IN THIS ISSUE

From the President .............. 2
Camp Discovery........... 3
Research in Progress: Generic Drugs: A Welcome Savings, But Are They Right for All? .............. 4
Epilepsy Awareness Month.............. 5
Flame of Hope Awards Reception.. 6
Epilepsy Entertainment Gatherings (EEG)... 6
The Power and Wonder of the Human Spirit .............. 7
Calendar of Events.................. 8
November is Epilepsy Awareness Month...

November is epilepsy awareness month, a time to spread the word about epilepsy. Although we know more than ever about epilepsy and have more treatments available, as many as 40 percent of those who have epilepsy still experience seizures.

Equally disturbing is the misunderstanding about this condition. So many people do not know enough about this condition that affects so many people. They do not recognize seizures. This can result in bad treatment by people one sees everyday—family members, teachers, schoolmates, colleagues, and unfortunately, the police.

This spring, a neighbor who saw Daniel Beloungea acting strangely in a park called Oakland County Sheriff’s office. When he did not respond to the police, he was tasered and ultimately hit with a baton, arrested and charged with disorderly conduct and two counts of resisting and obstructing a police officer and committed to a psychiatric facility for violent offenders. His real “crime” was having a complex partial seizure while walking in a public place which made him unaware of the police and of his actions.

He has now been released, but this story highlights the continued need to educate police and firefighters about epilepsy. What makes this story sadder is that there have been similar reports from all over the country. There have even been situations where an individual has been shot because he remained unresponsive to the police while seizing.

The Epilepsy Foundation of Michigan offers a nationally developed training to police and firefighters who are the first responders in matters of first aid. We will continue to offer it to the police and fire departments. We are also able to offer legal assistance on a limited basis through the Epilepsy Foundation national office’s Jeanne A. Carpenter Epilepsy Legal Defense Fund.

It’s important that we educate people about epilepsy, and we need your help to do it. Too many people do not recognize a seizure or do not know appropriate first aid. Join with us to “Spread the Word.” We need volunteers to tell their story, help us take information to public places, and represent us at health fairs. We need people to join our Speakers Bureau to speak to civic groups, local businesses, and the general public to tell their personal story about epilepsy.

Throughout this issue you will read about various programs and events that you can get involved in. Don’t let the opportunity to make a difference pass you by. Please help us create more understanding about epilepsy, and help make it safer for people to be full members of their community.

Not another moment lost to seizures
Camp Discovery was held from August 20 – 24. The camp provided a wide range of activities for participating children with epilepsy, including rock wall climbing, swimming, kayaking, sports, arts & crafts, archery, karaoke, and more. Thanks to an overwhelming response to our requests for volunteer assistance, we were able to provide an impressive level of medical care and general supervision. 74 children from across the state attended (an increase from 54 children last year and 32 children two years ago).

Campers’ Quotes

“Other kids have epilepsy too, so I can be myself.”

“Abby has a wonderful time at camp every year! She comes home so much more excited about life and better equipped to deal with the challenges she faces every day.”

“I learned (at camp) that just because you have epilepsy doesn’t mean that you have to be different.”

“I learned more about the different kinds of epilepsy at camp.”

“It was great fun and I can’t wait until next year. Thank you!”

You are cordially invited to attend the Epilepsy Foundation of Michigan’s

Gallery of Hope

Please join us for a free, one-hour breakfast that promises to be an inspirational and informational glimpse at the Foundation and the people we serve. A solicitation will be made with no obligation.

December 5, 2006 - 8:00 A.M. - 9 A.M.

The Birmingham Community House, 380 South Bates Street, Birmingham, MI 48009

To reserve your seat or if you are interested in becoming a table captain, please call 1-800-377-6226 ext. 1-217 or email bromines@epilepsymichigan.org.

www.epilepsymichigan.org
Generic Medications Can Save People Money

Generic drugs are currently estimated to save consumers at least $8 to 10 billion a year at retail pharmacies because they cost less than the brand name versions of the same product. Congress and many federal agencies actively support the increased use of generic medications as a way to save money in healthcare. Because medications are a major cost of epilepsy, the availability of less expensive versions of brand name medicine can be very good news for people with epilepsy.

