Caring for the Caregiver: YOU

The ADA Restoration Act: Make Your Voice Heard
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In this season of giving, I wanted to acknowledge an often overlooked but absolutely critical member of any health care team—the caregiver for a person with a chronic disorder, like epilepsy. As a caregiver, you might feel like you are alone—the only person out there who experiences the stress, frustration, but also the tremendous rewards that come from helping someone to overcome the daily hurdles that are part of having a health disorder. However, you are not alone. It is estimated that 50 million Americans provide help for their loved ones with special needs.

For those of you who give so much all year long, it is important to remember to take care of yourself, too. Inside this issue, you will find advice on how to cope with some of the natural feelings that come with being a caregiver, as well as tips on how to stay healthy while balancing so many responsibilities. When you give so much, it’s sometimes hard to remember to give back to yourself—to take a break, relax and refuel.

In this issue, we also salute our longtime colleague and friend, the immediate past chair of the Epilepsy Foundation’s board of directors, Tony Coelho. Tony’s tireless efforts on behalf of all people with disabilities—including people with epilepsy—are remarkable. His unflagging energy and commitment to ending stigma for people with epilepsy and leveling the playing field for all people with disabilities is the cornerstone of an outstanding career in politics and the private sector. Tony’s story of overcoming the hurdles he faced as a young man with epilepsy—ultimately becoming one of the most powerful men in the House of Representatives—is truly inspiring.

At the close of the year, I would like to take the opportunity to express my gratitude to all the people who support the Epilepsy Foundation. It is through your goodwill that we are able to achieve our goals as we work toward making life better for people with epilepsy—and their caregivers.

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Chuck Sparks lives in Grapevine, Texas with his wife Lauren and their three children, Allison, Chandler and Shelby. He is a club manager at Sam’s Club.

BY CHUCK SPARKS

Life is full of surprises and having a child born with a disorder I knew nothing about was a big one. It’s funny how you can become an expert on something when you need to be. And I needed to be. My daughter Shelby began having generalized tonic clonic seizures over seven years ago. She wasn’t even 5 months old. My wife and I were petrified. How things have changed. Her “events” have changed in type, frequency and duration many times. They seem so commonplace now.

Shelby’s seizures are a part of everyday life. A day WITHOUT a seizure is now a big event.

It’s a helpless feeling to watch my child suffer. The helplessness multiplies as we try endless pharmaceutical combinations and treatments hoping that the next one will bring control. To date, control has eluded us. Because of this, we can’t hire a teenager to baby sit. We have to rely on trusted adults to volunteer and we cherish our precious time out. Shelby has severe developmental delays. She developed on the slow side of normal until she was 18 months old, at which time we saw an abrupt halt in progress. In all the years since, she has only gained about four months’ worth of intellectual, social and physical development. At 7 years old, Shelby operates like a child not quite 2. She speaks in one-word utterances, can’t run and needs help feeding herself. She has grown so big that changing her diaper has become one of the biggest challenges of all. We spend our time running from doctors to therapists and meetings at school. Sometimes, I mourn the fact that my daughter will probably never live independently. And today, I mourn the stacks of medical bills waiting to be paid, and yet...

Shelby is a wonderful gift from God. I have watched her bring out the best in those around her as children—normally so self-centered—learn sensitivity and how to nurture someone who is different. Shelby’s special gift is love. She brightens the day of many strangers as she asks for hugs wherever we go. We call her our world-champion cuddler. She loves to sit in my lap and snuggle. Shelby has prompted the involvement of our entire family with the Epilepsy Foundation. My wife, mother and mother-in-law wrote a book about Shelby that introduces young children to seizure disorders. I serve on my local board and raise money to increase epilepsy awareness and improve the lives of those who suffer with the disorder.

At times, I find myself focusing on my daughter as a cause—something to be fixed. But it would be a tragedy to keep thinking that way and miss the blessings of today. I pray for Shelby to be healed and I wish she were developmentally appropriate. But the bottom line is, if Shelby never gets any better, my life is so much richer because she’s in it. I know a lot of others who would say the same thing.

“...The bottom line is, if Shelby never gets any better, my life is so much richer because she’s in it. I know a lot of others who would say the same thing.”

In My Own Words is a column featuring the voices of people affected by epilepsy.
Inheriting Two Genes for Epilepsy Might Reduce Your Risk for Seizures

According to new research, inheriting two genes for epilepsy might make you less likely to have a seizure. Researchers from Baylor College of Medicine found that genetic mutations that can individually cause epilepsy together might actually make you less likely to have a seizure. Their findings were published in the journal Nature Neuroscience.

There has long been suspicion among scientists that some cases of epilepsy are, to a certain extent, due to a genetic problem and they are searching for the particular genes involved so new treatments can be devised.

The two defects highlighted in this study involve the Kcna1 gene, which is involved in the transport of the chemical potassium in and out of brain cells, and the Cacna1a gene, which plays a role in regulating calcium levels and the release of neurotransmitters in the brain. Kcna1 has been linked to severe seizures in temporal lobe epilepsy, which affects the part of the brain involved in speech, sight, sound and memory. Mice with defective Kcna1 genes can die suddenly as a result. The second gene, Cacna1, is linked to absence epilepsy.

When mice were bred with both gene defects, rather than experiencing more severe symptoms, they experienced dramatically reduced seizures and did not die suddenly.

The research, led by Dr. Jeffrey Noebels, points toward new ways of treating certain types of epilepsy. Lead author of the study, Dr. Albert Glasscock of the Baylor College of Medicine, is excited by the results. He said, “For those of us involved in the study, it was a novel idea that two genes that cause epilepsy, when combined in the same animal, could make an animal that was less epileptic. The counterintuitive nature of the whole study was very satisfying.”

This study was funded by the Epilepsy Foundation and the Milken Family Foundation.

First author of the study, “Masking Epilepsy by Combining Two Epilepsy Genes,” Dr. Albert Glasscock of the Baylor College of Medicine, talked to EpilepsyUSA editor Lisa Boylan about the findings and why they are significant for people with epilepsy.

EpilepsyUSA: This study showed that genetic mutations that individually cause epilepsy together might be seizure protective. How did you come to those findings?

Dr. Glasscock: We generated a mouse with two different ion channel gene mutations, both of which cause epilepsy independently. These two mutations had mutually opposing excitability defects and affected similar brain regions. So by virtue of those two characteristics, in this case, we found that the mutations were able to mask the effects of one another in the brain producing a mouse that was less epileptic.

EpilepsyUSA: How could these findings help in new ways of treating epilepsy?

