Seniors AND Caregivers

Lower Your Risk for Osteoporosis
Surviving the Holidays on the Ketogenic Diet

An exclusive report on seniors, seizures and what caregivers need to know.

www.epilepsyfoundation.org
Message from the Chair

In 1988, as a member of the U.S. House of Representatives, I authored the Americans with Disabilities Act (ADA) because I knew firsthand how a person could be qualified to do a job, but still be excluded from employment because of misunderstanding and fear.

When legalized bigotry left me unemployed and unemployable because of my epilepsy, I learned that work means much more than financial stability. My passion for expanding job opportunities for Americans with disabilities is rooted in my experience—in the pain and personal failure I felt when I was prevented from working—and in the confidence and ability to contribute I rediscovered when I was finally able to find work again.

I have always been outspoken about my disability. I believe that if you want to change people’s perceptions, particularly of hidden and stigmatizing disabilities like epilepsy, you have to be outspoken about it. People have to see that any one of us could be affected by disability, that people with disabilities are not somehow “other” than those without.

Even though my epilepsy did not interfere with my ability to work or participate in other daily activities, I was unfairly denied many opportunities simply because of the stigma associated with my health condition and the ignorance of others. As we all know, stigma and ignorance about epilepsy persists today and still results in the denial of equal opportunity to many.

It seems to me, if you cannot get a job because of your medical condition, or if you lose a job because of your medical condition, you should be within the ADA’s intended protection. You should be permitted to demonstrate whether or not you can perform the essential functions of a job. Instead, federal courts, relying upon the Supreme Court’s failure to carry out congressional intent, misapplication and misunderstanding of the ADA, have so narrowly construed the ADA as to have effectively written people like me out of my own bill!

These courts have ruled that people with conditions like epilepsy, diabetes, HIV, cancer, hearing loss, and mental illness who manage their disabilities with medication, prosthetics, hearing aids, etc.—or “mitigating measures”—are “too functional” to have a disability; consequently, they are denied the ADA’s protection from employment discrimination. The courts have created a no-win situation by allowing employers to say a person is “too disabled” to do the job but not “disabled enough” to be protected by the law. The case is thrown out of court and the individual is never given the chance to do the job.

It’s time for Congress to change that.

We are asking Congress to take legislative action to address the specific problem of the exclusion of coverage for individuals specifically intended to be protected by the ADA. We are looking to Congress to undo the restrictions placed by the Supreme Court on the classes of people protected by the law, and reopen the remedies available to those who successfully prove they were unfairly discriminated against on the basis of disability (perceived or actual).

I believe that the promise of the American Dream should be within reach of all Americans because, for generations of Americans, the right and ability to work at a trade or profession was the key to individual realization of that dream, and the national prosperity that followed.

As a society, we need to embrace the idea that people should be employed based upon whether they can do the job—NOT based upon whether they have a physical or mental condition.

Tony Coelho
On the Cover:

Seniors and Seizures: An Exclusive Report on Seniors, Seizures and What Caregivers Need to Know 7

John McCain Lends His Support to Epilepsy 8

Osteoporosis and Antiepileptic Drugs by Janet Yagoda Shagam 9

Surviving the Holidays on the Ketogenic Diet 15

National Walk for Epilepsy 21
The National Walk for Epilepsy is a 5K family oriented, non-competitive walk to raise funds for research, treatment and education programs for people with epilepsy and their caregivers.

In My Own Words
by Evelyn Vogeler
A 74-year-old woman recounts her recent diagnosis with epilepsy.

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Lynn Szkoda doesn’t think of herself as a caregiver, but rather as a parent who does what needs to be done. She reflects on caring for a child with epilepsy and how important it was for her to find a support network.

Epilepsy in the Elderly
by Ilo E. Leppik, M.D.
Extra attention to the evaluation of seniors on antiepileptic drugs is essential.

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by Lisa Boylan
Mary Lou Connelly found that writing a book about her son’s experience with epilepsy was “liberating.” Featuring an excerpt from the book detailing her family’s perseverance.

In Brief 4

December 2006

IN EVERY ISSUE

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Evelyn Vogeler is 74 years old. She was diagnosed with epilepsy about 3 years ago and “didn’t believe it at first.” She is retired, the mother of nine children and grandmother to 23 grandchildren. Evelyn recounts how she discovered she had epilepsy and how she responded:

I was working and I noticed when I read my own notes back to myself at my job—it just sounded sort of strange, not like me. So I thought, “Maybe I’m just getting old and I should quit my job.” So I did and I stayed home.

One time I went out to eat with one of my friends and when I came to I was sitting in the restaurant and she was yelling my name, “Evelyn, Evelyn!” I thought, “Hmm, she sure is strange standing there yelling my name!”

I thought it was just one of those things. I was suffering a sense of denial for quite a while. I didn’t take it seriously. The seizures would only last 2 or 3 minutes—the kind I have are partial. I just kind of go into a place of my own for a minute or two and then I come back. In my strange little world I thought, “It’s aging and it will go away and won’t come back.”

What really pushed me to go someplace and get a good physical was, I was driving in a car in my hometown, Omaha, Nebraska. I was coming from the gym and I was rather tired so I stopped at a place to get something to drink because I thought I needed some water. I drove down the street and when I woke up I was sitting in the middle of a park with my car banged up against a tree. People were praying over me.

I woke up and I thought, “What are these people doing?” I got up and had to look at the car to realize what had happened. It turned out really well—no one was hurt and I wasn’t hurt—but I really realized that maybe I should do something.

So I went to the Mayo Clinic. They said it was epilepsy. I looked it up in the dictionary and it means somebody who has seizures. I thought, all right that’s what I have.

As far as people’s behavior towards me, when I started telling people I had epilepsy, I got very different kinds of reactions. I wouldn’t see friends for quite a while; they wouldn’t call as much. My husband was getting to where he’d look at me a little strange to see if I was going into one of my “things.”

I got to the point where I didn’t want to go anywhere or do anything. I went into sort of a depression because I thought, “Here’s my old age and I was going to have fun, going to dinners and the kids were all raised, the bills were paid—I was free.” I just thought we were going to have a place to live and we could go hiking—we could do all this stuff.

I was frightened and concerned about what the rest of my life was going to be like. Then I came to the point where I could kind of gradually understand this thing a little bit.

I want to find some kind of medication where I can tolerate the side effects. And I want more information from other people on how they get through this. I think that would help me too. When I first found out I had epilepsy—that road to accepting it and getting the right kind of help wasn’t exactly easy because I never thought about epilepsy. Nobody in my family’s ever had it, I didn’t know anybody who had it.

For the holidays, Evelyn plans to go home to Omaha where eight of her nine children live. She says, “I have to go home for Christmas!” Then she will be reevaluated by a new doctor and plans to be more faithful—and patient—about trying to find the right medications to treat her epilepsy.

In My Own Words is a column featuring the voices of people affected with epilepsy.
Epilepsy Research Foundation Awards Funds to Three Promising New Epilepsy Therapies:

Four Foundations Join to Support Chinese Herb Compound: a Biodegradable Drug-Releasing Brain Implant and a New Refractory Epilepsy Agent

The Epilepsy Research Foundation, a collaboration of several non-profit organizations, including the Epilepsy Foundation, the Epilepsy Therapy Development Project and Finding a Cure for Epilepsy and Seizures, together with the Milken Family Foundation, a private philanthropic foundation, recently announced recipients of translational research funds totaling over $400,000 to advance three promising new epilepsy therapies. The announcements were made during the annual meeting of the American Epilepsy Society, the professional organization of epilepsy care providers and scientists, convened in San Diego.

“About one third of people with epilepsy or one million men, women and children in the United States face persistent seizures despite all currently available therapies. Many others must accept significant side effects as the price for seizure control,” said Warren Lammert, a cofounder and chairman of the Epilepsy Therapy Development Project and Epilepsy Foundation board member.

