THE JOURNEY: A Mother and Son Face Epilepsy Together

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From The President

We hear from people with epilepsy and their families daily about the challenges they face. One major challenge is that many anti-epileptic medications have just gone off patent. The 90’s was the Decade of the Brain; many new medications were developed and came on the market. When a pharmaceutical company develops a new drug, they are given 20 years of exclusive rights to sell that drug. However, the 20 years begins when the drug is tested, and it might take eight years to get it approved by the FDA.

The good news is that when a drug goes off patent, generic manufacturers can start making the drug. This is good for many people because the generics are cheaper than the brand name. In these hard times, having a generic alternative can really save money, and many people do very well with the generic version. The bad news is that some people with epilepsy find that they have reactions to different generic formulations.

Andrew is a high school student who lives in Traverse City. He had been on a brand name drug for over a year and it was controlling his seizures. After the generic was approved for this drug, his mother was told by the pharmacy that the insurance company would not cover the name brand anymore, so they switched to the generic version. They did not anticipate the problems they would face. Andrew began to experience major mood swings and started having three to five seizures a week. He had to miss school, and started seeing the doctor once a week. His medication dosage was doubled, but even this did not help him.

Finally, Andrew, his family, and his physician had had enough, and they decided to consult with the insurance company. They were met with resistance when they requested that the insurance pay for the drug that had worked so well for him. Finally, Andrew’s mother and doctor were able to find a way for him to take the original brand name drug, but it still took several weeks for the seizures and side effects to subside. His mother questions how much money was actually saved during this process.

We are also getting reports from people who are willing to pay an additional amount of money to stay on their drug. However, many people are not given the opportunity to choose, and they find that their medication has been switched by the pharmacy without notice. That happened recently to one woman who lives in White Lake. She is pregnant with her first child. Her epilepsy is currently well controlled, and she does not want to risk making a change at this important time in her life. Her mail order pharmacy automatically switched her epilepsy medication because the drug had come off patent since she first filled it. When her doctor ordered a new prescription that read “dispense as written” to a local pharmacy, they switched it, too, telling her she had no choice.

However, change appears to be imminent. Beginning on July 1st, the FDA will require the generic manufacturers to submit more information to get approval, including any studies that do not show bioequivalence. Currently applicants must submit study data showing bioequivalence within FDA’s range. The FDA is amending the regulation because they believe that data from additional bioequivalence studies may be important in determining whether the proposed formulation is bioequivalent, and to increase understanding of how changes in components, composition, and methods of manufacture may affect product formulation performance.

Whether one should or should not switch formulations of a drug is something that must be discussed with a doctor. Not everyone has an adverse effect. We would advise, however, that anyone who is making a switch should not put themselves in a risky situation (like behind the wheel of a car) for a period of time.

If you are interested in learning more or voicing your opinion on this subject, I invite you to join us at our 11th Annual Legislative Recognition Breakfast on May 5. You will have the opportunity to speak with the legislature and share your concerns about medication switching.
THE JOURNEY: A Mother and Son Face Epilepsy Together

Darcy Pugsley and her son, Jimmy, have become familiar with the dangers and pain that may be associated with epilepsy. Jimmy has been having seizures for the majority of his life, and Darcy has made it her mission to nurture her son so that he can live a healthy and enjoyable life.

When Darcy gave birth to Jimmy on May 2, 1992, she felt like the luckiest woman in the world. Everything was going as planned. But reality soon set in when the doctors realized that Jimmy was not breathing on his own. He was transported to the University of Michigan Hospital where he stayed for 2 months. Darcy and her husband, James, visited Jimmy each day, praying that they would be able to take him home. Finally, the day came when Jimmy could breathe without assistance and go home. “(Holding our son) was the most wonderful feeling,” Darcy recalls.

It was a hot summer day in 1995 when Jimmy had his first seizure. Darcy was outside with her son when he began shaking uncontrollably. Darcy took him inside and cooled him off, and the seizing stopped. Darcy tried to forget the traumatic event but was unable to do so, as Jimmy had another seizure soon after. This time, Jimmy was rushed to the hospital where a pediatrician examined Jimmy and suggested that he see a neurologist. But soon, Jimmy’s symptoms disappeared and Darcy and James decided not to see the specialist.

Jimmy did not experience any seizures for the next eight years, and it seemed as if the seizures had stopped for good. One evening, when Jimmy was lying in bed, he had a violent seizure that lasted about four minutes. Darcy and James called the paramedics and were disappointed to discover that even they did not know what had happened to Jimmy. It was now apparent that Jimmy needed to see a neurologist. After running several tests, the neurologist concluded that Jimmy had suffered a grand mal seizure. The diagnosis was epilepsy.

Jimmy began taking medications to control his seizures, and they seemed to be working. Although Jimmy’s seizure activity was unstable up to 2007, the Pugsley family is happy to report that Jimmy has been seizure-free since March of 2008.

For the past four years, Jimmy has attended the Epilepsy Foundation of Michigan’s Camp Discovery. The best part is, Jimmy enjoys spending time with other kids affected by epilepsy, just like him. He was also awarded the opportunity to be an ambassador for the Foundation as a 2009 Terrific Teen, where he will act as a role model for other teenagers who are living with epilepsy.

