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The Magazine of the Epilepsy Foundation

epilepsyUSA

JULY/AUGUST 2007

It's Time for... Back to School!

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in school



Mood disorders
and epilepsy



How to talk to your
child about depression



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message from the chair

More than 36 years ago, musician John Lennon recorded the song *Power to the People*. This chant-like tune carried a message for the times, possibly for all times. Ultimately, it's people who have the power to change the human condition. It's people who influence social change. In the end, it's people — like you and me — who may make a difference in the way we live as an organized society.

So, while I am proud of the efforts of organizations throughout the world who focus on making life better for people with epilepsy, I am even prouder of the individuals — the people — who act as the voice and muscle behind a movement of change in the way people with epilepsy are perceived and treated in our society.

Yes, the Epilepsy Foundation and its affiliated organizations throughout the country are doing good work in raising public awareness, raising funds for more research, advocating for change within state and federal government and delivering much-needed programs. But without the individual efforts of people, both with and without epilepsy, the Foundation would be simply another ant trying to move a rubber tree plant.

Since becoming involved with the Foundation, I have been impressed with the leaders, staff and volunteers who are working hard to make a difference. But I've been even more impressed with the passion and energy of people who have epilepsy and their care-

givers. They don't settle for less than they deserve. They are outspoken and genuine in their efforts to make a better life for themselves and others who experience the same conditions and issues. They are the constant reminder to those of us who do not have epilepsy of why we are involved with this cause. You provide the motivation, inspiration and passion to become more involved.

The Epilepsy Foundation continues to "stand" for everyone with epilepsy in every part of the country and in every situation so that not another moment is lost to seizures. But we don't — and we cannot — do it alone! Thankfully, many of our constituencies — perhaps even YOU — have risen to the challenge to speak up and out to those who discriminate against people with epilepsy and to those who simply don't understand epilepsy.

Not everyone who has epilepsy stands up to the challenge, however. Quite frankly, some are simply physically unable to stand. Others are concerned about the reaction they may receive as a result of speaking up. And others still don't know exactly how or where to direct their energy. Believe me, I do understand.

The Epilepsy Foundation cannot, however, change the world and the way it views epilepsy without your help. The Foundation cannot end the stigma associated with epilepsy without more people with epilepsy standing up and letting the world know they are a productive part of society.

You have the power! You have the power to make a difference, not only in your own life, but in the lives of others by becoming involved in your community or reaching out to your local Epilepsy Foundation affiliate, or by letting others know you have epilepsy and what it means. While I don't have epilepsy, a number of people with epilepsy have told me what an exhilarating experience it is to talk to others about their condition. They said that their fear melted away when their friends and colleagues reacted far more positively than they had imagined. Of course, there is the occasional example of when someone may have reacted more negatively, but the risk must be worth it when it represents an opportunity for replacing ignorance and fear with understanding and acceptance.

In the end, the power is in you. And the Epilepsy Foundation will do everything it can to stand behind you and offer the programs and services you may need in using your power.



Steve Sabatini

epilepsyUSA

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CONTENTS

July/August 2007

IN EVERY ISSUE

In My Own Words	3
In Brief	4
Letters to the Editor	21
Marketplace	22



ON THE COVER

6 Back to School: Creating a Safe and Supportive School Environment for Kids with Epilepsy

BY EILEEN FRUEH A special section with everything you need to know to get your child ready for the upcoming school year.

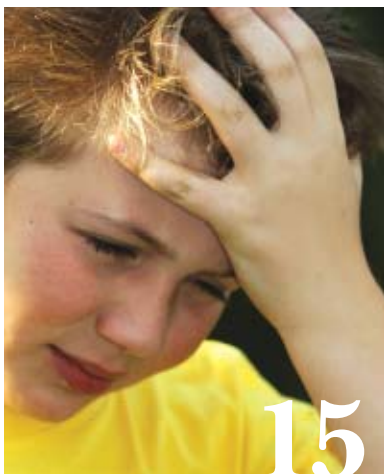
13 Comorbidities in Epilepsy BY ALIYAH BARUCHIN

Research into comorbidities may hold enormous promise.

15 Depression in Children and Adolescents with Epilepsy BY JAY SALPEKAR, M.D.

Depression is present in approximately one quarter of children with epilepsy. Find out what you need to watch for in your own child.

COVER PHOTO CREDIT: PURESTOCK/GETTY IMAGES



12 / The Ketogenic Diet: How to explain your child's special dietary needs to a school nurse.

Also, kid-friendly recipes for your Keto Kid.

17 / Suicide and Epilepsy BY BRENDA PATOINE

A recent study links epilepsy and suicide. Read more on the connection and also find out how to get help for yourself or someone you know.

CASSIE HALL In My Own Words...

HOW I GROW IN NOWHERE LAND



Cassie Hall is 18 years old and lives in Aliquippa, Pa. with her family. They own two miniature horses, a dog, a cat named Chicken and two tadpoles. She is a member of the Lincoln Park Performing Arts Charter School's Creative Writing Program, the National Honor Society, the Environment Club and orchestra. She plans to attend college and study psychology and writing. She loves taking vacations

with her family, especially summer vacations with her grandparents.

BY CASSIE HALL

The first place I could ever formally name my odd reaction to light was in an office at the local neurological center. The words *petit mal epilepsy* (absence seizures) were almost comforting because they sounded so official, despite the fact that it was an affliction and, yes, it was afflicting *me*. At least my vocabulary for seizures expanded beyond *crazy trips to Nowhere Land I take while riding a bus, while flipping on the trampoline, etc.* I also knew that in older novels, characters with epilepsy were considered to be *possessed*.

I remember watching my mother sitting quietly in the corner of the doctor's office that day, two years ago. I could see her face vanishing and reappearing as the doctor's white-sleeved arm bent and extended over my face. He was moving my limbs around, checking for flexibility. After about two minutes of this air-Twister, he reviewed my scores on the EEG and MRI tests I had taken earlier that month. He said, "These scores verify that you have

epilepsy. People with absence seizures are typically physically disabled."

My mother's eyes darted to me, her darling child, who was suddenly disabled. My own 16-year-old eyes seared into the doctor's as he scrolled over the test scores in his hand. He must have caught on to my mother's hyperventilating and my lack of breathing because he blurted out, "Oh, no, *you're* not disabled! That's why it's so strange that you have this kind of epilepsy!"

Misunderstandings like this, with general people and professionals alike, have always been a part of dealing with absence seizures. I mean, consider what the characters in those novels had to put up with! A lot of misunderstandings are unavoidable, even in an open-minded society free of harsh labels like *possession*.

Following that adrenaline-rush-day of diagnosis, however, the effort to make people understand became tiring, especially when many people would mistake it for a *mental* instability. My story tapered down from a grand, elaborate explanation of the disorder—that would make any neurologist swoon from my knowl-

edge of scientific terms—to a curt, "It's what happens when the sunlight hits my eyes." Developing patience was a part of growing up, despite how inadequate I felt at first from having the disorder.

So what are absence seizures, according to a person

who experiences them firsthand? To all the people who ever sat next to me on a sunny day on the school bus, they were what you mistook for disinterest when I rolled my eyes and turned my head away from you as you spoke to me. To the people who have marched beside me in band, they were what made me drop the slide of my trombone to the ground. To all of the people who have the condition and may be confused and frustrated with all the complex terms they hear from their doctors, absence

“I've learned that another way to define absence seizures is that it is not me. Despite all social misunderstandings and inconveniences involved with having epilepsy, I am stronger than my condition; it will not tie me down.”

Continued on page 5

Congressional Leadership Introduces ADA Restoration Act of 2007

On July 26, the 17th Anniversary of the signing of the Americans with Disabilities Act, bipartisan Congressional leaders—including Majority Leader Steny Hoyer (Md.), Rep. Jim Sensenbrenner (R-Wis.), Senator Tom Harkin (D-Iowa) and Senator Arlen Specter (R-Pa.)—introduced the ADA Restoration Act with strong support from the Epilepsy Foundation, the National Disability Rights Network and the larger disability community.

Over the past 17 years, the courts have narrowed the definition of disability so much that people with epilepsy and other conditions who manage their disabilities with medication or other forms of treatment are viewed as “too functional” to have a disability. While these same people may be denied a job or fired because an employer mistakenly

believes they cannot perform the job, they are still denied the ADA’s protection from employment discrimination.

“Since its passing in 1990, various judicial entities have diluted this landmark legislation, determining that they, better than Congress, knew whom Congress had intended to protect with this powerful piece of legislation,” said Tony



Coelho, key author of the ADA and Immediate Past Chair of the Epilepsy Foundation. “They undermined Congress by putting the burden on disabled people, making them prove they are disabled enough to be protected under the law, rather than on making other entities prove they have not discriminated against disabled people because of their disabilities. In fact, they have at times ignored it when companies admitted to committing such acts of discrimination.”