“We, as a conjoined group, focused on addressing epilepsy in all its forms, are once again excited to support such exceptional potential in breakthrough epilepsy research,” said Eric R. Hargis, Epilepsy Foundation President and CEO. The funded projects include the following:

**Recipients of the Fall 2006 Epilepsy Research Foundation Funds**

**A New Approach for Refractory Epilepsy**

Detlev Boison, Ph.D., Associate Scientist, Director Epilepsy Program, R.S. Dow Neurobiology Laboratories, Legacy Research, Portland, Oregon and David L. Kaplan, Ph.D., Chair, Department of Biomedical Engineering, Director, Bioengineering & Biotechnology Center, Tufts University, Medford, Mass., are the recipients of a grant to pursue the development of adenosine-releasing brain implants for the treatment of temporal lobe epilepsy. Adenosine, an endogenous neuromodulator, has potent anticonvulsant properties and requires long-term delivery directly to the brain. This study aims to develop intraventricular implants of biodegradable silk protein polymers in combination with adenosine for therapeutic delivery of adenosine in a rat model. Both the silk polymer and adenosine are approved by the U.S. Food and Drug Administration for clinical use, and this study aims to engineer a safe delivery system for adenosine that can be employed in clinical feasibility and safety trials.

**Clinical Validation of a Valued Chinese Herb in Epilepsy Treatment**

Steven Schachter, M.D., Professor of Neurology, Harvard Medical School, Associate Director of Clinical Research, HMS Osher Institute, Director of Research, Department of Neurology, Beth Israel Deaconess Medical Center, will pursue a Phase IIA dose-escalation study for the treatment of epilepsy with Huperzine A. This compound, derived from a Chinese herb, is available in the U.S. as a dietary supplement and approved for the treatment of Alzheimer’s disease in China, having been administered to over 1,400 healthy volunteers and patients in numerous trials, demonstrating safety and tolerability. Dr. Schachter and colleagues discovered the anticonvulsant properties of Huperzine A in preclinical studies. This study will evaluate this compound as an add-on therapy in patients with refractory epilepsy for its safety and tolerability as well as provide a preliminary assessment of its effectiveness for seizures and its actions on mood and memory.

**Anti-epilepsy Agents Modified to Cross the Blood Brain Barrier**

Grzegorz Bulaj, Ph.D., Department of Medicinal Chemistry, College of Pharmacy, University of Utah, received a grant to pursue research in the development of a galanin-based therapy for the treatment of refractory epilepsy. Galanin, a neuropeptide, possesses both anticonvulsant and antiepileptogenic activity when injected directly into the brain. This study aims to chemically synthesize four galanin analogs modified to facilitate transport through the blood brain barrier to overcome this obstacle. These analogs will be evaluated for their biological stability, bioavailability, potential toxicity and anticonvulsant efficacy and potency following intraperitoneal and oral administration. This study is part of a larger preclinical investigation anticipated to result in the selection of one or two Investigational New Drug candidates for advanced preclinical testing.
Jeanette Fisher had never experienced seizures in her life when, at 76, she started blacking out, turning rigid and falling to the floor. She said when she passed out while her friends or family were nearby, they would become very upset because they didn’t know what was wrong with her. However their lack of understanding caused them to leap to some wild conclusions. She said they threw her in bed and told her to, “Sleep it off!” because they assumed she was drunk. Her diagnosis of epilepsy did little to improve their reactions, instead, she said, “They avoided me worse!”

Then her seizures became more severe; she couldn’t walk straight and was exhibiting signs of dementia. Her doctor in northern Minnesota thought it might be Alzheimer’s or Parkinson’s and was ready to put her in a nursing home. But first he recommended a second opinion from Dr. Ilo Leppik, director of research at MINCEP Epilepsy Care Center in Minneapolis and past chairman of the Professional Advisory Board of the Epilepsy Foundation.

When Jeanette reached Dr. Leppik he recalled, “She was so bad off that we admitted her.” They gave her an

“A lot of older people with epilepsy are just being over treated and over treatment is causing them all kinds of problems, which are being passed off as just being old age, or Alzheimer’s, or something else and it could easily be corrected just by getting the right amount of medicine.”
evaluation with chemical tests, hooked her up to an EEG and checked her drug levels. He said, “The big difference in our program is we measure what is called unbound, or free levels.” He explained that one of the medications Jeanette was on, Dilantin (Phenytoin), “is tricky to use because it’s highly protein bound and that when you measure the code level, which is usually what’s measured, it is possible to get an under reading in older people because older people have less protein binding.” He said, “Her total Dilantin level was in the ‘normal’ range, but when we looked at the unbound level she was clearly toxic.” She was overmedicated but standard tests were not revealing that information.

In addition, she was on Depakote (valproic acid), which was also interfering with the Dilantin binding and affecting the measurements. When Dr. Leppik realized what was happening, he lowered her doses. He said, “As the medication cleared out of her system and we got her on the appropriate amount of medicine, she actually walked out of the hospital.”

She had come into the hospital in a wheelchair, confused and bound for the nursing home, but left under her own steam and immediately got back to dancing with her husband, an activity both of them loved. Dr. Leppik said, “They really enjoyed each other’s company.”

They had 11 more years together when, in 2003, Mr. Fisher passed away at the age of 93.

Minnesota-born writer F. Scott Fitzgerald famously mused that “There are no second acts in American lives.” Fellow Minnesotan and slightly less well-known novelist Jeanette Fisher is living proof that axiom is not always so.

After her husband’s death, Jeanette moved into an assisted living facility. She said she didn’t want to “sit around and mope,” so she picked up a pen and wrote her first novel, Two Sexy Widows, longhand. When she went to see Dr. Leppik on one of her annual visits to his office in Minneapolis, he asked her what was new and she said, “Well, I published a book.” She later said, “I was sort of at a loss so I decided I had to do something different, you know, to keep my mind busy. I thought it would be fun to write a book like that.”

She describes the process of writing as therapeutic because it gives her something to do and makes the time go faster. When Dr. Leppik looked at the book he said, “My God! A 90-year-old woman writes this stuff!” He added, “It’s an interesting book—it’s pretty good!”

Jeanette has been seizure-free for several years and says, “I can go anywhere now and feel confident.” In addition, she is nearly finished with a second novel on 19th century Norwegian immigrants. She said Dr. Leppik has already put in an order for the book.

Reflecting on his patient, Dr. Leppik says, “She is such a clear example of what would have happened if her doctor up in Walker had not been really good and said, ‘OK I need a second opinion on this before I ship her off to a nursing home.’” He speculated that if the doctor had not sought a second opinion Jeanette “might have lived another 4 or 5 years sedated, overmedicated and not able to walk.”

Dr. Leppik believes that overmedicating older people is fairly common and it’s going unrecognized in the United States. He said, “The problem is that many doctors are using the same doses for older folks that they would use for a younger person.” He continued, “A lot of older people with epilepsy are just being over treated and over treatment is causing them all kinds of problems, which are being passed off as just being old age, or Alzheimer’s, or something else and it could easily be corrected just by getting the right amount of medicine.”

Jeanette says, “Dr. Leppik has been very good to me.” She is happy to have her epilepsy under control and adds, “I feel great now; I don’t even think about it anymore.”

For his part, Dr. Leppik said people like Jeanette Fisher are one of the reasons he continues to practice medicine. “It’s very gratifying to know that she has a good quality of life and she’s still enjoying life. You look at what could have happened to her if her doctor hadn’t sent her to us. It’s just such a tragedy in the waiting and then you wonder how many other Mrs. Fishers there are in this country.”

For more information:

Dr. Leppik’s new book, Epilepsy: A Guide to Balancing Your Life, is available online in the Marketplace section: www.epilepsyfoundation.org

MINCEP Epilepsy Care in Minneapolis, MN, is a comprehensive epilepsy care center that specializes in evaluation, treatment, consultation, research and psychological services for adults and children with seizure disorders. www.mincep.com

Seniors and Epilepsy: www.epilepsyfoundation.org
In response to the growing incidence of epilepsy in seniors, the Epilepsy Foundation conducted a needs assessment of its local affiliate programs for seniors with seizures and their caregivers. Tess Seirzant, member of the Foundation’s Professional Advisory Board and Co-Chair of the Seniors & Seizures Initiative said, “Our goal is to make sure that services are available to seniors. We wanted to look at what is being offered already, especially to seniors in the affiliate network, and secondly to identify what needs they would have for future programming.”

Epilepsy has commonly been considered a disorder that affects young people; however older Americans make up the highest percentage of the 200,000 people newly diagnosed with epilepsy each year in the United States. Currently about 570,000 people over the age of 65 have epilepsy; however because the seizures are more difficult to discern, caregivers, family members and seniors themselves are not recognizing the symptoms.