Sadly, in 2007, Jimmy’s father passed away. Darcy and her son are now left to battle epilepsy without James. But they are not alone. “I want to thank the Epilepsy Foundation (of Michigan) for their support,” says Darcy. “My son and I don’t feel so alone anymore.” They continue to work as a team in order to overcome the struggles that epilepsy has presented. “I finally realized what my purpose in life is,” Darcy proclaims. “It’s to take care of my son.”
Epilepsy Advocacy: Pressing and Important Issues

There are several pending legislations in Lansing that, if passed, could affect the quality of life for people in Michigan who are living with epilepsy. We encourage you to read about the following bills and take action by contacting your State Senator or Representative. Together, we can make a difference.

**Patient Safety Legislation**

*House Bill 4408, Senate Bill 318*

The passing of these bills would require pharmacists to consult with a physician and patient before switching antiepileptic medications from brand-name to generic, generic to generic, or generic to brand-name.

While switching medications may have no affect on some people with epilepsy, others have reported to the Foundation breakthrough seizures or side effects. Antiepileptic medications are very precise and small variations in drugs can cause dangerous effects. Switching medications without a physician’s consent and monitoring can result in breakthrough seizures even in people who have been seizure-free for years. The Foundation is interested in keeping people on the medication that controls their seizures, whether that medication is brand-name or generic.

**Physician Liability and Driver’s Licensing**

*Senate Bill 110 & 111*

These bills would limit the liability of physicians who voluntarily report on someone with epilepsy to the Secretary of State. The Epilepsy Foundation believes that physicians should not be required to report their patients’ epilepsy to protect the doctor-patient relationship, as this causes patients to become less than honest with their physicians, thus not getting the kind of treatment required to control their epilepsy. Currently, physicians do not release information to the state because it is a breach of the patient confidentially agreement and they can be sued for a potential automobile accident caused by their patients. Because they do not have protection from lawsuits, physicians have not been willing to provide medical information on a patient who appeals the 6 month wait for a driver’s license. The consequence is that people with epilepsy who are able to operate a motor vehicle safely are sometimes unable to obtain a license.

**Mandatory Motorcycle Helmet Use**

*House Bill 4028 & 4138*

House Bill 4028, if passed, will rescind the current mandatory motorcycle helmet law for adults over the age of 19. The Foundation does not support the passing of this bill, as it would be dangerous for those currently living with epilepsy and could potentially produce even more cases of epilepsy in the state of Michigan.
About 25 percent of all epilepsy cases are attributed to some kind of head injury, and motor vehicle accidents are the leading cause of head injuries. Studies have shown that, if given the choice, many motorcycle riders will choose not to wear helmets, thus putting them in danger. Safety devices, such as helmets, can aid in the prevention of epilepsy.

A second bill (House Bill 4138) was introduced that, if passed, would require those who choose not to wear a helmet to purchase a personal protection insurance policy.

*Please join the Epilepsy Foundation of Michigan in advocating for these causes at the 11th Annual Legislative Recognition Breakfast and Michigan Kids Speak Up! on May 5, 2009.*

For more information, or to register, please contact Pam Bird at (800) 377-6226, option 1, ext. 204, or visit our website at www.epilepsymichigan.org.

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**Help Us Better Serve You**

If you are an adult with epilepsy, please take the time to fill out this Epilepsy Self-Management Checklist for adults. Upon completion, please contact a representative at the Epilepsy Foundation of Michigan to further discuss your answers. Completing this checklist will allow the Foundation to better serve your needs. If you are a parent of a child with epilepsy, we have a checklist for you, too. Please contact the Foundation for more information.

Check the box for statements that are true for you:

___ The goal of epilepsy treatment is “no seizures, no side effects.”
   My doctor and I are working together to reach this goal.
___ I know what type of seizures I have and what type of epilepsy I have.
___ I know about the four major treatments for epilepsy.
___ I know the risks of living with epilepsy and what I can do to stay healthy and safe.
___ I’m sure that others will know what to do if I have a seizure.
___ I know all the things I can do to improve my seizure control and overall health, and I’m trying to do them.
___ I’m not bothered by any effects of epilepsy on memory or thinking.
___ I know about the link between epilepsy and depression, symptoms of depression, and treatments for depression.
___ I have chances to get together with friends who accept me for who I am.
___ I have people I can talk to about epilepsy.

**FOR WOMEN ONLY**

I understand...

___ How female hormones can affect seizures.
___ How drugs for epilepsy can affect bone health, birth control pills, and pregnancy.

*If you are in the West Michigan area, please call Mia Cooke at (616) 454-7979.
For all other locations, please call (800) 377-6226, option 2.*
“Ask the Staff”

I AM AN INDIVIDUAL WHO IS TOUCHED BY EPILEPSY AND AM LOOKING FOR A WAY TO GET INVOLVED WITH THE FOUNDATION. I’D LIKE TO VOLUNTEER BUT I’M NOT SURE WHERE TO BEGIN. CAN YOU GIVE ME ANY SUGGESTIONS?

