have completely different mechanisms of action; ones that are unrelated to specific compounds that are currently available. We still need to make greater strides in finding drugs with novel mechanisms of action that will enable us to control seizures with very minimal side effects.

A third category that we need to explore further is the development of agents that reduce the chances of developing epilepsy in the first place, after a person incurs an insult to the brain. In other words, drugs that are not antiepileptic, but are antiepileptogenic.

EpilepsyUSA: What is the distinction?

Dr. Ettinger: Whereas antiepileptic drugs are used to try to control seizures that are symptoms of an existing epileptic disorder—antiepileptogenic drugs are neuroprotective drugs that protect the brain and nerve cells from developing seizures in the first place (such as may occur after significant head injury, a stroke or a bleeding event in the brain).

EpilepsyUSA: Do those kinds of drugs exist now?

Dr. Ettinger: There is soft evidence for several agents currently in use, but we need to make further strides in this area.

Another aspect of epilepsy treatment is, for those individuals who are evaluated for potential epilepsy surgery, we are improving our ability to spot abnormalities on pictures of the brain. Sometimes the EEG—the brainwave test—does not provide us enough information to be sure of where the seizures are coming from. If we can find subtle structural abnormalities on pictures of the brain, we are much more likely to be able to offer epilepsy surgery. We are constantly improving the technology associated with these brain pictures, thereby improving our detection of these subtle abnormalities. This can lead to more and better surgical cures for uncontrolled seizures.

EpilepsyUSA: What do you see in terms of improving the interaction between doctors and patients in order to make treatment and diagnosis more effective?

Dr. Ettinger: There are many challenges that remain in this regard, in part because health care providers are being asked each year to see more and more patients in shorter amounts of time. This places additional challenges on the doctor and the patient to comprehensively cover all the aspects of diagnosis and treatment that need to be discussed during a routine office visit. Since it is unlikely that this problem is going to go away anytime soon, patients can help this problem by taking the time to prepare information and prior medical records before stepping into the doctor’s office.

I have been stressing how essential it is for patients to take an active role in their health care.
**EpilepsyUSA**: What kinds of information?

**Dr. Ettinger**: Information about their seizures, what the seizures are like, how often they occur, what they look like, what have observers seen, what it feels like, information about the medical conditions that the person has giving rise to the seizures, what is the diagnosis, what was the treatment, and how was it evaluated. These are common sense questions but it takes effort to organize this information for the doctor.

As a physician, who has been very involved with the Epilepsy Foundation as well as a number of patient advocacy societies, I have been stressing how essential it is for patients to take an active role in their healthcare. This is one important element.

For example, at our epilepsy center [The Comprehensive Epilepsy Center, Long Island Jewish Medical Center, www.epilepsylongisland.com], our patients complete a detailed seven-page form that they can access from our Web site before even arriving at our office.

Another strategy is a checklist of items that doctors and patients should discuss on routine office visits. It’s very important for physicians to remember to review side effects of medications, precautions before undergoing tests, how our patients are coping with epilepsy and issues related to quality of life.

Another important advance in our dealing with epilepsy is the recognition of the importance of assessing for comorbid mood disorder symptoms among patients with epilepsy. Depression and anxiety are very common in epilepsy. We are making slow but incremental progress in educating clinicians to emphasize this in their routine evaluations of patients with epilepsy. I also believe that we are making progress in removing the stigma of having depression with epilepsy, in part because clinicians and patients are beginning to understand that depression is strongly related to the biological underpinnings of epilepsy.

**EpilepsyUSA**: So is depression more complicated than just feeling bad about having epilepsy?

**Dr. Ettinger**: Right. In other words, a simple notion would be that depression is just a reaction to having a bad chronic disorder. But in fact depression is likely strongly associated with biological conditions that give rise to seizures and can independently bring about depression. Other mechanisms for depression include medication effects and the seizures themselves. This is important to emphasize so that patients don’t feel that acknowledging depression symptoms is a sign of weakness or deserves a feeling of shame. Depression is eminently treatable but treatment depends first upon recognizing it.

**EpilepsyUSA**: What medications, surgeries or alternative treatments are you keeping an eye on for the near future?

**Dr. Ettinger**: I think that one of the exciting areas that I’m really keeping an eye on is the neurostimulation treatments that may offer additional hope of substantial treatment of seizures that cannot be eliminated through routine medication therapies or focal epilepsy surgeries.

