Mark Your Calendars: The National Walk for Epilepsy
Sunday, March 27, 2011

Still Standing
Stanley Hunter’s NFL dreams were derailed by seizures. Find out how he persevered and found happiness.

Plus: Caregiver 101
Having Hollywood put epilepsy on the map, especially during November, National Epilepsy Awareness Month, meant so much to me.

On November 7, in New York City, I did something I never thought I would do: I walked down the red carpet for a movie premiere of *Morning Glory*, starring Harrison Ford and Diane Keaton! What made it even more special was, I walked down the carpet with Board member Denise Pease and Professional Advisory Board member Blanca Vazquez. Why were we there, walking down the red carpet with A-list movie stars? Because Hollywood producer J.J. Abrams wanted to give a special shout-out to a cause that’s close to his heart: *Talk About It!*

This was an outstanding event that we got to experience because of the generosity of J.J. Abrams. Abrams is a great friend of our champion, Greg Grunberg and he is also the godfather of Greg’s son, Jake, who has epilepsy. They decided to use this venue as a way to talk more about epilepsy. Everyone on the red carpet was talking about epilepsy, including Harrison Ford, Rachel McAdams, and so many other A-list stars!

I can tell you, as a woman living with epilepsy, I have for the majority of my life experienced so many people living in the shadows and not even saying the word epilepsy. This movie premiere (see pages 15-16) helped shine a light on epilepsy and the Epilepsy Foundation. It shows we are no longer in the shadows! Having Hollywood put epilepsy on the map, especially during November, National Epilepsy Awareness Month, meant so much to me.

As you know, this year’s National Epilepsy Awareness Month was an unprecedented success and it’s all thanks to YOU! I hope all of you will keep the momentum going and continue to support the *Get Seizure Smart* campaign! Tell all of your friends to visit www.GetSeizureSmart.org, because epilepsy awareness isn’t about just one month—it’s about getting the message out all year long. We heard from so many people in the epilepsy community. One of hundreds of people wrote and said: *I had a great time distributing the Get Seizure Smart quiz. I like the idea that working together we can spread the word about epilepsy.*

That’s what it’s all about—working together. Get Seizure Smart also got people thinking and talking about the 5th annual National Walk for Epilepsy. This year’s Walk will take place on **Sunday**, March 27, 2011, on the National Mall in Washington, D.C. It is not too soon to register for the Walk, which is such a wonderful event. I encourage you to attend the Walk because now that we have epilepsy awareness on everyone’s radar, having thousands of people congregated on the Mall, all together, will show what strength we possess in numbers.

I love the Walk and I have attended every single year—including the first Walk when I had to come in a wheelchair. Nothing was going to keep me away from this event! I look forward to seeing you in Washington, D.C. on March 27, 2011!

Joyce Bender

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www.epilepsyfoundation.org
1-800-332-1000
Follow us on twitter @EpilepsyFdn
Stanley Hunter is a senior at Clemson University majoring in sports management. He played linebacker for the Clemson Tigers and currently serves as a student coach for the team.

It was Tuesday afternoon, July 28, 2009, and I was sitting in Clemson head football coach Dabo Swinney’s office discussing my future in college football. A few weeks before, I had suffered four of the worst seizures I had ever endured and had been pulled from all team activities. This meeting, along with other countless meetings with my trainers, doctors and neurologists, ended with the same result—I had to quit football. This was by far one of the toughest decisions I have ever had to make: giving up what I thought I lived for because of a condition that I still did not fully understand. I did not know what was happening at that moment in my life, but I did know I had to move on. I believe that everything happens for a reason and this was no exception. That may sound crazy coming from a former high school football star with a great shot at a future with the NFL, but in reality this was only one of many obstacles I have overcome throughout my life.

When I was 10 years old, my mother was sentenced to a 25-year to life sentence for trafficking cocaine. My father was never around during this time, so my childhood was the exact opposite of what a child’s life should be. Though my mom never abused drugs, I was frequently in the midst of drug abusers. It was not unusual for my sister and me to see pounds of drugs on the table, countless amounts of cash on the floor and out of our numerous residences. I can remember being in our home with no food, water or lights on many occasions. However, I was never abused in any way and I still have a close relationship with my mother. I was just compelled to grow up faster than most other kids.

After my mother went to prison, my sister and I went to live with my father. Though I always wanted to have a relationship with my dad, the experience was daunting. I felt like my father owed me something because of the time we spent apart, but he had other priorities. He had a new wife and was responsible for raising nine other children, all but two by different women. I felt alone; I was hurt. I started to question why I was dealt such a bad hand in life at such a young age.

Not long after I went to live with my father, I picked up a football for the first time. I was a freshman in high school and I had never played sports because of my mother’s lifestyle. I was pretty good, and football gave me a sense of purpose. I finally began to feel more like somebody. I had friends, I had coaches who cared about me, but most of all I had a chance to take all of my frustrations out on the football field. However, a year later, adversity struck again. As a sophomore in high school, I was diagnosed with epilepsy. Although I suffered a number of seizures in class and at home, they were under control at this time. Soon I was cleared to play again, and in my mind that was all that mattered. Football had become my life, and by the time I was a senior, I was being recruited by most colleges in the country. I would end up choosing to play for Clemson University in Clemson, S.C., so I could stay closer to my mom and the rest of my family. My life was finally making sense.