Are Generic Drugs For Epilepsy Right For Everyone?

Although research is still limited, it appears that generic versions of medications can be used safely and effectively for most people with epilepsy. The results of taking generic drugs should be the same as when using the brand name drug. However, while generics must be the same medicine, the FDA allows for a certain range of variability. One of the issues that needs to be examined is whether that range should be narrower for anti-convulsant medications.

Some individuals report problems, however. Physicians who treat people with epilepsy have also reported that some people have “breakthrough” seizures when switching from brand to generic versions of a drug – or among generics made by different manufacturers. A “breakthrough” seizure is one that occurs unexpectedly in someone who has had good seizure control. This has historically been a problem with some of the older drugs used to treat seizures.

Because seizures are serious events that can have considerable cost to one’s health, well-being, and pocketbook – and can even be life threatening, either as a direct result of the seizure, or because the seizures occur unexpectedly while someone is driving or in another dangerous situation -- experts in epilepsy and its treatment have routinely advised against switching among different versions of the same drug without physician guidance, monitoring and oversight. As epilepsy advocates suspect and some new research is confirming, the cost savings in the less expensive medications may be lost when overall health costs and societal consequences are taken into account for those patients who experience breakthrough seizures or troublesome side effects when switched from their usual seizure medicine.

Foundation Opposes Mandatory Substitution for Antiepileptic Drugs

The Epilepsy Foundation of Michigan has opposed mandatory substitution of generic drugs for brand name since generics first became available because of concerns about reported breakthrough seizures in some people with epilepsy when they are switched from one version of a medication to another. Other medical organizations focused on the treatment of epilepsy have had similar positions.

The concern centers on several issues, not just the extreme consequences of having breakthrough seizures.

• Is the therapeutic range accepted by the FDA to show “bioequivalence” of a generic version with a brand name drug too broad, allowing for too much variability in levels of the product that controls the seizures? The FDA has recognized that some epilepsy drugs had a “narrow therapeutic index,” and therefore the generic version could not be substituted without the agreement of the physician and the patient.

• Is there something about the nature of antiepileptic drugs that creates problems with switching among versions of a drug?

• What is the impact of the “bioavailability” of the medicine? In other words, while chemically a brand name and generic version drug are similar, are there differences in the way a body processes the drugs because of other ingredients used to make the two drugs?

These questions continue to be concerns today.

Information obtained from national Epilepsy Foundation.
Epilepsy Education is Important

SEIZURES AND YOU: TAKE CHARGE OF THE FACTS

A national survey conducted by the Epilepsy Foundation showed there is a widespread lack of knowledge about epilepsy among teens. Some teens thought epilepsy was a mental illness; others thought it was contagious. Many said they would not date a person with epilepsy. Others believed that people with epilepsy couldn’t work or attend regular schools. This lack of understanding and misinformation often results in teens with epilepsy feeling socially isolated and pressured to keep their seizures a secret. In fact, these myths and misperceptions often endanger students with epilepsy.

To educate teens, the Epilepsy Foundation of Michigan has rolled out a new program called Seizures and You: Take Charge of the Facts. This epilepsy awareness program targets teenagers in middle school and high school.

Program Goals

Students who complete this program will:

• Demonstrate a basic understanding of epilepsy as a medical condition;
• Identify and learn about different types of seizures; and
• Know what to do and what not to do when someone is having a seizure.

How Do You Bring This Program To Your School?

Please contact the Epilepsy Foundation of Michigan at 1-800-377-6226.

Wear Your Support

JEWELRY SHOWCASING THE FOUNDATION’S LOGO IS NOW AVAILABLE

These stunning pieces provide epilepsy awareness by showcasing the Foundation’s logo. Fifty percent of the proceeds will help fund our programs and services allowing us to further our mission of “empowering people with epilepsy to live productive lives.”

All the silver, including the silver on the leather cord is sterling and rhodium plated, for a non-tarnish finish. The leather cord is adjustable between 16” and 18”.