Seizures among seniors are often subtle—spaced out episodes alternately described as “going to a different place” or “thoughts skipping.” These kinds of seizures are known as complex partial seizures and can often be mistaken for common signs of aging because they affect feeling, movement or consciousness. Tess Seirzant describes complex partial seizures as “subtle” and added, “People might think, ‘Mom is tired, she’s having a senior moment.’” She said, “Sometimes that’s how it’s dismissed. People can actually have an alteration of consciousness, but to the observer’s eye it may look as though the person is a little bit spacey or disconnected from what’s happening.”

Seirzant said caregivers and family members should look for whether these kinds of incidents are happening on a routine basis and if they are reasonably distinct. She said caregivers should watch for alterations in their loved one’s behavior because they know them the best. She also recommended putting the pieces together and comparing notes with other relatives to see if they have observed the same kinds of inconsistencies.

The needs assessment revealed a strong desire to continue or develop programs to meet the increasing needs of seniors, caregivers and providers in the future. The next step will be to develop pilot programs across the country to help effectively identify and respond to seizures in seniors.

• **Recognition**—helping seniors, caregivers or providers with the competency to recognize a seizure and distinguish it from other behaviors that may be similar but not indicative of a seizure;

• **Awareness**—increase the level of information related to the prevalence of seizures among the senior population at all levels—caregivers, providers, seniors and the general public;

• **Treatment**—increased information and training for first and second level responders. Also supply information related to medications that may be used to treat seizures.

The Foundation will be enhancing its programs and services in three categories:

The Seniors and Seizures Initiative

An Exclusive Report on Seniors, Seizures and What Caregivers Need to Know
What Can You Do?

Handling Convulsions in an Older Person

- Ease the person having the seizure into a reclining position on the floor or flat surface.
- Put something soft and flat under the head.
- Turn him or her gently on to one side to prevent choking and keep the airway clear.
- If the person having the seizure is seated, turn gently to one side so any fluids drain away from the mouth.
- Don’t try to force anything into the mouth. Seizures do not cause people to swallow their tongues.
- Don’t try to give fluids or medicine until the seizure is completely over and the person is fully alert again.
- Don’t try to restrain the jerking movements. Muscles contract with force during seizures. Applying restraint could cause tears in the muscle or even break a bone, especially in elderly people whose bones may be fragile.

Responding to Confusion in an Older Person

Confusion may occur during a complex partial seizure or during the recovery period after other types of seizures. In either case, the same basic rules apply:

- Remove anything from the area that might cause injury or could be a hazard to someone who is temporarily unaware of where he is or what he's doing.
- Don’t try to restrain an older person who is wandering and confused during a complex partial seizure. If danger threatens, guide gently away.
- People may be quite agitated during these episodes. Trying to restrain them, or grabbing hold, is likely to make the agitation worse and may trigger an aggressive response.
- Be reassuring, comforting and calm as awareness returns. If confusion persists, get a medical evaluation.

Warning Signals

Most seizures, even in elderly people with other health problems, end naturally without any special treatment. Although emergency medical assistance should be obtained when someone has a first seizure, subsequent seizures usually do not require special treatment.

However, it is always possible for more serious problems to develop. Here are a few ways to spot them:

- Watch the time. If the convulsive shaking and jerking of a tonic clonic seizure lasts longer than five minutes, or starts up again shortly afterwards, call an ambulance or follow specific instructions from the doctor on in-home care. Non-stop seizures, which doctors call status epilepticus, are quite dangerous for elderly people. Prompt medical care is needed.
- Check for secondary injuries. Seniors who have seizures may break bones, so special care should be taken to find out if there’s any unusual pain following a seizure. Headaches are quite common, but a severe headache after a seizure in someone who doesn’t usually have them should be checked out.
- Call for help if breathing is labored following the seizure, if there is chest pain, or unusual pain of any kind, or if consciousness does not return after a few minutes.
- Be aware that periods of confusion lasting more than one hour associated with seizures may signal that something is seriously wrong.

If an older person with a seizure disorder who does not have a mental impairment seems to slip in and out of a confused or agitated state with few intervals of normal awareness, you may be seeing another kind of continuous seizure activity. This, too, should be evaluated at a hospital.

Special Circumstances

If you are living with an older person with seizures who has other medical problems, check with the doctor about how he or she wants you to respond when a seizure happens.

Find out whether the doctor wants to be notified every time or just in certain circumstances.

Ask whether or when you should call an ambulance; and if there are any special warning signals that you should be on the lookout for.

John McCain Releases Public Service Announcements to Raise Awareness

John McCain (R-AZ) is lending his support to the more than 3 million Americans who live with epilepsy. He released a series of radio and television public service announcements (PSAs), putting a prominent and recognizable face to an often misunderstood disorder.

McCain’s connection to epilepsy is a personal one because his father, the late Admiral John S. McCain, Jr., experienced seizures.

McCain appears in the PSAs, brandishing his trademark straight-talking style, as he addresses the audience and delivers a succinct message intended to educate a broad scope of people with essential information on epilepsy and seizures.

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Eric Hargis, president and CEO of the Epilepsy Foundation, said, “We hope Senator McCain’s commitment to raising awareness will help make more people with epilepsy comfortable and willing to openly discuss their condition with family, friends, teachers, colleagues and employers.” The Foundation is grateful for McCain’s assistance on this vital campaign.
Many patients and their doctors are not aware that accelerated bone loss and osteoporosis are long-term side effects of taking certain antiepileptic drugs (AEDs). This makes it especially important that older men and women who take medication to control seizures discuss bone health with their neurologists and primary care physicians.

Research shows that people who have epilepsy are 2 to 3 times more likely to break a bone sometime during their life than people who do not have this condition. These findings, according to Mayo Clinic epilepsy specialist Jerry Shih, M.D., also imply that elderly epilepsy patients have a higher incidence of broken bones than other people of the same age. While these findings may seem worrisome, it is important to remember there are ways to lower your risk for osteoporosis and bone fractures even though you are taking medication to control seizures.

Understanding Your Bones

It might be hard to believe that bones are living organs. Composed primarily of collagen, several calcium-containing compounds and specialized cells, bones are responsible for supporting your body and storing calcium. The two cell types relevant to bone density and osteoporosis are the osteoblasts and the osteoclasts. These cells respond to hormones, physical stress, calcium blood levels and bone-repair needs.

The osteoblasts, or bone-producing cells, make collagen and an assortment of other organic substances. The osteoclasts contain and secrete calcium-dissolving acids and are responsible for bone remodeling or bone loss.

The presence of bone remodeling cells makes it appear that bones have built-in mechanisms for self-destruction. This seems odd until one realizes that bone, in addition to providing physical support, also stores the calcium you need for other important bodily functions, such as normal heart muscle contractions.

Calcium dissolved in blood moves into bone when osteoblasts make new bone, and moves back into blood when osteoclasts break down bone in response to low calcium blood levels. Like breathing, the balanced movement of calcium in and out of bone is a fundamental body function, which is why calcium and the vitamin D needed to efficiently absorb it are such important nutrients.

Many factors alter the balance between calcium storage in bones and calcium release into blood. Some of these factors include low estrogen and testosterone levels, a sedentary lifestyle, diets low in calcium and vitamin D and taking medication to prevent seizures.

What is Osteoporosis?

The National Institutes of Health defines osteoporosis as a “skeletal disorder characterized by compromised bone strength predisposing an individual to an increased risk of fracture.” This all-encompassing definition acknowledges situations that prevent people from achieving optimal bone mass as young adults and conditions that lead to accelerated bone loss later in life.
Clinicians often describe osteoporosis by its cause. Primary osteoporosis is reduced bone strength resulting from age-related decreases in the sex hormones. Although affecting women earlier and more frequently than men, it is important to remember that primary osteoporosis adversely affects bone density and quality of life for men too.

In contrast, secondary osteoporosis results from the intertwined contributions of behavior, lifestyle and disease. Studies reveal that up to 1 out of every 3 postmenopausal women and half of osteoporotic men have bone loss resulting from secondary causes such as alcohol and tobacco use and rheumatoid arthritis. The impact of secondary osteoporosis on bone loss makes it especially important that people who take AEDs talk to their doctors about ways to minimize risk for osteoporosis and bone fractures.

