

**GREETINGS FROM OUR  
EDITOR-IN-CHIEF**



What better way to kickoff the month of May than with an early celebration? This month, Epilepsy.com honors fathers everywhere —the ones who carry us on their shoulders and teach us what it means to catch our first ball, fly our first kite , and ride our first two-wheeler without training wheels. In addition, we also gear up for the AES mid-year meeting in June, where healthcare professionals on the front lines of epilepsy care will meet to explore the latest research in the diagnosis and treatment of epilepsy. From this meeting we will be bringing you the most current research and hot topics. Speaking of Hot...in this issue we bring you news from the FDA, the latest research from the American Academy of Neurology Meeting, and an in-depth article exploring the newest technology in Implantable Devices.

**Steven C. Schachter, MD**  
Editor-in-Chief

**NEWS YOU CAN USE**

**FDA ADVANCES FEDERAL E-HEALTH EFFORT**



The U.S. Food and Drug Administration (FDA) recently

announced its federal effort to create electronic health records for Americans within the next decade by making it easier to share drug information electronically. FDA is moving the effort forward by adopting the Systematized Nomenclature of Medicine (SNOMED) as the standard computerized medical vocabulary system to be used to electronically code important terms in the Highlights section of prescription drug labeling. This move will allow healthcare professionals nationwide electronically to access and share critical health and treatment information more easily and efficiently.

To read more go to: [www.fda.gov/bbs/topics/NEWS/2006/NEW01361.html](http://www.fda.gov/bbs/topics/NEWS/2006/NEW01361.html)

**THE SCOOP FROM THE 58TH AMERICAN  
ACADEMY OF NEUROLOGY MEETING**

**LONG-TERM EFFECTS OF THE KETOGENIC DIET**

Seizure control with the ketogenic diet may come at a price, according to a retrospective review presented by Darcy Groesbeck at this year's 58th annual meeting of the American Academy of Neurology.

Groesbeck and her colleagues Renee Bluml, M.S., R.D., L.D., a nutritionist, and Eric Kossoff, M.D., a pediatric neurologist, all from Johns Hopkins Medical Institutions, Baltimore, M.D., reviewed the charts

**MARK YOUR CALENDAR**

Upcoming epilepsy-related conferences, symposiums and events include:

**June 11-June 16, 2006**  
**10th International Child Neurology Congress**  
Montreal, Canada

**June 15-June 17, 2006**  
**1st Annual American Epilepsy Society Mid-Year Meeting**

of 28 children (15 boys, 13 girls) who had remained on the ketogenic diet for 6-12 years (mean 7.8) for the treatment of epilepsy. Three (11%) became seizure free, 21 (75%) were greater than 90% improved, and 4 (14%) had 50-90% improvement in seizure frequency. In addition, 9 (33%) were able to discontinue all antiepileptic drugs. Overall, medications decreased from an average of 2.1 to 1.3 per child ( $p=0.003$ ).

"If you put kids on the diet, efficacy can be maintained for a long time" observed Groesbeck. She also noted that, "The diet may require a lot of tweaking in the early stages to make it work."

To read more go to: [http://professionals.epilepsy.com/page/ar\\_1146740857.html](http://professionals.epilepsy.com/page/ar_1146740857.html)

## **IMPLANTABLE DEVICES COULD STOP SEIZURES IN THEIR TRACKS**

Antiepileptic drugs have provided tremendous relief for many people with epilepsy. But around one-third of patients with epilepsy continue to have seizures despite medication, according to Brian Litt, M.D., an associate professor of neurology and bioengineering at the University of Pennsylvania, and a member of the Epilepsy Foundation's professional advisory board.

Epilepsy surgery can cure another 7 to 8 percent of patients, but many patients cannot undergo the procedure because their seizures originate at multiple seizure focuses, or because a focus is in or close to a critical region of the brain where surgical removal carries a high risk of impairing normal function.