**EpilepsyUSA**: What is the primary advantage of device-based therapies versus pharmacological therapies?

**Dr. Ettinger**: I think the advantage is that it offers an alternative when the other therapies are not working adequately.

**EpilepsyUSA**: So there is hope on the horizon?

**Dr. Ettinger**: This is a very exciting time with tremendous hope for great breakthroughs just over the horizon.
Adam Todd and Megan Monica, ages 7 and 12, have never met each other, but they are part of an extended family—the epilepsy community. Both children are being raised by parents who definitely go the extra mile—not just for them, but for many other children and parents who are trying to navigate a path in the sometimes confusing world of health care, legal rights and education. Megan’s mother, Nancy, and Adam’s parents, Dale and Sara, share their stories.

The expression “it takes a village” is part of the vernacular by now, referring to how an entire community needs to pull together to raise a child. If you have a child with epilepsy, however, those words represent much more than a societal ideal, they literally define what it takes to create a seamless structure of support around a child.

ACCIDENTAL ADVOCATES

Dale and Sara Todd’s son Adam was diagnosed with epilepsy when he was 3 years old. Adam was enrolled in preschool and was experiencing tonic-clonic seizures. If he had one in the morning, his parents observed that he was likely to then have a cluster of seizures. His parents knew administering Diastat would prevent the clustering and get him, as his father said, “some semblance of a quality of life for the rest of the day.” However, the school administrators “did not have a good comfort level for administering the Diastat.” So either Sara or Dale would have to go to the school, involving time and travel, to administer the medication.

When Adam entered public school, his parents developed an Individual Education Plan (IEP) for him and met with the school nurse who would, essentially, change their lives. When Sara and Dale brought up the discussion of Diastat, they touched on the protocol from the previous school and the discomfort they encountered. The school nurse, Mary Vorwerk, immediately responded, “What’s the big deal?” Dale said, “You know, guys aren’t supposed to cry, but I looked at my wife and we welled up a little bit. Our eyes got wet because it was a comfortable feeling knowing that the school nurse was willing to embrace our son.”

Dale has become a visible and tireless advocate for his son. He said, “I’m one of these folks that’s always on the side of the underdog it seems. Well, life’s strange twist is, the underdog I’m fighting for is my own kid.” He acknowledged that he and Sara did not set out to become advocates. “We found ourselves in this position because nobody else was saying what needed to be said.” He hopes “through advocacy and research we can find the reason why my son continues to have seizures.” He also described his advocacy as a form of therapy and likened the constant uncertainty of whether Adam is going to have a seizure to a “detective story that we find ourselves in every day.” He added, “You know, you don’t have a real choice in it; you have to be an advocate.” Dale is working within his state of Iowa to recruit a pediatric epileptologist for the university and he also feels that school nurses should be an important part of a district’s employee base. He said, “We’d love to see nurses at every school.”

Sara Todd is a nurse who initially did not know much about epilepsy aside from basic neurological information. She said, “Now I know more about epilepsy than I ever hoped to know.” She added, “We have found we really need a support crew around us. If Dale and I were just doing this alone, it would really be hard. So we’ve cultivated the school nurse, our health secretaries and the teachers and I think our advocacy for Adam is contagious. I remember his first teacher that he had for pre-K—an awesome wonderful enthusiastic teacher. She said, ‘I got to tell you that I’m a little scared.’ She said, ‘If I fail this kid, I will quit teaching.’ She started out the very first day of school saying, ‘You know what? We’re going to talk about differences. We’re all different. Suzie has a

“ I’m one of these folks that’s always on the side of the underdog it seems. Well, life’s strange twist is, the underdog I’m fighting for is my own kid.”

BY LISA BOYLAN
MANAGING EDITOR, EpilepsyUSA

It Really Does Take a Village

www.epilepsyfoundation.org
peanut allergy, so we can’t bring any food in the classroom that has peanuts in it or peanut butter.” She finished by saying, “Adam has seizures. Sometimes he might fall on the ground and shake, and that’s just what’s going on with him.”

Sara says she feels like Adam’s first teacher laid the groundwork for demystifying Adam’s condition. She also emphasizes the importance of assembling a team, while acknowledging that there is no precise road map for that. She and Dale have arranged for a one-on-one associate for Adam, a physical therapist and respite care. She said as a nurse she knew these kinds of services existed but never imagined she would be eligible as a recipient. She said any feelings of guilt subsided when she and Dale realized, “we just need to get out.” She said, “In spite of all this, Adam’s got such a good little spirit.”