Dr. Glasscock: It has implications for drug treatment and genetic diagnosis. For people who suffer epilepsy due to potassium channel gene mutations, it suggests that blocking certain calcium channels might be useful for them. Conversely, a drug that blocks potassium channels might be useful for people with epilepsy due to calcium channel mutations. Our findings also show that just because you carry an epilepsy mutation, it does not mean you will have the disorder.

EpilepsyUSA: In addition to the other information from this study, it’s also good news for parents who both have epilepsy, right?

Dr. Glasscock: Yes, it should be. Although we do not currently have drugs that specifically target these two particular types of ion channels, for those who suffer drug-resistant seizures, it should provide hope that new and more effective classes of drugs are out there waiting to be discovered.

EpilepsyUSA: Why is research focusing on genes to predict neurological disorders?

Dr. Glasscock: Overall, one of the goals of contemporary medicine is to be able to generate a personalized genetic profile for an individual that would allow a physician to accurately predict the diseases for which one has a predisposition. With that information, the best therapy can be selected first, rather than as a result of trial and error. In the future, doctors could also intervene with a preventative treatment to cure seizures before they even begin. However, we are not at that point yet.

EpilepsyUSA: How will the findings from this study help researchers in formulating treatment regimens for epilepsy?

Dr. Glasscock: In this study we had mice with absence epilepsy because of a calcium-channel gene defect. We gave them a drug called 4-aminopyridine, which blocks potassium channels, and we showed that it actually made their absence seizures disappear. The implication is that potassium channel blockers may represent a new class of drug that could help some people with absence epilepsy.

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C aregivers of friends and relatives with chronic disorders, such as epilepsy, often feel that they are alone, but they’re not. Caregiving is becoming more common in the United States. According to the National Family Caregivers Association (NFCA), one in five adults in America serves as a family caregiver. These 50 million Americans provide a vast array of nursing, transportation, chore assistance, financial help, homemaking and other services to loved ones who have a chronic disorder or disability, are elderly, or have other special needs. The value of these “free” services is conservatively estimated to be $306 billion annually.

As a caregiver, you’re often on-call 24 hours a day, seven days a week. Sometimes the prolonged stress and physical demands can strain even the most capable person. You want to provide the best possible care, but in the process you can pay a high price by neglecting your own physical and emotional health. In fact, caring for yourself is one of the most overlooked elements of being a caregiver.

Caregiving and Controlling Frustration

The Critical Step: Asking for Help

You cannot take on all the responsibilities of caregiving by yourself. It is essential that you ask for and accept help. Discuss your needs with family members and friends who might be willing to share caregiving responsibilities. People will not realize you need help if you do not explain your situation and ask for assistance. Remember, you have the right to ask for help and express your needs.

When to say “Yes”

Don’t be afraid to say “Yes” if someone offers to help. Say “Yes” at the moment a person offers to help rather than saying “maybe” and waiting until you are in a fix. Have a list handy of errands or tasks you need help with. Keep in mind that people feel useful and gratified when they are able to help others.

When to say “No”

Often, caregivers are pulled in multiple directions. In addition to the demands of caregiving, you may feel com-

Approximately 50 million American families and friends provide unpaid care to another adult, sometimes around the clock. Wives, daughters, sons, partners, fathers, nieces, brothers—provide approximately 80 percent of the long-term care in the United States.
1 Caregiving is a job and respite is your earned right. Reward yourself with respite breaks often.

2 Watch out for signs of depression, and don’t delay in getting professional help when you need it.

3 When people offer to help, accept the offer and suggest specific things that they can do.

4 Educate yourself about your loved one’s condition and how to communicate effectively with doctors.

5 There’s a difference between caring and doing. Be open to technologies and ideas that promote your loved one’s independence.

6 Trust your instincts. Most of the time they’ll lead you in the right direction.

7 Caregivers often do a lot of lifting, pushing, and pulling. Be good to your back.

8 Grieve for your losses, and then allow yourself to dream new dreams.

9 Seek support from other caregivers. There is great strength in knowing you are not alone.

10 Stand up for your rights as a caregiver and a citizen.

The Lifespan Respite Care Act was signed into law by the president in December 2006. The bill authorizes competitive grants to states to make quality respite available and accessible to family caregivers, regardless of age, disability or family situation. However, the Lifespan Respite Care Act cannot be implemented unless it is funded soon. The Epilepsy Foundation worked diligently to ensure passage of this legislation and is actively supporting funding for this important program in Congress. The Foundation recognizes that respite is often the critical relief that caregivers need to maintain their own health, strengthen families and avoid out-of-home placements.

Here are three steps to taking better care of YOU:

• Make Time for Yourself
You may feel guilty about needing or wanting time out for rest, socialization and fun. However, everyone deserves regular and ongoing breaks from work, including caregivers. “Respite” providers can give you the opportunity to take the breaks you need. Respite breaks may be provided by in-home help, adult day care, “friendly visitor” programs, friends and neighbors, or other means. The important point is to allow yourself to take a break from caregiving. See “Resources” at the end of this article for organizations that might help you give yourself time off from caregiving.

• Take Care of Yourself
Although caregiving may make it difficult to find time for yourself, it is important to eat well, exercise, get a good night’s sleep and attend to your own medical needs. When you do not take care of yourself, you are prone to increased anxiety, depression, frustration and physical distress that will make it more difficult to continue providing care.

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Laurie Kelly was frustrated.

The Lynchburg, Virginia resident had written her congressman, Bob Goodlatte, several times. Her request was relatively simple: Endorse a bill to protect people with epilepsy from discrimination in the workplace.

Kelly had good reason to contact him. As the mother of a child with epilepsy, she knew that people with the condition face discrimination on a daily basis. By helping to get the bill enacted into law, she could help protect her daughter from facing discrimination in the future.

As a social studies teacher, Kelly also knew that civic involvement is the cornerstone of our democracy. Politicians are elected to represent the voters of their community. Unless she contacted Representative Goodlatte, a Republican, how would he know whether to support or oppose the legislation?

At first, it seemed like an easy sell. The bill, H.R. 3195—known as the ADA Restoration Act—had strong support from more than 220 of Goodlatte’s colleagues, both Democrats and Republicans, in the House of Representatives. More than 40 supporters were Republicans, including one of the bill’s primary authors, Representative James Sensenbrenner of Wisconsin.

Despite this strong support, and Kelly’s best efforts, she couldn’t persuade Representative Goodlatte to add his name to the list. However, she never thought of giving up. “Anyone who knows me knows how passionate I am about this,” Kelly said.

The Impact of Action

More than 3 million Americans are affected by epilepsy. Yet, unlike Kelly, only a small fraction are involved in the Epilepsy Foundation’s advocacy efforts. Without those voices, we cannot address the many issues affecting people with epilepsy.

“The strength of the Foundation lies in the collective voice of people with epilepsy and their families,” says president and CEO Eric Hargis. “When we speak up, we educate elected officials about epilepsy. But we also generate support for funding, ending discrimination and improving access to medical care.”

