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The Epilepsy Foundation of Michigan cordially invites you to attend our

Open House

Wed., Aug 1 from 4-7 PM

20300 Civic Center Drive, Suite 250, Southfield

Please join us for an opportunity to meet and greet with Foundation staff and take a tour of our Southfield Office. Pictures of our programs and events will be on display for your enjoyment and an assortment of refreshments and beverages will be provided.

Please RSVP by July 25, (248) 351-7979 ext. 1-236 or via email at

events@epilepsymichigan.org
From The President

The Epilepsy Foundation of Michigan advocates for policies that make it easier for people with epilepsy to live with their condition. We spend significant time working with legislators and other government officials so that government policy will not make it harder on families touched by epilepsy.

We are committed to work on issues that effect people with epilepsy, and we know that actions by citizens communicating with their elected officials are far more effective in influencing public policy. As a result, we have been holding an annual legislative recognition event for nine years. The purpose of the event is to bring together people with epilepsy and family members with their state Representatives and Senators. It’s an opportunity for the policy makers to learn first hand what it is like to live with epilepsy, and to hear the Epilepsy Foundation of Michigan policy priorities.

This year’s event, held on May 8, was our biggest yet. We had 52 advocates and 27 legislators. After breakfast, the advocates visited the offices of elected officials who were unable to attend and left our publication, A Call to Action.

In addition to this year’s event, the Foundation launched a new program, Michigan Kids Speak Up. Modeled after the national Epilepsy Foundation’s Kids Speak Up program, advocates between the ages of 8 and 16 spent the day in the Capitol. They started by attending the Legislative Recognition Breakfast, had training about how to be heard in Lansing, visited offices of the Senators and Representatives, and went on a tour. Ten young people along with their parents participated in the event this year.

At the breakfast, we spoke on a few things we are concerned about. These are:

• Access to Specialty Care: Too many people are not controlled and are not getting to the epilepsy specialists they need.

• Access to Medication: Switching of medication at the pharmacy has become more common, whether from brand to generic or between generics. Representative Espinoza and Senator Gleason are introducing legislation that would prevent pharmacies from switching medication without the consent of the patient and the physician.

• Mental Health Parity: Insurance policies often restrict mental health visits more than other medical visits, and as a result, people do not get the care they need. The Foundation supports mental health parity. Currently, several bills (HB 4390-93 & SB 332-35) have been introduced in both houses of the legislature.

Next year, we hope for even more participation in both programs. The Foundation is already planning for next year’s events.
WOMEN AND EPILEPSY FORUM ENLIGHTENS AND EMPOWERS

Attendees of the Women and Epilepsy Forum on May 11th got the chance to learn from medical experts and each other about the unique challenges confronting women with epilepsy. Topics included Women and Epilepsy: An Overview, Epilepsy in the Childbearing Years, Depression in Women with Epilepsy, Women’s General Health Issues, and Epilepsy and Relationships. Eighty-three percent of attendees rated the forum as “excellent” and “agreed very strongly” that the content presented increased their knowledge level about issues facing women with epilepsy. If you would like to receive handouts from the forum or related information, please contact the Foundation at 1-800-377-6226, option 1, ext. 302 or rderry@epilepsymichigan.org.

WEEKEND RETREATS

Building Stronger Families and More

The Southeast Michigan Family Weekend Retreat took place on May 18-20 in Taylor, Michigan. Attendance was high with thirty-five individuals representing ten families. Participants learned to identify their individual and family strengths through working together to complete challenges; sharing stories; and bonding as a whole group. Topics explored included communication, coping, and relating. By the end of the weekend, participants were not only building stronger families but establishing a stronger community.

One attendee had this to say when asked if she would recommend the retreat to another family: “Yes, it is a great way to get information, get things off your chest, and to build a stronger family”.

The Foundation looks forward to having the same success at our West and Southeast Michigan Adult Weekend Retreats.

UPCOMING RETREATS

Adult Weekend Retreat

A retreat for adults with epilepsy and one adult support person. (You must bring a support person and they must be 18 years or older.) The focus of the retreat is building stronger relationships.