We’re always looking for new volunteers here at the Epilepsy Foundation of Michigan. In these challenging economic times, volunteers are more important than ever, and we have a wide array of volunteer opportunities available. Some of these opportunities include preparing mailings, making phone calls, data entry projects, assisting at fundraising events, public speaking, being a camp counselor, and much more! We even have a new campaign called “Spread the Word,” in which volunteers will be spreading awareness about epilepsy by sharing their stories, taking information to physicians and local media outlets, and helping to educate the public about seizures and the Epilepsy Foundation of Michigan.

To learn more about our many volunteer opportunities, please visit us on the web at www.epilepsymichigan.org, or call us at (800) 377-6226, option 1, ext. 204.

I’M A PERSON WITH EPILEPSY AND I’M WONDERING IF THERE ARE ANY NEW ANTIEPILEPTIC MEDICATIONS AVAILABLE.

Three new antiepileptic medications are either available or will soon be available in the United States. BANZEL™ (rufinamide) is a new therapy now FDA-approved for the adjunctive treatment of seizures associated with Lennox-Gastaut syndrome in children 4 years and older and adults. BANZEL, produced by Eisai, Inc., is now available for prescription. The FDA has also recently approved UCB’s Vimpat® (lacosamide) for use as an add-on therapy for the treatment of partial-onset seizures in people with epilepsy who are 17 years and older. Vimpat is expected to be available for prescription in early 2009. In addition, an FDA Advisory Committee voted to recommend approval of Ovation Pharmaceutical’s Sabril (vigabatrin) as a treatment for infantile spasms (IS) and for intractable complex partial seizures. If, as expected, the drug is approved, it will become available in the United States (the drug has been available in Canada for several years). Please contact the Epilepsy Foundation of Michigan for more information on the safety, efficacy, and availability of these medications.

Do you have a question you’d like answered? If so, please give us a call at (800) 377-6226, option 1, ext. 218, or email skahn@epilepsymichigan.org.
**EPILEPSY FOUNDATION OF MICHIGAN: CALENDAR OF EVENTS**

**APRIL**
- April 2  Southeast MI Meet & Greet Open House
- April 23  West MI Meet & Greet Open House

**MAY**
- May 5  Legislative Breakfast & Michigan Kids Speak Up!
- May 16  Summer Stroll for Epilepsy™ (Midland)
- TBD  Southeast MI EEG-Detroit Tigers Baseball Game

**JUNE**
- June 6  Summer Stroll for Epilepsy™ (Kalamazoo County)
- June 13  Summer Stroll for Epilepsy™ (Metro Detroit)
- June 20  Summer Stroll for Epilepsy™ (Grand Rapids)
- June 22  4th Annual Paul Neu Memorial Golf Classic
- June 28-July 2  Camp Discovery

**JULY**
- July 18  Southeast MI EEG-Bocce Ball & Picnic

**AUGUST**
- August 19  Southeast MI Meet & Greet Open House

**SEPTEMBER**
- September 5  West MI EEG- White Caps Baseball Game
- September 18  Epilepsy Today Conference (Metro Detroit)
- September 19  Southeast MI EEG-Bowling & Pizza Party
- September 24  West MI Flame of Hope

**OCTOBER**
- October 1  Southeast MI Flame of Hope
- October 22  West MI Meet & Greet Open House

**NOVEMBER**
- November 7  Epilepsy Today Conference (Kalamazoo)
- November 13  Epilepsy Today Conference (Port Huron)
- TBD  Southeast MI EEG-Plymouth Whalers Hockey Game

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**Fund-Raise…Your Way!**

The Epilepsy Foundation of Michigan is pleased to announce the debut of a new nationwide fundraiser—Talk About It! @ Dinner. Throughout the year, friends of the Epilepsy Foundation of Michigan and affiliates across the country will host dinner parties to raise awareness and money for the Epilepsy Foundation and its mission. Host kits are available online. We have provided many convenient tools, such as host guides, invitation templates, thank-you note templates, and more! For more information, please contact the Development Department at (800) 377-6226, option 1, ext. 217. Fund-raise your way today!
DO YOU HAVE A FACEBOOK ACCOUNT?

If so, be sure to add “Epilepsy Michigan” to your friend list! You can also join our group, Epilepsy in Michigan, and support our cause, Epilepsy Foundation of Michigan. This is a great way to acquire information about epilepsy, learn about the Foundation, and connect with people all over the world who are affected by epilepsy.

Planned Giving

Does your estate plan provide for your favorite charitable organization?

With some preparation today, you can ensure the Epilepsy Foundation of Michigan continues to provide quality products and services to our consumers beyond your lifetime through bequests and estate planning.

Please consult with your attorney or tax consultant for more information, or contact the Epilepsy Foundation of Michigan at (800) 377-6226.

HEADLINES is now available via email. Please provide us with your email address by visiting our website at epilepsymichigan.org, so you can begin receiving your newsletter and other announcements easily. You also will be helping us reduce mailing costs. Thanks.