At the introduction of the ADA Restoration Act, Rep. Steny Hoyer said, “Courts have ruled that medication or other corrective measures have made ADA claimants ‘too functional’ to be considered ‘disabled’ under the law.

“Let me be clear: This is not what Congress intended when it passed the ADA. We intended a broad application of this law. Simply put, the point of the ADA is not disability; it is the prevention of wrongful and unlawful discrimination.” Hoyer concluded, “Passage of this legislation is critical to helping us achieve the ADA’s promise—and creating a society in which Americans with disabilities can realize their potential.”

» CHIEF JUSTICE TAKEN TO HOSPITAL AFTER SEIZURE

Chief Justice John G. Roberts, Jr., fell on July 30, 2007, near his summer home in Maine after suffering what doctors describe as a benign idiopathic seizure, according to a Supreme Court press release. A benign idiopathic seizure means “a seizure for which there is no specific identifiable cause such as a scar, growth, stroke or other obvious cause,” according to Dr. Alan Ettinger, a member of the Epilepsy Foundation’s professional advisory board.

Dr. William Turk, chair-elect of the professional advisory board, elaborates, “A seizure results from an abnormal electrical discharge in the brain and there are many possible causes. Head trauma, fever, medication issues, and underlying illnesses may all cause seizures. They may also occur for no known cause, and are referred to as idiopathic. Seizures that continue to recur and are unprovoked are referred to as epilepsy.”

Is it epilepsy?

Epilepsy is a condition in which a person has two or more seizures without a clear cause. Some people refer to themselves as having a seizure disorder, though technically this is epilepsy. A seizure happens when a brief, strong surge of electrical activity affects either part or all of the brain. For 70 percent of people with seizures and epilepsy, the cause of their condition is unknown.

“Because epilepsy can be a stigmatized condition, some people shy away from using the word—saying instead that they have seizures or a seizure disorder. This is in fact epilepsy, and it is important to help eliminate and eradicate myths, fears and stigma, that the correct term—epilepsy—be used,” said Eric Hargis, President and CEO of the Epilepsy Foundation.

“The Epilepsy Foundation cannot comment specifically on Chief Justice Roberts’ seizure, which is presumably being evaluated by experts to determine the underlying cause and appropriate treatment, if any. The Foundation offers information, resources, advocacy and support services to everyone with epilepsy and seizures, including the Chief Justice and his family as they go through the process of evaluating seizures of unknown origins,” said Steven Sabatini, Chair of the Foundation’s Board of Directors.

RELATED INFORMATION:

Driving: John Roberts did not drive for several months after his first seizure in 1993. Whether an individual is legally able to drive after a seizure depends on each state’s driving laws. To review the driving laws in your state, visit epilepsyfoundation.org/drivinglaws

What Causes a Seizure? A seizure happens when a brief, strong surge of electrical activity affects either part or all of the brain.

Types of Seizures: The kind of seizure a person has depends on which part and how much of the brain is affected. To learn more about what causes seizures and what types of seizures there are, visit epilepsyfoundation.org

In My Own Words

Continued from page 3

seizures are a test. Not a three-letter acronym test like the SAT. Not even a test that can measure things other people can read off a paper and tell you their meaning.

Keep reading.

The Awkward Age can be a transforming era in life that involves temporarily morphing into some kind of reptile—internally or externally. By the time I made it to the neurologist's office, I was already a turtle: an introvert who retreated behind a hard shell. However, the antiseizure medications I was taking transformed me into a Teenage Mutant Neuro-Turtle—in some ways they empowered me, but in others, I was still abnormal. For instance, the first medication did nothing to remove my seizures, even though my doctor and I agreed to increase my dosage

every two months if nothing happened. The most the medication *did* remove was the hair from my head and my normal bodily functions. I apologize for the disturbing images—if they disturb you—but that's the truth. It's worth knowing that it's never wrong to approach your doctor if you don't agree with the medicine he prescribes for you.

After a year of deteriorating on the first medication, I decided to switch to a different one. The second flux of pills was excellent in taking care of seizures, but it made me irritable, unhappy and antisocial. It wasn't "righteous," as a fellow Neuro-Turtle would say. My family tiptoed around me. I got the hint that things were wrong with me behaviorally when it came time to decorate for Christmas. I couldn't enjoy even that. If there's ever a time when you're about to implode at the thought of stringing tinsel and making cookies, something needs to be checked out. And let me warn any readers who may be frustrated with the side effects of their current prescription: scrapping a medicine cold-turkey is not the right thing to do, no matter how much better off you think you'll be without it. When I threw my pills away on Christmas Day, as a little gift to myself, I did not realize that I was putting myself at

risk for a tonic-clonic seizure, the type of seizure I'd been fortunate enough to never experience. It may seem like this warning is obvious, but us Neuro-Turtles understand

that sometimes a person is willing to do anything to get rid of something they don't want in their system.

I think that in the two years since my diagnosis of epilepsy I am closer to the people who do understand the person, even if they cannot understand the condition. I still get questions like, "Can you babysit tomorrow night or would your seizures make that difficult?" from my mother, but I don't take it personally. I've learned that another way to define absence seizures is that it is not me.

Despite all social misunderstandings

and inconveniences involved with having epilepsy, I am stronger than my condition; it will not tie me down. Epilepsy complicates transportation for me, and it makes conversations aboard the bus difficult, but it will not hinder me from boarding that bus and getting to where I need to be. I move on, further and further in my life, despite the recurrent trips to Nowhere Land on the way. The closest I can come to describing the act of passing your own test would be through the words of the poet e.e. cummings: Strengths of determination are those "which i cannot touch because they are too near."

I want to go to college to write and to study psychology. It is ironic that I yearn for insight on the mind when I suffer from a condition that can prevent mental functioning or focus. To counter my neurological adversity, I've doubled up on a prescription medication and purchased polarized blue sunglasses made especially for seizure prevention.

Kowabunga, dude.

Reprinted with permission from the Epilepsy Foundation Western/Central Pennsylvania.



“ It is ironic that I yearn for insight on the mind when I suffer from a condition that can prevent mental functioning or focus. ”



Back to School

**Creating a Safe and Supportive
School Environment for
Kids with Epilepsy**

BY EILEEN FRUEH, SPECIAL TO *EPILEPSYUSA*

Seizure Management FOR SCHOOL-AGE CHILDREN

Parents of children with epilepsy will tell you:

It's one thing to manage a child's seizures at home where you can keep an eye on them. It's another when the kids head off to school. Parents often swap stories of the challenges they face.

One family worries that their daughter, who is ambulatory during her seizures, has wandered outside the school without a buddy.

Another family is concerned about their child's failing math grade. Recent changes in medication have affected their child's memory and ability to concentrate.

A third copes with the social effects of their son's epilepsy. His classmates were frightened and confused by a recent seizure and have been avoiding him. His parents are working with the school nurse to educate the children about seizure disorders and cultivate compassion and caring.

As many as 325,000 school-age children, ages 5-14, have epilepsy. Thankfully, with medication, surgery, a special diet or vagus nerve stimulation, most go to school and fully participate in school activities.

However, children who continue to have seizures may run into problems. Many of these problems can be overcome or prevented through appropriate management by an informed school staff, particularly the classroom teacher and school nurse.

It is important for parents and schools to work together to create a safe and supportive environment for students with seizures to grow, learn and achieve their full academic potential.



“As many as 325,000 school-age children, ages 5-14, have epilepsy. Thankfully, with medication, surgery, a special diet or vagus nerve stimulation, most go to school and fully participate in school activities.”

Meeting the Teacher

Parents should take the time to meet with their child's teacher before the beginning of each school year to discuss what type(s) of seizures their child has, how to recognize them, how the teacher should respond to them and how the teacher can prepare the other students so that they understand and accept the child.

The Epilepsy Foundation offers several sample forms that can aid in this process. These include a questionnaire for parents to complete prior to meeting with the school, a student interview form, a seizure information sheet to provide teachers with basic information about a student's seizures and medications and an anecdotal record form teachers can use when reporting a seizure and/or medication side effects. (*For more information on these forms, see page 11.*)

Many parents find that they must meet with teachers and other school personnel more than once, either to update them when a child's seizures and/or medications change, or to offer retraining when a school's response to a seizure does not live up to expectations.

Because seizures can happen while the child is with a substitute teacher, some parents have found that it is helpful to create a laminated card listing the child's current medications, seizure protocol and emergency contact numbers. Others rely on an "emergency backpack" containing a blanket or towel to place under the child's head, a change of clothing and a card with emergency first-aid instructions.

Working with Your School Nurse

The school nurse plays a pivotal role in seizure management. Many children with epilepsy control their seizures with antiseizure medications that must be taken from one to four times a day. In many states, the school nurse has the primary responsibility for administering these medications during school hours.



School nurses also work with the parents to develop a seizure action plan, a tool that organizes and communicates the student's health care and educational needs. A seizure action plan helps ensure a safe environment for the student, while maximizing opportunities for learning and development.

