

**STOP EVERYTHING.**

**YOUR HELP  
IS NEEDED.**

**STAY CALM.**

**SOMEONE IS HAVING A SEIZURE...**

by Deb Ilardi, RN, BSN, Clinical Editor

*“Come with me now. My friend is having a seizure in the cafeteria!” Ten years of emergency room nursing come flooding back as I race down the long corridor with this student. GO TO THE SCENE. THINK AS YOU’RE GOING. ACT WHEN YOU ARRIVE.*

*So we’re on our way. The student with me is a splendid young lady, a high school sophomore on a mission to get the school nurse. We don’t know each other but I recognize her role as the friend, who also knows the student’s actual location, and she seems to know that I am the person she wants at the scene. I ask her who the student is. The hallways are noisy and I don’t quite hear her clearly. We’re halfway there now. I turn and look directly at her as she replies again. I remember; this student has had seizures and I have spoken to her parents several times over the past month. As luck would also have it, I know the student from my previous assignment at an elementary school, know her siblings and parents, know her medications, and know her neurological history and recent diagnosis.*

*Things are going smoothly. Not everything is “textbook,” but the overall response is positive. My companion also mentions that the student’s boyfriend is with her and has seen her “seize” before; he knows what to do. He sent this girl to get me.*

*Now I formulate my plan. When I arrive in the cafeteria, there will be approximately 400 students in the room, and several staff members with walkie-talkies. I check my watch. Within 10 minutes the cafeteria will empty and refill with a new group of students. The hallways will be nearly impassible without assistance. So I need to assess the student, identify a key helper with access to a communication device and a runner for supplies. I know the other nurse in our school of 2,300 students will contact the family as soon as I get the name to her. Now, I can see her. She is still seizing. I am ready. The plan is in motion. One of the principals is there with his walkie-talkie, ready to do anything I ask. I send a student to tell the other nurse to call the parent, instead of tying up the walkie-talkie person. The extra minute will allow me to get the 911 system activated, since the seizure has already lasted for over five minutes. Her last seizure, at home, lasted a half hour and required hospitalization. Our school’s emergency response team is ready. I begin directing the responders.*

**I**t comes as no surprise to any of you that someday you will need to respond to an emergency. We talk about it, prepare for it and rehearse it. There may be a school term where emergencies are multiple, and yet years can go by without the need to call “911” or even splint a limb or stop bleeding for anyone with a serious injury. The age of the students you care for does not eliminate this possibility, for practicing school nurses know that emergencies can happen anywhere, and involve anyone. The fact that we are trained to respond in a sensible, logical, professional manner is one of the things lost in the misunderstandings of the role and importance of the school nurse. In fact, I recently read a newspaper article where a high-level officer of a national association representing schools declared, once again, that school health services were less important in the educational process than other educational support services. The proposed solution of hiring health aides was applauded in this same article. The public does not recognize that when a life-threatening emergency occurs, a health aide cannot respond at the same level of care as a registered nurse. In the interim between incident and arrival of emergency medical services, precious time to help is lost.

## Focusing on Epilepsy

I learned about epilepsy in college. As part of my course in pediatric nursing, many childhood chronic illnesses were covered in detail. Later in my career, as a public health nurse, I remember attending a seminar on epilepsy. And as an emergency room nurse I saw people having seizures. Ten years ago, as a school nurse, I attended a wonderful program presented by a representative of the Epilepsy Foundation for school staff. When you are called upon to apply what you know, to respond to that emergency, you realize how valuable the resources available to us are, and how much we need them to supplement the basics.

## What to Do During a Seizure

“Epilepsy is a common neurological condition, the general term used for more than 20 different types of seizure disorders produced by brief, temporary changes in the normal functioning of the brain’s electrical system. These brief malfunctions mean that more than the usual amount of electrical energy passes between cells. The sudden overload may stay in just one small area of the brain, or it may swamp the whole system. Of course you can’t see what’s happening inside a person’s brain, but you can see the unusual bodily movements, the effects on consciousness, and the changed behavior that the malfunctioning areas are producing. These changes are what we call seizures.” (2003, Epilepsy Foundation of America).

This explanation, from the EFA pamphlet “Seizure Recognition and First Aid,” provides a way of informing school staff without overwhelming them. Knowing that they may send for assistance from a school nurse will offer them an additional sense of relief should they encounter a student in class, at an event, or even in the hall who is “seizing.” But all adults responsible for students should have some basic knowledge of how to intervene while they are waiting for you to arrive. Without sophisticated equipment or expert first aid skills, they can still be helpful. You know this. They also need to be empowered. Preparation is the key to handling emergencies, not only for you but for others as well. I find this pamphlet, which includes a poster detailing different seizures and action to take, could be used by distributing it with an emergency care plan when a student is identified as having epilepsy. You could circle the appropriate type of seizure and the care anticipated. One of the most important aims of epilepsy education is in helping people understand that the behavior witnessed is outside the control of the individual experiencing it. This student, staff member, or parent deserves to be treated with respect, understanding and normality in daily life. And they need your help to make that happen, especially after having a seizure in a public arena such as the school.