**Risk, Osteoporosis and AEDs**

The risk factors for osteoporosis involve a combination of issues that range from gender to dietary habits (see Table 1). Some, such as gender and age, you cannot control. However, you can reduce your risk for osteoporosis by eating a well-balanced diet, refraining from smoking, limiting alcohol consumption and engaging in bone-bearing exercise such as walking. According to the World Health Organization, having osteoporosis is the number one risk factor associated with the bone fractures and spinal column changes that cause reduction in height and chronic back pain.

Research shows that taking the anticonvulsant drugs listed in Table 2 have a clear association with accelerated bone-loss rates. The reasons are an active area of research, but in some cases involve AED-induced increases in the liver enzymes that destroy the vitamin D you need to absorb and use dietary calcium.

A recent study published in *Neurology* shows that sodium valproate (Depakote) and other non-enzyme inducing AEDs also decrease bone mineral density. With this evidence in mind, many investigators believe that even the newer AEDs may also adversely affect bone strength.

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**Table 1. Risk Factors Associated with Osteoporosis**

<table>
<thead>
<tr>
<th>Risk Factor</th>
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<tbody>
<tr>
<td>Female gender</td>
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<tr>
<td>Advanced age</td>
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<tr>
<td>Low testosterone or estrogen levels</td>
</tr>
<tr>
<td>Small bones and premenopausal body weight of less than 127 pounds</td>
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<tr>
<td>White or Asian ethnicity</td>
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<tr>
<td>Smoking</td>
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<tr>
<td>Calcium-deficient diet</td>
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<tr>
<td>Use of certain medications that include AEDs and steroids</td>
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<tr>
<td>Other medical conditions such as cancer, malabsorption syndromes and parathyroid gland diseases</td>
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<tr>
<td>Family history of osteoporosis</td>
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</tbody>
</table>

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**Table 2. Some Antiepileptic Drugs Associated with Accelerated Bone Loss**

<table>
<thead>
<tr>
<th>Generic Name</th>
<th>Proprietary Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carbamazepine</td>
<td>Tegretol</td>
</tr>
<tr>
<td>Phenobarbital</td>
<td>Luminal</td>
</tr>
<tr>
<td>Phenytoin</td>
<td>Dilantin</td>
</tr>
<tr>
<td>Primidone</td>
<td>Mysoline</td>
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<tr>
<td>Valproate</td>
<td>Depakote</td>
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**How Do I Know If I Need Treatment for Bone Loss?**

At this time, there is no defined protocol used to identify, treat and monitor postmenopausal women and elderly men who take medication to control seizures. Many clinicians use guidelines that include instructing patients on good bone health practices, recommending calcium and vitamin D supplements, referring patients for bone density scans and monitoring blood levels for various markers of efficient calcium absorption and balanced movement of calcium in and out of bone.

According to Michael Lewiecki, M.D., of the Clinical Research and Osteoporosis Center located in Albuquerque, New Mexico, not enough doctors understand the importance of referring patients who take anticonvulsants for vitamin D blood level and bone density screening tests. Lewiecki states that for people who take anticonvulsants, “it can take surprisingly large doses of vitamin D to reach the desired vitamin D blood level of 30 to 60 nanograms per milliliter of blood.” Because there are side effects associated with taking too much vitamin D, it is important that you use such supplements only with your doctor’s supervision.

The bone density evaluation, also called Dual Energy X-ray Absorptiometry or DEXA, allows clinicians to identify...
When Lynn Szkoda posted her very first message about her daughter Ally to the Epilepsy Foundation’s “Parents Helping Parents” online forum, she had no idea what kind of response she would get.

“I didn’t find the forum until a year after Ally’s diagnosis, when I was beside myself looking for certain foods to start the ketogenic diet. To post and walk away and then go back and find 10 responses was overwhelming! I was no longer alone!”

The need to feel that you are not alone is commonly expressed by parents and other caregivers of children with epilepsy. The Epilepsy Foundation estimates that there are more than 3 million people with epilepsy in the United States, 300,000 of whom are children under the age of 14. Twenty-five percent of them experience persistent seizures despite the treatments they receive, and therefore usually require some kind of regular assistance from a parent or other caregiver. If each one of those 25 percent had only one caregiver—and most have two parents and a host of other relatives providing care—that’s at least 75,000 caregivers, many of whom feel that they’re in it alone.

But they’re not. Caregiving is becoming more and 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.

Of course, Lynn Szkoda doesn’t even think of herself as a caregiver. “I’m just a parent and parents do what needs to be done.”

Doing What Needs To Be Done
Just what does a caregiver for a child with epilepsy do?
There’s no set job description because there are many different kinds of seizures and every child is unique. The job involves the usual exhausting litany of daily parenting tasks, from cooking dinner and supervising math homework to buying last-minute birthday presents and driving to baseball practice. Plus, it involves a variety of special responsibilities related to the child’s epilepsy.

Some of the typical tasks include:
• providing seizure management and basic first aid to keep a child safe during his or her seizures
• giving medication, often several different types that must be given several times per day at precise dosages
• tracking medications and their side effects to find a combination that achieves the greatest level of control, which is often a lengthy, trial-and-error process that can take years
• keeping accurate and lengthy medical records
• serving as the primary liaison with the child’s doctor
• navigating complex and often confusing medical insurance systems
• providing transportation to and from medical appointments
• working with the child’s teacher, school nurse, principal and others to ensure that the school is properly prepared to respond to the child’s epilepsy
• educating friends, classmates, family members and others about epilepsy
• helping the child maintain a positive sense of self-esteem
For parents whose children are on the ketogenic diet, the responsibilities are even greater. Parents must be careful not to allow the child to eat anything—even cookie crumbs or toothpaste—that isn’t on the diet or hasn’t been pre-measured or pre-weighed.

All This and A Job, Too?

Many parents of children with epilepsy work outside the home, but have to adjust their work schedules to care for their children. In fact, the NFCA notes that 6 out of 10 family caregivers who are employed alter their work life (and consequently their family’s financial status) by cutting their hours or taking unpaid leave to meet their caregiving responsibilities. In 2000, the typical working family caregiver lost $109 per day in wages and health benefits due to the need to provide full-time care to a loved one at home.

Lynn, who formerly worked full time as an engineer for a construction company, now works 10 to 20 hours per week with no benefits. “I’m lucky enough to have a flexible work place and a husband with good health insurance,” she explains. “I literally have had to call into work and say that I can’t come in because Ally is seizing and I honestly have no idea when it will stop for me to get into the office. I can check my work e-mail from home and they know that they can call me. My husband also uses Family Medical Leave Act time to attend all of Ally’s doctor’s appointments and to be there for scary things like sedated MRIs and blood draws. We would love for me to be able to work full time now that our kids are older, but Ally can’t really be left alone yet.”

Care for the Caregiver

When asked what helps her help Ally, Lynn can’t say enough about the support the other parents in the online forum have given her. “The forum is always open—you’d be surprised at the 3 a.m. posts—and you don’t need a babysitter to access it!” Lack of child care, she noted, is a major barrier to joining support groups in her local community. She wouldn’t be able to leave Ally with anyone in order to attend the meetings. The online forum solves this problem for her.

She also finds that local support groups don’t offer enough people whose issues are similar to her own. “At our local support group, there was a nice couple whose daughter just found out she had epilepsy as she was leaving for college. Her experiences are very different from Ally’s. That’s not much of a support system. Online, there is such a large pool of people in all different circumstances who can tell you what has worked for them. It’s a family.”

The support of these online friends has made a world of difference to her. “I can’t believe that I didn’t have that support system for the first year after Ally’s diagnosis,” Lynn reflected. “I had to completely rely on my husband for support that first year and that was too much pressure on both of us. My mom loves Ally very much, but she’s like any grandmother. She would just cry. That wasn’t that helpful! Now, I’ll post a message to the forum about a medication we’re thinking about trying and get feedback from other parents who have been there. Each child is like its own personal chemistry lab; there are no two cases that are alike. You have to try different options to see what will work. You can benchmark what you’re doing against what other parents in the forum have tried,” she explained.

“Plus, other parents have different skills and talents. Some are excellent researchers. They will find and share articles. Others will just give you a hug when you need one.”

Parents of other children with epilepsy can be more of a support network than lifelong friends who just don’t get it.” “My friends will ask, ‘How’s Ally?’” Lynn noted, “and we have to say, ‘The same,’ or ‘Only three seizures last night.’ They’re impatient. They want to know when this is going to go away.”