According to Hargis, the growth of community-based epilepsy programs are an example of how the system works. These programs, funded by the national Centers for Disease Control and Prevention, are developed by the Epilepsy Foundation—often in conjunction with other national organizations and experts and administered by local epilepsy affiliates. They provide critical services to people affected by epilepsy.

For example, funds are used to create support groups for teens, increase epilepsy awareness in schools, train school nurses, educate first responders and provide culturally competent information on caregivers.

None of these programs existed before 2000. But the Foundation launched a spirited campaign to persuade Congress to provide the necessary funding. Advocates across the country called, wrote and met with their representatives and senators. They wrote letters to newspapers, talked with their neighbors and some families even came to Washington, D.C.

Success didn’t happen overnight. The combination of personal stories and political “muscle” ultimately helped convince Congress to take action. Now, each year, Congress spends more than $7 million on community-based epilepsy programs. With your help, that number will continue to grow.

Doing Her Part

Laurie Kelly decided to up the ante. If her single voice wasn’t enough to convince Representative Goodlatte to endorse H.R. 3915, she knew what to do. Get more voices.

Working with the Foundation’s advocacy team, Kelly crafted a petition urging Goodlatte to endorse the bill. By collecting signatures on the petition, she could show Representative Goodlatte that many in their central Virginia community support protecting people with epilepsy from discrimination.

Kelly was hesitant at first, because she had never asked people to sign a petition. But she realized that the price of inaction was too costly. Her school’s annual Social Studies Fair provided an excellent opportunity to speak with friends about the matter and collect signatures.
“As I was telling parents about what we were learning in class, I told them if they were feeling really patriotic they could even sign a petition that I was sending to Bob Goodlatte,” she said. “I was able to explain a little bit about [the issue] and was able to get 13 signatures!”

On a roll, Kelly connected with Jamie Swann, Tiffany Eimers, Terri Evans and other local families affected by epilepsy. Within two weeks, the small group collected more than 200 signatures on the petition and Jamie’s letter to the editor was published in the Roanoke Times (circulation 90,000).

The week after Thanksgiving, Kelly mailed the signatures to Representative Goodlatte. Despite all her hard work, she was cautious about her prospects for success. “I really hope these efforts make some sort of change for the better,” she said. “But if they don’t, I will know I have done my best to make the world a better place.”

Be Part of the Solution... Become an Epilepsy Advocate!

With fierce competition in Washington, D.C., the Epilepsy Foundation needs thousands of people like Laurie Kelly. People willing to raise their voices, share their personal stories and educate their elected officials about epilepsy. That means you.

Help us secure greater funding, stop discrimination and improve access to care. It’s a small commitment of time that can make a huge difference.

Sign up today to become a member of the Epilepsy Foundation’s Speak Up, Speak Out network. You can register by returning the form on this page, or by visiting our Web site: www.epilepsyfoundation.org/advocacy.

Name: _______________________________________
Address: _____________________________________
City: _________________________________________
State: _____________________ Zip: ______________
E-mail: _______________________________________

Please return to: J. LaMountain/Epilepsy Foundation, 8301 Professional Place, Landover, MD 20785.

Caring for the Caregiver: You
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• Seek Outside Support
Sharing your feelings with a counselor, pastor, a support group, or with another caregiver in a similar situation can be a great way to release stress and get helpful advice. You may want to contact the organizations under “Resources” below or look in the community services section at the front of the Yellow Pages, under “Counseling” or “Senior Services” to find services to help you get some caregiver support.

Resources

Family Caregiver Alliance
National Center on Caregiving
180 Montgomery Street, Suite 1100
San Francisco, CA 94104
(415) 434-3388
(800) 445-8106
www.caregiver.org
E-mail: info@caregiver.org

The National Family Caregivers Association
10400 Connecticut Avenue, Suite 500
Kensington, MD 20895-3944
(800) 896-3650
(301) 942-6430
www.thefamilycaregiver.org
E-mail: info@thefamilycaregiver.org

ARCH National Respite Network
and Resource Center
(800) 473-1727
www.archrespite.org/index.htm
Call to find local respite providers.

Visit the Epilepsy Foundation’s online forums at www.epilepsyfoundation.org

Credits


Adapted with permission from the Family Caregiver Alliance. For more information, visit the FCA Web site at www.caregiver.org or call (415) 434-3388.
The following is adapted from an article that ran in consecutive issues [March/April, May/June 2002] of EpilepsyUSA.

One thing Tony Coelho knows a lot about is the fear of the unknown. It’s something that gripped his parents from the time he was 15 years old.

That was the year he was in a pickup truck accident on his family’s farm, which is what appears to have caused his epilepsy. After the accident, he started having seizures. But it would be several more years before he got the diagnosis.

“My parents were told from day one that it was epilepsy. My parents refused to let me know about it. They knew from day one,” he said. “The original doctor told them about it. My parents took me to different doctors and after each new visit, would tell me the doctor didn’t know.

“So I went through a series of doctors and continued having seizures and it was just this mystery thing, this thing I had. I had never heard the word epilepsy. There was no reason for me to,” Coelho continued. “I believed my parents and the doctors and we kept trying to find out what was wrong with me.”

After a series of doctors, his parents started taking the teenager to what Coelho calls “witch doctors.”
His parents had always believed that if a person had epilepsy, they were possessed by the devil, so they kept trying to prove to themselves that their son didn’t have epilepsy. When they couldn’t do that, they tried to eliminate “the spirits.”

“I went through three witch doctors and you know they did all of the praying in tongues and poured hot oil all over my chest and my forehead and burnt candles on my body and all sorts of strange things and I finally rejected it and told my parents, ‘No. I will not go to anymore witch doctors.’”

“When I graduated from college, I was still having these things that I didn’t know what they were. I never got frightened by them,” Coelho said. “It was just this unknown thing.”

**A Change of Plans**

Coelho graduated from Loyola University in Los Angeles in 1964. He was student body president his senior year and by the time graduation rolled around, Coelho had many companies making promising job offers.

But he had already made a decision—one that his girlfriend of five years wasn’t that fond of.

“I told her that I loved her but that I had decided to go into the priesthood. That was a tough breakup,” Coelho admitted. “My fraternity brothers kidded the hell out of me, because they knew I was the kind of guy who liked to have fun. The Jesuits were wonderful. They were excited about my becoming a priest.”

But it wasn’t to be. Coelho went to the doctor for a medical exam, which was required before being admitted into the seminary.

And that’s when he found out he had epilepsy.

“This wonderful doctor told me and asked, ‘Haven’t you ever been told?’ ‘No,’ I said. ‘They didn’t know what it was.’ The doctor said, ‘Of course they knew what it was. It’s very clear. You have epilepsy.’”