West Michigan – July 28-29 at Ramada Inn in Battle Creek S.E. Michigan - September 29-30, 2007 at Ramada Inn Downriver in Taylor, MI

Space is limited, so call today! Contact Sheryl Darroch at (800) 377-6226, ext. 1-231 or sdarroch@epilepsymichigan.org for an application.

Kids Speak Up 2007 (April 23-25)

The Epilepsy Foundation of Michigan’s young adult representative for the national 2007 Kids Speak Up was 16 year old Tyler Frohreip from Schoolcraft, Michigan. The event held in Washington, D.C., allowed Tyler along with forty-five kids with epilepsy from all across the country to meet with their elected legislators to tell their stories in an effort to raise funding, awareness, and ultimately find a cure for epilepsy.

The conference opened with a dinner and social event at which kids could meet other kids from all over the nation who had epilepsy just like they do. At the dinner, local artists were on hand to draw caricatures of participants while basketball star Mighty Mike Simmel (who himself has epilepsy) from the Harlem Wizards wowed the kids with basketball moves and powerful motivational messages.

The next day was full of class time, helping the kids create their own personal message and preparing them for a day on the hill to meet with their legislators. In addition, the kids had an opportunity for some fun with a choice of a trip to the Science Center or a tour of Washington, D.C.

The last and most exciting day consisted of visiting Capitol Hill to meet with legislators including Senator Stabenow, Senator Levin, Congressman Upton, Kollenberg, and McCotter. They also visited other congressional representatives’ offices from Michigan, speaking to their aides and leaving behind folders which included the Epilepsy Foundation message asking for Michigan representatives to recognize and support the Foundation’s agenda:

1. ... restore funding for critical epilepsy public health programs at the Centers for Disease Control and prevention (CDC), the Health Resources and Services Administration (HRSA) and the National Institute of Health (NIH).

2. ... the importance of the Americans with Disabilities Act, by asking them to make clear that people with epilepsy have protection against discrimination in the workplace if they have seizures. Congress should enact legislation to restore the coverage and protections lost under the ADA due to court decisions limiting who is protected. Congress should also reject any amendments to the ADA or new legislation that would weaken protections under the law.

3. ... legislation and strong funding for education of students with epilepsy and other disabilities. Asking congress to fully fund all parts of IDEA programs, No Child Left Behind, and Higher Education Programs.

Other Michigan representatives included Tyler’s mother Rhonda Frohreip, Epilepsy Foundation of Michigan Volunteer Advocates Lisa and Donna Sternfeld from West Bloomfield, the Epilepsy Foundation of Michigan’s Education Specialist Cynthia Handford RN, Epileptologist Gregory Barkley, MD and Epileptologist Brien Smith, MD both from Henry Ford Hospital’s Comprehensive Epilepsy Program. All participants did a great job advocating on behalf of people with epilepsy.

www.epilepsymichigan.org
RESEARCH IN PROGRESS:

Epilepsy-Related Knowledge and Attitudes Among Teens with Epilepsy, Teachers, and the General Teen Population

A fair amount of research has been conducted on knowledge and attitudes about epilepsy among children and adolescents with epilepsy, their peers, and their teachers. Negative attitudes and lack of knowledge are present in each of these groups and can contribute to psychosocial problems, mental illness, and reduced quality of life among youth with epilepsy.

TEENS WITH EPILEPSY

A study by Baker et al. (2005) found that adolescents with epilepsy showed higher levels of depression, anhedonia (inability to experience pleasure), and social anxiety than adolescents without epilepsy. The higher levels of depression and social anxiety were due in part to having a low level of epilepsy knowledge, which was also significantly associated with lower levels of self-esteem.

Psychosocial outcomes are also affected by attitudinal factors. For instance, Dunn et al. (1999) found that having a negative attitude toward epilepsy, dissatisfaction with family relationships, and unknown or external locus of control increased the risk for depression in adolescents with epilepsy.

TEACHERS

In a survey of 512 elementary and middle school teachers in the U.S., Bishop et al. (2006) found evidence of negative attitudes toward students with epilepsy and deficits in epilepsy-related knowledge. Despite overall attitudes being positive, certain responses were troubling. For example, the majority of respondents believed that people with epilepsy “prefer to live with others with similar characteristics” and are “more likely to develop and express criminal tendencies.”