By working long days and nights doing manual labor jobs, I learned a valuable lesson. I knew that no matter what else I did in my life, I needed to get my college degree.

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FDA APPROVES AFINITOR FOR TUBEROUS SCLEROSIS

The U.S. Food and Drug Administration has approved the cancer drug Afinitor (everolimus) to treat patients with subependymal giant cell astrocytoma (SEGA) associated with tuberous sclerosis (TS), a rare genetic disorder. This approval was for treatments of SEGA that cannot be treated with surgery.

TS causes benign (non-cancerous) tumors to grow in the brain and in other parts of the body including the eyes, lungs, liver, heart, skin and kidneys. TS occurs as a result of genetic mutations that lead to the development of tumors and results in a variety of possible symptoms including learning and developmental disabilities, skin abnormalities, seizures and lung and kidney disease.

SEGAs are considered a major diagnostic feature of TS and are slow growing tumors, seen in 6 percent to 9 percent of patients. The disease can be fatal for patients who develop complications with tumor growth on the brain. Surgery is used to remove the tumor growths in some patients.

“Patients with this disease currently have limited treatment options beyond surgical intervention,” said Richard Pazdur, M.D., director of the Office of Oncology Drug Products in the FDA’s Center for Drug Evaluation and Research “It is important for research to continue in rare diseases where patients have few or no existing drug treatment options.”

The drug was approved under the FDA’s accelerated approval program. The program allows the FDA to approve a drug to treat serious diseases with an unmet medical need based on an endpoint thought to reasonably predict clinical benefit. The company is required to collect additional longterm efficacy and safety data confirming the drug’s benefit. This program provides earlier patient access to promising new or existing drugs while the confirmatory clinical trials are being conducted.

Afinitor was first approved in March 2009 to treat kidney cancer after patients fail treatment with Sutent (sunitinib) or Nexavar (sorafenib).

ASSISTANT SECRETARY FOR HEALTH ON NATIONAL EPILEPSY AWARENESS MONTH

U.S. Assistant Secretary for Health Dr. Howard K. Koh issued the following statement on November 19, 2010:

National Epilepsy Awareness Month in November is an opportunity to improve public understanding about a condition described for many centuries but still poorly understood. More than 2 million people in the United States have epilepsy, with about 150,000 developing the condition each year. New cases of epilepsy are most common among children and adults older than 65.

Epilepsy actually represents a group of diseases with a broad spectrum of presentations and severity. Symptoms can range from a momentary disruption of the senses, to short periods of unconsciousness or staring spells, to frank convulsions. While for some, epilepsy can be well managed, for too many, optimal management is elusive, leading to devastating consequences.

The U.S. Department of Health and Human Services (HHS) has addressed epilepsy for many years. In particular, HHS agencies promote diverse programs to support people with epilepsy and their families, including:

- The National Institutes of Health, which supports basic biomedical research;
- The Centers for Disease Control and Prevention, which conducts epidemiological research along with campaigns to raise public awareness and education;
- The Agency for Healthcare Research and Quality, which oversees patient-centered outcomes research regarding the efficacy, safety and tolerability of antiepileptic treatments;
- The Food and Drug Administration, which ensures the safety and effectiveness of drugs that improve the health of people living with epilepsy in the United States;
- The Health Resources and Services Administration, which funds a national program to improve access to comprehensive, coordinated health care for children and youth with epilepsy who live in medically underserved areas; and
- The Administration on Children and Families, which supports the University Centers of Excellence in Developmental Disabilities Education, Research and Services program, including three with projects focusing on young people with epilepsy.

We hope that improved understanding among the general population can lead to more research, better health for those affected and the end of the emotional isolation suffered by too many.

Recently, we convened experts from across the Department to integrate our efforts and reinvigorate the public health response to this disease. As a result, HHS has now partnered with a coalition of epilepsy scientific and advocacy organizations to commission a landmark Institute of Medicine study on the public health dimensions of epilepsy. The study will recommend national priorities and strategies for improving the lives of those with epilepsy with respect to dimensions of health care, human services, health literacy, public awareness and public health.

We would like to thank our partners—both governmental and private sector—who are working tirelessly to educate the public and to improve the quality of life for people with epilepsy. We hope that improved understanding among the general population can lead to more research, better health for those affected and the end of the emotional isolation suffered by too many.

I urge all of you to learn more about epilepsy and support efforts to treat and ultimately cure this condition.

For more information about epilepsy, visit www.cdc.gov/Epilepsy.
Caregivers with Epilepsy

What happens when the person giving the care has epilepsy?

BY ALYSSE MENGASON, SPECIAL TO epilepsyUSA
Some would argue that mothers have the toughest job in the world. Eileen Warren believes mothers, or even fathers, with epilepsy could rule the world!

Eileen was diagnosed with epilepsy when she was in her early 30s. She was an incredibly busy woman with a career in high-tech and a family, including an 8-year-old daughter. Then her world stopped short when she had her first seizure.

That was then. Now, at 51-years-old, the Boston-area mother of 25-year-old and 14-year-old daughters is also a grandmother to an 18-month-old boy. No one else in her family has epilepsy. She no longer works and gave up driving 17 years ago. Her primary role is being a caregiver to her family.

“I admit I have a very hard time with the driving issues. My husband does all of the driving for our family, which has meant, at one time or another, shouldering the transportation for four people,” said Eileen. “Doctor and dentist appointments, school meetings, play dates, dance lessons, music and soccer—I feel a bit guilty because it can be a burden on him.”

