

# PediNeuroNEWS

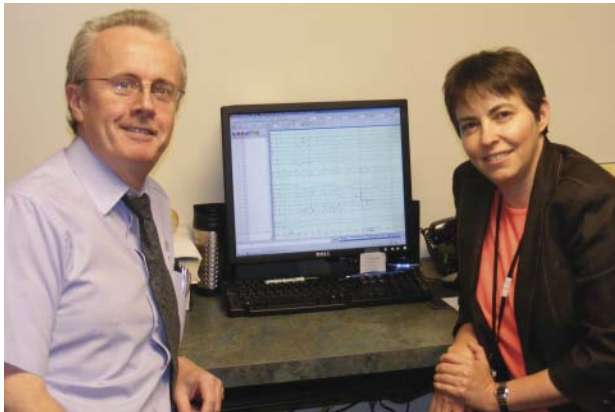


EXCEPTIONAL CARE. WITHOUT EXCEPTION.

Diagnosing and treating children with autism, epilepsy and other neurological disorders.

FALL 2008

## YOUNG ALGERIAN PATIENT FINDS INNOVATIVE EPILEPSY CARE AT BMC



Rinat Jonas, M.D. and Keith Davies, M.D. collaborated to perform electrocorticography on young patient.

Epilepsy specialists teamed with neurosurgeons to employ for the first time at BMC a technique that would allow them to test brain function during surgery. The procedure, electrocorticography, involves putting electrodes directly on the brain to measure electrical activity.

“We knew this was her only chance to receive cutting-edge surgical care for her epilepsy. I am very grateful to our compassionate epilepsy team, who responded so quickly to her need,” said Rinat Jonas, M.D.

The epilepsy specialists at Boston Medical Center were especially concerned about a young patient who had come to them through the emergency room. She was having multiple seizures every day and in dire need of surgery, but was in the United States on a tourist visa valid for only three months.

The little girl, just five years old, could no longer go to school and needed someone to watch her constantly. The seizures would come without warning at any time, while she was playing at the park, walking across the street or even just eating a snack.

Her father, a shop keeper from Algeria, was desperate to help her. He showed physicians at Boston Medical Center the images of his daughter’s brain that had been taken in his home country. There was a lesion on her right frontal lobe that had to be removed.

Planning for such a surgery could take months, as physicians must perform extensive tests to determine how much of the brain tissue surrounding the tumor should be removed to stop the seizures without compromising brain function. In this case, however, the clock was ticking. The little girl’s doctors knew they would have to be innovative in order to provide her with optimal care.

Epilepsy, a seizure disorder, is often a frightening condition for young patients and their families, and it has far reaching effects on their lives. Physicians at BMC work with these patients and their families to find the appropriate treatment to stop the seizures. About 70 percent will respond to drug therapy. The little girl from Algeria was among those who did not. For her, surgery was the best option.

BMC staff worked quickly to set up the surgery in time to give her a few weeks to recover before she needed to return home. Preparations involved getting the equipment and training necessary to do the electrocorticography. The procedure is done using regular EEG monitoring equipment, but requires special sterile electrodes and connections that can be placed directly on the brain.

Specialists monitoring the child during the surgery were able to determine that little more than the tumor needed to be removed. The entire operation went smoothly. Within days the child recovered. A short time later she was on her way back to Algeria in the arms of her relieved mother. She is now responding to medicine, which she will continue to take for about two years. ■

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Upon joining Boston Medical Center as chief of pediatric neurology four years ago, I was determined to build a strong division that reflected the organization’s commitment to *exceptional care, without exception.*

Inspired by this mission and by BMC’s reputation as a leader in neurological care—including the discovery of phenytoin and inventing the EEG—my colleagues and I have worked collaboratively and passionately to build a vibrant and comprehensive program in Pediatric Neurology.

Our dedication to clinical excellence and comprehensive care is reflected in the fact that we have grown from a division of one half-time clinical neurologist to a staff of seven full-time clinicians in three short years. In this and future newsletters, we highlight special areas of expertise, interest and skill of the dedicated individuals who comprise the Pediatric Neurology team.