$28 for the flame piece and $35 for the enamel piece, including sales tax.
The Epilepsy Foundation of Michigan was pleased to host two Flame of Hope award receptions this year to honor individuals for their dedication to our mission; not another moment lost to seizures. The Flame of Hope-West Michigan was held at Noto’s in Grand Rapids on September 28, 2006. The Flame of Hope-Southeast Michigan was held at the Community House in Birmingham on October 3, 2006. Both events honored the Foundation’s Winning Kids with awards and a memorable candle lighting ceremony, and presented three prestigious awards: Flame of Hope Advocacy Award, Flame of Hope Service Award, and Flame of Hope Community Leadership Award. There was no charge to attend the event due to the generosity of our sponsors. Mercantile Bank of Michigan sponsored the event in West Michigan and the event in Southeast Michigan was sponsored in part by Ortho-McNeil Pharmaceuticals and Henry Ford Health System. The Flame of Hope was a wonderful opportunity for us to thank all of the sponsors, donors, volunteers, and supporters that allow us to serve people with epilepsy throughout Michigan.

**EPILEPSY ENTERTAINMENT GATHERINGS (EEG)**

The Epilepsy Foundation of Michigan is pleased to announce the EEG (Epilepsy Entertainment Gatherings) program. This exciting new program was launched in response to consumer requests, to provide monthly opportunities for people with epilepsy and their families to meet and share with others facing similar challenges in an informal, recreational setting. The program kicked off with a Detroit Shock game and tailgate party and has been followed by a Whitecaps baseball game, Beach Party Potluck, and Summer Party. The events have been well-attended despite inclement weather.

**Upcoming EEG Dates:**

- **Saturday, November 18th**
  - Game Show Extravaganza!!
  - 2:00 p.m. – 4:00 p.m.
  - Sunnybrook Golf Bowl Motel, Sterling Heights

- **Thursday, December 14th**
  - Holiday Open House
  - (Southfield Office)
  - 4:00 p.m. – 7:00 p.m.

**RSVP to**

1-800-377-6226 ext. 1-231

Special thanks to Debra Black, Affordable Flowers of Birmingham, and Terry Matthews of Piano Perfection.
The Power and Wonder of the Human Spirit

Lauren Boling was born in May of 1986; she was 9 lb 1 oz. God really prepared her for the long journey ahead. Lauren’s seizures were formally diagnosed when she was about 2 weeks old. I had witnessed her doing unusual, repetitive movements a few times and took her to see the pediatrician. (She went into a seizure just as we walked into his office and he was able to see it).

In hindsight I realized that she was probably having them while I was pregnant with her, stiffening until I thought she would break one of my ribs and waving her hand open palmed during an ultrasound just like she would during her early seizures.

At first we were in shock, we had no idea what to expect. After a week long stay at Motts Children’s Hospital in Ann Arbor, we had a brief reprieve with medication. Five months later the calm gave way to the storm. The seizures came back with a vengeance despite the anticonvulsants and we began the true odyssey of epilepsy. At one point, Lauren had over 120 seizures in one day. Unable to get them under control, the doctors put her in a drug induced coma. She was 6 months old and they feared she would seize herself to a vegetative state.

We found ourselves hoping for a tumor, something they could fight. How can you fight something you can’t see, something so elusive yet relentless? We were desperate.

Ultimately, the Hospital connected us to a specialist in St. Louis; they flew us down on a small plane with a doctor and a nurse. Lauren was admitted into Washington University Hospital under the care of Dr. Sidney Goldring. After extensive retesting and multiple drug trials, Lauren underwent a left temporal lobectomy.

Epilepsy has altered all of our lives. It can rob a person of their freedom and independence. Their lives must be customized for safety, they lose their autonomy.

But there’s a ripple effect, when someone you love has epilepsy. How can you not fear for their health and safety? How can you not ache for their loss? And yet how can you not feel moved by their successes? How can you not feel awed by their resilience and perseverance?

Lauren has opened our eyes to the power and wonder of the human spirit. Her struggle with epilepsy reminds us how precious and precarious life can be. I think we feel a deeper love and appreciation for one another and express it more freely because of it.

We discovered the Epilepsy Foundation in the late 90’s, when Lauren’s seizures returned with the onset of puberty. We found out about a seminar in Traverse City and we felt hope for the first time. We were no longer alone in this journey.