Eileen is not alone. There are thousands in the caretaker population who deal with epilepsy themselves. And, as challenging as it is to care for someone living with epilepsy, providing care when you are the one with epilepsy can feel overwhelming. Still, epilepsy doesn’t have to determine a person’s capabilities when it comes to caring for others.

“Let’s face it, there are a lot of medical illnesses that can impact a caregiver and epilepsy is a relatively benign condition when looked at in this way,” according to Dr. Darren Fuerst, Assistant Professor in the Department of Neurology at Wayne State University in Detroit and a neuropsychologist at the Detroit Medical Center.

“Seizures can appear to be, in some cases, a terrible event, when in reality they affect behavior for only a relatively brief period of time. If the caregiver or others react to seizures as a catastrophic event, then they will be just that, regardless of the actual impact that they have on caregiving.”

Patty Mazzarese is one of those caregivers who understands just how to react to one of her seizures. The 36-year-old Erie, Pa., mother of three was diagnosed with epilepsy in 5th grade. Her family has never known her without her seizures.

“My life is very structured, but I don’t feel much different than other moms or parents caring for their children. I’m involved in my oldest daughter’s school, I grocery shop, I get to run errands. The only difference is, I don’t drive and I have seizures, so I must have someone with me at all times,” said Patty.

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Patty never learned to drive, so she really doesn’t miss it. “My restrictions are ones I put on myself. I won’t give my kids a bath alone. I don’t go outside with them alone. I’m always cautious when I hold my youngest, my baby boy, because of my fear of dropping him in the event of a seizure.”

“My 5-year-old and 3-year-old both know how to react.”

PATTY MAZZARESE

“Caregivers with epilepsy must be sensitive to potential seizure triggers, and must work to prevent them. They must take their antiseizure medications as prescribed, with an eye towards minimal side effects. When seizures occur, they must determine the actual impact that a seizure has had on their caregiving behavior, which is probably minimal. If it has been negatively affected, they will have to modify their behavior to minimize the impact that seizures have on their caregiving.”

Patty remembers an incident when she and her family were baptizing one of her kids a few years ago. “I was holding the baby and all of a sudden a seizure struck. Later, my husband told me that I must have known what I was going through because I had such a tight grip on the baby, I was never going to let her go!”

More than anything, I know it must be exhausting for my husband. I can’t remember the last time he did something for himself…”

EILEEN WARREN

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PATTY MAZZARESE

Both women are honest with their kids about their epilepsy. They don’t hide anything about their conditions. “My kids learned seizure safety as soon as they were old enough to comprehend exactly what a seizure was like,” said Eileen. Patty and her family took the same approach. “My 5-year-old and 3-year-old both know how to react.”

Still, Patty and Eileen both go through periods of frustration and worry. “More than anything, I know it must be exhausting for my husband. I can’t remember the last time he did something for himself, like play tennis or fish, things he used to enjoy,” said Eileen. “My reliance on others can really get to me,” said Patty. “But, I know there are people who have it much worse than me, so I feel lucky.”

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EILEEN WARREN
Caregivers of people with chronic disorders often feel alone, but they are not. We turned to our own constituents and to one of our most popular groups on our own eCommunities, Parents Helping Parents, (www.epilepsyfoundation.org/ecommunities) for advice.
• **Be prepared.** Know what your loved one’s seizures look like, what medications to give and how to administer them. Learn the definitions and types of seizures. Keep an up-to-date medication list and description of the seizures in your notebook with dates and descriptions of all seizure activity. Keep a list with you whenever you leave the house, along with all emergency medication in case of a seizure.

• **Avoid isolation.** Seek support where it is available to you in your life and community. If family is unavailable, seek help from friends, neighbors, and community programs. Support groups let you know you are not alone and can provide you with valuable information.

• **Exercise your body and mind.** At least 30 minutes of exercise daily will help you fight depression. Read, research, do Sudoku or crossword puzzles to exercise your mind. This will keep your brain healthy and occupied to help you avoid rumination and worry.

• **Counseling.** Find a good counselor you can share your fears and worries with to help you manage your stress. This will help you stay strong in emergencies.  
  —Virginia

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Approximately 50 million families and friends provide unpaid care to another adult, sometimes around the clock. Relatives and partners provide about 80 percent of the long-term care in the United States.

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• **Share what’s going on.**

• **Accept help from loved ones, family, friends, neighbors.**

• **Change doctors if you’re unhappy.**

• **Make time for each other as a couple—date nights are good, if you can find a trustworthy sitter.**

• **Make time for siblings to ensure they know they are special and don’t resent a brother or sister who requires more care and support.**

• **Find a hobby where you can escape, even if only for minutes a day.**

• **Always be hopeful.**

• **Keep the faith or hang tough—whatever keeps you going, inspired and comforted.**

• **Live life and engage in activities with as much normalcy as possible.**

• **Drink red wine—good for the health, the soul and sanity!**  
  —Mary Lou
Make your relationship with your spouse a priority: Having two healthy, happy parents is going to help your child in the long run more than spending every waking moment with your child and burning yourself out.

Don’t be afraid to express your needs to others: Your spouse and friends should not be expected to be mind readers just like you should not expect yourself to be superwoman/superman!

—Lynn

There are only four kinds of people in the world—those who have been caregivers, those who are currently caregivers, those who will be caregivers and those who will need caregivers.