In this issue, I invite you to learn more about our innovative work in epilepsy and seizure disorders. Also, we offer an overview of our programs and members of our staff who are dedicated to assuring that patients and families receive compassionate care, support and education.

We trust that these newsletters will provide a resource for the medical caretakers of children, underscore our mission and broaden the impact of the care provided by Pediatric Neurology at BMC.

Sincerely,

Karl Kuban, M.D.  
Division Chief

## EPILEPSY CARE – FOR THE WHOLE FAMILY



BMC offers one of the most advanced and most specialized programs of its kind.

The Boston Comprehensive Epilepsy Center was launched in 2005 at BMC to meet the medical and personal needs of children and adults with epilepsy, as well as the needs of their families. The pediatric epilepsy team is focused on improving the quality of care for all individuals with epilepsy, but is especially interested in studying measures that will improve the care of children and teens.

“Epilepsy is so much more than a seizure disorder. You can’t just treat the seizures, you need to address all of the many conditions, which commonly impact the lives of persons with epilepsy,” said Laurie Douglass, M.D., Director of Pediatric Epilepsy and EEG at Boston Medical Center. “We wanted this to be a family-oriented place where people of all ages could get care for a lifetime if needed.”

For decades, clinicians, researchers and lay persons have concentrated on eliminating or

limiting the frequency of seizures in the hope of improving the lives of persons with epilepsy. Seizure control is important. However, quality-of-life studies of children with epilepsy have shown that even with good seizure control and normal intelligence, they still have high rates of psychosocial problems extending into adulthood; they are less often employed, more likely to have substance abuse and are at higher risk of having mental health disturbances.<sup>1</sup> Further, when children with epilepsy and their parents were asked to list in order of importance their concerns about epilepsy, seizure control rated much lower in importance than the cognitive effects of epilepsy, medication side-effects, independence and social problems.<sup>2</sup> Persons with epilepsy also are at increased risk of obesity, sleep disorders and bone thinning.

“I am grateful to be working with such a great team of physicians, nurses, social workers, nutritionists and technologists. All are very

knowledgeable in the care for the medical, psychological, and educational needs of persons with epilepsy,” said Douglass.

Seizure specialists across the globe are studying ways to best address the complexity of needs for persons with epilepsy. “Here at Boston Medical Center, we believe that quality care must start with education. The unpredictable nature of seizures often leaves patients and families feeling anxious and vulnerable. Education, however, gives them back some sense of control, empowering them to make important life and medical decisions,” said Douglass. “In addition, research has shown that the outcome of children with epilepsy is related to how the parents cope with their child’s disorder.” The Family Support Assessment Clinic was designed to overcome this possible obstacle by helping families to develop healthy coping strategies early in the treatment process.

Patients and families who come to BMC for their care will have access to state-of-the-art diagnostic testing, as well as the latest medical, dietary and surgical therapies. Special attention is paid to the many medical, social and psychological issues that children with epilepsy may face.

To contact the Boston Comprehensive Epilepsy Center, Pediatric Epilepsy Program call 617-414-4501 or fax 617-414-4502.

1. Camfield P, Camfield C. *Epileptic syndromes in childhood: clinical features, outcomes, and treatment.* *Epilepsia* 2002; 43:27-32.

2. Arunkumar G, Wyllie E, Kotagal P, Ong HT, Gilliam F. *Parent- and patient-validated content for pediatric epilepsy quality-of-life assessment.* *Epilepsia* 2000;41:1474-1484. ■



Karl Kuban, M.D., and Paul Rosman, M.D., collaborate with pediatric neurology resident.

## PEDIATRIC NEUROLOGY RESIDENCY PROGRAM OFFERS TOP-NOTCH TEACHING ALONG WITH WORLD-CLASS CARE

The future of pediatric care depends on the training being given to physicians now. With this in mind, Boston Medical Center’s Division of Pediatric Neurology has developed a world-class residency program that augments the care offered to patients, while teaching new doctors.

Residents work alongside seasoned professionals who are committed to caring for their young patients and their families, while advancing the field of pediatric neurology through research.