The plan should be specific for each student and should include instructions for both basic first aid as well as appropriate emergency responses to ensure the child's safety in the event of an acute seizure emergency. Many action plans include the following guidelines:

For all seizures:

- *Keep calm*
- *Remain with the student until he or she is fully alert*
- *Do not offer food or drink*
- *Reassure the student after the seizure is over*

For absence seizures:

- *Make sure the student has not missed key parts of the lesson*

For simple partial seizures:

- *Ensure the student is fully oriented to person, place and time before resuming activities*
- *Comfort and reassure the student if he/she seems confused or frightened*

For complex partial seizures:

- *Speak to the student softly and calmly*
- *Reassure the student that he/she is safe*
- *Move harmful obstacles to ensure safety*
- *Allow a wandering student to walk in a contained area*
- *Stay with the student until complete awareness of environment is regained*
- *Help reorient the student if he/she seems confused afterward*

For generalized tonic-clonic seizures

- *Stay calm and reassure the student that he/she is safe*
- *Reassure the other children that the student will be fine shortly*
- *Ease the student gently to the floor and clear the area around him/her*
- *Cushion the student's head*
- *Turn the student gently on one side*
- *Do NOT put anything in the student's mouth*
- *Do NOT hold the student down*
- *Let the student rest until full consciousness returns*

Of course, each child is unique and parents should work with the school to create an individualized seizure action plan that outlines the specific needs of their particular child. Here are just some of the accommodations that parents have included in their children's seizure action plans, depending on the child's unique needs:

- The child should be seated at the front of the classroom so the teacher can be more aware of his or her seizures and to diminish distractions
- The child should be escorted to the restroom and lunchroom
- When the child participates in activities on risers (e.g. choir), the child should stand on the lowest riser
- The child should have extra test time or untimed tests
- The child should be closely monitored during PE activities
- The child should stay indoors during recess on hot days
- The child should be allowed to wear a hat if needed to dim classroom lights

School nurses also play a key role in helping train teachers and staff to respond appropriately to seizures and in creating a positive environment among teachers, staff and fellow students with respect to a child with epilepsy. This helps to minimize stigmatizing beliefs, reinforce the need for compassion and support the student's positive self-image.

Seizures and School Work

Many children with epilepsy do well in school, but seizures can affect school performance in subtle ways. Seizures can affect a child's memory and processing skills. After a seizure, some children are unable to remember anything that happened the previous day or immediately afterwards. Medications can also affect a child's attention span and ability to concentrate.

Parents need to help teachers understand how epilepsy can affect a child's school performance.

Ginny Miller, a Kentucky mom whose 15-year-old son has epilepsy, often trains teachers about the effects of seizures on school performance. "I tell them, 'Imagine you have the flu. Plus, you've taken a nighttime cold medicine. You head off to school and must perform on par all day, feeling awful, and do all of your work. In addition to that, the teacher pats you on the back and speaks to you the whole time to encourage you along. Now, write the alphabet backwards with your non-dominant hand, while swinging your opposite foot backwards in a circle.' Kids with epilepsy take medication every day that makes them feel that way. That helps teachers really identify with what their students are going through."

Continued on page 11

Wisconsin Teen and School Nurse Team Up to Educate School about Epilepsy



Elizabeth Barrett with her school nurse Kitty Murphy.

Many schools bring in a health expert to train teachers and staff about epilepsy when a student experiences seizures.

After Elizabeth Barrett of Sauk Prairie High School in Prairie du Sac, Wis., began having seizures at school, the school was lucky to find a well-prepared and gifted trainer: Elizabeth herself.

Elizabeth, 16, started having seizures at age 7. She had approximately one focal or absence seizure per year, always at home. Her seizures followed such a regular pattern that she never had a seizure management plan at school and was seizure-free for most of middle school. When she had her first tonic-clonic seizure at the end of her eighth grade year, school officials were surprised. None of her teachers even knew she had epilepsy.

Epilepsy Foundation. More than 20 individuals attended, including the principal, vice principal, office staff, Elizabeth's guidance counselor, her teachers and four or five of her closest friends.

Kitty, as a trained health educator, covered the basic facts about epilepsy, including the causes and types of seizures, and how to administer first aid. Elizabeth shared her personal experiences. "I told them about what it's like after having a seizure," she explained. "It truly can be a frightening experience and I wanted them to understand what a person goes through."

Her hard work paid off. A few weeks after delivering the training, Elizabeth had a tonic-clonic seizure in the school hallway and injured her nose as she fell. Several of the teachers and friends who had attended the training were present.

“As a health educator, I know what an impact personal stories can have. People are more likely to listen and to internalize the information when it comes from the person themselves. But it is very important that the person be a responsible spokesperson and present all of the facts accurately.” **KITTY MURPHY**

As she entered high school, her father, Matthew, indicated on her school form that his daughter had epilepsy and the school nurse, Kitty Murphy, called him to develop a basic plan of action.

In February, Elizabeth unexpectedly had two seizures within a week, breaking her regular pattern. She decided that it would be a good idea to educate her teachers and approached Kitty to ask if she would help her plan a training. Kitty readily agreed.

"Elizabeth had a clear goal," the school nurse said. "She needed the people around her to know what to do."

The fact that the training would be delivered by Elizabeth herself presented a great opportunity. "As a health educator, I know what an impact personal stories can have," Kitty explained. "People are more likely to listen and to internalize the information when it comes from the person themselves. But it is very important that the person be a responsible spokesperson and present all of the facts accurately."

The two worked together to plan and deliver the training, gathering materials and handouts from the

"They did great," Kitty recounted. "In fact, I don't think they even realize just how great they did. Several of them checked in with me afterwards to review how they had responded and ask how they could do better next time."

Many other classmates witnessed Elizabeth's seizure and were confused and worried, so she and Murphy decided to conduct another training for Elizabeth's entire class. "The kids seemed interested," Elizabeth noted. "They were receptive and said that the training helped. My friends told me that they definitely learned something new."

Some students might be reluctant to talk about their epilepsy, but Elizabeth feels that it's best to be open about it. "In middle school, I was shy about it. I didn't want to admit that I had epilepsy. But in high school, I became more aware. I wanted people to know about epilepsy and not to be afraid of it. Students with epilepsy shouldn't be afraid to talk about their experiences and educate other people. The experience of telling people about my seizures and teaching them about basic first aid has really helped me."

They Think It's the Way They Should Be

Classmates and Teammates Pitch In

As with all kids, it is beneficial for children with epilepsy to participate in sports and other extracurricular activities. Such activities are a great way for children with seizures to make new friends, develop skills and build self-confidence.

Some activities, such as swimming and climbing, will require extra supervision and may not be advised by the child's doctor. But, when teachers and coaches are properly prepared and when reasonable safety guidelines are followed, children who have seizures can have a positive, enjoyable experience. As Derrick Roberts found out, your teammates can also make a big difference.

Derrick, a ninth grader in Oxford, Ind., isn't new to seizures on or off the field. He has had epilepsy since he was a young child. From the beginning, other children helped out.

"Derrick's first grade teacher is responsible to the biggest extent for the way that other kids in school responded to him," Derrick's mother, Donna, explained. "She felt that they weren't too young to carry out small tasks to help out when Derrick had a seizure."

Derrick's teacher established a buddy system, pairing each child with a buddy to walk to the office or other places in the school building. That way, Derrick wasn't singled out. Then, as part of the rotating classroom jobs, one student each week was assigned to go across the hall and get a second adult if the teacher needed assistance during a seizure. The boys went as a group to the restroom.

"The kids knew how to handle seizures and they also knew the signs of one," Donna Roberts said. One year, Derrick spent some time in the hospital and then went back to school. He was walking to the resource room with another student when he had a seizure. The other student stayed with him. "He told someone that Derrick was his responsibility and that he refused to leave him. What a friend."

Derrick's friends were also supportive outside the classroom. When he was in the fourth grade, he decided to play baseball. The rules required that all children have playing time, but it was a difficult summer for Derrick, who was having frequent seizures. "Sometimes he would go up to bat and make it for a while and sometimes he would have a seizure right away," his mother recalled. "It seemed to always happen when there were one or two kids on base."

The umpire agreed to allow Derrick's mother and the coach to run onto the field when Derrick had a seizure, but not to stop the game. Donna was impressed by what her son's teammates decided to do.

"Every single game, the kids stood as still as statues when (Derrick) went down and the coach and I went running out. The other team would score, and that was just fine with his teammates. The coach told the kids they could pick up the ball and play it out, but the kids said, no, it was more important that Derrick was OK."

Once, Roberts was sitting in the stands when Derrick had a seizure and she heard another mother yelling, "Why the heck are they all just standing there?" Roberts ran onto the field and then came back and explained to the other mother about Derrick's seizures and his teammates' practice of standing still and waiting for him.

"She asked me if the children had been coached to do it. I told her, no, it was just something they chose to do. They seem to think it's the way they should be. At the next game, I heard a grandfather screaming at his grandson to stop standing there and the mother whom I had talked to told him what was up. She asked him not to stop the children because they were showing respect for a teammate. Later, that grandfather told me that Derrick was the luckiest kid on earth to have such great friends and teammates."