—Former first lady Rosalynn Carter

Choose your battles! Keeping a peaceful, stress-free household is very important.

—Sharon

One of the very best things I have found for caregivers: Come to eCommunities! [www.epilepsyfoundation.org/ecommunities]. I don’t want any parent out there to feel as lonely and afraid as I did before I found Parents Helping Parents on eCommunities.

It’s definitely my best source for advice. No one ever told me about this community, I stumbled upon it after almost a year of loneliness and desperation. I hope that every other caregiver finds us if they haven’t already!

—Tricia

Don’t be afraid to apologize so that your child realizes that even you can break down sometimes. I admit that I’ve lost it with my daughter when she’s been raging, but afterwards, I’m not ashamed to tell her I’m sorry for yelling at her. She usually hugs me and says, “That’s OK, Mommy, I’m sorry, too.”

Joining a support group (such as the Parents Helping Parents forum on eCommunities) is what has helped me the most. I felt like I was going insane before and that no one related to me. Sharing advice, listening to others who have been down your road before or even simply venting is very helpful.

Start taking walks. I was never a walker before, but I’ve been walking lately and it is so relaxing! (And pretty good for you, too).

—Shea

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—Shea
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In My Own Words

I was forced to make a final decision to hang up my cleats and focus on my health and obtaining my college degree. My football dreams were over.

All of a sudden, my life had totally shifted, but if I had learned anything in life it’s that when one door closes, another one opens. My coach offered me an opportunity to remain on scholarship and work as a student coach. Now I had an opportunity to further my education and earn my college degree. I also had an opportunity to remain part of the team and experience coaching, something I had always wanted to try after my playing days were over.

I’m going to be a better father one day, a better brother, a better husband and friend because of my struggles and my ability to turn a negative into a positive.

At this point in my life, I’m the happiest I have ever been. I have experienced all kinds of adversity, and I’m still blessed to be standing on two feet. I know plenty of people who were in my same shoes growing up who ended up dead or behind bars. When I have an opportunity to speak to groups, people always want to know how I made it. I can only thank God for where I am today. I don’t blame my parents for my childhood because I learned valuable lessons from it. Not having clothes, shoes or toys like other kids has made me appreciate the things I have today. I don’t blame my coaches, teachers or friends for things that have happened because all those situations have made me a better person.

I’m going to be a better father one day, a better brother, a better husband and friend because of my struggles and my ability to turn a negative into a positive.

The In My Own Words column gives people whose lives are affected by epilepsy the chance to share experiences and solutions to their problems. These are real stories by real people that show strength, resilience, optimism and courage. We hope they will inspire others.
When 4-year old Joseph Martin Gomoll, who had Dravet syndrome, died unexpectedly in March, his family wanted to do something special in his memory. They wanted to raise money and bring more awareness to this severe form of epilepsy, which in addition to seizures, causes poor development of language and motor skills, hyperactivity and difficulty relating to others.

Joey shared many interests with his father, but they really bonded over music. He loved everything about music and his face would light up when he listened to it. His favorite thing was to dance around whenever he heard a song. Because music was the centerpiece of Joey’s world, his father, Mike, wanted to celebrate Joey’s life through music, so he established the Joseph Gomoll Foundation.

Joey’s Song was born.

The Gomoll Foundation’s goal is to truly make a difference for the Epilepsy Foundation, so they aim to sell 10,000 CDs with their first release, which will result in thousands of dollars targeted for epilepsy research and awareness!

Mike drew on the skills and experience of friends, along with music industry connections, to get Joey’s Song off the ground. Within weeks, what started as asking a few friends like Justin Currie of del Amitri for a song, blossomed into a commitment from more than eighty artists into a projected series of CDs. The first of these CDs, Joey’s Song Volume One, is being released Jan. 25, 2011.

Artists on this first release include: AA Bondy, Neko Case, Cowboy Junkies, Crash Test Dummies, Robbie Fulks, Thea Gilmore, Steve Wynn, Matthew Ryan and the Handsome Family, with many other artists on board for future CD releases.

Along with the songs donated for the Joey’s Song series, many of the artists are also recording special children’s songs. Lowen and Navarro have donated a fun-filled live version of The Wheels on the Bus. And Matthew Ryan is contributing his version of You Are My Sunshine.

“It is a testament to the spirit and soul of the artists. They hear a story—see a cause—and it moves them to act. There were many times in the first months after Joey’s death that we wept tears of sorrow,” says Mike, “but the response from the music community also led to some of the first tears of joy we, as a family, shed. Not a day goes by that I don’t think of Joey and, through music, it brings a sweet smile to my face.”

Joey’s Song is an opportunity for all music lovers to make a difference by purchasing a CD. Most of the songs have not been released before or are alternate and live versions of an artist’s hit records. It is a collection of songs unavailable anywhere else. And it supports the Epilepsy Foundation in its mission to create a better world for people living with epilepsy through services, education, advocacy and research.

You can pre-order the CD at www.joeyssong.org or www.epilepsyfoundation.org/store.

If you would like to stay up-to-date on the progress of the Joey’s Song series of CDs, become a fan of Joseph Gomoll Foundation on Facebook or follow them on Twitter @end2seizures.

Proceeds will go to the Epilepsy Foundation, with a portion to other special education and support programs.