Knowledge deficits were more prominent than negative attitudes. Only 14% had received adequate training on epilepsy and seizure management in their teacher training. In addition, only 43% were familiar with different seizure types and what they look like, and 28% did not think that epilepsy could have significant effects on mood, memory, and learning.

THE GENERAL TEEN POPULATION

A national survey by Austin et al. (2001) collected data about the prevailing attitudes, perceptions, beliefs and behaviors about epilepsy among the general teen population. Of seven diseases mentioned, teens were least familiar with epilepsy. Only about half of the teens (52%) surveyed had ever heard of or read about epilepsy. Furthermore, the majority of teens surveyed did not know about the specific nature of epilepsy. For example, they did not know if it is contagious, if it is a mental illness, whether doctors know its cause, or if people die from seizures. Additionally, two-thirds (67%) of teens responded that they would not or probably not know what to do if someone had a seizure.

Fortunately, the Epilepsy Foundation of Michigan offers programs to address knowledge deficits and negative attitudes in each of these groups. The Teen to Teen support group, Camp Discovery, the Epilepsy Entertainment Gatherings program, and Family Retreats directly assist teens with epilepsy; the Seizure Smart program trains teachers; and the Take Charge of the Facts program trains the general teen population. Please contact the Foundation to find out more about these programs.

Article references available upon request.
EEG ATTENDANCE BREAKS RECORD

There was a record breaking fifty-seven (57) people (73 including staff and volunteers) attend the Detroit Tigers Baseball game on Sunday, April 22nd. EEG Go’ers cheered on the 2006 American League Champion Tigers to a victory against the Chicago White Sox. The final score, after extra innings, was 6-5. Way to go Tigers! The temperature was a record breaker also. What a beautiful, hot, April day.

On May 12, eleven daredevils came out to C.J. Barrymore’s for another fun EEG event. Go-carts, climbing rock walls, bungee-jumping, putt-putt golf and laser tag, as well as feasting on pizza, salad, breadsticks and wings were some of the days planned festivities. A fun time was had by all!

June is our month to focus on fundraising here at the Epilepsy Foundation of Michigan. There is a Summer Stroll for Epilepsy ™ in four different cities to raise funds so that the Foundation can provide programs like this one. So, in June, a special EEG for Summer Stroll participants was held to show our appreciation for their hard work in raising funds for our Foundation. Following the Summer Stroll for Epilepsy ™ on June 9th, the Foundation had a Scavenger Hunt at the Detroit Zoo. Eighteen (18) people participated and learned some interesting facts about the animals at the zoo.

The next quarter’s EEG events are a Beach Party Potluck, a Detroit Shock Basketball Game, and a trip to Miller’s Big Red Apple Orchard. Don’t miss out on the fun!

For further details on these events please go to the EEG page on our website, www.epilepsymichigan.org, and click on EEG Readings or call Sheryl Darroch at (800) 377-6226, ext. 1-231.

The Epilepsy Foundation of Michigan proudly Presents

The Epilepsy Today 2007 Conferences

How can these conferences benefit you?

Enhancing the quality of life for people with epilepsy is the objective of these conferences. They are designed for individuals with epilepsy, their families, and others whose lives are touched by epilepsy -- including caregivers and professionals serving people with seizures.

TOPICS DIFFER AT EACH LOCATION, BUT MAY INCLUDE:

• Current Treatments and Diagnoses for Epilepsy
• Improving Memory, Attention and Cognitive Abilities: A Neuropsychological Perspective
• Transition from Youth to Adulthood: Planning for Independence
• Employment Issues for People with Epilepsy
• Depression and Epilepsy
• Epilepsy and Sleep
• Complementary Therapies for Epilepsy
• Epilepsy Open Forum/Q&As
• Finding Health Insurance that Works for You

DATES & LOCATIONS
October 19 - Metro Detroit (Sheraton Detroit Novi)
October 25 - Grand Rapids (DeVos Place)
November 2 - Kalamazoo (The Fetzer Center)
November 13 - Port Huron (Thomas Edison Inn)