## Emergency Care Planning

So much happens “behind the scenes.” Yet we miss an important opportunity to be recognized for our expertise if we don’t discuss the planning with someone in the school. For each of you it will be different, but I challenge you to find a way of letting the school staff know what goes into preparing for a smooth response to an event such as the one described above. Since teachable moments are rare, do this teaching while the event is still in the active consciousness of the

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school's administration. I was able to have it added to the monthly agenda for our Post-Response Team meeting.

Having a detailed nursing care plan for all students with special healthcare needs is ideal. Having an emergency care plan is essential. While no universal care plan will be perfect for each situation or each individual school, common elements will include the demographic data of name, age, address, parent/guardian contact numbers, hospital preference and other medical history, including current medications, other medical conditions, name of physician and a signed, legal release of information form. All this information needs to be accessible to someone other than you in an emergency.

*Back in the cafeteria I realize several things. The school's other nurse can easily find our emergency plan for the student and contact her parents or reach someone else who can find the parents if they are not at their emergency numbers. Momentarily it occurs to me that if I had been at my previous school, where I might have been the only school nurse, I would have wanted to delegate this responsibility. Time was of importance and I was busy with the student. I'm not sure I had ever prepared for that eventuality. I try to remember to make sure the emergency plan is easily accessible to someone else. I need to be available to verbally direct that person to the information on how to reach the parents or someone who will know where they are.*

The National Association of School Nurses' publication *S007 — Students with Seizures: A Manual for School Nurses* is an item worth considering as a resource manual for your office. Created as a collaborative effort between the Epilepsy Foundation® and NASN in 2001 (7" x 10", 156 pages), this manual will serve as a tool to use in planning as well as in meeting with school staff to show where you obtained reliable, organized materials for your planning. "As a student's advocate, case manager, and primary source for health education, the school nurse plays a pivotal role in ensuring that children with epilepsy are afforded a healthy and happy school experience that provides them every opportunity for learning. This manual is designed to assist in this effort." (NASN, 2001).

## Epilepsy Foundation Resources

"The Epilepsy Foundation is a national charitable organization, founded in 1968 as the Epilepsy Foundation of America. The only such organization wholly dedicated to the welfare of people with epilepsy, our mission is simple: to work for children and adults affected by seizures through research, education, advocacy and service." (EFA, 2003).

Most easily reached through their website, <http://www.epilepsyfoundation.org>, this organization backs up its statements with expedience and excellence. Materials are copyrighted, but available to anyone who requests them both online and by telephone at 1-800-332-1000. Some of the materials I received are "Teacher Tips About Seizures," "Questions & Answers About Seizure Disorders," "Kids & Seizures: Know The Hidden Signs" and "Children and Epilepsy: The Teacher's Role." By ordering one free copy of each publication you will be able to

decide for yourself which materials will be appropriate for your work setting, your parent population, and your own office reference library.

*I had prepared for the emergency care of this student and I was aware of the EFA established and recognized guidance that an ambulance be called if a seizure lasts more than five minutes. My next task was to talk to the administrator through the process of activating the 911 system.*

*What happened after that was a gratifying sequence of events carried out by other support staff. A path was cleared, students were moved aside, someone went to wait for the ambulance at the entrance and navigate the emergency personnel through the maze of halls and students to the scene. In my head I kept track of time, monitored the student's symptoms and protected her from harm. When she stopped seizing and stopped breathing, I also had the skills required to help her. And when I was able to turn her care over to the emergency responders, the other school nurse was at my side with a pen, a transfer sheet and the school health record so I could transcribe information to accompany her. Yet another friend of the student had located her older sister, who was prepared to accompany her to the hospital, and able to assume responsibility for her glasses and other personal items.*

While these things are not unique to students with epilepsy, they demonstrate how remarkably important it is to the whole event that we were able to execute them. The value of all the planning you do, and the review of that planning with the staff that might be involved, can be witnessed in just one event.

## Widely Recognized, Poorly Understood

In December 2003 a press release by the EFA highlighted a National Centers for Disease Control and Prevention study on the public knowledge of epilepsy, especially those who knew someone with the disorder. "In 2002, a national survey of 4,397 adults found that nearly one-third know someone with epilepsy...only about 40% are knowledgeable about the disorder, and only half of them agree with knowing what to do if a person around them has a seizure" (EFA, 2003). The study's authors recommend that information about epilepsy should be made available in community settings such as work places, schools, churches and stores to improve the general public's knowledge. "The Epilepsy Foundation has always placed a major focus on public education including current efforts to educate young people at an age when attitudes are just being formed," says Eric Hargis, president and CEO of the Epilepsy Foundation. He continued, "During November — National Epilepsy Awareness Month — the Foundation conducted a major campaign, Entitled to Respect, to engage youth aged 10 to 18 in acceptance of children with epilepsy at school and in the neighborhood." (see sidebar on page 23). Although this campaign began last year, knowledge of the type of support and programming available may be of interest to you in planning events for the next school term for your school. I encourage you to visit the EFA website frequently.