Making a Difference

Every day, all across the country, people are thinking of creative ways to raise funds for the Epilepsy Foundation so we can educate the public about epilepsy and fund research that will one day lead to a cure. We want to highlight their contributions.

JOEY’S SONG FOR EPILEPSY
BY TANYA R. SWEENEY, SPECIAL TO epilepsyUSA

**Joey’s song for epilepsy**

BY TANYA R. SWEENEY, SPECIAL TO epilepsyUSA

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Sirena Doty, age 11, recently battled a rare epilepsy syndrome called electrical status epilepticus during slow sleep syndrome (ESES). Sirena is one of less than one percent of children with epilepsy to have ESES and to also receive life-altering brain surgery.

The doctor came into the hospital room and said, “Sometimes viral infections like strep throat can trigger seizures in kids with epilepsy.” To our amazement, that is how we found out our daughter had epilepsy.

But Sirena’s story doesn’t start that day. It starts one year before, in a doctor’s waiting room, where we were completing tests for an array of symptoms to try and figure out what was happening to our bright, intelligent, happy little girl.

One doctor said she had acid reflux, another said she had irritable bowel syndrome, in an effort to explain the severe stomach pains she would get. One doctor said our 5-year-old was depressed. Her symptoms increased and the seizures were more frequent.

Halfway through kindergarten, as she sat on her bed pulling off her socks, Sirena made a gurgling sound that was like nothing I had heard before. I remember thinking to myself: It doesn’t take that much effort to take off socks, so I went into her room and found her staring straight ahead, eyes lost, unresponsive, just sitting there with her throat moving in and out like she was trying to get her breath. In fear, I grabbed her face and demanded her to talk to me. “Sirena Nichole, are you OK?” Nothing, no answer back.

Sirena came out of the seizure crying, scared and confused. I tucked her into bed, told her it was just something that happened and we would find out what it was the next day when we went to the doctor’s office.

I went to my computer and began typing, “staring,” “unresponsive,” “gurgling sounds,” and what flashed back to me blew me away: brain tumor, brain abnormality, seizures, disease—the list went on and on. My husband and I feared the worst and went to bed knowing the following day was going to change our lives forever.

We showed up the next day at the doctor’s office and said to the receptionist: “We aren’t leaving until the doctor sees us.”
The doctor told us we needed to get an MRI and an x-ray and sent us to the hospital. She said she would contact us when she got the results. We went home that night with no answers, but we didn’t wait long. The next day, Sirena had her first tonic-clonic seizure—it lasted 6 minutes. She had another one in the ER waiting room, then in the actual ER she continued to have a seizure each hour for the next 3 hours.

Once she was admitted to the hospital, the doctor on call came into her room and said, “Sometimes viral infections like strep throat can trigger seizures in kids with epilepsy.” That was the first time we knew our daughter had epilepsy. The doctor saw the results from her previous MRI and that’s how he knew. We had no idea.

After that stay in the hospital, we spent the next 7 months trying to find seizure control. After an array of medication cocktails, three MRIs and examinations by multiple doctors, we finally found it. My husband and I thought getting seizure control was the key and when we accomplished that, we could focus on other things. We did not know seizure control would be the easy part of this long road.

Over the next 2 years, we watched our daughter slip away. As a young child, she was so intelligent and could hold a conversation with any adult. She was smart, often sassy beyond her years, and always wanted to act older than she was. Sirena was losing bits and pieces of who she was every day. Suddenly tying her shoes became difficult, if not impossible. Age-appropriate milestones never arrived. Her day-to-day activities and ability to learn were suffering.

We reached out to all of our doctors to try and find out why this was happening—this regression of our daughter’s basic life skills and the loss of her childlike happiness. She was a pre-teen who should be asking questions about life, sleepovers and make-up.

In an effort to stop the regression, Sirena repeated second grade. We followed up that same year with additional tutoring in math; extended hours of special education; additional academic testing; neuropsych testing—anything to try and figure out the best way for Sirena to learn and retain what she learned. In the end, it made little difference.

During a routine outpatient EEG in June 2007, Sirena accidently fell asleep. This led to a key finding. During those few minutes of sleep, Sirena’s EEG showed subclinical spike-and-waves occurring almost continuously during non-rapid eye movement sleep. The neurologist came into the room and began to explain why this particular brain wave is so “special.” We did not leave that day with a diagnosis, but we received articles on Landau Kleffner Syndrome.

In researching LKS, we saw some similarities to Sirena’s symptoms, but other descriptions did not seem like her at all. We took this information back to our local neurologist. That discussion led to another year of waiting. Her seizures were under control and that was important. We waited and continued to watch our daughter regress further into an abyss.

One year later, we went back to the neurologist and asked him to complete testing so we could find out if Sirena had LKS. They recommended experimental trials that were shown to improve the regression in cognitive ability caused by LKS. This included a high-dose steroid trial as well as a high-dose Valium® trial. Again, we took this information back to our local neurologist, who was not comfortable with the recommendation.

At this point, June 2008, we did not know what to do next. Because we had two different professional opinions, we decided we should get a third. That is when we called Cleveland Clinic in Ohio. In October 2008, we saw our fourth neurologist, Dr. Elaine Wyllie. Dr. Wyllie has a great deal of experience working with difficult cases of epilepsy and other epilepsy-related syndromes such as LKS. Sirena was diagnosed, not with LKS but with a similar syndrome called electrical status epilepticus during slow sleep syndrome (ESES).