“Recently, some friends and I took our children swimming at a lake,” she recounted. “My friends wanted to stand around and talk. I was thinking, ‘I’m going to talk to you, but I can’t look at you. I’ve got to keep my eyes on Ally in the water.’ I couldn’t concentrate on what they were saying because I was so focused on Ally. I thought, ‘Gee, couldn’t you get your kids to swim closer so that Ally’s not up to her nose in the water?’”

Other things separate both Ally and Lynn from their old friends. Sleepovers are out. Fireworks are out. “When Ally was on the ketogenic diet, we dropped off the face of the earth. My husband and son could go out places, but Ally and I stayed home for a year. After a while, people don’t call you anymore. They don’t mean anything by it, but that’s just the way it is.”

Leaving the House

Lynn believes that most parents of kids with epilepsy need occasional respite care, but it’s rarely available. Now that her daughter’s no longer on the ketogenic diet, her own need for a break has somewhat diminished; it’s easier for her to leave the house for short periods of time. “Ally’s fairly well managed now, and her older brother likes to babysit, so if my husband and I both need to leave the house, we can. But one of us always comes home to give Ally her medication. She absolutely has to take it at the proper time and that’s too much responsibility to leave on my son.”

Lynn has also found a great deal of support from her new church community. “The last time we went through a bad time with Ally’s medication, I had very little support. Now, if I went through a bad time, I wouldn’t have to cook. People would be there for us. Next time, I’ll be smarter about asking for help.”

Visit the Foundation’s online forums at www.epilepsyfoundation.org.
The likelihood of developing epilepsy begins to increase after age 50, and the risk of developing epilepsy increases with each passing decade. The incidence of a first seizure is 52–59 per 100,000 in persons 40–59 years of age, but rises to 127 per 100,000 in those 60 and over. Among persons 65 years and older, the active epilepsy prevalence rate is approximately 1.5 percent, which is about twice the rate of younger adults. As the elderly population continues to grow, more people are likely to receive antiepileptic drugs (AEDs).

The causes of epilepsy in the elderly differ from those in younger adults. The most common identifiable cause of epilepsy is stroke, which accounts for 30–40 percent of all cases where the cause is known. Brain tumor, head injury and Alzheimer’s disease are other major causes. In approximately half of the cases, the precise cause cannot be identified and is diagnosed as cryptogenic in the elderly. While most elderly have complex partial seizures, there are difficulties encountered in making an accurate diagnosis because physicians usually think only of convulsions and do not know that brief periods of confusion could be seizures.

Assessment of AED treatment results and toxicity in older patients is challenging because seizures are sometime difficult to observe. Signs and symptoms of toxicity can be attributed to other causes (e.g., Alzheimer’s disease, stroke, etc.) or to co-medications and the elderly patients may not be able to accurately self-report problems. Extra attention to the evaluation of elderly patients treated with AEDs is required. Families should be aware that many of the signs of overmedication can easily be mistaken for “getting older.” These include memory loss, tremor, confusion, falling from loss of balance and sleepiness.

Epilepsy and AED use is very common in nursing homes. A large nursing home database, which has information about the diagnosis of every nursing home resident over 65 years of age, shows that during 2001 approximately 10 percent of all nursing home residents were being treated with an AED. Approximately 7 percent had a diagnosis of epilepsy listed and the others were being treated with an AED for behavioral conditions or pain. Approximately 1.5 million elderly people reside in nursing homes; therefore, as many as 150,000 nursing home elderly may be taking AEDs.

The AED concentration in the brain determines both the antiseizure and the toxic effects of the drug. This is why measuring the levels of AEDs can be helpful in guiding treatment. The usual test for AED concentration measures the total concentration in the blood. But blood contains both drugs that are in the liquid part of the serum (unbound or free) and the drug that is attached (bound) to proteins. Only the unbound drug concentration in serum is in direct equilibrium (balance) with the concentration at the site of action. Therefore, measurement of the unbound concentration is the best measure of activity.

However, measuring the unbound concentration requires an extra step and doubles the cost of the test, although it provides the best correlation with drug response. Most AEDs are not highly protein bound and measuring the total (free plus bound) is adequate. Three of the major AEDs (carbamazepine, phenytoin and valproic acid) are highly bound, and binding is frequently...
altered in older persons. This is because they may be receiving other drugs that may change the binding, or they may have lower amounts of serum protein. In these patients, measuring the total concentration underestimates the actual amount of AED at the site of the action. A reading of the total level, which seems to be in the safe range, may actually be too high. To give an example, phenytoin is usually 90 percent bound and 10 percent free. This means that if the total level is measured at 20mg/L, the free or unbound is 2mg/L. Most younger adults have an effective range of 10-20 mg/L total, which means the effective range for free or unbound is 1-2 mg/L.

Many elderly, however, may have only 80 percent bound and 20 percent free. This means that if a total in an older person is 20 mg/L, the free is actually 4 mg/L (20 percent of 20). An older person with a free level this high may appear to have Alzheimer’s or Parkinson’s disease—acting confused, shaky and unable to walk. A physician who does not know about free levels may see a pattern of the problems with confusion and walking. Unfortunately, the concentration values used to guide treatment in younger persons for phenytoin, valproate and carbamazepine may be too high for older persons. Unbound or free levels should be measured in the elderly if they are receiving a highly protein bound drug. In my experience, I have seen many elderly persons whose blood levels are “normal” so the physician does not suspect AEDs to be the cause of memory loss, confusion, dizziness and falling. Because older persons are more sensitive to the side effects of a drug, the “therapeutic range” used for elderly should be lower. More research needs to be done to determine the correct levels to be used for the elderly. It is very likely that the “usual therapeutic ranges” used for adults are too high for the elderly. For now, levels below the “usual” or at the low end of “usual” should be used.

**Phenytoin:** The AED phenytoin (Dilantin) has been available since 1938 and is still the most widely used AED by the elderly. It makes up 50-60 percent of all AED use by community dwelling and nursing home elderly. However, it has a narrow therapeutic range and complex pharmacokinetics. It is absorbed slowly and is approximately 90 percent bound to serum albumin.

Smaller maintenance doses of phenytoin are needed in the elderly to attain desired unbound serum concentrations, and relatively small changes in doses (less than 10 percent) are recommended when making dosing adjustments. In the elderly, a daily dose of 3 mg/kg appears to be appropriate, rather than the 5 mg/kg per day used in younger adults. This 3 mg/kg dose is only 160 mg/day for a 52-kg (115 pound) woman, or 200 mg/day for a 66-kg (145 pound) man.

One nursing home survey revealed that residents were taking phenytoin doses similar to those used in younger adults. Consequently, there is a great potential for inadvertent overdose in the nursing home population. A range of 5 mg/L to 10 mg/L total, rather than the 10-20 mg/L used for younger persons, may be more appropriate as a therapeutic range for the elderly.

**Valproic Acid:** Valproic acid (valproate, Depakote) appears to be the second most commonly used AED in nursing homes. It is often used for control of behavior as well as epilepsy. Valproic acid, like phenytoin, is associated with reduced protein binding and unbound clearance in the elderly. As a result, the desired clinical response may be achieved with a lower dose than usual. Because the serum elimination half-life is prolonged, the dosing interval can be extended. If the albumin concentration has fallen or the patient’s clinical response does not correlate with total drug concentration, measurement of unbound drug should be considered.

**Carbamazepine:** Carbamazepine is used almost as much as valproate in the elderly. A few studies have shown that its elimination may be more affected by age than phenytoin, but more studies are needed. As for the other drugs, usually lower doses need to be used. Carbamazepine also has a tendency to lower sodium levels and should not be used with diuretics, which also have this effect.

**Drug Interactions**

Other medications taken by elderly patients can alter the absorption, distribution and metabolism of AEDs, thereby increasing the risk of toxicity or therapeutic failure. For example, calcium-containing antacids and sucralfate reduce the absorption of phenytoin. The absorption of phenytoin, carbamazepine and valproate may be reduced significantly by oral antineoplastic drugs (drugs used to treat cancer) that damage gastrointestinal cells. In addition, phenytoin concentrations may be lowered by intravenously administered antineoplastic agents. The use of folic acid for the treatment of megaloblastic anemia may decrease serum concentrations of phenytoin, and enteral nasogastric tube feeding can also lower serum concentrations in patients receiving orally administered phenytoin.

