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WELLNESS & EPILEPSY

When most people think of epilepsy, seizures come to mind. Those of us in the epilepsy community know what a seizure is, and chances are, we know that seizures can look different in every person. There are many different types of seizures and it’s expected that 70 percent of people who have epilepsy will become seizure free. But for many, epilepsy can mean disruptions at work, school, driving, and day-to-day activities.

Treatment for epilepsy has usually centered on control of seizures. Today, there are a number of medications as well as devices and the possibility of surgery for those living with epilepsy. But what has become so surprising is the overall effect that epilepsy has on a person’s health and wellness. Are people with epilepsy living the healthiest life they can live?

In 2005, the State of Michigan, at the request of the Epilepsy Foundation of Michigan, included five questions about epilepsy in their Behavioral Risk Factor Survey. This survey asked people all over Michigan about their general health. 1.8 percent of Michigan residents reported that they had epilepsy.

The study showed that for people who do not have epilepsy, 85 percent said they were in excellent or good health. Of the people who said they live with epilepsy, only 50 percent said they were in excellent or good health.

Recently, policy makers and advocates have been concerned that people with chronic diseases like epilepsy or disabilities are not encouraged to develop good health habits. As a result, the Epilepsy Foundation of Michigan decided to focus its fall conference on wellness. This regional conference, Wellness and Epilepsy, is scheduled for November 12-13, 2010, at the Rock Financial Showplace in Novi.

Friday night features an appearance and presentation by “Mighty Mike” Simmel, an athlete with epilepsy and team member of the Harlem Wizards. Friday night will also feature a health fair and a chance to network. Discussion topics on Saturday include current treatments, complementary treatments, stress management, adopting healthy behaviors including exercise, healthy eating, and sleep.

We are honored to have very talented and knowledgeable speakers from all over the state presenting at this conference. For those living with epilepsy, families and members of the medical community, this conference will certainly help us make the link between living with epilepsy and living the healthiest life you can live. We hope you will join us!

To learn more or to register, visit the Foundation’s website at www.epilepsymichigan.org or call 800-377-6226.

Register Today! The Epilepsy Foundation of Michigan’s Wellness & Epilepsy Regional Conference promises to be one of Michigan’s premier educational and networking opportunities for people with epilepsy, family members, and professionals who serve them. Join us!

Register online at www.epilepsymichigan.org or call 800-377-6226.
Back to School... Preparation for a Child with Epilepsy

With the hot summer coming to a close, kids all around the state are preparing to head back to the classroom. A child with epilepsy may have some special needs and concerns, and the Epilepsy Foundation of Michigan can help you prepare him or her for the school year.

“If parents take the lead, you’ll end up with better results,” according to Russell Derry, Director of Education for the Foundation. “Be an advocate for your child, make sure you have a sound plan in terms of informing teachers, administrators, school nurses and even other students about your child’s seizure patterns.”

Every child with epilepsy should have a seizure response plan, in writing and approved by your doctor. This plan should be shared school-wide. You can also make sure the school is aware of your child’s epilepsy through an Individualized Education Program (IEP) and/or a Section 504 plan.

“You can also ask your child’s teacher to partner in your child’s care by recording his seizures,” said Derry. “Not only will your child benefit, but the teachers will learn more about epilepsy.”

The Epilepsy Foundation of Michigan has several resources for sending a child with epilepsy to school. You can request a packet of literature on seizures to give to the school. There are also several sections of our website, ‘Parents’ and ‘School Programs’ that can assist you in preparing your family for this important time.

“This is not something you have to do alone,” said Derry.

To learn more, visit our website, www.epilepsymichigan.org or contact Russ Derry at 800-377-6226 option 1, ext. 302.

Fundraising for the Epilepsy Foundation of Michigan... Your Way!

Many times, an Epilepsy Foundation of Michigan event doesn’t seem to work with your family’s busy schedule, but you want to contribute with both time and effort.

How about organizing your own fundraiser? It’s easier than you think! They’re called Third Party Fundraisers.