“Trainees want to come to our program because of the high quality of care we provide to our patients, as well as the strong, fundamental training we offer,” said BMC’s Karl Kuban, M.D., Division Chief.

The Pediatric Neurology Residency Program provides trainees with a rich educational experience in a setting that offers extraordinary exposure to pediatric neurology. It includes a strong bedside component, as well as didactic teaching.

*Continued page 3*

## CLINIC HELPS FAMILIES COPE WITH ILLNESS



Parents often bemoan the fact that children do not come with an owner's manual. The challenges become even more difficult when a family must cope with dramatic changes, such as the diagnosis of a chronic or life-threatening disease. Questions often come more rapidly than answers as parents struggle to help their ill child and his or her siblings cope with the challenges such an illness brings.

Boston Medical Center created the Family Support Assessment Clinic to help parents find answers more quickly. Trained counselors are available to meet with families to better understand and handle their reactions.

"It can be a traumatic experience for everyone involved when a family learns that a child is suffering from a serious illness," said Mental Health Clinician Maria Trozzi. "We are here to help educate parents about what is an age-appropriate reaction for their children and to give them tools to guide

their children through a difficult time."

Children often show their feelings through their behavior. Sudden changes, such as acting out or withdrawing, may be a parent's first clue that something is wrong.

The clinic was established through the Division of Developmental and Behavioral Pediatrics as a resource to provide families with developmentally appropriate information. Staff members of the clinic work closely with specialists in the Division of Pediatric Neurology to help guide patients from initial diagnosis throughout treatment.

In some cases, a pediatric neurology specialist may call a counselor from the clinic to immediately help a family. Families can also get a referral to the clinic from their child's pediatrician.

"We can help parents find the right words to talk to their children and work through the range of emotions they may be feeling," Trozzi said. "Children are resilient if adults in their lives know how to help them cope with the challenges they face."

Counselors can also help families determine what other aid they may need, such as longer-term counseling. They also enable parents to gain support from extended family, the community and the schools, which can help alleviate the isolation that occurs with a traumatic loss or diagnosis of a chronic illness.

To contact the Family Support Assessment Clinic, please call 617-414-3668 or fax 617-414-7915. ■

## INTRODUCING



**Mental Health Clinician  
Maria Trozzi**

Children understand things differently than adults, and they can not always express their emotions with words. Mental Health Clinician Maria Trozzi helps parents understand the hidden messages their children are sending.

A nationally recognized expert in the field of family resilience and loss, she has flown around the world helping communities cope with traumatic experiences. More recently, she has brought these skills to the newly created Family Support Assessment Clinic at Boston Medical Center.

Through the center, she works with parents as they help their children to understand and cope with dramatic changes such as the diagnosis of a serious illness.

"My goal is to give parents the information they need and the tools they need to reach out to their children and guide them," she said.

Trozzi is author of *Talking with Children About Loss*, a book that helps parents understand their children's perspectives on grief and how to help them work through it. She is also director of the Good Grief Program at Boston Medical Center, which provides national training, crisis consultation and direct services to families and health care professionals. ■

### PEDIATRIC NEUROLOGY RESIDENCY PROGRAM continued from previous page.

The program benefits the staff members as well, challenging them to stay on the cutting edge.

"Often, the teacher is learning, too, while in the process of preparing and carrying out teaching mandates," Kuban said. "This process helps ensure that we are knowledgeable about and often part of the leading edge of what is occurring in our field."

The residents chosen for the program have done well academically. They are energized by their interactions with their teachers, colleagues, peers and students.

Program organizers seek trainees who are passionate about child neurology and inquisitive and excited about clinical medicine.

These highly qualified residents become an integral component to providing comprehensive care at Boston Medical Center.

"As mentors and teachers, we strive to inspire our residents and help them develop their interests based on their strengths," Kuban said. "Our rigorous training program is set in an upbeat and supportive atmosphere."

Residents learn how to think about clinical problems and how to practice pediatric neurology in a way that enables them to deliver the finest patient care.