TO REGISTER, PLEASE CALL (800) 377-6226 option “1”, ext. 302 OR EMAIL rderry@epilepsymichigan.org

www.epilepsymichigan.org

DETOIT SHOCK BASKETBALL GAME
Auburn Hills, MI
Thursday, August 9
6:00 pm Tailgate
7:30 pm Game

MILLER’S BIG RED APPLE ORCHARD
Romeo, MI
Saturday, Sept. 22
1:00 pm

BEACH PARTY POTLUCK
Waterford, MI
Saturday, July 21
12:00 pm - 3:00 pm Rain or Shine!
Harleigh, far left, with miniature horse and friends at Camp Discovery

Harleigh’s Story

By Darielle Lukaart

On April 19, 1995 we were blessed with the greatest gift we could have been given. Our daughter Harleigh arrived, following a normal pregnancy with no notable difficulties during labor. Harleigh had her first seizure on December 3, 1995 at the age of 7-1/2 months. She was in critical condition and the doctors were not sure she was going to survive. She suffered respiratory difficulties; the seizure lasted a little more than an hour before they could stop it.

On December 2, 1996 she had another major grand mal seizure on the way home from the grocery store. The seizure lasted about 40 minutes before they could stop it. However, while still in ER following a chest x-ray she began seizing again and went into respiratory arrest. She couldn’t breathe on her own and respiratory was too busy to come. The ER doctor intubated her and bagged her until respiratory could get there. They took her to ICU to hook her up to a ventilator. There must have been angels watching over her because she came out of it and they removed the tubes. There wasn’t any apparent neurological damage. Had we not been at the hospital when she went into respiratory arrest she wouldn’t be with us today. We were not equipped to handle the respiratory difficulties and save her life. The doctor said that was the worst seizure he had ever experienced.

Over the years, Harleigh has had periods of seizure control, as well as more “close calls”. What seizure control she has attained has come at a cost. The medication had affected her cognitive ability and she is not at age level for gross motor capability. She has resource support at school for math and reading and a social worker for emotional support. She has maintained fairly good grades with the support of her school. Harleigh is also somewhat restricted in her social activities. She is not able to attend sleepovers because most parents are not trained in seizure first aid; however she has had sleepovers. She has gone where we have gone which has made it more difficult for her to relate to kids her age. She tends to gravitate to adults. Some kids at school say she has a “Harleigh disease”. She cannot ride her bike without a “buddy”. She can never swim alone. She’s 12 years old and we cannot leave her at home alone for 10 minutes to run to the grocery store a mile down the road simply because her seizures are not mild. It is not uncommon for her to reach the five minute mark. We keep Diastat on hand for those times. Our cupboard looks like a pharmacy. We have worked hard to make her life as “normal” as possible. She hates the seizures and how they make her feel different.

Through all the negativity associated with seizures there are positives. She is a charismatic young lady who has a great deal of sensitivity to those who may be viewed different. She is the first to welcome the new person to school. She loves all animals; particularly horses, canoeing with her Dad, going to the movies, riding her bike, reading, and hanging out with the couple of friends she has. She is learning to sew this week.

One of the best things we could have ever done for her was to send her to Camp Discovery. Her first visit was in 2005. It was one of the most difficult things we did as parents, letting her go off with strangers for several days, trusting them to take care of her. It was also one of the best things we did for her. It was difficult for her in the beginning because she hadn’t ever been away from home before. She came home a more independent girl. She wanted to do more for herself. She had difficulty riding a bike before she left and tackled it on her return. She came back a more confident child who realized she really wasn’t “different” after all. She was more confident about herself and learned what friendship, acceptance, encouragement, and teamwork are all about. She canoes, swims, performs karaoke, singing around the campfire, horses, and learns more about her medical condition (all while under the supervision of trained personnel). There is no safer place for her than with us at home. Next to that it’s Camp. Her face lights up when we mention it. She loves camp so much she wants to be a counselor there when she gets old enough!