Currently, such patients have little recourse. One implantable treatment device is FDA approved: the vagus nerve stimulator (VNS) – which is inserted under the skin near the collarbone, where it periodically applies mild electrical stimulation to the vagus nerve that connects parts of the upper body to the brain, which can lead to a decrease in the number and severity of seizures. Although the device is safe, it isn't universally successful. About one-third of patients experience a major reduction in the number of seizures, another one-third experience moderate improvement, and the final third experience no change or even an increase in seizures.

Today, however, advances in computer software and engineering have produced a new generation of implantable devices that may hold greater promise, though proponents insist it's too early to be sure they are a significant improvement over the VNS. The new devices take a more direct approach. They provide electrical stimulation to the seizure focus. 'Open loop' devices provide constant or intermittent stimulation, similar to the VNS.

To read more go to: [http://professionals.epilepsy.com/page/ar\\_1146575959.html](http://professionals.epilepsy.com/page/ar_1146575959.html)

## **DO NO HARM**

I had departed for San Francisco for 5 days of vacation. Leaving one little girl behind in the hospital had made my departure much more difficult. That little girl was my patient Angela, a lovely 6-year-old in whom epilepsy had been diagnosed a year and a half ago. Because all the medication options had been exhausted and her seizures were becoming more frequent and severe, Angela had undergone epilepsy surgery at our center. The neurosurgeon had performed a new procedure: transections of areas that could not be removed safely (because it would have caused permanent weakness).

Oak Brook, Illinois

**July 02-July 06, 2006**

**7th European Congress on Epileptology**

Helsinki, Finland

**July 13-July 16, 2006**

**Tuberous Sclerosis Alliance National Conference**

Bloomington, IL

**July 26-July 29, 2006**

**International Neuropsychological Society Mid-Year Meeting**

Zurich, Switzerland

**July 28-August 08, 2006**

**5th International Course on Epilepsy: Surgically Remediable Epilepsies**

Venice International University, San Servolo, Venice, Italy

## **STAY TUNED**

- Clinical Practice Tools:
  - Drug Interaction Sheets for You
  - Downloadable AED Sheets for Your Patients
- Personal stories from healthcare professionals treating patients with epilepsy
- News from the AES Mid-yr meeting

To read more go to: [http://professionals.epilepsy.com/page/ps\\_1098900431.html](http://professionals.epilepsy.com/page/ps_1098900431.html)

## ABOUT THE EPILEPSY THERAPY DEVELOPMENT PROJECT



The Epilepsy Therapy Development Project is a 501 (c) (3) not-for-profit corporation. The organization was founded by three fathers of young children with epilepsy, along with their children's doctor, a leading researcher and clinician in the field of epilepsy. Our mission is to advance new treatments

for people living with epilepsy.

The Epilepsy Therapy Development Project is also the sponsor of [epilepsy.com](http://epilepsy.com) and [epilepsy.com/professionals](http://epilepsy.com/professionals). We are working to build [epilepsy.com/professionals](http://epilepsy.com/professionals) into the most comprehensive source of information, tools and interchange available online for patients, practicing neurologists, and for the research and therapy development community.

To learn more about our programs, please visit [The Epilepsy Therapy Development Project](http://TheEpilepsyTherapyDevelopmentProject). You can help us reach our goals and continue support of [epilepsy.com](http://epilepsy.com) with your [donations](#).

## WE NEED YOUR HELP

[Epilepsy.com/professionals](http://Epilepsy.com/professionals) is building a resource section of useful practice tools for the professional community. If you have a form, patient information sheet, or other useful handout for patients with epilepsy, and you'd like to share it with thousands of your colleagues by adding it to the resource section of [epilepsy.com/professionals](http://epilepsy.com/professionals), please email it to [jenna@epilepsytdp.org](mailto:jenna@epilepsytdp.org) or fax it to (703) 437-4288, and we'll take it from there. Thanks!!

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