Derrick hasn't always been so lucky. In middle school, he had some trouble with bullies who picked on him in the restroom and tripped him in the cafeteria. Because Derrick has difficulty remembering names, he couldn't tell his teachers who the bullies were. Other students, including old classmates from elementary school and friends from his middle school basketball team, stepped in to help him and to identify the bullies.



Derrick Roberts, a ninth grader from Indiana, has had seizures since he was a young child.

“Derrick's first-grade teacher is responsible to the biggest extent for the way that other kids in school responded to him. She felt that they weren't too young to carry out small tasks to help out when Derrick had a seizure.” **DONNA ROBERTS, Derrick's mother**

CHECK IT OUT: *Seizures and You: Take Charge of the Facts* is a proven epilepsy awareness program targeting teenagers in middle and high school. It is designed to educate teens, dispel myths and reduce the perceived stigma associated with epilepsy. If you are interested in bringing this program to your school, please contact your local Epilepsy Foundation affiliate. To look up your local affiliate, go to epilepsyfoundation.org/aboutus/AffiliateLookup.cfm

School Forms to Aid in Seizure Management

The Epilepsy Foundation offers several sample forms that can aid in educational planning for students with epilepsy. The free boilerplate forms can be adapted to meet individual and institutional needs. Copies are available for downloading on the Epilepsy Foundation Web site or can be obtained through your local affiliate.

The forms include:

■ Questionnaire for Parents

This form is to be completed by the student's parent(s) to assist school personnel in recognizing a student's seizure(s) and responding appropriately. It includes space for parents to provide details about the student's seizure patterns, medications and how they are to be administered, precautions that should be taken during physical education and recess and other issues. The parents' questionnaire should be updated annually or when any changes occur.

■ Student Interview Form

A student can provide valuable information about his or her epilepsy that is helpful in health management planning. This form is to be completed by the school nurse through an interview with the student. It should be updated every six months or when changes occur.

■ Seizure Information Sheet

This form was designed to provide classroom teachers with basic information about a student's seizures and medication. It should be signed by the school nurse and given to the teachers at the beginning of a school year, when a diagnosis is made, or when changes occur.

■ Teacher's Anecdotal Record

This form is to be completed by the student's teacher or other school personnel when reporting a seizure and/or medication side effects. It includes space for teachers to record a description of the seizure or behavior observed, what behavior immediately preceded and followed the seizure, what procedures were followed by the teacher/observer, and other details.

To download these forms, visit epilepsyfoundation.org/schoolforms. Also, check with your local Epilepsy Foundation affiliate to ask about help in developing your child's plan.

Seizure Management

Continued from page 8

The care of children with epilepsy is a mutual concern of parents, teachers, school administrators, nurses and the child's health care providers. By working together, they can help the child achieve success in school life.

Parents and Schools: Tips for Effective Communication

Effective communication between parents and schools is a two-way process, generating the understanding and support that professionals and parents all need to make decisions about a child's educational program.

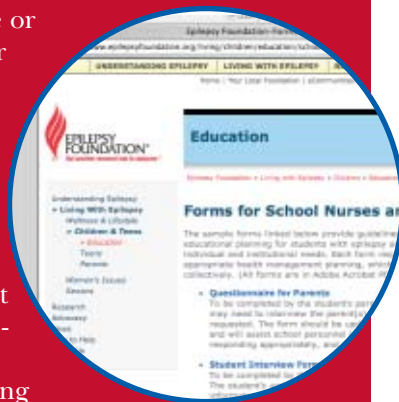
The PACER (Parent Advocacy Coalition for Educational Rights) Center, Inc. offers the following tips for parents to foster meaningful communication with schools:

- Make sure the focus stays on the child.
- Be prepared. Know in advance the important points to discuss and questions to ask. Write them down and check them off as they are asked.
- Listen. Listening will help you gather information about your child and help you understand other viewpoints.
- State your issues clearly. Communicate in an honest and direct manner.
- Ask questions. Asking questions can be an effective way of clarifying a point and keeping the line of communication open.
- Address comments and questions to the person who can best answer them.
- Restate your concerns if you are not heard the first time.
- Be confident. A parent never has to feel guilty or embarrassed asking questions or assertively pursuing the appropriate services for the child. It is your role and your right.
- Work together. Remember that neither you nor the professionals have all the answers. Work together as a team to find solutions. Everyone at the meeting has the same goal—to provide an appropriate educational program for the child.

The key to effective communication is preparation and willingness to be actively involved in planning the child's educational program.

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Eileen Frueh is a freelance writer and editor who has been covering health and education for 15 years.



Back to School on the Ketogenic Diet!

A sample letter to a school nurse and delicious recipes to help make your Keto Kid feel healthy and included.

Here is a sample letter you can adapt to submit to your school nurse to make your child's adherence to the ketogenic diet go as smoothly as possible:

Mrs. Povanda,

Bryce is on the ketogenic diet to control his seizures. We call it his "magic diet" since it makes his seizures "disappear." He has been on it for one year, and we are thankful that he has been seizure free for almost one year. The diet is very strict and limited in calories. I must calculate a recipe for every meal and then weigh it exactly on a gram scale. Bryce cannot have anything to eat or drink other than water (in addition to what I send). Even some drinks (and suntan lotions, toothpastes, etc.) that say sugar-free actually have sugar in them and can cause Bryce to have a seizure.

Unfortunately, the world we live in centers around food. This is one of the greatest challenges for Bryce and me. He does take ownership in his diet, and understands that if he cheats, he may have a seizure.

I am hopeful he'll do well in kindergarten with those issues. I have become very creative and can reproduce many kid-type foods like magic pizza, magic muffins, etc. If there will be some special occasion and I know ahead of time, I can usually make something for Bryce that will allow him to feel included.

Please feel free to tell his classmates, if needed, about his "magic diet." We are open and forthright about Bryce's seizures and his diet. This may be needed, if you notice other children offering Bryce their food, as an example.

Bryce really is doing well and is just like any other kid now. He needs help to scrape his bowls/plates when he's finished, because the diet is very exact and only works if he gets every last drop. That's about all the special attention he needs, however, and otherwise will be just one of the class.

Please feel free to call me at work or at home if you have any questions at any time.

Thank you! We look forward to a wonderful year!

Pizza with Pepperoni

Hunt's® tomato sauce: 10 grams
Planters® macadamia nuts, ground: 15 grams
Eggbeaters®: 19.3 grams
Hormel® beef pepperoni, sliced into eights: 2 grams (1 slice)
Heluva Good!® sharp cheddar cheese, grated: 12 grams
Canola oil (for crust): 7.5 grams
Canola oil (for sauce): 4.1 grams
Italian seasoning: small pinch

Crust: Mix eggbeaters, macadamia nuts and oil in a small mixing bowl with one mixer. Pour into nonstick skillet sprayed with Pam® and brown each side. Transfer onto a paper plate.

Topping: Mix oil, tomato sauce and small pinch of Italian seasoning in a small container (I use the plastic cups from Crystal Light® mix). Spread on pizza, trying to keep the oil from running off the sides. Top with grated cheese and pepperoni.

Hint: These can be mass produced ahead of time. I place a piece of wax paper on top of the finished pizza once it cools, then place 5-6 pizzas on top of one another in a larger freezer bag. Then at meal time, just remove from freezer, remove the wax paper and microwave for 30-60 seconds, or until cheese melts. This pizza looks very similar to a personal pan pizza. It can actually be cut into quarters and picked up to eat. Of course, the toppings can be varied as long as they are calculated into the meal. You can vary this recipe to include any pizza toppings that your child loves!

Quiche: Egg, Bacon and Cheese

Cream: 30 grams
Cheese: 10 grams
Bacon: 8 grams
Egg (XL): 19 grams
Butter: 15 grams

1. Crack the egg and mix the whites and yolk together with a whisk.
 2. In a small plastic bowl, measure out the egg, 10 grams of the cream, the cooked and crumbled bacon, the butter and the cheese and mix together with a whisk.
 3. Spray a nonstick, small individual quiche pan with Pam® and pour the mixture in.
 4. Bake at 350 degrees for 30-45 minutes, or until lightly brown on top.
- Hint:** This is an excellent meal to mass-prepare ahead of time and have on hand in the freezer for a quick breakfast or for travel.

Letter and recipes adapted from **KETO KID: HELPING YOUR CHILD SUCCEED ON THE KETOGENIC DIET** by Deborah Snyder, DO.
To order the book, go to page 22.

Comorbidities in Epilepsy

BY ALIYAH BARUCHIN, SPECIAL TO *EPILEPSYUSA*



An eight-year-old boy with epilepsy shows signs of learning problems and is having trouble at school. A 13-year-old girl with complex partial seizures complains of frequent abdominal pain. A 19-year-old whose seizures are well controlled by medication is diagnosed with depression.