Mary Vorwerk, Adam Todd’s school nurse, is an RN who works for the Cedar Rapids Community School District. She recognizes the importance of having school nurses in school, based on firsthand experience. She said, “It’s not putting on a Band-Aid at school anymore. There are a lot of health needs coming to school that we are involved with, more so than even 12 years ago. We do a lot of planning and writing individual health plans and protocols for children so that they can have a great experience at school and come to school just like anyone else.”

She finds satisfaction in her job because, she says, “I walk out of work and know that I have done something in my job today to help a student access health care.” She said, “Having school nurses in the buildings is a great asset to these students with health issues.” She praised the involvement of parents like Dale and Sara and said, “Adam is a wonderful little boy. He is very inquisitive; he loves to learn and read books; he loves to be at school; and has quite a few friends who know him. He is just a great addition to our school community.”

Sara Todd advises reaching out to places like the Epilepsy Foundation and to doctors. She says, “I think a lack of knowledge breeds fear. More information helps dispel the fears.”

THE LUCKIEST MOM IN THE WORLD

During delivery, Nancy Monica’s daughter Megan suffered a cut on her head caused by a fetal monitor. The cut later became infected with E. coli, causing Megan to run a fever. Her parents rushed her to the hospital and she suffered a stroke in transit from the first hospital to the pediatric ICU hospital. She fell into a coma for about 3 weeks. When she was 6 months old she started having infantile spasms and Nancy called the National Organization of Rare Disorders. They sent her a packet on epilepsy and she called them back and said, “You sent me the wrong thing. My daughter has epilepsy.” She explained, “That’s how naïve I was in the beginning. I had no idea it was epilepsy.”

Nancy’s naïveté has long since been replaced by a wide-ranging knowledge of epilepsy and what her rights are as a mother of a daughter with epilepsy. She uses her expertise not only as an advocate for her own daughter; she conducts clinical outreach services—seizure clinics—for the Epilepsy Foundation in North/Central Illinois for people with epilepsy who do not have access to specialized medical care. The clinics are geared for lower income people. She connects participants with top neurologists and support groups; develops IEPs and advises them on social issues such as employment and driving.

Nancy says the first thing she needed as a parent of a newly diagnosed child was “some little piece of hope to hang onto—that there was a possibility that my daughter was going to be OK.” She wrote to Exceptional Parent magazine and was connected with another mom. She said, “Even though she is in California and I am here in Illinois, it just gave me someone to go through it with.”

They are still in touch, 12 years later.

“I just think I am the luckiest mom in the world because to our whole family she is like the glue that holds us together.”

As part of her clinical outreach work, Nancy assists parents on developing IEPs for kids. She requests:

- Extended time for assignments.
- Tests read aloud in a quiet area.
- Unlimited time for tests.
- Graphic organizers to break down information.
- Highlighted instructions in different colors to distinguish changes in tasks.
- Use of a calculator.

She also has special recommendations for the high school students she sees at her clinics that are having seizures for the first time as they go through puberty. She counsels them to apply for their IEP a year in advance of 11th grade, whether they intend to use it or not, because the IEP needs to be in place for a full year before a student can apply for accommodations for taking college entrance exams.

Nancy calls Megan her “little miracle.” She says, “I just think I am the luckiest mom in the world because to our whole family she is like the glue that holds us together.”

Nancy learned the hard way how to be an advocate for her child, but she is generous with what she knows so other parents, teachers and children don’t have to travel the road alone.
Since the mid-70s, federal civil rights laws have mandated that public schools provide health services to students with disabilities as an accommodation or to ensure that the student can fully participate in and benefit from special education services. This mandate extends to emergency medication to treat cluster or prolonged seizures, which can cause devastating health consequences if not treated promptly. Unfortunately, many public school systems continue to prohibit staff other than school nurses from administering the standard emergency medication. In most schools, because nurses are not available throughout the school day and/or for extracurricular activities, this policy effectively denies many students with epilepsy their right to equal educational opportunity and places their health at risk.

It should be recognized that the position of many school administrators on this issue is due in part to the lack of clarity in their state laws that detail restrictions regarding persons who are authorized to administer medications for seizures and other conditions. These laws may suggest that only licensed nurses are authorized to administer the standard emergency medication in schools. However, school administrators and state bodies (such as boards of nursing) that enforce these laws fail to recognize that this emergency medication can be, with minimal training, safely and easily administered by non-medically licensed school personnel such as instructional assistants. Because many of these state laws contain express exceptions for medications of this type (that is, emergency medications or those that do not require specialized skills to administer), the laws may not actually prohibit unlicensed school personnel from administering the medication.