“Then he told me, ‘You’re 4F. You can’t go into the military. You won’t be sent to Vietnam. But you also can’t go into the seminary. You can’t be a priest.’”

The doctor explained that a law of the Catholic Church, dating from 400 A.D., prohibited people with epilepsy from entering the priesthood.

It was potentially shattering news to the young man with a religious vocation—but its first impact was actually liberating.

“I walked out of there feeling whole,” Coelho said. “Upset with my parents, but whole. It wasn’t the end of the world.

“I loved the way the doctor explained it; I understood it. All of a sudden I knew what was going on,” he continued. “He gave me medication for the first time. I never had anything before to feel comfortable with. He gave me phenobarbital.”

Coelho now takes Topamax daily.

“Walking out of there, I remember clearly even now, getting into my car and thinking things were better. Absolutely. This is great. I know what’s going on,” Coelho said. “So I can’t be a priest—big deal—I can do something else. I wanted to be a priest, but you know, you can’t do everything you want in life, so I accepted that.”

That acceptance, however, was short-lived. What the doctor didn’t tell him was that California law required physicians to send a letter to the Department of Motor Vehicles to let them know when any of their patients were diagnosed with epilepsy.

A couple of weeks later, the letter from the DMV arrived. Coelho’s license was revoked.

He also became increasingly irritated with his parents for not being honest with him over so many years. He decided to wait several weeks before confronting them.

“I called them and said, ‘I have some good news. I can’t be a priest, but I know what my problem is. I have epilepsy.’”

His mother, Coelho continued, was the strong one in the family. “She immediately said, ‘No son of mine has epilepsy.’ I could see, feel and hear—in her tone—real rigidity. We talked after that, but never about my health—for 29 years. It was very superficial. Not a real relationship.”

‘What is There to Live For?’

Other problems began to snowball. “I couldn’t get a job,” Coelho said, “At that time, job applications specifically asked if you had epilepsy and I couldn’t find anyone willing to hire me.”

The companies that had been trying to recruit him just a month before suddenly didn’t have any job open-

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ings. He gave up the job search and became depressed. “I started drinking,” Coelho said. “I was drunk every day. And it was quick. It didn’t take long, just a matter of weeks before everything fell apart.”

Before long, he started thinking about committing suicide.

“I loved my church. I loved my family. But all of a sudden, I thought, you know, what is there to live for?” Coelho remembered. “God had rejected me, the church had rejected me, and my family had rejected me.

“I thought it was so unfair that everything was taken away from me. But there was no appeal,” he continued. “In those days, so what if they discriminated against me because I had epilepsy—there was no one to appeal to.”

“When I authored the Americans with Disabilities Act, it was because of my own experiences,” he said.

He said he will never forget the day he describes as the day he “snapped out of it.”

“Like every other day during that time, I was drunk,” he started. “I was on a hill looking over a park, specifically at a merry-go-round. I used to go there a lot to get drunk.

“And I’ll never forget listening to the music and then actually looking at the merry-go-round and looking at the kids that day,” Coelho continued. “I snapped. I said to myself, that’s the answer right there—being like those kids—believing. Not letting people get me down.”

So, from that day forward, he pushed aside those other, darker thoughts and started believing in himself.

‘The Good Lord Was with Me’

As great as it is to believe in yourself, it doesn’t pay the rent. Coelho still needed to find a job. A friend of a friend of a friend let him know that Bob Hope was looking for someone to live with his family.

“So I jumped at the chance,” Coelho said. “He became my mentor.”

America’s favorite comedian liked to take long drives and Coelho would join him. “We did a lot of talking and it was Hope who finally suggested I look to politics as a way to reach people the way I had planned to do in the priesthood.”

It was because of Hope that Coelho began to work on the staff of Rep. B.F. Sisk (D-Calif.) in 1965.

Two years later, he met Phyllis Butler, an aide to Rep. Andy Jacobs (D-Ind.), and fell in love.

He was apprehensive though, because of his epilepsy and decided not to get too seriously involved—he didn’t think he could take it if she rejected him because of his seizures.

But she didn’t reject him. She loved him, too. And soon, the two were married.

Coelho’s political career was also going well. After being on staff for five years, he became Sisk’s top assistant. By the time he resigned to run for Congress himself, he was fairly well-known by staff and members of the House alike.

In 1978, Rep. Sisk decided to retire and Coelho took the opportunity to seek election for the seat Sisk was vacating—California’s 15th Congressional District.

During that first campaign for election, Coelho’s opponent raised the issue of epilepsy in public. He asked how people would feel if Coelho went to a meeting at the White House and had a seizure.

“The press called me and the good Lord was with me,” he said. “Off the top of my head I said, ‘Well in the 13 years I’ve served in Washington I’ve known a lot of people who have gone to the White House and had fits. At least I’d have an excuse.’ It was a great line.”

It killed the issue. There were no more snide comments about epilepsy from his opponent and by January 1979, he was in Washington, D.C., as a new member of the U.S. House of Representatives.

“I think I was very lucky to have had 13 years as a
staff member with Representative Sisk,” Coelho stated. “I didn’t come in totally awed by all of these people who were already there.”

Coelho was determined to use his inner strength to be effective. And being effective meant making life better for the individual people in his district.

**Committed to the Cause**

Coelho knew his constituents needed a champion. “They need someone who will fight for them. That’s an important part of the job. I’ve always felt very strongly about that.”

But that wasn’t the only goal. Now, he was finally in a position to make a difference for people with epilepsy and other disabilities. He set to work on involving himself in the process of getting laws passed.

“I thought from day one that it was important to use my podium (of a congressional seat) to make a difference on disabilities,” he said. “And so I started as a freshman member to get involved with amendments to bills, speaking up and strategizing to get bills passed.”

Only a short time passed before Coelho’s involvement started to make a difference. Invited to give the keynote address at the 1979 Epilepsy Foundation National Conference, Coelho told the audience:

“I will be an advocate for legislation that will help. I am committed to this cause and while I can’t promise miracles, I do pledge that my office and I will do the best we can.” In 1982, Coelho became a member of the Epilepsy Foundation’s Board of Directors.

It didn’t take long before Coelho was testifying before House and Senate committees to seek increased funding for epilepsy research and ensure the rights of people living with epilepsy. He always identified himself as a person with epilepsy.

“I was very open about my epilepsy from day one. I felt that if I had a seizure in front of people, well, that’s just the way it is. Life is all attitude,” Coelho said. “What counts is how you deal with what you’ve been dealt.”

“I thought I could be effective regardless of my disability,” he continued. “My disability, to a great extent, has made me a stronger person. I’ve tried not to look at it from a negative point of view. My philosophy on life has been that people can never reject me as much as I’ve already been rejected. I don’t mind being told no—it just makes me try harder.”