As if dealing with the uncertainty and difficulty of epilepsy weren't enough, many children and teens with epilepsy also experience comorbidities—concurrent medical or psychological conditions of various kinds. Several different types of comorbidities exist in epilepsy. Cognitive comorbidities are learning problems that cause difficulty in school and can have lasting effects on educational and professional success. Psychiatric comorbidities are behavior and mood problems including Attention Deficit Disorder (ADD), depression, anxiety disorders and combinations of these conditions. There are also physical comorbidities, ranging from headaches to ulcers to chronic fatigue. And there are the psycho-social issues of having to deal with the stigma that surrounds epilepsy, the experience of having seizures in public, the difficulty of peer relationships and the discrimination that people with epilepsy often encounter in schools, jobs, sports and social settings.

Comorbidities create some of the most challenging issues for people with epilepsy and their families. “The packet of having cognitive, linguistic and psychiatric comorbidities makes this a very difficult illness to deal with, even if your seizures are controlled,” says Rochelle Caplan, M.D., professor and director of the Pediatric

Neuropsychiatry Program at UCLA. Researchers agree that rates of comorbidities in people with epilepsy are high; some studies show twice the rate of ADD as in the general population, and estimates are that as many as 50 percent of people with poorly controlled or other complicated epilepsies have psychiatric or behavioral comorbidities.

A number of intersecting variables affect who experiences which comorbidities, and how severe their impact is—and it can be extraordinarily difficult to tease these variables apart. Some are basic epilepsy factors: age of onset of seizures, frequency of seizures, duration of treatment, effects of medication and so on. “The earlier the onset of seizures, usually the more severe the seizure disorder, the more difficult to control the seizures are, and the more medications the kids are on,” says Dr. Caplan. “So these are all very confounding variables, all of which can contribute to behavior and cognition.”

Joan Austin, D.N.S., a researcher and professor at the Indiana University School of Nursing who has studied epilepsy comorbidities extensively, believes that seizure frequency is often key. “We do find that the more seizures they have, the more likely they are to have mental health problems,” she says. “And even in the type of seizures that are relatively benign, the kind they outgrow, we find that these children also have behavior problems.”

Yet Dr. Austin also feels that social variables can be enormously important. “We’ve found that families who are fairly organized in the way they approach life—you could almost say the environment’s pretty organized—that those children actually do better at school and behaviorally,” she says. “The family environment is very impor-

“The most recent research indicates that some cognitive and psychological comorbidities actually predate the onset of seizures.”

tant. In families who work together, have routines, and the child has rules to follow — not a rigid family, but an organized one — these children are better able to compensate for some of the cognitive deficits and do better than anticipated in school. And children who are in these families also do better behavior-wise; they don't have as many mental health problems.”

The recent “Curing Epilepsy 2007” conference held at the National Institutes of Health (NIH) in March highlighted the issue of comorbidities—a clear indication of

Continued on page 19

RECOGNIZING MOOD DISORDERS

Twelve Symptoms Suggestive of Depression

- Awakening in the middle of the night
- Change in appetite*
- Crying
- Difficulty concentrating*
- Fatigue*
- Lack of pleasure in activities
- Irritability
- Nightmares
- Thinking about death or suicide
- Trouble falling asleep
- Unexplained pain (headaches, stomach aches, shortness of breath)
- Unwillingness to get involved in activities

*These symptoms are also commonly caused by AEDs.

How Do I Know if I Have a Mood Disorder?

Many patients experience problems with mood. You may have a mood disorder if you feel anxious, depressed, irritable, or have feelings of fear, panic, or pain that are not easily explained by your seizures or other medical causes. Depression is the most common mood disorder experienced by people with epilepsy and may affect more than half of people with uncontrolled seizures. Some common symptoms of depression are sadness, loss of interest in or enjoyment of activities, excessive feelings of guilt, change in appetite and weight, trouble sleeping, and tiredness.

If you have mood symptoms that affect your usual activities, tell your doctor and consider seeing a mental health professional to be screened for depression. Sometimes, AEDs and brain dysfunction can cause similar symptoms and mimic depression. A health professional can help you sort out the cause of your feelings. The impact of mood disorders on your life is at least as important as your seizures and should receive the same attention to treatment. Do not hesitate to bring up this subject during an office visit.

How Might Mood Problems Affect Me?

You may notice that even though your seizures are controlled, or nearly so, you are having problems at work or getting along with your family or friends. Your mood may change for a few days before or after a seizure. You may be irritable or depressed without realizing it. You may get angry without reason. You may have physical symptoms such as a headache, chest or stomach pain. Your mood may be affected by the reaction of other people to your epilepsy.

Your family and friends may be good observers of your behavior. You may wish to ask them if there are any behavior problems that you are not aware of (see Twelve Symptoms Suggestive of Depression above). Mood disorders such as depression may also contribute to sexual problems.

How Might Mood Problems Affect My Child Who Has Epilepsy?

Children who are depressed may be angry, cranky or irritable and be difficult to control. They may complain of not being loved, spend more time crying, or have trouble sleeping or eating. If your child has any of these symptoms of mood disorders, discuss them with your doctor who can make a diagnosis and determine whether treatment is needed.

Can Mood Problems Lead to Alcohol or Drugs?

Sometimes people resort to using drugs or alcohol in order to feel better. They may not even realize they are doing this. If you find

you are drinking more alcohol than usual, or have started using recreational drugs, this may be a sign that you are suffering from a mood disorder related to your epilepsy. Ask your doctor to help you determine whether a mood disorder is responsible for your alcohol or drug use. Alcohol or drugs provide only temporary relief from mood problems and may lead to increased seizures. Alcohol and drugs may also cause mood problems or make your mood problems worse.

Can Mood Disorders Result in Suicide?

Sometimes people with feelings of depression think about suicide. Feelings of hopelessness or helplessness may seem so severe that they will never go away. Suicide is more common in people with epilepsy than the general population. Even if you don't think these thoughts are important, you should mention them to your doctor or other health care provider. If you or someone you know are thinking about suicide:

- Seek immediate medical or mental health attention. Call 911 if necessary.
- Do not let the person stay alone.
- Prevent the person from access to guns, medication that may be used for overdose, or other dangerous items.

Can Epilepsy Surgery Cause Mood Problems?

Although epilepsy surgery will hopefully eliminate your seizures, it is not uncommon to experience depression after surgery. Even if you did not have a mood disorder before surgery, you may have psychological distress afterwards. This appears to be related to the biological changes in your brain caused by the surgery. (An additional factor may be the adjustment you have to make to a life without seizures, which will be a big change.)

If the surgery cures your epilepsy, the mood disorder usually disappears. In the meantime, the mood problems may require treatment with medication and/or psychotherapy. It is important to continue to see your neurologist regularly after the epilepsy surgery, even if you are seizure free. In most cases, the long term benefits of successful epilepsy surgery outweigh the risk of developing a mood disorder after surgery. For most patients, mood symptoms improve after epilepsy surgery.

How Can My Doctor Tell if I Am Having Mood Problems?

It may be very difficult for your physician to notice that you are having mood problems because it is likely that you will only spend a few minutes in the office together. Mood problems can come and go, and you may feel fine the day that you see your doctor. You may also feel uncomfortable discussing your feelings and hesitate bringing up the issue, and your doctor may not ask. Consequently, it will help if you bring a member of your family or a friend to help discuss how you are feeling and behaving.

A calendar of your feelings, just like your seizure calendar, will also be useful. You can write down the days that you are depressed or irritable, or any times you became excessively angry. Your doctor will listen to you and may ask you to complete a questionnaire.

If there is evidence that you have significant mood problems, your doctor may suggest treatment, usually with antidepressant medication. Your doctor may also refer you to a mental health specialist, such as a psychologist or psychiatrist.

For more information on epilepsy and mood disorders visit:
www.epilepsyfoundation.org/programs/mood/

Depression in Children and Adolescents with Epilepsy

BY JAY SALPEKAR, M.D., SPECIAL TO *EPILEPSYUSA*

“Physicians now recognize that many types of depression result from a neurochemical disorder of the brain that goes beyond the stress of having a chronic disease, and prompt treatment is required.”



ne of the most common psychiatric comorbidities in pediatric epilepsy is mood disorder, specifically depression. Depression is present in approximately one quarter of children and adolescents with epilepsy, and is reported to be even more common in adults. Some

studies report depression as present in as many as 60 percent of adults with uncontrolled or other complicated forms of epilepsy. Given the frequency of depression in adults, it stands to reason that depression may be significantly underreported in children.

This is unfortunate, as depression can be extremely dangerous, and in some cases even more debilitating than seizures. Depression can even be life threatening as suicidal ideas and even attempts may be insidious and ultimately catastrophic. (Recent studies have shown that up to 20 percent of children with epilepsy have thought about suicide.) Depression can be subtle and difficult to identify. Many clinicians are not experienced in identifying depression. As mentioned in the article regarding psychiatric comorbidity (page 13), mental health care may be difficult to find for many families. Even epilepsy specialists who are well intentioned in addressing comorbid depression may be unsure on how to proceed.