Many drugs displace AEDs from plasma proteins, an effect that is especially serious when the interacting drug also inhibits the metabolism of the displaced drug. This occurs when valproate interacts with phenytoin. Several drugs used on a short-term basis (including propoxyphene and erythromycin) or as maintenance therapy (such as cimetidine, diltiazem, fluoxetine and verapamil) significantly inhibit the metabolism of one or more AEDs by the P-450 system. Certain agents can induce (i.e., speed up) the P-450 system or other enzymes, causing an increase in drug metabolism. The most commonly prescribed inducers of drug metabolism are phenytoin, phenobarbital and carbamazepine. Ethanol (alcohol), when used chronically, also induces drug metabolism.
Surviving the Holidays on the Ketogenic Diet

If your child is on the ketogenic diet, the holidays can present a minefield of challenges in terms of avoiding tempting treats. Here are some options reprinted, with permission from the publisher, from Keto Kid: Helping Your Child Succeed on the Ketogenic Diet by Deborah Snyder, DO.

- Use food color creatively—make red whipped cream on cheesecake (see recipe below) for Christmas.
- Use fancy paper plates, paper cups and muffin cups creatively. The same old eggs and blueberries for breakfast served on a Santa plate suddenly become special.
- Make Jell-O in a holiday color and use cookie cutters to cut the Jell-O into holiday shapes.
- Prepare for the holidays by doing crafts together (rather than baking cookies or making candy houses, etc.) It can be as simple as a construction paper cutout, or as elaborate as making tree ornaments.

Recipes!

Apple Eggnog

Cream: 70 grams  
Egg (XL): 32.8 grams  
Apple juice: 12.8 grams  
Canola oil: 3.8 grams  
Liquid sweetener: 20 drops  
Vanilla: 5 drops

1. Mix egg whites and yolks together in a bowl, then measure out amount and cook in the microwave about 1 minute or until done.  
2. Mix all in a blender.

Hints: Each sip is ketogenically balanced, so this meal would work if your child is sick and not very hungry. (My son, however, preferred muffins or cupcakes on sick days). This meal is also great for travel. Your child can drink it in the car without any major consequences if a drop is spilled or it is not 100% scraped (again, because every sip is ketogenically balanced). It can also be frozen and eaten with a spoon for a special treat.

Apple Caramel Cookies with Milk

Apple: 4.3 grams  
Butter: 9.4 grams  
Hillshire Farms XL egg: 10 grams  
Nasoya tofu: 11.7 grams  
Bickford caramel flavoring: 5 drops  
Cream: 10 grams

1. Peel, dice and measure the apples.  
2. Mix the egg yolk and white together and measure.  
3. Mix all the ingredients together, divide in two and bake in a muffin pan sprayed with Pam at 350 degrees for 20 minutes or until browned.  
4. Let the cookies sit in the muffin pan to cool to allow the butter to soak back in.

These desserts would not normally be served as extras, but rather as the meal itself on special occasions.

Cheesecake with Strawberries (or Blueberries)

Philadelphia cream cheese: 32 grams  
Breakstone sour cream: 12 grams  
Eggbeaters: 20 grams  
Cream for cheesecake: 20 grams  
Cream for topping: 20 grams  
Butter: 5.5 grams  
Strawberries: 14 grams (or 7 grams blueberries)  
Liquid sweetener: 40 drops

Note: The ketogenic diet is not a do-it-yourself diet. It is a serious form of treatment that, like other therapies for epilepsy, has some side effects that should be carefully monitored. When carefully monitored by a medical team familiar with its use, the diet helps two out of three children who are on it and may prevent seizures completely in one out of three. It is a strict diet, and takes a strong commitment from the whole family. For more detailed information on the ketogenic diet visit: epilepsyfoundation.org
1. Spray a small Pyrex bowl with Pam.
2. Measure all ingredients in a microwave-safe bowl, then microwave for about 1 minute or until all ingredients are melted.
3. You can chop up the fruit and mix it in also, or hold for the topping.
4. Remove from microwave and mix together with a spatula, then pour into the Pyrex bowl.
5. Bake uncovered at 350 degrees for about 30 minutes, or until browned.
6. Once cooled, whip the cream and a few drops of sweetener and place on top (and fruit if not put inside).
7. You can also drip a small teaspoon of Walden farms Chocolate Syrup on top to make it extra fancy. If not using the chocolate syrup, you could add 5 drops of vanilla to the recipe instead.

Hints: This is a great recipe to mass-produce. I find it very good for parties, holidays and sick days. You can make a swirl by adding a few drops of food coloring to the cheesecake after you transfer it to the Pyrex bowl: then swirl the food coloring around. You can also color the entire cheesecake or just the whipped cream to match the colors used for each holiday. The cheesecake freezes well; just leave out in the fridge the night before needed or defrost in the microwave.

Pumpkin Pie

Flavorite canned pumpkin: 80 grams
Cream: 60 grams
Butter: 12.3 grams
Liquid sweetener: 30 drops
Vanilla: 5 drops
Cinnamon: small pinch

1. Whip all of the cream. Use 40 grams of the whipped cream in the pumpkin pie and 20 grams for the topping.
2. Combine the 40 grams of whipped cream along with the other ingredients in a mixing bowl and whip together.
3. Pour the mixture in a small Pyrex dish sprayed with Pam.
4. Fill a shallow baking pan with about 1/4 inch of water and place the Pyrex dish on top of it. Bake at 350 degrees for about 30 minutes, or until edges start to brown.
5. Once cooled, top with the remaining whipped cream.

Note: This is a very large portion. You may even consider using only half the serving and using the remaining calories for turkey and green beans, or another favorite.

(Pumpkin pie recipe adapted from A Family’s Guide to the Ketogenic Diet handbook from Children’s Hospital, Pittsburgh, PA)
The Journey of One Woman’s Heart
One mother’s experience with epilepsy and how it shaped her family’s life.

Mary Lou Connelly begins each chapter of her book, *Missing Michael: A Mother’s Story of Love, Epilepsy and Perseverance*, with a quote—a pearl of wisdom here, a shard of truth there—but the most compelling one, by Elizabeth Stone, accents the first chapter of the book and sets the tone for subsequent chapters: “Making the decision to have a child—it’s momentous. It is to decide forever to have your heart go walking around outside of your body.”

The metaphor effectively nails the pride, the fierce protective-ness and the helplessness inherent in parenthood. If having a child is exposing an integral part of yourself to the world, however, writing a book about that child—who has epilepsy—is a further leap into vulnerable terrain.

As she writes in her acknowledgements, “I have exposed a part of my family’s soul, the place where we live.” Clearly, it was a story that she needed to tell and the subject of the book, her son Michael, was her biggest champion in getting it done. She says, “He really started getting on me about it. He was pretty convinced he wanted this story to be told.”

Mary Lou’s son Michael was diagnosed with epilepsy when he was 5 years old. Over the years she kept a journal of her family’s struggles, accomplishments and setbacks and finally decided to write a book. As a nurse she had done a lot of professional health writing, she enjoyed the process and—most importantly—found it therapeutic.

Navigated a labyrinthine course of medications (Phenobarbital, Keppra, Klonapen, Topamax), schools, recreational activities and basic life-coping skills in a quest to find the right balance for Michael and themselves. Michael began experiencing the first stings of his peers’ rejection in third grade. His medication dulled his senses, making it difficult to respond to questions quickly. Mary Lou said, “He felt stupid. He wasn’t as alert because of the medication. So, while his seizures were controlled in third grade, the side effects of the medication were troubling in terms of school work and coordination.” Boys who had been his best friends started picking him last for games. Mary Lou said he “became more isolated and he definitely recognized that he was no longer a part of the particular group that he had been a part of.”

Mary Lou observed her child—her heart—being mistreated on the often cruel topography of the playground. She says, “Of course you want everything to work out well for your children. You want them to feel that they belong, but there’s very little that you can do about it when that occurs except to make them feel secured and loved at home.”

Because of her experience in the health care field she knew only too well how vulnerable they were as a family. She says, “I think for parents who have children with a chronic illness it can either make you grow stronger and create a better union or it can, in many instances, be so stressful that it can dissolve families.” She continued, “For us, it’s just been something that brought us closer together.”