The standard out-of-hospital medication for treatment of prolonged or cluster seizures is Diastat® Acudial,™ a rectally administered preparation of diazepam. (Diazepam is in a class of drugs called benzodiazepines, which are central nervous system depressants.) The medication is FDA-approved and was specifically developed to be administered by people without medical training, such as parents, teachers and other caregivers. Other medications, which also may be administered by non-medical personnel, may sometimes be appropriate.

It is critical that school administrators ensure that a range of school employees are trained and available to administer Diastat (and similar medications), because, oftentimes, there is not a full-time licensed nurse available every day in the school, or for extracurricular activities and field trips. Because the medication is particularly effective when administered within 15-30 minutes of seizure onset, and permanent neurologic damage may result with a delay in administration, non-licensed school staff must be immediately available.

Because rectally administered diazepam and similar medication for seizures can be administered by non-medical personnel who have received proper training, lack of access to a doctor or full-time nurse is not an acceptable reason to refuse to administer the medication at a child’s school. The Epilepsy Foundation urges school administrators (as well as childcare providers) to work with the child, his or her parents and the child’s treating physician to learn how and when to administer the appropriate treatment. (For the Foundation’s position statement on this issue, visit our Web site at www.epilepsyfoundation.org/advocacy/care/treatmentsinschool.cfm.)

Federal Educational Civil Rights Laws and Medication Access

Courts and state education agency hearing officers have ruled that schools are required to ensure that Diastat and similar medications are administered to comply with the Individuals with Disabilities Education Act (IDEA), the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act (Section 504). These laws require schools (and other service providers such as day care facilities) to provide health services and accommodations for children with epilepsy and other disabilities to ensure that they can access and benefit from the educational program. (Section 504 and the ADA provide comparable protections for students with disabilities in the context of education, while the IDEA provides a much more detailed framework of educational rights to students whose disabilities adversely affect their ability to make educational progress. For more information on these laws, see the Epilepsy Foundation’s fact sheet on the subject, available at www.epilepsyfoundation.org/answerplace/Legal/educationlaw/.)
Nevertheless, many schools that do not have nurses on site rely on emergency medical services (911) to respond to a student experiencing a seizure. This practice, in addition to delaying treatment, can result in unnecessary psychological trauma to the child and his or her parents, and, of course, saddle the family with potentially significant hospital bills.

Other school administrators have chosen instead to place a child with epilepsy at a school away from his or her neighborhood — sometimes in a segregated setting serving children with disabilities — where a nurse is present full-time. This practice may conflict with the right of children with disabilities to be educated in the “least restrictive environment,” that is, to be educated with non-disabled peers to the maximum extent appropriate. Courts have found a preference in Section 504, the ADA and the IDEA for placement of students in the schools they would attend if they did not have disabilities. Although there is no absolute right to such neighborhood school placement, it is illegal to place a student in a more restrictive placement solely on the basis of his or her disability, for administrative convenience, or because of the configuration of the service delivery system. Therefore, it may be a violation of the law to place a student with epilepsy in a separate school simply because that is where a nurse is located full-time.

As discussed below, these practices are sometimes prompted by state “nurse practice” laws. These laws establish standards on licensing and educational requirements for nurses, and specify which types of treatment or medication may only be provided by licensed nurses. Some state education codes may also restrict certain types of medication administration in school to licensed nurses.

State Laws on School Medication Administration

State nurse practice laws and state education codes generally specify that only licensed nurses may administer medication in schools when specialized nursing sciences knowledge and training are required to assure safety. School administrators sometimes mistakenly assume that the standard emergency seizure medication requires such specialized knowledge and training. Therefore, they argue that these state laws do not authorize instructional assistants and other non-medically licensed staff to administer this medication. However, virtually all studies conclude that caregivers without specialized medical knowledge or training can safely and effectively administer the medication and monitor any side effects.

In a case in which the Epilepsy Foundation and its Central Ohio Affiliate had significant involvement, an Ohio court recently found that state law does not prohibit non-medically licensed school employees such as instructional assistants from administering Diastat (Lancaster School District Support Association v. Board of Education, Lancaster City School District, Ohio Ct. of Common Pleas, March 6, 2006). In this case, the school district had established a policy requiring non-medically licensed school employees to administer the medication, and this was challenged by the employees’ union. A copy of the court’s decision is available online at www.epilepsyfoundation.org/epilepsy/legal/genattyresources.cfm.