ESES is a rare disorder and its cause is unknown. One study revealed 0.5 percent of children with epilepsy have ESES. Sirena, however, was seizure-free yet still experiencing this syndrome during sleep, which made her case even rarer. ESES is defined as rapid deterioration of cognitive functions, behavior, IQ and language, while experiencing a profound decrease in intellect and poor memory. Most children do not return to normal levels after prolonged effects of ESES. Even with medical advancements, little is known about ESES. There are no medications that exist for ESES. There are limited courses of treatment—the most widely used are high-dose steroids and benzodiazepine, but these are not permanent treatments. Yet there are doctors like those at Cleveland Clinic who are breaking the way to new treatment options for ESES, such as brain surgery.

In October 2009, after Sirena completed two experimental trials of steroids and benzodiazepine with no improvements seen on her EEG, the doctors told us Sirena might be a candidate for surgery that could maybe

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J.J. Abrams and Paramount Pictures Honor TalkAboutIt.org During World Premiere Event for Morning Glory

November 7, 2010 — The stars came out in New York City to talk about epilepsy and help America and the world Get Seizure Smart, thanks to an enduring Hollywood friendship. J.J. Abrams and his Bad Robot Productions produced the new movie Morning Glory, starring Harrison Ford, Rachel McAdams, Diane Keaton, Jeff Goldblum and Patrick Wilson.

Abrams dedicated the premiere event to his best friend Greg Grunberg’s Web site, TalkAboutIt.org. That site, created by Grunberg in collaboration with the Epilepsy Foundation, brings Hollywood personalities, epilepsy experts and the general public together to help improve the conversation about epilepsy awareness, seizure recognition and proper first aid.

Abrams said, “When so many millions—50 million people in the world—are affected by this condition... this seems like one of the most obvious opportunities to inform people and to help educate.”

The event was covered by major entertainment television shows, magazines, newspapers and Web sites. The movie’s premiere, in November, helped the Foundation achieve our goal of getting over 1 million people seizure smart during National Epilepsy Awareness Month!

“There is a history of epilepsy in my family... and I know how important it is to talk about it.

HARRISON FORD
Natasha Bedingfield, singer and songwriter for the Morning Glory soundtrack.

Mario Lopez covered the event for Extra.

Rachel McAdams and Jeff Goldblum

Greg Grunberg is featured in a poster thanking the cast and crew of Morning Glory and the studio executives from Bad Robot and Paramount Pictures at the benefit party held at The Boathouse in Central Park following the premiere screening.

Harry Smith of The CBS Early Show with Joyce Bender (left), Chair of the Epilepsy Foundation Board of Directors and Board Member Denise Pease.
To treat and characterize epilepsy, epileptologists combine the diagnostic arts with precision technologies such as the electroencephalograph, or EEG, a brain function exam sensitive to the abnormal electrical signals typical of seizures.

“The EEG is one of the most important tests patients with possible epilepsy undergo, and the EEG technologists who administer the test are among the first health care providers they meet,” explained Duke University Medical Center neurologist and epileptologist Aatif Husain, M.D. “If the EEG is not performed with the utmost care, it may lead to misdiagnosis,” which he said makes qualified EEG technologists “vital members of the health delivery team for patients with epilepsy.”

EEG technologists work in a variety of settings: hospitals, intensive care units, clinics, research facilities, operating rooms—and the Epilepsy Monitoring Unit (EMU).

Epilepsy and other seizure disorders represent “the vast majority of patient referrals for EEG services,” said University of Michigan Health System EEG technologist Lisa Lovely, who also directs the Carnegie Institute electroencephalographic technology program in Troy, Mich. “Basic EEG testing requires technologists to have a fair amount of knowledge regarding epilepsy,” she explained. “Techs need to know how various epilepsy drugs affect EEG recording; how to recognize a seizure; and even how to render appropriate first aid.”

Formal EEG technologist credentialing includes education specific to epilepsy, said Janice Walbert, who directs the American Board of Registration of EEG and Evoked Potential Technologists (ABRET) in Springfield, Ill. ABRET requires a two-part written and oral exam for the Registered EEG Technologist designation. A subsequent Certification in Long Term Monitoring (CLTM) is “an ideal credential for technologists who choose epilepsy monitoring as a career path,” Lovely said.

From neurologist colleagues in his home country of Pakistan—where he practiced years ago—Aatif Husain has had a window on the importance of credentialing. Limited training opportunities and few trained technologists have made for a “big difference” between Pakistani and U.S. EEG technologists. More recently, however, foreign-trained EEG technologists have been able to take ABRET examinations.

As a result, “their training and quality have improved,” Husain said.

Clinical professional
Beyond credentials, Husain looks for empathy, compassion, the ability to calm “tremendous anxiety,” and intelligent teamwork in the EEG technologists with whom he works.

First and foremost, Lisa Lovely considers herself part of a team, responsible to assure her team leader—the epileptologist—gets the best data possible. She’s also clear about her role with patients. “I tend to their needs, but in no way offer any opinion about the EEG,” she explained. “The patient receives that information directly from the physician.”

In practice for 31 years, EEG technologist Margaret Walcoff has worked with patients in all stages of epilepsy, from the earliest seizure to those seeking surgical options after years of other treatments.