“We constantly hear from people touched by epilepsy, who want to help, and they have their own ideas for events and fundraisers,” said Brianna Romines, Development Director for the Epilepsy Foundation of Michigan. “We love this, because an event organized by our supporters really helps us stretch our reach and gives us much more presence in the state! As much as we’d like to hold events every week of each month, our event schedule is full and we can only do so much.”

A fundraiser can be anything from a tea party (something that’s been done before) to a concert to a marathon run. You just have to follow some simple guidelines (see our website, www.epilepsymichigan.org/thirdparty).

“It’s crucial to set your goals and make sure you stay organized,” said Romines. “And, you must stay in touch with us. With the help of family, friends, co-workers and neighbors, you can organize a fantastic event, and the best part... you can be as creative as you wish!”

What’s a successful Epilepsy Foundation of Michigan Third Party Fundraiser? The Thanksgiving Day Fun Run, in Canton, hosted by Family with a Cause. The Murray family organizes this event each year with the proceeds going directly to the Epilepsy Foundation of Michigan.

“This is one example of a wonderful event that was conceived and organized by supporters of the Foundation, and it’s really taken off! Each year, there are people who look forward to participating!”

For more information on organizing a Third Party Fundraiser, please contact Brianna Romines at (800)377-6226 option 1, ext. 217 or visit our website, www.epilepsymichigan.org/thirdparty.
2010 proved to be another fantastic summer for Camp Discovery! Now in its 7th year, 70 campers experienced all of the great things camp has to offer, from rock climbing to swimming to arts & crafts, more memories were made!

“Watching a child realize that he can do something he never thought possible, like ride a horse or climb a rock wall…it’s magical!” said one camp volunteer.

Camp would not be possible without the dedicated staff of more than 50 volunteers, which included medical professionals and counselors. Camp is also a chance for kids with epilepsy to experience something they perhaps have never seen.

“For many of our kids, this is the first time they see someone else having a seizure. It’s just another way they form bonds and realize that they are not alone in this.”

To learn more about Camp Discovery or to get involved, visit our website, www.epilepsymichigan/campdiscovery.
Heat waves are nothing new during Michigan summers, but summer 2010 was especially “hot” for participation in the Summer Stroll for Epilepsy! Thanks to you, we set some great records: nearly 1,700 people gathered to make up almost 100 teams around the state.

Sponsors, participants, volunteers, vendors and donors helped us raise awareness and much-needed funding for the many programs and services we continue to provide. This year, Strolls were held in Detroit, Grand Rapids, Kalamazoo and Midland.

It’s not too late to contribute to your favorite team or stroller, you can learn more at www.epilepsymichigan.org/stroll.

And, you can begin to plan your 2011 team! All dates and times will be announced in January.

To view more photos of the Foundation’s programs and events, please visit www.epilepsymichigan.org/photos.
Talking the Talk During a Doctor Visit

The appointment has been on your calendar for weeks, but when you finally step into your neurologist’s office and the visit begins, you are at a loss for words.

It can happen to any of us. Our neurologist or epileptologist needs to get crucial information from us in order to continue care, but we must be able to verbalize the state of our epilepsy. Dr. Aash Shah, MD, a member of the Adult Comprehensive Epilepsy Program at Wayne State University/Detroit Medical Center has some advice for patients and their caregivers.

"Be prepared, whether it’s a routine check or a first-time visit,” said Dr. Shah. “Go into that appointment as if you and your doctor are a team. The more information you can provide, the better chance you have of formulating a plan for treatment, whether you’re talking about prescriptions or even surgery.”

The Epilepsy Foundation of Michigan asked Dr Shah to suggest 5 key points to mention at each visit with your neurologist.

1. Tell your doctor how many seizures you have had since the last visit and the timing of the seizures. Are they happening at night? During the early morning? In other words, keep a detailed seizure log. Your neurologist needs this in order to continue care.