The court found that administering Diastat does not require “specialized knowledge, judgment and skill derived from the nursing sciences,” and therefore is not restricted by the Ohio Nurse Practice Act. Also, the court noted that, in any case, administering Diastat to a child experiencing a generalized seizure constitutes a medical emergency, and therefore falls under an exception to the Act. In this case, there were apparently a number of safeguards in place. The court, therefore, determined that the school district may (under a separate provision of Ohio law) direct non-licensed school personnel to administer the medication. These safeguards included a signed parental request, instructions from the prescribing physician and appropriate training for employees.

The court concluded by observing that “Unfortunately, it does not appear possible for a school nurse to be present at all times in every school building. Accordingly, just as it is important for education professionals to be trained in other life preserving emergency procedures such as the Heimlich maneuver or CPR, it is important that educational professionals become adequately trained at administering this potentially life saving medication.”

Affiliate Advocacy Efforts

The Epilepsy Foundation’s affiliates have pursued a range of advocacy strategies in order to address the concerns of school administrators about state law restrictions on medication administration. Some affiliates have worked to change the state laws that may arguably restrict non-medically licensed school personnel from administering

**SEIZURES REQUIRING EMERGENCY MEDICATION**

Most seizures last less than 1 to 2 minutes and are harmless. However, some people may experience prolonged seizures (of 5 minutes or more) or severe repetitive (or “cluster”) seizures. Emergency medication is needed to address these conditions, as they may lead to a serious medical emergency, called “status epilepticus.” SE is defined as a seizure lasting 30 minutes or longer (though some experts use 10 minutes as a benchmark), or as intermittent seizures lasting that period from which the patient does not regain consciousness. There are an estimated 100,000-150,000 cases of this condition per year, with the largest proportion of cases among children under the age of 10. The condition can cause permanent neurological damage. For more information on epilepsy and medications, including Diastat, see the Foundation’s Web site at http://www.epilepsyfoundation.org/answerplace/Medical.
this medication. For instance, in 2005, largely as the result of the efforts by the Kentuckiana Affiliate, the Kentucky governor signed into law a bill that authorizes such personnel to administer Diastat (along with glucagon for diabetes treatment) in public, private and parochial schools. The statute provides that schools shall require that at least one school employee, who has met state competency requirements (and consents to provide the medication), be on duty at each school during the entire day to administer Diastat (and glucagon) in an emergency. Other affiliates are considering promotion of similar amendments to state laws and regulations.

Some affiliates have been advocating that state officials interpret existing state law in a way that allows non-medically licensed school personnel to administer anti-seizure medication. In fact, most state nursing practice laws and some education codes carve out exceptions to their medication administration restrictions, allowing such personnel to administer medications in emergency situations or when specialized nursing skill is not involved. Following the lead of the court in the Ohio case, a number of affiliates are making the argument that Diastat administration falls within these exceptions.

Almost all affiliates are available to provide training to school employees on administration of Diastat, as well as other advocacy services to promote full access to emergency medication in school. To locate the affiliate serving your area, go to www.epilepsyfoundation.org/aboutus/AffiliateLookup.cfm.

The Foundation’s Legal Defense Fund Can Help

All family members who are currently confronted with a denial of full access to emergency seizure medication in school, day care, aftercare or other settings are encouraged to contact the Foundation’s Jeanne A. Carpenter Epilepsy Legal Defense Fund for assistance. The mission of the Fund is to protect the civil rights of people with epilepsy through education, advocacy and increased access to legal services. The Fund provides legal guidance to individuals experiencing epilepsy-related discrimination and their families, along with referrals to a nationwide network of cooperating law offices. For more information about the Fund and a range of advocacy resources for individuals and attorneys, visit www.epilepsylegal.org. The Fund can be contacted at legalrights@efa.org or 1-800-332-1000 (select option 4), or a request for legal assistance can be made via the Fund’s Web site (click on “Consumer Legal Center”).

The writer is the director of the Jeanne A. Carpenter Epilepsy Legal Defense Fund.
On March 31, 2007, thousands of people from across the country are expected to take an historic 5K trek to raise awareness and money for epilepsy research to ensure that not another moment is lost to seizures. The National Walk for Epilepsy is presented by the Epilepsy Foundation and Ortho-McNeil Neurologics, Inc. Sponsoring organizations include the American Epilepsy Society (AES), the Epilepsy Therapy Development Project and many comprehensive epilepsy centers.