“EEG technologists are the front line in assessing and diagnosing seizures,” explained Walcoff, who directs the...
Carolina Spine and Neurosurgery Center neurodiagnostic laboratory in Asheville, N.C.

Often uncertain about what they have seen, first responders—teachers, friends, parents—may medically admit a person whose first seizure manifests as a staring spell, unresponsiveness, or a sudden behavioral disorder, Walcoff said. After taking an in-depth history, an EEG technologist can help sort through the complexity.

“We help differentiate epileptic from non-epileptic seizures, and classify seizures after they are diagnosed,” said EEG technologist Maureen Donnelly, EMU clinical supervisor at the Children’s Hospital of Philadelphia.

Whether they work primarily in the EMU or elsewhere, all EEG technologists at the hospital have “training specific to epilepsy monitoring,” Donnelly said, an approach that makes sense to Janice Walbert. EEG technologists, she explained, often find themselves outside the EMU, “in the operating room, for instance, with a patient awaiting electrode implantation or surgery to remove a part of the brain causing seizures.”

“Better, more reliable, and more optimistic outcomes for patients with seizures.”

Evolution and expansion

Over her twenty-nine years in the profession, Lovely said EEG technology has substantially evolved, most notably as recording data opened to “a nearly infinite number of possibilities” with sophisticated computerization. Once-rigid printed scrolls took on entirely new levels of digital flexibility, accuracy and compatibility “with many other forms of testing,” she said, including real-time neurological imaging.

The field has also expanded to monitor peripheral nerves, the muscle-nerve interface, and intricate neurosurgery. EEG technologists can record both sensory and motor nerves during spinal and seizure surgeries, Margaret Walcoff explained, permitting surgeons to test potential outcomes on the spot.

All the advances—in training, technology, and the quality of technologists—have, Walcoff said, helped create “better, more reliable, and more optimistic outcomes for patients with seizures.”

Sirena’s Story

Continued from page 14

“Parent goggles” were coloring our impressions. As the appointment grew near, we began to wonder if Sirena’s surgery had worked. We knew what we had seen, but faced post-surgery follow up. This visit would tell us if the big question: “Did it work?”

On the day of Sirena’s surgery, December 10, 2009, thoughts were swirling around in my head: Sirena will turn 11 years old in 9 days. Will she get to enjoy her birthday? Will she remember her birthday? The surgery took 6 hours—a very long and terrifying 6 hours. Sirena pulled through just like the fighter I knew she was and, not only that, she pulled through with flying colors. Seven days later, we were flying home and Sirena had no paralysis, no loss of speech or memory, no infections and—most of all—no seizures. Our hearts filled with joy, but then we faced the big question: “Did it work?”

Sirena recuperated beautifully and started school again. She flourished and we were amazed at the transformation right before our eyes. Both her body and her mind grew. She was suddenly the pre-teen girl we had been anxiously waiting to see. As parents, nothing brings you more happiness than to see your children grow and learn and we were finally experiencing that once again.

In August 2010, we flew back to Cleveland for a post-surgery follow up. This visit would tell us if the surgery had worked. We knew what we had seen, but as the appointment grew near, we began to wonder if what we saw really was true. We wondered if our “parent goggles” were coloring our impressions. The test results revealed that the ESES was gone. Not only that, but Sirena had a normal EEG for short term memory and language, we could possibly stop the ESES that was so violently stealing our daughter away from us. The downside to surgery, though, was we could possibly take speech and memory away from our daughter.

This was by far the most difficult decision I have ever had to make in my life, and I hope I am never faced with the challenge again. On one hand, Sirena was not having seizures. She was going to school and was a happy kid who loved her family dearly. On the other hand, because of her developmental delays, Sirena didn’t realize how her life was affected by ESES. If ESES continued to wreak havoc on her brain, we would ultimately have a 15-year-old with the IQ of a second grader. That was not fair to Sirena. We had to push past our fear of the surgery and look toward the future. I was torn about the decision until two different doctors said, “If it was one of my children, I would do the surgery.” That’s when we knew it’s what we had to do.

On her twenty-nine years in the profession, Lovely said EEG technology has substantially evolved, most notably as recording data opened to “a nearly infinite number of possibilities” with sophisticated computerization. Once-rigid printed scrolls took on entirely new levels of digital flexibility, accuracy and compatibility “with many other forms of testing,” she said, including real-time neurological imaging.

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All the advances—in training, technology, and the quality of technologists—have, Walcoff said, helped create “better, more reliable, and more optimistic outcomes for patients with seizures.”
Dear Editor:

I just finished reading the article in epilepsyUSA, Epilepsy as a Spectrum Disorder [Issue 5, 2010] by Gordy Slack, and I am so pleased that someone has finally written about this subject in this way. My daughter has had epilepsy for 4 years and I am continually finding new information pertaining to her particular struggles. Not only does she suffer from migraine headaches, but she also has memory issues and struggles academically. She was even considered to possibly have Attention Deficit Disorder (ADD). She is currently not on medication because of how it affects her learning.

Until reading the article, I had not come across anything that explored or explained the difficulties of epilepsy in this way. Since her diagnosis, my husband and I have considered the connections, but our suspicions were never validated. Mr. Slack is so right that we need to educate the doctors in treating the whole patient and all that goes with the diagnosis of epilepsy.

Again, thank you for publishing such an informative and much-needed article. Not only should we be aware of the connection between epilepsy and other disorders, but we need to explore ways to help people who are struggling with them.