Depression has historically been regarded as solely an artifact of the stress of chronic epilepsy or as a medication side effect. Many clinicians have an attitude that depression may be an expected development given the stress of having seizures and suffering the consequent drastic adjustments in lifestyle. However, modern understanding

of depression has shown it is a medical condition based upon brain dysfunction. That is, depression is not merely the result of psychological stress or social circumstances.

Physicians now recognize that many types of depression result from a neurochemical disorder of the brain that goes beyond the stress of having a chronic disease, and prompt treatment is required.

Children and adolescents who are depressed may not state that they feel sad or depressed. Children may be very irritable or have little tolerance for frustration. A child who is cranky or is significantly unsettled by even minor frustrations may be exhibiting depressive symptoms. What might be especially confusing for parents is that depressed children might not have the energy or desire to go out, but might actually appear to enjoy themselves once they are in a

social situation. Children or adolescents may isolate themselves from peers or reject overtures from others and can become hypersensitive to rejection. Often basic functions like regular appetite or sleep schedule may be impaired. Children may also describe a decrease in energy, a feeling of being tired all the time or complain of vague aches or pains like headaches or stomach upset.

Eventually a child might feel helpless regarding their condition or hopeless about the outlook for the future. At worst, a child may describe not wanting to be alive, or even contemplate suicide. One key feature of clinical depression is that these feelings are not consistent with reality. A child with depression might have negative thoughts and feelings regardless of the parental encouragement, the adolescent's apparent educational and social successes, and a good prognosis or stability of his or her epilepsy.

The most important thing for parents to do is to observe children for a significant change in their routine. Whereas any child may have bad days or even an extended period of feeling "down," depression is more sustained—symptoms are often present for a matter of weeks or more. A child who gradually rejects activities he usually enjoyed or has a significant change in functional level, may have depression. Parents should be bold enough to ask, even about difficult subjects such as suicide. A child will still have such thoughts whether anyone asks them or not, so it is important to face up to the possibility.

Asking a child about symptoms of depression can be challenging, and does require a sensitive approach. A line of questioning that gradually addresses depressive symptoms may be the best strategy. A parent or clinician can start with simple questions and progress based upon how the child responds. An example of such a line of progressive questions is listed below:

- Are you finding things that you like to do?
- How often do you feel happy?
- Do you think you are as happy as most of your friends?
- Do you often feel like nothing will turn out good for you?
- Do you feel like you don't even want to be alive?

A child or adolescent who describes symptoms of depression may require professional help, especially if they are having difficulty functioning at school or at other activities in which they are engaged. Many children will improve with talk therapy from a psychologist, social worker or a children's or adolescent's psychiatrist. Social

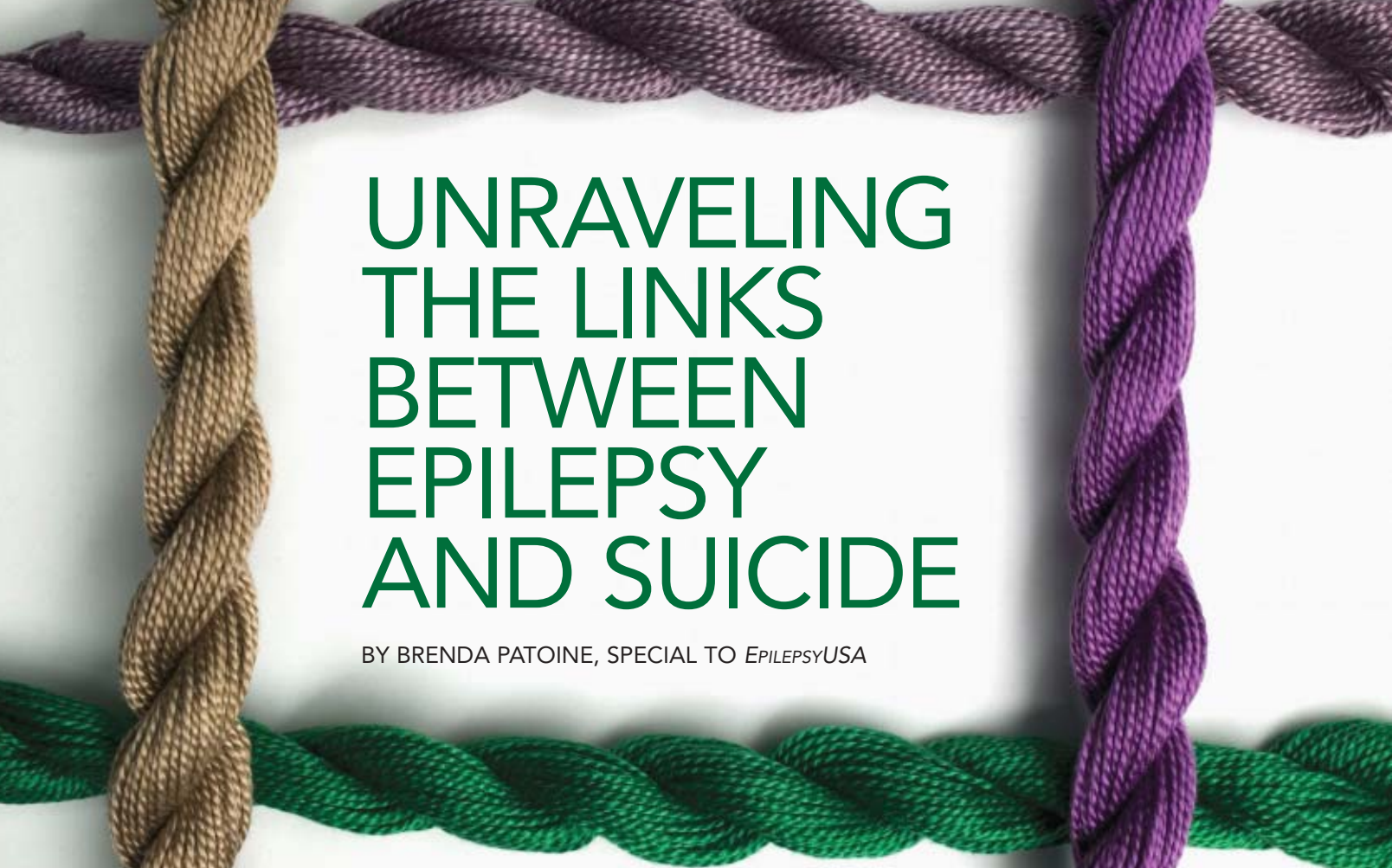


“ A child with depression may have negative thoughts and feelings despite parents' best efforts or the reality that the child actually has a good prognosis or adequate stability with his or her epilepsy. ”

groups are also important, especially if it is possible to facilitate interaction with other children with epilepsy. If these efforts are ineffective or if suicidal ideas are present, then serious consideration should be given to treatment with medication. Sophisticated studies regarding medication treatment for children and adolescents with depression are uncommon, but some do show significant improvement. The most common antidepressants used for children and adolescents are SSRIs (Serotonin Selective Reuptake Inhibitors). SSRIs are a mainstay of depression treatment and, with careful usage, can yield tremendous improvement. The approaches to treating depression in children with epilepsy are similar to those for children without epilepsy.

Depression is, unfortunately, common in children and adolescents with epilepsy. However, the good news is that depression is very effectively treated so long as it is identified. Identifying and treating depression may be one of the most important aspects of care for children and adolescents with epilepsy.

Dr. Salpekar is the director of outpatient services at the Center for Neuroscience and Behavioral Medicine, Children's National Medical Center, and the Assistant Professor of Psychiatry and Pediatrics at George Washington University School of Medicine. He serves on the Epilepsy Foundation's professional advisory board.



UNRAVELING THE LINKS BETWEEN EPILEPSY AND SUICIDE

BY BRENDA PATOINE, SPECIAL TO *EPILEPSYUSA*

A large Danish study provides strong new evidence for an increased risk of suicide among people with epilepsy, raising a cautionary flag for families and clinicians and adding new urgency to research aimed at understanding the reasons why.

Previous studies have uncovered an association between epilepsy and suicide, but their relatively small size has left many questions unanswered. The myriad confounding social and medical factors that influence suicidal tendencies complicate the issue greatly. In particular, it's been difficult to sort out the impact of co-occurring psychiatric disorders, especially depression.

Unraveling this puzzle was a primary goal of the current study, says its principle investigator, Jakob Christensen of Aarhus University Hospital in Denmark. "We know that psychiatric disease is associated with epilepsy. The main issue now is to separate psychiatric disease from epilepsy. For that you need a very large study."

Christensen and his collaborators identified more than 21,000 suicides in Denmark between 1981 and 1997, tracking and comparing incidence of epilepsy and a spectrum of psychiatric disorders with a control group of 423,000 Danish citizens that did not commit suicide. Data on demographic and socioeconomic status was also taken into account.