Coelho’s successes are so striking that some people might feel they are out of reach in their own lives. “It doesn’t mean that everyone can be a congressman. But it does mean that you can be a success in whatever you’re doing. And it does mean that you can be a positive influence no matter who you are,” he continued.

Sometimes, even the setbacks have their benefits. “I was born and raised in a town of 2,000 people. I lived on a dairy farm. If my parents had accepted the doctor’s diagnosis, I probably would have been drugged up and never would have done anything,” Coelho admitted. “They would have loved me in a way that would have restricted me. I probably would have never gone away to college.”

“But because they didn’t tell me about my epilepsy,” he concluded, “they were never able to prevent me from trying to succeed.”

After Coelho was elected to Congress, it didn’t take long for him to emerge as a leader of his party. He served as Chairman of the Democratic Congressional Campaign Committee from 1981 to 1986 and then as Majority Whip in the House from 1987 to 1989. He also served in senior positions on the Agriculture, Interior and Administration Committees during his years in Congress.

**It All Comes Back to the ADA**

However, the most significant event in his legacy of contributions to public life was Coelho’s authoring of the Americans with Disabilities Act, recognized as one of the most important pieces of civil rights legislation in the last 30 years.

“The Civil Rights Act was enacted in the 1960’s,” Coelho said. “Do we still have discrimination against people of color? Yes. The ADA was passed in 1990. Do we still have discrimination against people with disabilities? Yes. But are we better off? Yes, definitely better. Will we get better in the future? Yes. Will we have setbacks? Yes.”

Coelho is the first to agree that the mere signing of a
This year’s annual Epilepsy Foundation Distinguished Achievement Awards Gala honored immediate past chair and former congressman, Tony Coelho, for his lifetime of achievement. In addition to Coelho’s distinguished career in politics, he was the primary author and sponsor of the Americans with Disabilities Act (ADA), which passed with tremendous support from both parties and the president.

The significance of Tony’s contribution to Americans with disabilities is especially relevant this year, as the Americans with Disabilities Restoration Act was recently introduced in order to restore the ADA to its original intent as powerful civil rights legislation meant to protect disabled Americans—including those with epilepsy—from unfair discrimination.

The Gala was held at the elegant waterfront venue, Chelsea Piers, in Manhattan, on September 25, 2007. Guests representative of Tony’s lifelong commitment to public service happily convened to salute a volunteer, a champion for people with disabilities and a friend.
Tony connects with Epilepsy Foundation board treasurer Denise Pease.

Geraldine Ferraro presents the Epilepsy Foundation’s 2007 Distinguished Award to her former colleague in the House of Representatives.

The Epilepsy Foundation’s current board chair, Steve Sabatini, said, “Tonight, we are honoring Mr. Tony Coelho for a lifetime of tireless dedication to people with epilepsy—in fact—to all Americans with disabilities.”

House Majority Whip, Steny Hoyer, honorary chair of the Gala, worked closely with Tony Coelho to shepherd the Americans with Disabilities Act to overwhelming approval in 1990. He sent his congratulations and remarks of appreciation via videotaped message from Washington, D.C.

Tony gets a chance to take the stage with the band to sing We Are Family.

Tony was involved with all aspects of the Foundation’s work, however his passion has always been directed toward helping kids. He was instrumental in establishing a camp for children with epilepsy in California called, appropriately, Camp Coelho. A portion of the funds from this year’s Gala will go toward creating the Tony Coelho Camp Scholarship Fund, which will help send young people to camp.
law doesn’t guarantee change, but does offer opportunities. Some of those opportunities have been narrowed for people with epilepsy—an irony that is all too clear to the ADA’s chief author.

“I’m disgusted with what the Supreme Court has done recently,” he acknowledged. “For the Supreme Court to say that the intent of the Congress was for people with epilepsy not to be covered by the ADA is despicable.

“Why would I write a law that in effect eliminates the very people who I represent and am part of? It’s ridiculous. For the Supreme Court to say that the intent of Congress was such, did they ask anyone in Congress? They don’t know what the intent of the Congress was; they’re just interpreting it the way they want to.”

Coelho remains integrally involved in making sure the ADA remains true to its original intent. He is a strong supporter of the bipartisan legislation, the Americans with Disabilities Restoration Act. He said, “I firmly believe that the time is right to restore the ADA to its original intent and meaning.” He was supportive when leaders from both parties introduced the ADA Restoration Act on July 26, 2007, the 17th anniversary of the ADA.

What People Think

“I think to a great extent, people with epilepsy are out in the open,” Coelho said. “Am I happy where we are? No. “We have entertainers and comedians who make fun of us and that is very heartbreaking,” he continued.

Coelho believes it’s important for people with epilepsy and for the Epilepsy Foundation to keep up the fight for recognition and respect. “We have to let the public know that we feel strongly about epilepsy and don’t think it’s something to be made fun of,” he said.

Coelho is also committed to helping children. He said, “Kids are our future. Kids are our greatest resource. Kids are our everything,” he said. “Young people with epilepsy need to know that they can succeed at whatever they want to do if they have a real desire. That the American dream includes them.”

But, Coelho added, it’s also important to get young people who do not have epilepsy to understand what it is—and what it’s not.

Working with young people, he believes, takes time, but is a great investment. “Our money should be spent working on kids—kids with epilepsy and kids in general about the perception of epilepsy.

Perceptions Start With Us

Coelho also thinks people with epilepsy can do a lot to improve attitudes about the disorder by not being negative.

“When you talk to people, don’t be defensive, there’s no reason to be. You are what you are,” he said. “If you treat epilepsy negatively, you pass that on to the people you talk to.

“It’s also important to be involved in helping others. I think the way we resolve our problems is to reach out and help other people with epilepsy or other disabilities,” Coelho continued.

“Now, I’ve come to terms with my epilepsy, so this is easy for me to say. It wasn’t always easy,” he said. “But, it’s easy for me now and that can be the case for everyone—you just have to come to terms with it.”

The critical part, Coelho believes, is loving yourself and knowing who you are. And sometimes, it’s a matter of finding strength in unexpected places.

“I have to say—and this might sound a little out there—the greatest gift God gave me was my epilepsy because, in effect, it forced me to know myself. It forced me to know what I was all about. I know myself and I deal with who I am,” he said.

“Sometimes people say I’m arrogant about it,” Coelho confided. “What I am is very comfortable with who I am and very comfortable with what I believe in.”

When Coelho speaks to young people, he always tells them to look into a mirror.

“If you think you’re too short, you can’t do anything about it. But, if you don’t like the color of your hair, you can change it,” he says to them.