The Connelly’s met each challenge—and there were many—with a solution. Mary Lou recognized early on that they would need to set aside special time for themselves—as a family—so they started taking vacations when Michael was about 10. She says the vacations were “a sense of salvation of sorts—a chance to regroup and chill out and come back and face whatever had to be faced.”

There is no one-size-fits-all category when it comes to epilepsy treatment. Nor is there one prescriptive way for a family to cope with a child’s epilepsy diagnosis.

The family rallied and supported one another, but they made a conscious effort to keep their struggle mostly to themselves. Because they lived in California, they felt the need to shield their family—3,000 miles away on the East Coast—and limited their discussion of Michael’s epilepsy from co-workers and friends.
In one of the more moving passages in the book, Mary Lou recounts a rare time when she did call on one of her parents for help. Michael was having breakthrough seizures and her parents were visiting for the holidays. She writes:

Early one morning, during my parents’ stay, he had a tonic-clonic seizure. Barry had already left for work. My father was in the bathroom close to Michael’s room. I called, “Daddy.” He came in and saw Michael in the final stages. I am so sorry even to his day that I called out to him. I vividly remember catching a glance of my sweet father’s face reflected later in the bathroom mirror.

She says, “He was a fire chief; he was a very strong man. I think he just felt kind of powerless that he couldn’t do anything to help and he was looking at his 10-year-old grandchild having a seizure and he couldn’t do anything. I think my regret is that it caused him too much pain.” She adds, “On the surface he seemed very calm and controlled and so I think it caused him pain, it hurt him in a way that I hadn’t seen him hurt before. I still regret it.”

Their decision to shield family and friends, she now reflects, was not healthy. She says, “We did hold a lot in when we probably should have shared and could have gotten more support from people when we were in a time of need. I think that the book, in a sense, has been pretty liberating for all of us because it just puts it out there.” She adds, “Denial is definitely a coping mechanism, but it may not be the most healthy one.”

The family continued to strategize, trying new medications and choosing different schools. Michael attended a small private school for 7th and 8th grades that they hoped would be a good fit because of the reduced student-to-teacher ratio. But Michael began having breakthrough seizures during the day that, once again, caused his peers to shun him. During his first week of school he was hospitalized.

The purpose of writing the book was to "help increase awareness about epilepsy and how it can impact lives." She says, “It was very liberating.”

The most challenging times were in his junior and senior years of high school because, until then, he had never had a tonic-clonic seizure in a school setting. He was on the ketogenic diet and the family was optimistic that he was weaning himself off drugs and steadily becoming more alert—more like himself.

Then, starting in May of his junior year and continuing to December of his senior year, he had a full blown tonic-clonic seizure every 3 weeks—six of which occurred on campus. The paramedics came; he was hospitalized—the routine was exhausting for everyone. His neurologist recommended going back on a drug he had been on.

Continued on page 19

An exclusive excerpt from Missing Michael: A Mother’s Story of Love, Epilepsy and Perseverance by Mary Lou Connolly

Stolen Slumber

Lying in the dark, listening to the silence, it’s sometimes impossible to push the bad thoughts away. Day-to-day worries are replaced by anxiety that is caused by envisioning a series of unthinkable scenarios. In the stillness, I tense up, toss my body about, and shake my head trying to free myself from images of a seizure in the shower, a lengthy tonic-clonic seizure we do not hear at night, a fall down the stairs. Then...deep breaths as I try to imagine waves lapping onto the seashore, saying over and over to quiet my racing mind, “Be still, be still, be still.”

I hear a rustling of sheets. What’s going on? I should check. I walk down the hall and peek in Michael’s room. He’s still. I make my way back to bed next to Barry, trying not to disturb his sleep as I restlessy tuck in again. I chide myself of course. This is what I used to do when the kids were babies...tiptoe into their rooms to assure myself they were breathing. Later, I hear a groan. Was that a movement? This time I pick up my pace down the hall. Michael’s breathing is heavy now. He’s noisily snoring. He must have had a brief tonic seizure. Satisfied it’s over, I retrace my steps and attempt to quietly re-enter my own bed.

As morning approaches, I hear a familiar and unwelcome sound that I liken to an old man crying out in agony. It must be 4:00 or 5:00 a.m. Barry joins me in the hallway run for these; the more lengthy and severe tonic seizures. Sometimes, they last a minute or two and sometimes longer. We can go back to our bed after the five to fifteen second tonic seizures now. We can even manage to close our eyes—sleep after them—most times. But the aftermath of the longer-lasting tonic seizures is a different story. First, there is the pure visceral fear of seeing your child’s body writhing, eyes rolling back, lips turning blue. When will he take a breath? How long will this last? How long is TOO long? We watch...count...cradle him in our arms. Then there is the relief; it’s over. But it’s not really over. His body is exhausted, the mind spent. Sleep, baby, sleep. I will stay by you till your heart stops racing and you are peaceful in your post-seizure state.

How many seizures are too many in a night? What does this do to the brain? How will they impact Michael’s function tomorrow, next week, next year? Will there ever be a treatment these seizures respond to? What if we don’t hear a seizure? What if we’re not here? What if they never become controlled? What if...

Oh, yes, nighttime...in addition to the chronic worry and anxiety, it’s also the perfect eniron for second guessing. Barry has said many times we shouldn’t second guess our decisions. After all, they’re over and done and we cannot reverse course. He does well with this mode of action. However, my nature as a “bogtrotter” (Barry’s description of my pessimist side) will not allow me to peacefully accept our past choices. Thus, I lay there and fret over school choices, medication regimens, the timing of the diet, the surgery, the decision to take a year off after high school, and so on and on and on.

And, in the silence of the night, I grieve. I grieve Michael’s losses: friendships and moments, days, weeks, even months of childhood and adolescence because he can’t remember them.”

...in the silence of the night, I grieve. I grieve Michael’s losses: friendships and moments, days, weeks, even months of childhood and adolescence because he can’t remember them.

Missing Michael: A Mother’s Story of Love, Epilepsy and Perseverance by Mary Lou Connolly

DECEMBER 2006   EpilepsyUSA   19
The Journey of One Woman’s Heart

Continued from page 18

previously and Mary Lou put her foot down, saying, “No, there just has to be something else, we can’t go backwards!” She began seriously investigating the Vagus Nerve Stimulator (VNS).

Michael had the VNS implanted in 2002 when he was a senior in high school. It took a little time to adjust the settings, but then he enjoyed a year-and-a-half seizure-free. There have been subsequent episodes where his seizures have not been under control but nothing, Mary Lou says, like it was prior to the implant. She states, “It’s made a real difference in terms of quality of life.”

Mary Lou explains that the purpose of writing the book was to “help increase awareness about epilepsy and how it can impact lives.” She says, “It was very liberating.”

She is also delighted with the reception her book has received, mainly because it has spoken to individuals who, she says, “were dealing with their situation and they felt isolated and now they know that they have a place to go—they have a support system that’s available—so that’s really gratifying.”

Michael graduated from high school in a ceremony that was emotional for the whole family. Mary Lou writes in her book:

The pictures afterward captured a handsome young man with an enormous grin and hugs for anyone close by, including a couple of very pretty graduates who singled him out and told him “I’ll miss you.” The camera captured a mosaic of relief, accomplishment, finality, and pride in all our faces.

After high school Michael took a year off because school had been a constant struggle for him in terms of medications, side effects, hospitalizations, slowed responses and the reactions of his peers. He’s now taking classes at a local community college. Mary Lou observes, “For the first time in his life he actually enjoys going to classes and is getting a lot of satisfaction from learning. She adds, “The combination of drugs and the Vagus Nerve Stimulator has really changed his life.”

Philosophically, Mary Lou notes that “All in all obviously if I could go backwards and change things, I would have Michael’s life not be complicated by having epilepsy.” However she says she has “a lot of hope that during Michael’s lifetime there is going to be a discovery of either a new medication or a new technology that will make his life even better.” She emphasizes, “I am really hopeful for the future.”

Mary Lou never expected to be an integral part of the epilepsy community; however she speaks with great admiration of her experience with the Epilepsy Foundation in San Diego, where she serves as a board member: “I have met some phenomenal individuals. Kathy West, the executive director, has an incredible ability to maximize this little epilepsy foundation office.” She adds, “Her enthusiasm and ability to raise funds has been something I am in awe of.”