“Epilepsy is the third most common neurological condition behind stroke and Alzheimer’s—affecting more than 3 million Americans—but few people know that it can affect anyone, anywhere at any time,” said Eric R. Hargis, President and CEO of the Epilepsy Foundation. “The goals of the Walk are to raise public awareness about the condition and to secure much-needed funding to find a cure. We are also striving to create an environment where people living with epilepsy have equal access to all life experiences.”

The Walk will engage people with epilepsy, caregivers, doctors, government leaders, organizations committed to the epilepsy mission and the general public. It will take place on the first day of the National Cherry Blossom Festival, and is estimated to attract thousands of supporters to help raise $1,000,000 to support programs to eliminate stigma and raise awareness.

The Honorary Chair for this first-ever Walk is actor Greg Grunberg, who is best-known for his television roles as Sean Blumberg on Felicity, Eric Weiss on Alias and Matt Parkman on NBC’s new hit show, Heroes. Greg and his wife Elizabeth’s 10-year-old son, Jake, has epilepsy. “It is such an honor to participate in any way we can to raise awareness in the fight against epilepsy,” Grunberg said. “To be able to march on Washington with those directly affected and their families lets our family know we are not alone.”

Walkers will include those living with seizures and their caregivers; doctors, nurses and other healthcare professionals; government leaders; Epilepsy Foundation staff and volunteers; alumni from signature Epilepsy Foundation events such as Kids Speak Up and the Public Policy Institute; corporate walking teams; celebrities committed to the epilepsy cause; Epilepsy Foundation business partners and members of the general public. All of these participants will show their dedication to the mission of the Epilepsy Foundation: preventing, controlling and curing epilepsy through research, education, advocacy and services.

An online, virtual Walk is available for those who are unable to travel to Washington to participate. Virtual walk participants will have their contributions—and the money they raise—reflected on an online map of the world, which will grow brighter as more and more people become involved. Virtual walkers may participate by walking in their own community, as a team or by themselves. Once all walkers have reached the finish line, the total distance covered and the total amount raised will be displayed on the www.walkforepilepsy.org Web site.

Register for the event at www.walkforepilepsy.org, where they can also visit for more details about the event or to sign up as a volunteer at it. (Registration fees are $35 for adults and $20 for children 12 and under. The last day to pre-register is March 15, 2007). All registrants will receive a T-shirt. Although registration fees are not tax deductible, all pledges and donations raised are!

For information please visit us on the Web at www.walkforepilepsy.org.

Where: The National Mall, Washington DC
When: Saturday, March 31, 2007
See page 22 to register!

Greg Grunberg
(Star of NBC’s Heroes)
Chair,
National Walk for Epilepsy

“It is such an honor to participate in any way we can to raise awareness in the fight against epilepsy,” Grunberg said. “To be able to march on Washington with those directly affected and their families lets our family know we are not alone. See you all there!”
In an effort to educate children about how the brain functions and what happens when abnormal electrical activity in the brain causes seizures, the Epilepsy Foundation of North/Central Illinois, Iowa and Nebraska embarked on a unique partnership with the Discovery Center Museum in Rockford, IL. They enlisted the help of the only remaining pinball maker in the world, Stern Pinball, Inc. (also of Illinois), to make a pinball machine modeled on the brain—complete with a seizure feature that shuts the game down at random intervals.

Monique Adudell, development director for the Epilepsy Foundation, said, “When we were searching for a way to bring epilepsy out of the shadows and demystify it for children, we turned to Discovery Center as a potential partner because they are so creative and highly regarded.”

When the game is interrupted during a seizure, a panel lights up for a few seconds displaying a message that says, Seizure—stand by for game to resume. Discovery Center exhibit designer Bruce Quast, who came up with the idea for an interactive exhibit based on a pinball machine, said the seizure feature “helps the player understand that a seizure is nothing to be afraid of and, after a short while, things pick up where they left off.”

Nancy Monica (see article on page 13), featured speaker and an active volunteer for the Foundation, brought her 12-year-old daughter Megan, who has epilepsy, to the unveiling. Both were excited about the exhibit. Nancy said, “The unpredictability of epilepsy is probably one of the worst things. This shows kids that a seizure can happen and life goes on around you, but you can jump back in.” As she and Megan were driving to the exhibit, they had a conversation about Megan’s epilepsy. Megan asked, “Why did God pick me to have seizures?” Nancy responded, “Because you’re special and God knows when you grow up you’re going to tell other people what it’s like to have seizures and that you can still be happy—you can still have a regular life and have seizures.”