Through our experiences with Harleigh, we have learned that epilepsy is a medical condition. It has its limits but shouldn’t limit life. We have been blessed with a remarkable daughter. She chooses to be a strong minded, warm, and empathetic child who befriends those who don’t appear to be accepted by others. She chooses to welcome a new student to class or someone new to the neighborhood. We love our daughter and the strength, patience, and perseverance she has taught us. Harleigh didn’t choose epilepsy, it chose her. She now chooses to make the best of what it gives her.
To organize your 2008 Summer Stroll for Epilepsy™ Team, call 1-800-377-6226 ext. 1-217 or look for us online.

www.epilepsymichigan.org

The following Sponsors helped make this year successful:

Pamar Enterprises, Inc.
CMR Solutions, Inc.
Cyberonics
Blue Cross/ Blue Shield of Michigan
St. Mary’s Healthcare
Spectrum Heath
MMPC-Neurology
Neurosurgery of Kalamazoo
Bronson Healthcare Group
Borgess
Pfizer Inc
Meridian Advisory Services

And a special thanks to:

Amway Grande Plaza Hotel
Applebee’s
Belladonna Salon & Spa
Big Apple Bagels
Blockbuster Video
Cool Beans Café
Deb Bonner- Jafra Cosmetics
Grand Rapids Children’s Museum
Hilton-Grand Rapids Airport
Holiday Market
Ice Mountain
Intuitive Touch
Massage Therapy
Jammmin’ DJs
Johan’s Bakery
Kalamazoo Athletic Club
Mary Jo Sanders- KO World Class Boxing
Meijer, Inc.
Panera Bread
Roast & Toast Coffee
San Chez
Starbucks Coffee
Sweetwaters Donut Mill
Target- Farmington Hills
Target- Lakeside
Target- Portage
Target- Southfield
Target- Troy
Target-Eastland
Target-Kalamazoo
The Westin Southfield-Detroit
Walmart-Roseville

To view the complete photo galleries from all of our Summer Stroll for Epilepsy locations, please visit us at our website and click on the photo gallery link.
EPILEPSY FOUNDATION OF MICHIGAN PRESENTS

CAMP DISCOVERY

(Grades 3-10)

The Epilepsy Foundation of Michigan’s Camp Discovery provides youth with epilepsy a safe, structured and encouraging home away from home for 5 days and 4 nights.

CANOEING & KAYAKING • HORSES • ARTS & CRAFTS • SWIMMING AND MUCH, MUCH MORE!

Camp Discovery will be held at Sherman Lake YMCA Outdoor Center in Augusta, Michigan. Staff includes Foundation staff, pediatric neurologists, and Registered Nurses. Financial assistance is available.

For a camper application, or to sponsor a camper, please call 1-800-377-6226, ext. 1-231 or Email: sdarroch@epilepsymichigan.org.

Space is limited, and demand is ever-growing, so call today! For more information on Epilepsy Foundation programs, visit www.epilepsymichigan.org.

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.

CALENDAR OF EVENTS

JULY
July 21 - EEG Event - Beach Party Potluck
July 23 - 2nd Annual Paul Neu Memorial Golf Classic (Grand Rapids)
July 28-29 West Michigan Adult Retreat (Battle Creek)

AUGUST
August 1 - Summer Open House (Southfield Office)
August 9 - EEG Event - Detroit Shock
Aug. 19-23 - Camp Discovery

SEPTEMBER
Sept. 20 - Flame of Hope (West MI)
Sept. 22 - EEG Event - Miller’s Big Red Apple Orchard
Sept. 25 - Flame of Hope (S.E. Michigan)
Sept. 29–30 - S.E. Michigan Weekend Adult Retreat (Taylor)

OCTOBER
Oct. 19 - Detroit Epilepsy Today Conference
Oct. 20 - EEG Event - Halloween Party
Oct. 25 - Grand Rapids Epilepsy Today Conference

NOVEMBER
EPILEPSY AWARENESS MONTH
Nov.2 - Kalamazoo Epilepsy Today Conference
Nov.13 - Port Huron Epilepsy Today Conference
Nov. 17 - EEG Event - Indoor Water Park

DECEMBER
December 4 - Gallery of Hope (Birmingham)