Respectfully,
Dee Youker
Holland, Mich.
No one should be fired from a job simply because of a medical condition, but it happens all the time.

Every day, right here in this great country, people with epilepsy are denied employment or fired from their jobs simply because their employers are afraid and uninformed.

Discrimination against people with epilepsy happens in cities and small towns, in the north and in the south, in small companies and in big corporations. It happens to the young and the old, men and women and people of all races.

Nearly 3 million Americans live with epilepsy and seizure disorders and many face this kind of discrimination every day — probably even in your town. It’s just not right! And it has to stop.

When people are fired or discriminated against because they have epilepsy, the Epilepsy Foundation is the first place they turn. The Epilepsy Foundation created the Jeanne A. Carpenter Epilepsy Legal Defense Fund to seek justice and help protect the civil rights of people with epilepsy. Since 2003, the Jeanne A. Carpenter Epilepsy Legal Defense Fund has been providing legal advice and counsel through a network of attorneys to those who are affected by epilepsy but cannot afford expert counsel.

If you agree that a person should not be discriminated against simply because of a medical condition and you desire to help people with epilepsy live full, productive lives at home and at work, consider making a gift to support the Jeanne A. Carpenter Epilepsy Legal Defense Fund. You can use the envelope located in the center of the magazine, or mail your contributions to:

Epilepsy Foundation
Attn: Jeanne A. Carpenter Epilepsy Legal Defense Fund
8301 Professional Place
Landover, MD 20785-2353

Scan this Smart Tag with your smartphone and instantly go to the Legal Defense Fund donation page. iPhone, Droids, Blackberry and HTC can all accept this barcode technology. Visit http://gettag.mobi to download the application for free. If you do not have a smartphone please go to www.epilepsyfoundation.org/epilepsylegal and make a donation through our Web site.
The National Walk for Epilepsy® is a family oriented, noncompetitive walk in our nation’s capital to raise funds for research, education, advocacy, and services for people with epilepsy and their caregivers. This will be the fifth annual event, which over the last four years has had more than 25,000 participants and raised over $4 million. The 2011 National Walk for Epilepsy® promises to be the biggest event yet. Please join us on the National Mall in Washington, DC on Sunday March 27, 2011 and enjoy a morning full of activities for the entire family.

2011 National Walk for Epilepsy Registration Form (One form per walker.)

Visit walkforepilepsy.org for more information or for online registration.

First Name  Last Name  
Company                      
Address                      
City    State   Zip          
E-mail     Phone                      
Age  Date of Birth (mm/dd/yyyy)  
Male  Female                      
Emergency Contact Name   Phone                      
T-Shirt Size:  
Adult XL  Children’s L

I would like to be recognized as a person with epilepsy and instead of receiving a white T-shirt, receive a special purple T-shirt

How did you hear about the Walk? (check box in front of each option below)

Television  Mail  Newspaper  EpilepsyUSA
Online  Radio  Friend/Family  E-mail
Other

Did you participate in the 2010 Walk?  Yes  No

WAIVER AND RELEASE OF LIABILITY AND ASSUMPTION OF RISK AND INDEMNITY AGREEMENT. In consideration of being permitted to participate in the 2011 National Walk for Epilepsy (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 SUIT 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 agree to permit the use of my name and/or likeness in any record or communication relating to the Event for any legitimate purpose, without compensation or remuneration. I have read this agreement and understand that I have given up substantial rights by agreeing to it. We reserve the right to cancel in extreme circumstances. In that event, there will be no refunds; rather, your registration fee will be considered a donation to the Epilepsy Foundation.

Registration Fee and Donations
All mailed registration forms must be postmarked by Monday, March 14, 2011.

You can register online up to and including March 27, 2011.

Adult ($35)  Children 12 and under ($20)  Late registration
(Check www.walkforepilepsy.org for dates and locations for late registration and t-shirt pick-up)
I would like to make a donation of $________________.
Entry fee  Donation  Shipping*  Total
$___________ + $___________ + $5.00 = $_____________

*Please select the $5 shipping option if you would like your t-shirt mailed to you otherwise you must pick-up your t-shirt at late registration or on Walk day.

Team Name*
Team Code

*Note that each team must be established through the online registration process.

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8301 Professional Place
Landover, MD 20785

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**Epilepsy 101 – The Ultimate Guide for Patients and Families**
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Our Legacy Creates a Future for people living with epilepsy.

Will our children and grandchildren inherit a future free of seizures and stigma?

That depends on you and me, people who understand the challenge, and still dream of a future where not another moment is lost to seizures.

The Candle of Light Society is our community of committed individuals and families who invest in transforming life for people with epilepsy. By remembering the Epilepsy Foundation in our wills and estate plans, we leverage gifts of cash, life insurance, stocks, and other assets toward our shared vision of a future free of seizures and stigma. In addition to certain tax advantages, we receive insider progress reports, invitations to exclusive phone briefings, a complimentary subscription to epilepsyUSA, recognition in the Annual Report (optional), and personalized visits with senior Foundation staff at your convenience. Will you join us?

Our investments transform lives so that not another moment is lost to seizures.

Join us by signing up below and learn more about the advantages you can enjoy as a member of the Candle of Light Society.

- Please enroll me in the Epilepsy Foundation Candle of Light Society.

  - The Epilepsy Foundation is included in my will.
    - Amount of bequest (optional) $________
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