With 3,500 parts, 1,200 screws, nuts and washers, 115 lights, 70 switches, 100 connectors, 88 terminals, 356 tie wraps and a half a mile of wire, “Brain Pinball” is still no match for the complexity of an actual brain, however it is an excellent way for kids to learn about the brain and all of its functions and occasional malfunctions.

People approached the machine delightedly, ready to touch it and interact with it as it lit up like a—well, like a pinball machine, its components flickering, ringing, ricocheting and occasionally halting for a simulated seizure. People waited patiently for the game to resume, as though nothing had happened.

Donors for the project were:
Eisai Pharmaceuticals  •  William Howard Charitable Trust
Williams McCarthy LLP  •  Merritt Mott Family
Dean Alan Olson Foundation
Many people find it easy to delay making a will. They find it easy to procrastinate because they think estate planning is hard. But really, it’s not all that difficult – at least in most cases. In fact, creating a will can be as simple as ABC!

**Assets** Begin by making an inventory of all your assets: insurance policies, bank and brokerage accounts, art work and other collections, real estate holdings, vehicles, everything you own. Once you have the list, estimate the value of your assets and then deduct what you owe. This will give you a rough idea of the total value of your estate.

**Beneficiaries** Who do you want to receive your assets? First, consider family needs and obligations. Then review your charitable involvements and how a bequest could benefit them and create a lasting legacy for you.

**Confidants** Choose trustworthy persons to provide legal and other professional assistance, as well as a personal representative to help settle your estate. You may also need to select one or more trustees and guardians for any minor children.

Once you have listed and valued your assets, selected the beneficiaries for your estate and chosen the key persons to assist you now and after your death, it is time to act. Don’t delay. Contact an estate planning attorney right away and move forward.

If you need help finding a good attorney, ask your friends for suggestions or contact the trust department of a local bank for a referral. Ask around until you find someone you feel good about. If you wish, we can assist you in this process as well.

While creating a will is easier than you might have thought, it will take some time. But the end result is worth it. You will be well rewarded with a deep sense of satisfaction and peace of mind.

To make the process even easier for you, the Epilepsy Foundation offers a complementary Will Planning Kit. Included in this resource kit, are the following:

- ✔ Resource Guide #1: How to Make a Will that Works
- ✔ Resource Guide #2: Giving Through Your Will
- ✔ Resource Guide #3: In Control, Taking Charge of Epilepsy and Personal Finances

The Epilepsy Foundation’s Will Planning Kit is yours for the asking. To request your FREE will planning kit, please contact Daniell Griffin, Sr. Director of Individual Giving at 301-918-3741 or e-mail dgriffin@efa.org. Or, simply complete the coupon and mail it to:

Epilepsy Foundation
Attn: Development
8301 Professional Place
Landover, MD 20785

Please send me the Epilepsy Foundation’s Will Planning Kit

Name: _______________________________________________________________
Address: _____________________________________________________________
City: ____________________________ State: __________ Zip: ______________
Daytime Telephone _____________________________________________________
E-mail: _____________________________________________________________
I’d like your readers to know that it isn’t about generosity when it comes to helping those with a seizure condition obtain much-needed medication. It’s about compassion and concern . . .

I frequently visit your Web site to read the articles that address the latest in epilepsy research, especially the articles that address epilepsy in women. I have a particular interest in your Web site and magazine because I have complex partial seizures and I feel it’s important to keep informed on the latest epilepsy research.

On several occasions you’ve addressed in your magazine the importance of family members of someone with a seizure condition to become just as informed and aware of the condition as the person who has the condition.

I’d like your readers to know that it isn’t about generosity when it comes to helping those with a seizure condition obtain much-needed medication. It’s about compassion and concern—compassion for the person who has to deal with the consequences due to the condition and concern for that family member and what could happen to her if she is unable to access life-saving medication.

Even though there are plenty of families with a loved one who has epilepsy who are eager to become informed about the condition, there are always two sides to each issue. Sadly, I am presenting the other side.

Therefore, I encourage those families who have a loved one with epilepsy to show compassion and concern for that person and to become informed about the seriousness of epilepsy and the serious consequences that could occur if a person with epilepsy does not have access to life-saving medication.