“But look at who you are and accept who you are. If there’s something about you that you can change, change it. If there’s something about you that you can’t change, accept it.

“Once you find acceptance in yourself, it’s wonderful. You have tremendous freedom and then you have tremendous ability to help others,” Coelho said.

What’s Next?

“Jobs are the great equalizer in our society. Without a job, it’s hard to participate in the joys of life,” Coelho said. “I think with a job that gives you the opportunity to fail, as well as succeed, people with disabilities will succeed because they want that job and they will be loyal to that job and to their employers.”

Coelho also said he plans to spend more time with his family. “I love my kids and love for them to have opportunities to do things,” he continued. “And I want to provide them with the means to do as much as they want to do. If we have grandkids, I want to make sure they’ll have the opportunity to do what they want to do.”

Both of his daughters are young adults now, having benefited over the years from their father’s emphasis on the importance of public service and giving back to the community. “Now they’re out there starting to make a difference in the world and I’m so proud of them,” Coelho said.

“I still think I can make a difference. I can do it from a different pulpit,” Coelho concluded. “I still have a podium, because I demand it. What I want to do is devote more time to making life better for people with disabilities.”
An Uncommon Commitment to Being: The Epilepsy Company

UCB, Inc. Salutes Tony Coelho
And All Those Committed To The Epilepsy Community

Every day, we at UCB, Inc. strive to help individuals rise above and beyond the challenges of epilepsy. For us, it’s not enough to be a leader in developing effective treatments for epilepsy. We stand by each and every individual living with epilepsy—working not only to advance treatments, but also to enhance the lives of those who live with epilepsy.

This is why UCB, Inc. was honored to be a Platinum Sponsor of the Epilepsy Foundation’s 2007 Distinguished Achievement Awards Gala to honor the achievements of Mr. Tony Coelho—a person who exemplifies leadership in the epilepsy community.

As recipients of the 2006 Distinguished Achievement Award, we know that this award reflects tireless efforts to educate and assist patients, caregivers, and healthcare providers.

Mr. Coelho, the Immediate Past Chair and a current member of the Epilepsy Foundation’s Board of Directors, has been a prominent public servant and advocate for people with disabilities for more than 40 years. As a person living with epilepsy, Mr. Coelho knows firsthand about the stigma and discrimination people with epilepsy often face. Yet, Mr. Coelho overcame such obstacles to serve in the U.S. House of Representatives from 1978 to 1989.

Mr. Coelho had many distinguished achievements during his 13 years in Congress. Most importantly—especially for the more than 3 million Americans with epilepsy—he was the primary author and sponsor of the Americans With Disabilities Act.

We salute Mr. Coelho and others like him who remain committed and connected to the epilepsy community.

UCB, Inc. is committed to putting patients first, which is why we sponsor a number of unique patient programs:

- **Epilepsy Advocates** are people living with epilepsy, and caregivers of those living with epilepsy. These remarkable individuals share their triumphs over epilepsy as a way to teach and inspire other people living with epilepsy to make positive changes in their own lives. [www.epilepsyadvocate.com](http://www.epilepsyadvocate.com)
- **UCB Family Epilepsy Scholarship Program™** awards scholarships to people living with epilepsy, as well as to family members and caregivers of those living with epilepsy, making it the only program of its kind. Since 2005, UCB has awarded $375,000 in scholarships to qualified recipients. [www.UCBscholarship.com](http://www.UCBscholarship.com)
- **Canine Assistants Seizure Response Dogs**. This non-profit organization is dedicated to providing specially trained service dogs to children and adults living with epilepsy, physical disabilities, and other special needs. [www.canineassistants.org](http://www.canineassistants.org)
- **The H.O.P.E. Mentoring Program** (Helping Other People with Epilepsy) was created to allow people who live with epilepsy to educate others and share their experiences. This educational program trains people living with epilepsy to be “patient educators” throughout the epilepsy and neurology communities. [www.epilepsyfoundation.org](http://www.epilepsyfoundation.org)

UCB, Inc. is proud to be the only pharmaceutical company to sponsor Canine Assistants Seizure Response Dogs. This non-profit organization is dedicated to providing specially trained service dogs to children and adults living with epilepsy, physical disabilities, and other special needs. [www.canineassistants.org](http://www.canineassistants.org)

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Did you know when you give cash or stock for a charitable gift annuity with the Epilepsy Foundation, we give you back annual payments for the rest of your life? Sound too good to be true? It is true, though, and many of our friends are taking advantage of this opportunity.

Here’s how it works:
Say “Mr. Smiley” gives $10,000 to the Epilepsy Foundation for a charitable gift annuity. The annuity contract obligates the Epilepsy Foundation to pay him a set amount every year—either monthly, quarterly, semi-annually or annually. The amount he receives is determined by his age and, ordinarily, part of the payment is tax free.

Since Mr. Smiley was 75 years old when he established the gift annuity, his annuity rate is 7.2%. This means he will receive a fixed amount every year of $720. In addition, Mr. Smiley will receive a charitable deduction of approximately $4,498.80 in the year his gift was made.

Why does the Epilepsy Foundation provide gift annuities? To help our donors who want to make larger gifts, but can’t afford to reduce their cash flow. Also, it helps our donors who are planning to provide a bequest make the gift now so they can take advantage of the income tax charitable deduction. For older donors, an Epilepsy Foundation gift annuity may actually provide a larger payout from the asset than they might receive otherwise.

A deferred payment charitable gift annuity works well for younger donors who want to give to the Epilepsy Foundation and, at the same time, supplement their retirement programs. For example, a donor may designate a gift, say $5,000, for a gift annuity which would be “programmed” to begin payments at retirement age. The longer the deferral period, the higher the annual payment. Even though the donor will not receive payments from the annuity for several years, an income tax charitable deduction is available for the year in which the gift is made.

By careful management, the Epilepsy Foundation is able not only to make our scheduled annuity payments, but to have enough left over to help us carry forward our mission in the world. In other words, these annuities benefit the donors and the Epilepsy Foundation.

Our gift annuity program is loaded with benefits and we want you to know about them.

If you would like to receive a confidential illustration, please complete and return the coupon below (or e-mail the data required to rdev@efa.org). You may also call Daniell Griffin at 301-918-3741, for more information.

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Yes, I would like to receive a confidential illustration for a Charitable Gift Annuity

Name

Address

City, State, Zip

Daytime Telephone _______________________________ E-mail _______________________________

Date of Birth _______________________________ Potential Gift Amount: _______________________________

Send this form to: Epilepsy Foundation, Gift Planning Office, 8301 Professional Place, Landover, MD, 20785
Attn: Daniell Griffin, Sr. Director Individual Giving
If you have a choice, it’s usually better to give appreciated stock to the Epilepsy Foundation than to give cash. Here’s why: You receive an income tax charitable deduction for the appreciated value, not just the amount you paid for the stock. You may also avoid tax on the growth.