The results, published in *Lancet Neurology* and reported widely in the news media, showed that, overall, people with epilepsy had a three-fold higher risk of suicide compared to people with no history of epilepsy. Unsurprisingly, the risk was highest among people with a history of both psychiatric disease and epilepsy. Yet even after excluding those with psychiatric disease and adjusting for a number of other relevant social factors (e.g., marital and employment status, income, etc.), there was still a doubling of suicide risk among those with epilepsy.

When the investigators examined the timing of sui-

“Unsurprisingly, the risk was highest among people with a history of both psychiatric disease and epilepsy. Yet even after excluding those with psychiatric disease and adjusting for a number of other relevant social factors (e.g., marital and employment status, income, etc.), there was still a doubling of suicide risk among those with epilepsy.”

cide, they found a greatly increased risk during the first six months following a diagnosis of epilepsy. The risk waned considerably after one year post-diagnosis.

'Particularly Persuasive' Data

"This is a population-based study that is particularly persuasive and very well done," says Bruce Hermann, a neuropsychologist at the University of Wisconsin who serves as chairman of Epilepsy Foundation's professional advisory board. "I think it certainly adds significantly to previous literature suggesting that the rate of suicide is increased in people who have chronic epilepsy compared to the general population."

Columbia University epidemiologist Dale Hesdorffer, who is also a member of the Epilepsy Foundation's professional advisory board, notes that the Danish results are consistent with her own findings that a history of attempted suicide increases the risk for developing epilepsy. "[The Danish] findings about suicidality after the diagnosis of epilepsy are completely parallel to our findings about suicidality before the diagnosis of epilepsy," Hesdorffer says.

Hesdorffer's team studied a population of Icelandic children and adults newly diagnosed with unprovoked seizures, finding that a history of both major depression and attempted suicide independently increased the risk for developing seizures. This suggests that depression and attempted suicide may be due to different underlying imbalances in brain chemistry that are each somehow important to the development of epilepsy, she says.

"I think there is a potential for an underlying common vulnerability for both epilepsy and suicidality," Hesdorffer says. "The underlying problem is: What connects these disorders?"

Understanding Why

Research to understand the connections is in its infancy, but abnormalities in the brain neurotransmitter serotonin are one target of investigation. Serotonin dysfunction is strongly believed to underlie depression, and the most widely prescribed class of antidepressant drugs, so-called selective serotonin reuptake inhibitors (SSRI's), acts on this system. There is also considerable evidence from animal models of epilepsy to suggest that serotonergic dysfunction lowers the threshold for seizures.

A new study, published in *Biological Psychiatry* by Kenneth Alper and colleagues at New York University, lends support to the serotonin hypotheses. Capitalizing on Freedom of Information Act regulations that guarantee access to public records, the researchers obtained clinical trial data that had been submitted to the FDA as part of pharmaceutical companies' applications to market SSRI's for depression. Such trials, by their nature, include people with strictly defined major depression and exclude people with a history of seizures or any other neurological disease.

Since seizures are one of many adverse events that are tracked in drug trials, Alper's group was able to compare the number of seizures among people taking an SSRI to those in control groups, who took "dummy" placebo pills. They found that the people taking antidepressants had a

significantly lower incidence of seizures than those in the placebo group. Moreover, the placebo group's incidence of seizures was dramatically increased relative to the general population.

"This is the best human evidence we have that [seizure development] may have something to do with serotonin," says Hesdorffer. "The people in the placebo group presumably have the same underlying disturbances in brain chemistry as those receiving the SSRI, but they're not getting this extra boost of serotonin, and they're experiencing more seizures."

A Family Issue

Sorting out the many unanswered questions about the interplay of depression with epilepsy and suicide risk – and determining how best to intervene – will take time, given the complexities of the issue. In the meantime, the advice from experts is to be vigilant: learn about the signs of depression and suicide, and seek professional help if you notice any. Vigilance by family and friends is critical.

"Sometimes patients may get accustomed to being depressed, but their family members and loved ones are acutely aware of the depression," says Hermann. "It's now quite easy to check for the presence and severity of depression; it has a certain symptom complex and it responds to treatment. At its worst, it can lead to suicide, so it really needs to be taken seriously."

For more information about depression and epilepsy, please visit the Epilepsy Foundation's Web site: epilepsyfoundation.org.

Brenda Patoine is a freelance science writer and editor who has been covering neuroscience research for more than 15 years. She can be reached at bpatoine@aol.com.

Suicide Warning Signs

Seek help as soon as possible by contacting a mental health professional or by calling the National Suicide Prevention Lifeline at 1-800-273-TALK if you or someone you know exhibits any of the following signs:

- Threatening to hurt or kill oneself or talking about wanting to hurt or kill oneself
- Looking for ways to kill oneself by seeking access to firearms, pills, or other means
- Talking or writing about death, dying, or suicide when these actions are out of the ordinary for the person
- Feeling hopeless
- Feeling rage or uncontrolled anger or seeking revenge
- Acting reckless or engaging in risky activities, seemingly without thinking
- Feeling trapped, like there's no way out
- Increasing alcohol or drug use
- Withdrawing from friends, family, and society
- Feeling anxious, agitated, or unable to sleep or sleeping all the time
- Experiencing dramatic mood changes
- Seeing no reason for living or having no sense of purpose in life

SOURCE: U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES, SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION.

Comorbidities in Epilepsy

Continued from page 13

how central the topic has become in epilepsy research. And in the last several years, the work being done on comorbidities has experienced a paradigm shift that could have enormous consequences for epilepsy itself. It is a chicken-and-egg question. With comorbidities, “the norm has been to assume, to some degree, that a lot of these difficulties are attributable to recurrent seizures and medications and so on,” says Bruce Hermann, Ph.D., professor of neurology at the University of Wisconsin School of Medicine and Public Health, and chair of the Epilepsy Foundation’s Professional Advisory Board. But, he says, the most recent research indicates that some cognitive and psychological comorbidities actually predate the onset of seizures.

“People with epilepsy, even before they have epilepsy, are more likely to have a variety of things: depression, ADD, migraine, school problems. And these are all things that can be ascertained to have happened before the

“Research into comorbidities may hold enormous promise for epilepsy — if, for example, brain imaging can begin to identify underlying pathologies contributing both to epilepsy and to comorbid conditions.”

onset of seizures,” says Anne Berg, Ph.D., an epidemiologist at Northern Illinois University who studies epilepsy. Berg calls these essential comorbidities—conditions that may share an underlying brain pathology with epilepsy. “That’s why I think the NIH was interested in having comorbidities be highlighted this year,” she comments. “Increasingly there’s a sense with this essential comorbidity that it’s not that one condition is causing the other, but maybe they’re caused by the same thing. They’re reflective of the same brain disorder.”

It’s easy to gauge the centrality of comorbidities in the lives of people with epilepsy by the fact that adverse outcomes—psychological, behavioral, social and vocational problems—often persist even among people whose seizures have ended. “If you look at the cross-sectional studies of adults”—including those who no longer have seizures—“the rates of psychopathology are about 80 percent of patients,” says Dr. Caplan. “The quality of life of these patients is primarily affected by their behavioral problems and their vocational problems and all these other things, rather than by the presence of seizures.” Dr. Austin finds the same to be true of learning problems in children. “My research shows that if children with epilepsy are behind at school and then

“Comorbidities can complicate the struggle many families go through to find appropriate epilepsy care for their children.”

they stop having seizures, they don’t seem to catch up,” she says. “But we don’t really know why. And that’s one of the things we are studying—what would help these children do better at school.”

Dr. Berg also agrees. “There may be true ‘essential comorbidities,’” she says. “Even though they’re not having active seizures, even though they may be off medications, this is a group that still has tended to be a bit more depressed, have more learning disorders and other behavioral issues. So they’re a more vulnerable group.” But Berg believes that the right services might make the difference. Of adults who are still experiencing comorbidities from childhood epilepsy, she says, “These were people who maybe needed some extra help when they were younger, some extra understanding, some extra help in school, and didn’t get it.” By contrast, a group of patients that she currently studies “got lots of help. And maybe we’re going to see that this group actually does quite well, in the long run.”

Comorbidities can complicate the struggle many families go through to find appropriate epilepsy care for their children. “One of the big problems for families is identifying an appropriate physician. There are not a lot of epileptologists for children. They are hard to find; a family may not be in the right geographic area,” says Dr. Austin. “And mental health care is really hard to find. Then when parents of a child with epilepsy do find somebody, the psychiatrist or the psychologist may not know anything about epilepsy. And if they go to a doctor who only focuses on the seizures, then these families are struggling on their own with their child’s behavioral and achievement issues. Unfortunately, physicians rarely have a social worker or someone to help families identify resources in the community.”

“What I’d really like people who have pretty well-controlled epilepsy to realize is that, yeah, there’s some tough stuff, but just keep going. You’re great people. Live your life.”

ANNE BERG, Ph.D.