SINCERELY,
JEANNINE BEROITERAN
YOUNGSTOWN, OH

—Annie Mascorro

Expressions

The Cure

My mother met a psychic on the bus to Sacramento, a woman with purple glittered shoes, who, when pressed, told her what she wanted to hear: that I do not have epilepsy but a parasite in the brain, a worm drilling its way through a piece of fruit, something to be cut out, like my mother’s uterus when it bled too much years ago. When she called with the psychic’s news, I stopped my cooking, sat down, pictured my mother with tweezers. But what about the small fimbrial fingers receiving, the yolk in my hand, and that first time I saw my brain on the MRI — the gyri and the sulci folding in and out, my tongue and nose, the entire head lit up. I was a parent then, imagined my mother seeing me as a fetus for the first time on the sonogram machine. I thought, now here is a map at last, leading somewhere.

Annie Mascorro received an M.F.A. in poetry from The University of Montana. Her work has appeared in Calyx and on Montana Public Radio’s “Collegium Medicicum.” She is also the recipient of the 2007 Five Fingers Review poetry prize. She lives in Missoula, Montana.

We want to hear from you!
Give us your feedback. Share a personal story.
Ask a question.
e-mail: editor@efa.org
mail: EpilepsyUSA, 8301 Professional Place, Landover, MD 20785-2238
All letters to EpilepsyUSA must include your full name and home address.
Remember, if you can’t make it to the National Mall, you can still participate in the Walk right from your own hometown! Join us for the virtual portion of the Walk online at www.walkforepilepsy.org.

Registration Form

First Name __________________________ Last Name __________________________
Address __________________________
City __________________________ State __________________________ Zip __________
Phone __________________________ E-mail __________________________ Date of Birth __________

Registration Fee and Donations

☒ Registration
☒ Registration (12 and Under)
☒ I Want to Make a Donation of $_________

Payment Method

☒ Check Enclosed
☒ Please Charge My Credit Card
☒ Visa
☒ MasterCard
☒ American Express
☒ Discover

Card Number __________________________ Exp. Date __________
Signature __________________________

Make checks payable to Epilepsy Foundation.

WAIVER AND RELEASE OF LIABILITY AND ASSUMPTION OF RISK AND INDEMNITY AGREEMENT

In consideration of being permitted to participate in the Epilepsy Walk (the “Event”) as a walker, runner or volunteer, or in any other capacity, I, for myself, my heirs, next of kin, assigns and personal representatives,

represent that I am qualified, in good health and in proper physical condition to participate in the Event and that I will stop my participation if I believe this Event becomes unsafe.

acknowledge and understand fully that there are risks and dangers of serious bodily injury and death that could result from my participation in the Event from any cause. Being aware of these risks and dangers, I have voluntarily elected to participate in the Event and I FULLY ACCEPT AND ASSUME ALL RISKS AND ALL RESPONSIBILITY FOR ANY INJURY, LOSSES AND DAMAGES TO PERSON OR PROPERTY THAT I INCUR AS A RESULT OF MY PARTICIPATION IN THE EVENT.

I HEREBY AGREE NOT TO SUE AND TO RELEASE, DISCHARGE, WAIVE, HOLD HARMLESS AND TO INDEMNIFY THE EPILEPSY FOUNDATION AND ITS AFFILIATES and their respective officers, directors, employees, volunteers, sponsors, advertisers, participants, agents and representatives FROM AND AGAINST ANY AND ALL LIABILITIES, CLAIMS, DEMANDS, LOSSES, DAMAGES, SUITS AND PROCEEDINGS, REGARDLESS OF THE CAUSE. I have read this agreement and understand that I have given up substantial rights by agreeing to it.

Date __________________________ Signature __________________________
Printed Name __________________________

Sponsor Pledge Form

Walker Name __________________________
Address __________________________
Phone __________________________
Pledged $_________

Name __________________________ Amount $_________
Address __________________________
Phone __________________________

Name __________________________ Amount $_________
Address __________________________
Phone __________________________

Name __________________________ Amount $_________
Address __________________________
Phone __________________________

Name __________________________ Amount $_________
Address __________________________
Phone __________________________

Total Pledged $_________

Walk Presenters

www.walkforepilepsy.org
National Walk for Epilepsy
not another moment lost to seizures
Washington, DC & Online
Saturday, March 31, 2007
Registration Information Inside