Trainees have an opportunity to participate in well-developed programs in epilepsy, neurological disabilities related to preterm birth and cerebral palsy and neurobehavioral and neurodevelopmental disorders. ■

# NEW WEBSITE CONNECTS FAMILIES TO RESOURCES

LEARN ABOUT YOUR CHILD'S ILLNESS   NAVIGATE THE HEALTHCARE SYSTEM   PLAN YOUR CHILD'S EDUCATION   PAY FOR YOUR CHILD'S HEALTHCARE   CARE FOR YOUR FAMILY   RESEARCH   RESOURCES



Presented by Boston Medical Center  
**Special Kids Special Help**  
A RESOURCE FOR PARENTS

**Epilepsy**  
A person has epilepsy when he or she has had two or more seizures that were not provoked by things such as drugs or fever. There are numerous causes of seizures, including genetic conditions, infection, brain injury from trauma or stroke, and structural abnormalities of the brain. Commonly however, no cause can be identified.  
[Epilepsy in Depth >](#)

**Autism**  
Autism is a complex developmental disability that typically appears during the first three years of life. Autism impacts development in the areas of social interaction, communication skills, and behavior.  
[Autism in Depth >](#)

**Developmental Delay**  
A child's development is delayed if he or she is lagging behind other children of the same age in one or more of the following areas: speech and language, motor skills, intelligence, attention span, learning in school, behavior and emotional control, and social skills. Many such children catch up, but not all, and in some cases further evaluation is needed so the best possible treatments can be offered.  
[Developmental Delay in Depth >](#)

Special Kids Special Help is authored by the experts in the Division of Child Neurology and Developmental Pediatrics at Boston Medical Center.

Parents of children diagnosed with epilepsy, autism or developmental delay have an informative new resource to guide them through the challenges their families face.

They will find information about a wide range of topics from medical facts to educational options on the website, [www.SpecialKidsSpecialHelp.org](http://www.SpecialKidsSpecialHelp.org), developed by experts at the Division of Child Neurology and Developmental Pediatrics at Boston Medical Center.

“We recognize that parents are busy, and those who have children with special needs often can’t get to extra support meetings or to the library to do research,” said Laurie Douglass, M.D., director of Pediatric Epilepsy and EEG at Boston Medical Center. “This site helps them sort through the vast amount of information available.”

The website is a virtual social worker, providing critical insights as parents strive to learn more about their children’s illnesses, while making decisions about their care and other aspects of their lives.

“There is a lot of useful information available, but it can be difficult to filter out inaccurate information and quickly uncover what is most needed,” Douglass said.

On the Special Kids site, parents will find accurate articles, helpful tips and links to other useful resources that have been carefully screened. The site walks parents through navigating the health system, developing a therapeutic and educational plan for a child, paying for health care and generally supporting the family.

In addition, this site serves as a resource to other caretakers, teachers, daycare providers and physicians.

“We consider ourselves to be advocates for our young patients,” Douglass said. “Our goal is not just to treat the medical condition, but also to improve the child’s life and the life of the family.”

Special Kids Special Help was launched through a grant from the Red Sox Foundation. BMC plans to expand the site and translate information into other languages. Visit the website at [www.SpecialKidsSpecialHelp.org](http://www.SpecialKidsSpecialHelp.org). ■



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Boston Medical Center  
One Boston Medical Center Place, Boston, MA 02118-2393  
617.638.8000 | [www.bmc.org](http://www.bmc.org)



**Boston University** School of Medicine

Boston Medical Center is the primary teaching affiliate of the Boston University School of Medicine.

Boston Medical Center is a private, not-for-profit, 625-bed licensed academic medical center located in Boston’s historic South End. The hospital is the primary teaching affiliate for Boston University School of Medicine. Emphasizing community-based care, Boston Medical Center—with its mission to provide consistently accessible health services to all—is the largest safety-net hospital in New England.

Boston Medical Center provides a full spectrum of pediatric and adult care services, from primary to family medicine to advanced specialty care. Boston Medical also has the largest 24-hour Level 1 trauma center in New England.