## Enlisting Congress in the Effort to Lighten Epilepsy's Impact on Individuals

At a Congressional briefing in December 2003, key speakers from public health, medical and consumer arenas addressed these recommendations: expand the CDC Epilepsy program, fund the epilepsy program at the Health Services and Resources Administration, identify programs within the Department of Health and Human Services that can respond to the recommendations of the Living Well with Epilepsy II Conference, and increase funding for the National Institutes of Health. If you have an interest in these goals, consider stepping forward and advocating for the EFA. Some of your students and families may follow your lead as a supporter.

## The Ongoing School Nurse Role

The public has become increasingly aware of the importance of protection-of-privacy laws. They may not realize what the phrase "need to know" means or how it is put into action, so parents, staff and administrators will need your understanding, patience and persistence when it comes to confidentiality issues. Discovering ways to introduce education about illnesses like epilepsy to school staff may require some of your best ingenuity. It may be advantageous to work directly with a student and family when it comes to sharing such information. The long-term benefits are obvious. The school nurse-as-advocate role was never more challenging or more rewarding.

*My student returned home from the hospital the night of her event, and returned to school the next day, after an appointment with her neurologist. With the excellent partnership between the parent, student, guidance counselor, and school nurse, over the next several days we were able to update her emergency care plan, notify the school staff, with whom she regularly interacts, and meet with her and a few close friends to refine our plans. Sharing information with the general staff and student population is the subject of ongoing discussion.*

### REFERENCES

Seizure Recognition and First Aid, 300SFA, 2003 Epilepsy Foundation of America, Inc. 4351 Garden City Drive, Landover, MD 20785-7223 — (800) 332-1000 Site Copyright ©2001, 2002, 2003.

*S007 - Students with Seizures: A Manual for School Nurses* (2nd ed.), Nancy Santilli

Epilepsy Foundation: Introduction, <http://www.epilepsyfoundation.org/aboutus/index.cfm>

Epilepsy Foundation: Widely Recognized but Poorly Understood, <http://www.epilepsyfoundation.org/epilepsyusa/cdcsurvey.cfm>

Epilepsy Foundation: Monica Discusses the Entitled to Respect Campaign, <http://www.epilepsyfoundation.org/epilepsyusa/monicainterviews.cfm>

### RESOURCES

The Epilepsy Foundation of America, Inc (1-800-332-1000), 301-459-3700, FAX 301-577-2684, [www.epilepsyfoundation.org](http://www.epilepsyfoundation.org), [postmaster@efa.org](mailto:postmaster@efa.org), National Office: 4351 Garden City Drive, Landover, MD 20785-7223

The National Association of School Nurses Bookstore, <http://www.nasn.org/bookstore.htm>

American Epilepsy Society, 342 North Main Street, West Hartford, CT 06117-2507, 860.586.7505, Executive Director, M. Suzanne C. Berry, MBA, CAE, Ext. 510, [sberry@aesnet.org](mailto:sberry@aesnet.org)

## Monica Discusses the Entitled to Respect Campaign

Update Posted: November 11, 2003



Grammy Award-winning entertainer Monica, this year's Epilepsy Month celebrity, and Epilepsy Foundation representatives discussed the Entitled to Respect campaign on American Urban Network and Radio One radio stations.

Monica and Denise Pease, a member of the Foundation's national board of directors, are participating in national radio interviews.

On Tuesday, November 4, the popular singer and Pease were interviewed on American Urban Network stations and on the Russ Parr Morning Show, where they were also joined by the foundation's president and CEO, Eric Hargis. The Russ Parr program is aired on Radio One network stations and on many other radio outlets across the country. The program broadcasts weekday mornings and is heard by more than 3.2 million listeners.

Pease discussed her experience as a woman with epilepsy and dispelled common misconceptions about the condition. Monica noted that her decision to become this year's celebrity spokesperson was mainly due to the age demographic, saying, "Teenagers with epilepsy come in constant contact with large groups of people." Since young people can be unwittingly cruel, due mainly to ignorance, Monica feels it is important to tell the public about epilepsy in lay terms.

Hargis presented information about the Get the WORD Out! contest, which invites young people to submit essays, raps, songs and other expressions of what respect means to them. The contest ended November 30. More information is available on the Entitled to Respect website and by calling (800) 332-1000.



This page from the Epilepsy Foundation website can be viewed at: <http://www.epilepsyfoundation.org/epilepsyusa/monicainterviews.cfm>