She adds, “I don’t know what kind of charitable foundation I may have become involved in if it weren’t for epilepsy, but I know that for me the experience of working with the foundation in a volunteer role has been very satisfying.”
Announcing New “IRA-Friendly” Gift Opportunity

For a limited time only, individuals who have attained at least the age of 70 1/2 can donate to the Epilepsy Foundation from their IRAs and Roth IRA accounts while avoiding income tax on these distributions. This unique opportunity comes as a result of a new law signed by President Bush on August 17, 2006.

As a provision of the Pension Protection Act of 2006, plan owners can now donate up to $100,000 per year from their traditional and Roth IRAs. Donations are excluded from gross income and qualify as minimum distributions. Eligibility includes both the 2006 and 2007 tax year.

For example, Jim Smith is 75 years old; Linda Smith is 74. Jim and Linda enjoy a moderate retirement in Florida and they share a lifelong commitment to touching the lives of people who live with epilepsy and seizure disorders. As part of their year-end giving, they would like to make a $20,000 gift to the Epilepsy Foundation; $10,000 from each of their individual IRA accounts. By law, Jim and Linda are required to withdraw a minimum of 5% from their IRAs each year—an amount that exceeds their current income requirements. As an alternative to donating cash, Jim and Linda learned that new legislation permits them to donate $10,000 from each of their IRA accounts (to be paid directly to the Epilepsy Foundation). As a result, Jim and Linda will meet their minimum distribution requirement for 2006, avoid additional income taxes, gain a tax deduction, and most importantly, they have the opportunity to generously support the Epilepsy Foundation with a $20,000 gift.

Similarly, Sally Green is 71 years old, and enjoys living in a quiet New York community. Sally’s late husband, John, had epilepsy. To honor her late husband, Sally would like to make a gift of $5,000 to the Epilepsy Foundation. Sally asked her financial institution to write a check directly to the Epilepsy Foundation as part of her 2006 distribution. As a result, Sally will avoid additional income taxes, gain a tax deduction and—more importantly—she has an excellent opportunity to honor her late husband John with a $5,000 gift.

If you, or someone you know, would like additional information about how to include the Epilepsy Foundation in your financial planning, please contact Daniell Griffin at (301) 918-3741 or Jason Lewis at (301)-918-3750. A detailed explanation of these and other opportunities can be delivered by mail or in person. The Epilepsy Foundation’s planned giving staff are eager to assist you and your family in the gift planning process.

Please be sure to consult your financial advisor and always consider your family’s needs first. If you decide to make a gift to the Epilepsy Foundation, your generosity will make a difference in the lives of the more than 3 million people who live with epilepsy, and bring us one step closer to a cure.

Osteoporosis and Antiepileptic Drugs

Continued from page 10

and monitor people whose bones no longer contain enough mineral-containing substances to maintain sufficient bone strength. This exam provides information that helps your doctor diagnose your condition and provide the most effective treatment.

If your DEXA results show that you are at risk for bone fractures, your doctor may prescribe medication to reestablish a healthy balance between calcium storage and calcium release. Even if you take bone-strengthening drugs and exercise, calcium and vitamin D supplements still play an important role in improving your bone health. You can find a list of the medications used to treat osteoporosis in table 4.

The drugs listed in table 4 that end with “ate” are bisphosphonates. You must take these medications in the morning before you eat anything. It is also necessary to take these medications with at least 8 ounces of water, to remain seated or standing and to not eat anything for up to 60 minutes after taking any of these “ate” medications. This may mean you will have to make slight adjustments to your epilepsy medication schedule. Be sure to talk to your neurologist about the best way to do this.

A Teamed Approach to Improving Your Bone Health

Protecting older people who take medication to prevent seizures may require expertise and input from many medical specialists. In addition to working closely with your neurologist and primary care physician, an osteoporosis specialist may be helpful if you have already broken bones or if monitoring shows you are not responding to medication. Taking these important steps will reduce your overall risk for bone fractures.

Learning More

There is a lot to learn about epilepsy and reducing you risk for osteoporosis and bone fractures. However, you do not need to navigate the learning process by yourself. In addition to the information your doctors provide, you have many resources that range from local epilepsy and osteoporosis support groups to national organizations such as the Epilepsy Foundation (www.epilepsyfoundation.org) and the National Osteoporosis Foundation (www.nof.org). The National Women’s Health Information Center (http://www.4woman.gov) and the National Institutes of Health Osteoporosis and Related Bone Diseases National Resource Center (http://www.niams.nih.gov/bone) are other excellent resources.
The National Walk for Epilepsy is a 5K family oriented, noncompetitive walk to raise funds for research, treatment, and education programs for people with epilepsy and their caregivers.

**Saturday, March 31, 2007**
**On the National Mall in Washington, DC and Online Throughout the Nation**

**Events for Friday, March 30, 2007**
3 pm – 7 pm: Pick up walk kits at Marriott Metro Center, 775 12th Street NW, Washington, DC.

**Events for Saturday, March 31, 2007 on the National Mall in Washington, DC**
7:30 am – 8:45 am: Pick Up Walk Kits
8:45 am – 9:15 am: Pre-Walk Rally (Main Stage)
9:15 am: Walk Begins (Corner of Constitution Ave. & 10th St.)
11:00 am: Post-Walk Celebration & Kid’s Event (Main Stage)

**How Do I Get Involved?**
**Come to the National Mall on Saturday, March 31, 2007** — We will have a morning full of events dedicated to raising awareness and finding a cure for epilepsy. Besides the Walk, there will be a rally, kid’s events, and a post-walk celebration.

**Join Us Online at www.walkforepilepsy.org** — The National Walk for Epilepsy is truly a nationwide event. While marchers will gather on the Mall, if you can’t make it, your voice can still be heard.

Registration fees are $35 or $20 for children 12 and under. The last day to pre-register is March 15, 2007.

**Walk Presenters**
- Epilepsy Foundation
- Ortho-McNeil Neurologics
- WTOP
- NBC4

**Media Sponsors**

**Sponsoring Organizations**
- American Epilepsy Society
- Epilepsy Therapy Development Project

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

“It is such an honor to participate in any way we can to raise awareness in the fight against epilepsy. To be able to walk in Washington with those directly affected and their families lets our family know we are not alone. Thank you for this great honor. See you all there!”
– Greg and Elizabeth Grunberg

**How Do | Register?**
You have four ways to register:

1. **Visit** www.walkforepilepsy.org to register and set up your own personal or team page. You will be able to send e-mails via this page to your family and friends to invite them to pledge on your behalf, or;

2. **Call** 1-866-4EF-WALK (1-866-433-9255), or;

3. Complete and mail the registration form to National Walk for Epilepsy, 8301 Professional Place, Landover, MD 20785-7223, then pass around the sponsor pledge form to collect your pledges.

4. **Late Registration** - Friday, March 30, 8 am - 7 pm Marriott Metro Center, 775 12th Street NW, Washington, DC.

**Taking Epilepsy into the Light across America and Around the World...**

On Saturday, March 31, 2007, the National Walk for Epilepsy will be on the Nation’s front lawn — the National Mall. But if you don’t live near Washington, DC, you can still participate.

By visiting www.walkforepilepsy.org, you can sign up as an individual or join a virtual team to help us take epilepsy into the light across America and around the world.

Anyone who joins will help bring attention to the need to cure epilepsy, improve treatment, and raise awareness about the condition.

You will see a map of the world at www.walkforepilepsy.org. As more people join the National Walk for Epilepsy (either attending in DC or online), the map will become brighter, showing the increasing commitment from all of us to light the way to greater awareness and a cure for epilepsy.
Remember, if you can't make it to the National Mall, you can still participate in the Walk right from your own hometown! Join us for the virtual portion of the Walk online at www.walkforepilepsy.org.
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 towards 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 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) $____________
  ○ I plan to include the Epilepsy Foundation in my will.
  ○ Please send me more information about including the Epilepsy Foundation in my will.

Name ___________________________________________________________________________________________
Address ___________________________________________________________________________________________
City, State, Zip _______________________________________________________________________________________
Daytime Telephone ___________________________    Email _________________________________________________

Send this form to: Epilepsy Foundation, Gift Planning Office, 8301 Professional Place, Landover, MD, 20785
Atttn: Daniell Griffin, Sr. Director Individual Giving
Phone: 301-918-3741   Fax: 301-577-9056