Consider, for example, “Mrs. Jones.” She wants to give the Epilepsy Foundation a gift of $5,000. If she wrote a check for this amount, it would cost her $5,000.

Let’s assume, however, that Mrs. Jones has stock worth $100 per share that she bought years ago for only $10 a share—excellent growth, but not unusual for a good growth stock.

If Mrs. Jones gave 50 shares of this stock to the Epilepsy Foundation, the gift value and tax deduction would be $5,000, not the $500 she paid for these shares originally. In other words, her $5,000 gift would cost her only $500!

Also, consider the capital gains tax Mrs. Jones would have to pay if she sold those 50 shares outright. Ouch! She avoids all of that by simply transferring those shares to the Epilepsy Foundation. Since the Epilepsy Foundation is a qualified charity, the IRS permits us to sell those appreciated shares without paying tax. We are able to avoid the “growth tax,” and so does Mrs. Jones.

Now do you see why we encourage our donors to “give the growth”?

There are, of course, a few rules:

- First, you must have owned the stock for at least a year and a day prior to making the gift.
- Second, the value of the gift is determined by the average trading price on the day the gift is made.
- Third, the charitable income tax deduction can be applied, on an itemized return, up to 30 percent of the donor’s adjusted gross income, whereas a cash gift is deductible up to 50 percent.
- Fourth, if you are unable to apply all of the deduction in one year, you have an additional five years to use it.

Your accountant can explain these details and anything else that may apply to your situation. It’s prudent to obtain professional advice when making a non-cash gift.

You may agree that “giving the growth” is a good idea, but the process may seem difficult. You may think: “I’ve never done anything like that before.” Well, this is one reason we have an individual giving officer. Our senior director of individual giving, Daniell Griffin, can explain how the process works and assist you along the way.

Actually, giving stock is a common practice for many donors. It’s much easier than most people think. For more information, Daniell Griffin will be happy to discuss these matters with you personally. You can contact her by calling 301-918-3741.

Electronic Stock Transfer Information
DTC Delivery: DTC #418
A/C Name: Epilepsy Foundation – Contingency Account
A/C # 179-01595-19-368
Epilepsy Foundation Tax ID#: 52-0856660

If you have stock certificates, and you wish to transfer the physical securities, please send stock certificates to:
Solomon Smith Barney
1050 Connecticut Avenue, NW
Suite 800
Washington, DC 20036
Attn: Jim Lee
A/C Name: Epilepsy Foundation – Contingency Account
A/C # 179-01595-19-368
Epilepsy Foundation Tax ID#: 52-0856660
**In Brief**

Continued from page 4

**EpilepsyUSA:** What do you think the timeframe is for translating these discoveries into treatments for the general population?

**Dr. Glasscock:** That is hard to say. Trying to predict who is at risk for disease and who is not based on genetics and DNA sequencing may not be as far off as we thought, given the technological advancements that are going on now, and the ever-increasing number of known gene variants associated with epilepsy. In fact, we are already seeing a push for personalized medicine. However, I suspect it could still be another decade before we know how to interpret all of the genetic information we have. As far as our findings related to treating absence seizures, that discovery could be implemented sooner since the drug is already in clinical use.

**EpilepsyUSA:** What was your personal reaction to these findings?

**Dr. Glasscock:** My personal reaction was that it’s exciting. For those of us involved in the study, it was a novel idea that two genes that cause epilepsy, when combined in the same animal, could make an animal that was less epileptic. The counterintuitive nature of the whole study was very satisfying.

**EpilepsyUSA:** What do you think the timeframe is for translating these discoveries into treatments for the general population?

**Dr. Glasscock:** Definitely.

**EpilepsyUSA:** Is this good news for the field of epilepsy research?

**Dr. Glasscock:** Definitely.

**LEADING EPILEPSY GROUPS UNVEIL NEW SURVEY RESULTS CHALLENGING PATIENTS TO TAKE CHARGE OF THEIR HEALTH**

Results Demonstrate Patients’ Need to Spearhead Talks with Doctors about New Treatment Options

While the nation’s epilepsy specialists have adopted “no seizures, no side effects” as a major goal for people with epilepsy, a new survey shows that less than half of patients with active epilepsy are informed by their doctors about treatment options. The American Epilepsy Society and the Epilepsy Foundation recently announced results from the jointly sponsored patient survey underscoring the need for enhanced patient knowledge of treatment objectives and improved patient-physician dialogue for better epilepsy care. The two organizations are raising awareness of the survey results to empower patients to seek more from their treatment to improve epilepsy control. The survey was supported through a sponsorship by Pfizer Inc.

Fewer than half (47 percent) of those surveyed report that their doctor discussed alternative treatments with them, with neurologists more likely to do so than primary care providers. Least likely to be discussed is surgery, a finding that might suggest that a significant number of potential surgery candidates might not be aware of this option. In fact, many people with poorly controlled seizures do not get referred to epileptologists or specialized epilepsy centers that focus on more difficult to control epilepsy.

Also striking is that one-fourth (26 percent) of all patients surveyed said they did not know what their doctors would rank as a significant improvement in seizure control. While more than half (51 percent) of all patients feel that a 90 percent reduction or no seizures at all would be a significant improvement, only 35 percent feel their doctor would agree.

“This suggests a gap in communication and a lack of mutual agreement on what the treatment goal should be,” said Sandra R. Dewar, R.N., M.S., of the UCLA Seizure Disorder Center.

Social issues also are frequently left unaddressed. Only about half of those surveyed said their doctors discussed epilepsy’s impact on day-to-day activities, mood, and difficulty sleeping. Patients expressed a wide variety of concerns and fears regarding their epilepsy, such as telling others, being treated differently, inability to drive, becoming a burden on the family and fear of dying—issues that are infrequently discussed with patients.

In addition, the survey found nearly half of respondents (49 percent) who have at least one seizure a month nevertheless say they feel their seizures are very well controlled. According to Bruce P. Hermann, Ph.D., Chair of the Epilepsy Foundation’s Professional Advisory Board, “There clearly is a need to improve patient expectations about what proper epilepsy control really means. Our goal is to encourage people with epilepsy to become active partners in managing their epilepsy, and to know about treatment options so they can live the lives they want to lead. Discussion with health care professionals should not only include what to expect regarding treatment outcomes, but the impact of treatment and epilepsy on daily life.” Dr. Hermann is Professor of Neurology and Director, Matthews Neuropsychology Lab, University of Wisconsin School of Medicine and Public Health.