Dr. Caplan believes that children and teens with epilepsy often fail to get adequate mental health services partially because their parents don't know to ask for them. "The parents don't know what to request from their physicians, because they themselves are not getting the information that the psychiatric comorbidities are part and parcel of the disorder," she explains. "To get a psych referral, parents need to initiate that with the child's primary care physician and be quite assertive about it, so the parents often need to be educated. They actually know their kids have problems, but they might not be telling the physicians." Dr. Caplan also points to the dearth of appropriately trained psychiatrists and psychologists available to treat children and adolescents with epilepsy. Mental health professionals, she feels, should be a standard part of epilepsy care. "It's difficult dealing with epilepsy, just like it's difficult dealing with diabetes," she says. "But kids with diabetes get help; there are psychiatric and psychological professionals working on their treatment team. It should be the same thing for epilepsy."

Research into comorbidities may hold enormous promise for epilepsy — if, for example, brain imaging can begin to identify underlying pathologies contributing both to epilepsy and to comorbid conditions. For now, Dr. Caplan stresses prevention. "Early identification of possible risk factors for educational, language, and behavioral problems, and interventions—that I believe, can turn around the story," she says. "And it's never too early. This has to happen from the minute this illness is diagnosed—not just to focus on seizures. We've got to look at the whole picture." And for Dr. Berg, the important thing—barring the most severe difficulties that some people with epilepsy face—is to accept the fact of comorbidities, stay positive and keep moving forward. "All of us have things that are a little off; there's a range of variability in all of us. And recognizing what your limitations are just helps you exploit your strengths all the more," she says. "What I'd really like people who have pretty well-controlled epilepsy to realize is that, yeah, there's some tough stuff, but just keep going. You're great people. Live your life."

Aliyah Baruchin's health reporting has appeared in THE NEW YORK TIMES, ESSENCE, JOHNS HOPKINS HEALTH AFTER 50, and other publications. She can be reached at baruchin@comcast.net.

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COMMON MISTAKES WHEN CREATING A WILL



It's one thing to have a will, it's another to have a will that works well. In fact, there are some cases where it is probably better not to have a will at all than to have one that is defective or fails to accomplish your wishes. There are several ways you can make a mistake with your will. Here are four common mistakes:

Mistake #1: Do it yourself. State law dictates what is and what isn't legal in drafting and signing a will. A universal will form obtained at a stationery store or a homemade will is risky, to say the least. A good estate-planning attorney can ask the right questions to help you make sure you are covering all the bases in planning the disposition of your estate. To make sure things are done right, it is worth it to obtain professional help in preparing your will.

Mistake #2: Provide incorrect or unclear information. If you are making a bequest to a charity such as the Epilepsy Foundation, it is important to use the full legal name of the organization and address. This will avoid confusion and possible delays during probate. Our complete name and address is the Epilepsy Foundation (National Office) located at 8301 Professional Place, East, Landover, MD 20785. And be as clear as you can. If you are making a bequest for a specific purpose, spell out your wishes so the recipient will know exactly what you intended. Charitable organizations usually prefer unrestricted bequests, since this allows the board of trustees to apply the gift where it is needed most. Also, many organizations have well-considered policies directing the use of unrestricted estate gifts.

Mistake #3: Hide your will. A valid will that expresses your exact wishes is of no use if it is so well hidden no one can find it. In addition to storing your will in a safe place, make sure you tell the appropriate people where to find it.

Mistake #4: Overlook other transfer arrangements. A will provides only one way to transfer assets at death. If this document is not coordinated with other transfer arrangements, it may cause problems.

For example, what happens if your will provides for an equal division of your estate among family members and your life insurance policy earmarks the death benefit for the oldest child? The life insurance proceeds would go to the older child as well as a portion of the estate identified in your will. Therefore, one family member would receive far more than the others — probably not what you intended.

In an effort to avoid these common mistakes, please be sure to contact a lawyer prior to preparing a will. To order your two free brochures from the Epilepsy Foundation, *How to Make a Will that Works* and *How to Protect your Rights with a Will*, please contact Kay Arthur at 1-800-213-5821 or send an e-mail, rdev@efa.org.

letters to the editor

Dear Editor:

After reading Jimmy Breslin's *Long Island Newsday* column entitled "Chief Justice Didn't Bother to Talk About Seizure" on August 5, 2007, I am compelled to express my disapproval. Instead of maintaining respect for others by simply writing that Mr. Roberts had a seizure, Mr. Breslin used undignified and demeaning language to describe seizures by writing that Roberts "went down on his face" and was "hit by a blow that caused his sense to depart."

Mr. Breslin wrote that Dilantin and phenobarbital are the drugs generally taken for epilepsy that "could leave you at times as alert as wood" and "incapable of making a judgment on a parking ticket," which is not only inaccurate, but misleading. He wrote that epilepsy drugs "are acceptable for commoners," but not acceptable for someone with "a vote on young people dying in war, on a woman's body, on the health of millions."

The Epilepsy Foundation has worked tirelessly to counteract the myths and inaccuracies about seizures and epilepsy, which are perpetuated by people just like Mr. Breslin. Fortunately for all of us, the Epilepsy Foundation will continue to educate people worldwide so that others can recognize it's people like Mr. Breslin who are actually in the dark.

Sincerely,

Lisa Di Fiore-Ridolph
Smithtown, NY

Dear Editor:

My band had the honor of playing at the pre- and post-Walk rallies at the first National Walk for Epilepsy, on the National Mall in Washington, D.C., March 31, 2007. We were chosen to play after I submitted sound samples to the Epilepsy Foundation.

What the organizers did not know when they booked my band was that I have had epilepsy since I was in second grade. I am now 47 years old, and my seizures are finally almost totally controlled by Depakote. Because of medical advances I am able to swim in the deep end of the pool, I am legal to drive in all 50 states and I can front my band all night without having a seizure or an aura.

What an amazing day that was for me and for all my sisters and brothers in epilepsy in the crowd. That was the day I stepped out of the shadows—to see all the little children with epilepsy be able to be raised in a more enlightened world than I was. I was so proud and happy.

I'd like to thank all the members of my band for their loving and supportive understanding of my need to participate in this Walk: Andy Taylor, Ty Naquin and Ben Blake.

I would also like to thank Jeanette Montgomery of the Epilepsy Foundation for booking my band, and for the wonderful hugs she gave me that day. She also told me that everyone liked my band, THE COMMUTE, so much that we have been booked for the SECOND National Walk For Epilepsy on March 29, 2008!

Looking forward to seeing you all there on the Mall in Washington, D.C.!

Karie Naquin
Manager, Singer
THE COMMUTE
TheCommuteBand.com
Rockville, MD

We want to hear from you!

Give us your feedback. Share a personal story. Ask a question.

e-mail: editor@efa.org

mail: **EpilepsyUSA, 8301 Professional Place, Landover, MD 20785-2238**

All letters to *EpilepsyUSA* must include your full name and home address.

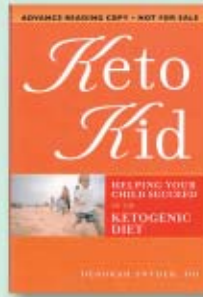
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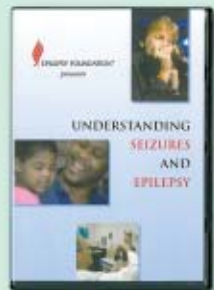
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Keto Kid: Helping Your Child Succeed on the Ketogenic Diet

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.



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Understanding Seizures and Epilepsy

This video (also available in DVD) gives an explanation of seizure disorders in everyday language. It uses footage of real seizures and explores what happens when someone has a seizure. Examples are given to show how others can recognize what is happening and

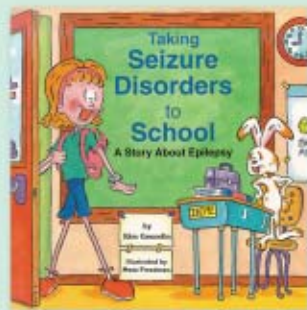
know what to do – and what not to do. In addition, people with epilepsy talk about how they would like friends, family and the public to treat them just like everyone else. Length: 11 minutes.

548USE VHS **\$14.95**
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Taking Seizure Disorders to School

By Kim Gosslin. Jay Jo Books, 1996.

This book for children is designed to dispel myths about epilepsy. It fills the need to explain seizures to classmates of children with epilepsy. An excellent learning resource for kids with epilepsy, their families and teachers; presented in a positive, upbeat and entertaining manner.



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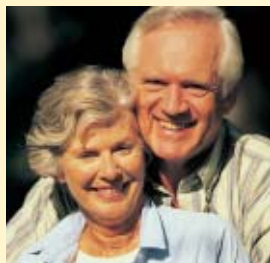
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The Candle of Light Society is our community of committed individuals and families who invest in transforming life for people with epilepsy. By remembering the Epilepsy Foundation in our wills and estate plans, we leverage gifts of cash, life insurance, 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.

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