2. What circumstances lead to your seizures? Are you stressed? Tired? Did you get too much sleep? If you are a woman, are you having an increase in seizures during your menstrual cycle? Have you exercised too much? Is it very hot outside when you have seizures? Every detail is crucial.

3. Make sure you let your doctor know about any and all side effects of your current medication(s). Something you might think is minor could be very significant.

4. Keep an accurate list of the medications you have tried in the past and what has and has not worked. This is especially critical if you are changing neurologists.

5. Begin to explore treatment options with your doctor. Is surgery an option? Are there other medical treatments you could try? Might there be some unconventional treatments that are right for you?

“It’s always good when a patient does his or her own research,” said Dr. Shah. “When you can ask questions about managing your own epilepsy, whether it’s related to a new medication or a surgical treatment, your neurologist will be able to design the right treatment with your help.”

For more information on epilepsy and how to work with your doctor, visit www.epilepsymichigan.org, or call the Epilepsy Foundation of Michigan at 800-377-6226.

Overcoming Obstacles:
2010 Scholarship Winner Conquers Epilepsy

Michael D. Hutton knows how to take on the challenges that epilepsy presents. He’s been tackling his seizures for many years with the help of his family, friends, teachers, doctors and the Epilepsy Foundation of Michigan.

Michael is the 2010 recipient of the Dakota Pequeno Memorial Scholarship.

“I am thankful for those people in my life who have helped me overcome the issues that at one time created obstacles for me,” Michael wrote in his essay application for the scholarship.

Michael has been accepted into the Culinary Arts Program at Schoolcraft College, and will begin taking classes this fall. His dream is to open his own pastry and coffee shop!

Congratulations Michael!

Dakota Pequeno lost her life to a seizure in 2006. In an effort to ensure that her memory lives on, her family established the Dakota Pequeno Memorial Scholarship. It is their way of giving an opportunity to others who aspire to do great things in life, just like Dakota.

For more information on this scholarship, or if you are interested in sponsoring a scholarship opportunity, please contact Brianna Romines in the Development Department at 800-377-6226 option 1, ext. 217.
EPILEPSY FOUNDATION OF MICHIGAN:
CALENDAR OF EVENTS

**AUGUST**
- August 4  Learn & Share Conference Call – Managing Pediatric Epilepsy
- August 19 West MI Meet & Greet Open House
- August 25 Southeast MI Meet & Greet Open House

**SEPTEMBER**
- September 1  Learn & Share Conference Call – Managing Memory Problems
- September 30 Southeast Michigan Flame of Hope Award Reception

**OCTOBER**
- October 2  Pankiewicz Cider Mill Tour
- October 6  Learn & Share Conference Call – Epilepsy & Sleep
- October 7  West Michigan Flame of Hope Award Reception
- October 28  2nd Annual Toasting Hope Wine Event

**NOVEMBER**
- November 3  Learn & Share Conference Call – Epilepsy Research: Today and Tomorrow
- Nov. 12 – 13  Wellness & Epilepsy Regional Conference

**December**
- December 1  Learn & Share Conference Call - Open Discussion

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**Planned GIVING**

**FUTURE GENERATIONS CAN BENEFIT FROM YOUR GENEROSITY AND PLANNING!**

Please consider leaving a bequest or beneficiary designation in your will for the Epilepsy Foundation of Michigan.

Leaving a legacy gift will ensure that the Foundation will always be here to help individuals touched by epilepsy. Thank you!

For more information, please contact your financial planner, or call us at (800) 377-6226.

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**DO YOU HAVE A FACEBOOK ACCOUNT?**

If so, be sure to add “epilepsyfoundation-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.
RETURN SERVICE REQUESTED

Wellness & Epilepsy
REGIONAL CONFERENCE
An Epilepsy Today Feature Program

November 12–13, 2010
Rock Financial Showplace, Novi, MI

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Friday night keynote speaker, "Mighty Mike" Simmel

Register online at www.epilepsymichigan.org or call 800-377-6226.

HEADLINES is 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.