Lauren was able to join a wonderful all though short lived Teen Activity Group. It offered not only support but also social opportunities that the teens so desperately longed for.

We’ve had many opportunities over the years for education, and support as a family. More recently Lauren and I were able to be a part of the YANA group, which is an acronym for You Are Not Alone. Lauren had a chance to meet and connect with other teens and feel the support of others who are traveling the same road, while I was able to meet and learn from other parents.

But I’m sure of all these wonderful things that the Epilepsy Foundation has to offer, Lauren’s favorite would be Camp Discovery! She has participated in camp for several years and she has benefited tremendously. Finally, she can do not only normal things with a sense of independence, but adventurous things as well. Canoeing, kayaking, hiking, rock wall climbing all while being supported and encouraged by a fabulous staff and many other campers who truly know how Lauren feels and what she goes through every day. What that does for these children and their psyche, is a wonderful and amazing blessing.

While there are many organizations out there who talk a good talk, the Epilepsy Foundation of Michigan actually gets in there and helps those who are suffering, it gives so much to the people who struggle with seizures and their families and because of all their hard work and effort, we have support, we have knowledge, we have a renewed self esteem, we have confidence, but most of all we have hope.

We are not alone.
Sue Boling (Lauren’s mom)
CALENDAR OF EVENTS

PICTURES OF HOPE
The Pictures of Hope is an opportunity for the Foundation to introduce our mission to business and community leaders.
November 10 – Kalamazoo
November 28 – Grand Rapids
December 12 – Grand Rapids
To attend, call 800-377-6226 ext. 1-217

EPILEPSY ENTERTAINMENT GATHERINGS (EEG)
November 18
Game Show Extravaganza!
Sunnybrook Golf Bowl Motel – Sterling Heights
Call 1-800-377-6226 ext. 1-231

EPILEPSY TODAY CONFERENCES
November 14 – Port Huron
To attend this conference, Call 1-800-377-6226 ext. 1-211.

GALLERY OF HOPE
December 5
Call 1-800-377-6226 ext. 1-217

HOLIDAY OPEN HOUSE
December 14th - Southfield Office
Call 1-800-377-6226 ext. 1-231

MARDI GRAS GALA
February 20, 2007
Call 1-800-377-6226 ext. 1-217

2007 SUMMER STROLL FOR EPILEPSY
June 2 - Celery Flats, Portage - Kalamazoo County
June 9 - Detroit Zoo, Royal Oak
June 16 - 6th Street Bridge Park, Grand Rapids’ Riverwalk
June 30 - Bayfront Park, Petoskey

2ND ANNUAL PAUL NEU MEMORIAL GOLF CLASSIC
July 23, 2007

2006 AMY FEDEL MEMORIAL CONCERT
benefiting Epilepsy Foundation of Michigan
December 9, 2006 - Show begins at 7:30 p.m.
First United Methodist Church, 1001 Green Road, Ann Arbor.
Suggested donation is $10.00 for adults and $3.00 for kids.
Advance reservations can be made by calling (734) 998-0360.

GoodSearch.com is a new search engine that donates half its revenue, about a penny per search, to the charities its users designate. You use it just as you would any search engine, and it’s powered by Yahoo!, so you get great results.

Just go to www.goodsearch.com and be sure to enter Epilepsy Foundation of Michigan as the charity you want to support. Just 500 of us searching four times a day will raise about $7300 in a year without anyone spending a dime! And, be sure to spread the word!

If you’ve already made your will...

Congratulations! But does it need to be revised?

Ask yourself:

Is my executor still appropriate and willing to serve?
__Yes __No

Does my will still meet my family’s needs, given any births, marriages, or deaths that have occurred?
__Yes __No

Does my will address the needs of my children or parents who would require care in my absence?
__Yes __No

Has my attorney reviewed my will in recent years so that my plans reflect current tax laws?
__Yes __No

Does my estate plan provide for my favorite charitable organizations?
__Yes __No

If you answered No to any questions, you may wish to review your plans. They may need to be altered to serve you as well as possible.