“It’s our role as physicians to remind patients to aim always for better seizure control, to inform them of all available medical options, and to devise a mutual plan for achieving optimal results,” said Paul M. Levisohn, M.D., of The Children’s Hospital, Denver, who chairs the American Epilepsy Society’s Practice Committee. “We look forward to working with the epilepsy community to help raise awareness about ways to better communicate and improve epilepsy management.”
Ray Robinson's *Electricity* begins rather slowly, with some quotes—then moves abruptly to a page filled with type some might call blurry while others won’t know what to make of it until they learn it’s supposed to be a typographical representation of a seizure. Then it all makes sense.

Then you fall into a page of reassuring thoughts, half sentences and momentary impressions that are a lull between the electrical pages that stretch to convey the disorientation, confusion and loss of control the main character, Lily O'Connor, experiences when she has a seizure.

Lily lives in the north of England and seems fairly content with her life. She writes notes to herself on the walls of her flat to remind herself of things she needs to do—like take her epilepsy medications—and remind her of who she is, something that is especially important when the police or EMTs have to bring her home after she has a seizure.

Lily's mother dies, setting in motion a series of events that drive the novel forward. Lily sells her mother's house with her estranged brother Barry and leaves her adequate life to go in search of her missing brother, Mikey. Her search is reminiscent of her own search for the missing moments in her life—moments lost when she has seizures.

Language is important in the book, and the author plays fast and loose with words and structures, throwing in bits of poetry and sliding some words in with spellings altered to better convey his intentions—while using pills and tablets for scene breaks and filling pages with variations of electrified type.

To bring in greater forcefulness and immediacy, Robinson effectively tells the entire tale in first-person present, taking the reader along on Lily’s ride and making the reader entirely forget a man is telling the tale.

The writer’s depictions of Lily’s epilepsy are remarkably accurate, for example the descriptions of Lily’s seizures; her fears of telling others about her epilepsy; her descriptions of her brain flipping off and on; and how she thinks about the days she’s missed due to seizures.

Lily goes to London and ends up finding a new boyfriend. She puts off telling him about her epilepsy, until she finally has a seizure in front of him. She explains her epilepsy to him—the tonic-clonic seizures, the absence seizures, how she sometimes smells things that aren’t there or walks around like she’s drunk. It is then that she feels he can finally see all of her. At that moment she feels completely naked for the first time with him.

Lily is not shy about having epilepsy. She says, “I’m important. I matter. I can do anything. I’m a sexy, strong woman that happens to have epilepsy. Do you get it? I have epilepsy but it’s not who I am.”

Throughout it all, Robinson realizes how important seizure disorders are in the lives of people who have epilepsy. For instance, when people think Lily’s the victim of domestic violence, she thinks, “Well, it wasn’t any bloke, it was me and my brain, my electricity slamming me into the ground. The stuff that turns the lump of meat in your skull into something alive—it was trying to [expletive] kill me.” Her seizures, the smackdowns she receives during them, they’re like when it all started, when her mother threw her down the stairs. Now her entire life is a stuck record of those broken memories.

*Electricity* is a wonderful story, told with exciting language and feeling. The novel is a deep, complex and thoughtful literary work about epilepsy.

Note: This book contains profanity and mature situations that might not be appropriate for young people.
Dear Dr. Lehrer:

Thank you for your message. I’m glad you appreciated the article.

There are of course different opinions about the idea that “seizures can beget seizures,” as you say, but that was precisely the message I was left with after interviewing several experts on the subject. The operative word is “can,” because it is by no means certain—for reasons still unclear—to quote my favorite line.

Thank you for your interest in EpilepsyUSA and your support of the Epilepsy Foundation.

Warm regards,

Brenda Patoine

The author of Unraveling Epileptogenesis: Research Yields Clues to How Epilepsy Develops, Progresses, Brenda Patoine, responds:

Dear Editor:

I appreciated the article on epileptogenesis you wrote in the recent EpilepsyUSA magazine [Sept/Oct. 2007]. The article talks about how the brain tries to repair itself after an insult, “But for reasons still unclear, the repair job is faulty, and the end result is a heightened predisposition to further seizures.” This is what epileptologists call “kindling” and it is very controversial. I too believe this. I have two children with epilepsy and am a doctor myself. Our neurologist doesn’t believe it.

What do you think?

Yours truly,

Elliott Lehrer

CORRECTION:

The article Forecasting Seizures [Sept./Oct. 2007] stated that the trial allowed NeuroPace to enroll 220 people is closed. The feasibility trial ended over a year ago and is closed, but the current pivotal trial is still open for enrollment.

The RNS System is a therapeutic device that uses technology to detect and suppress abnormal electrical activity in the brain before seizure symptoms occur. The new device builds on established neurostimulation technology that is FDA approved to treat Parkinson’s disease and essential tremor.

The RNS System Pivotal Clinical Investigation aims to assess the safety and effectiveness of RNS as an add-on therapy for reducing the frequency of seizures. Eligible participants should be 18 to 70 years of age with partial onset seizures that are refractory to two or more epileptic medications. For more information, visit www.seizurestudy.com or call 866-903-3678 about enrollment for this trial.
Keto Kid: Helping Your Child Succeed on the Ketogenic Diet

By Deborah Snyder, D.O., 2006. Provides parents with compassionate advice to help their children live on the Ketogenic Diet. The Ketogenic Diet is a mathematically calculated, doctor supervised diet that has been proven to control seizures when medications won’t work. It provides recipes for keto-friendly meals that make the limited menu more interesting.

212KTK $16.95

Electricity

A novel by Ray Robinson, 2007. Thirty-year-old Lily O’Connor lives with epilepsy, uncontrollable surges of electricity that leave her in a constant state of edginess. Prickly, up-front, honest and down-to-earth practical, Lily has learned to look after—and out for—herself. But when her mother dies after years of estrangement, Lily is drawn back into a world she thought she’d long since left behind, and as she plunges into the pandemonium of modern-day London, her seizures begin to intensify.

Note: This novel contains profanity.
214ELE $14.00

Epilepsy 101 - Video

Epilepsy 101 provides basic information for people who have been diagnosed with epilepsy (recurring seizures). The video describes the four major treatment options and through interviews with patients and physicians offers tips on how to limit epilepsy’s effects on people’s lives.

Length: 12 minutes.

VHS Format: 550EPI-V $14.95
DVD Format: 550EPI-D $16.95

To place an order for products from the Epilepsy Foundation Marketplace or to subscribe to EpilepsyUSA:

Call (866) 330-2718 or fax the order to (866) 687-4878

Find more on our Web site at www.epilepsyfoundation.org!
A JOURNEY OF A MILLION MILES STARTS WITH A SINGLE STEP

Join the Second Annual National Walk for Epilepsy to Benefit the Epilepsy Foundation.

When: March 29, 2008
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Visit www.walkforepilepsy.org to register.

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