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PLEASE JOIN US

FOR OUR FIRST OPEN HOUSE AT OUR NEW GRAND RAPIDS OFFICE,
AUGUST 21ST
FROM 3 P.M. – 7 P.M.
CHECK OUT OUR WEB SITE FOR MORE DETAILS.

Celebrating 60 Years of commitment and dedication
From The President

At its April meeting, the Epilepsy Foundation of Michigan Board of Directors took unprecedented action by establishing the Michigan Epilepsy Research Fund and seeding it with $10,000 for 2008. This fund will allow the Epilepsy Foundation of Michigan to support research through the Epilepsy Foundation and its partnerships, such as the Epilepsy Research Foundation, a partnership of the Epilepsy Foundation and the Epilepsy Therapy Development Project.

A new approach by the national Epilepsy Foundation allows an affiliated organization to support any research projects that have been determined to be worthy by an extensive peer review process. We can choose to sponsor a specific project or make general contributions to the effort. The Board decided to give priority to any research conducted by Michigan scientists. We recognize that we have several world class research institutions and scientists in our state, and we’d like to support them. We want to see Michigan become a leader in epilepsy research.

We also recognize that we need to steer more young people into neurology, and the national research program has done a great job of bringing young researchers into the field.

Those of us who have been concerned about epilepsy for a long time would like to see more research into this condition that would translate into better treatments and a cure. In the future, as more money is raised to support this initiative, it will be possible to be even more specific in the kinds of projects we could support. To that end, the Board has established a Research Committee, chaired by Nick Broggi to select projects. Other members are Dr. Elizabeth Garofalo and Andrew Vanchick.

At this writing, the Epilepsy Foundation has made three awards to Michigan researchers that should be noted.

**Lori L Isom, Ph.D., University of Michigan:** $75,000 award from a partnership of the Epilepsy Foundation, the American Epilepsy Society, and Parents Against Childhood Epilepsy to study the Role of Sodium Channel SCN1B in Pediatric Epilepsy. The results of the research will contribute to understanding of normal brain functions as well as how mutations in the gene lead to human pediatric epilepsy.

**Daniel Tice Barkmeister, Wayne State University:** $20,000 pre-doctoral research training fellowship to study Translating Human Gene Expression Profiles Of Interictal Spiking Into A Rat Model (Jeffrey A. Loeb, MD, Ph.D, Preceptor) One of the major challenges in developing effective seizure medications comes from animal models of disease that fail to mimic the human disorder. The closer the animal model is to the human disorder, the more likely a new drug developed using that model will actually work in patients with epilepsy. Funding for this project will help determine if this new model can identify new drugs to reduce seizures or even ‘cure’ epilepsy before it even gets started.

**Michele Kron, University of Michigan:** $20,000 pre-doctoral research training fellowship to study the Role if Adult Neurogenesis in Hippocampal Remodeling and Hyperexcitability during Pilocarpine-Induced Epileptogenesis, (Jack M. Parent, MD Preceptor) this study seeks to study changes in the brain that lead to experimental mesial temporal lobe epilepsy, specifically those at the cellular level that may involve neural stem cells. Mesial temporal lobe epilepsy is the most common type of intractable epilepsy in young adults.

We look forward in hearing about their research results in the future. Our initial contribution will go toward the next round of research proposals. Please join me in supporting the Michigan Epilepsy Research Initiative. If you choose to make a gift to fund this initiative, please indicate that you want the gift to go to research. I would welcome your call to discuss the initiative.
HILARY ROBINSON:

“Living with epilepsy is not easy.”

The alarm clock sounds every weekday morning at 6:30 in the Robinson household, signaling the beginning of a day filled with sacrifices, dedication and commitment to family. Hilary Robinson, married mother of three and matriarch of the family, rises from her slumber and prepares for the day's activities. Eleven-year-old David, a 6th grade Honor Roll student, readies himself for school, while 3-year-old Emily, being the independent toddler that she is, attempts to do the same. But it is 7-year-old Michael who requires the most attention from Hilary.

Michael is one of the more than 100,000 people in Michigan living with epilepsy. He first displayed signs of the condition at 3 months old, but it wasn't until a year and a half later that doctors officially diagnosed him with epilepsy. Michael has since developed autism, and last year the family discovered that he has Dravet Syndrome, a rare genetic defect characterized by mutated genes which predisposes infants and children to severe seizures.

Hilary gives Michael his first of two daily doses of medication by 6:45 a.m., including Zonegran, Klonopin, Vigabatrin and Frisium. She bathes Michael, helps dress him, then feeds her 7-year-old—all while tending to Emily in the process. But David's helpful hand gives Hilary the flexibility she needs to ensure Michael and Emily are properly prepared for school. She calls David's assistance “priceless,” and says the family takes a teamwork approach. “We all work together.”

She sees her kids off to school, and it's only then that the stay-at-home mom can exhale. “I get a chance to have a cup of coffee, run a few errands or do some things around the house,” she says. But whatever she does, Hilary keeps a telephone nearby at all times, just in case she receives a call from Michael's school.

Michael's intractable epilepsy causes him to have as many as 20 seizures a day. And with his limited verbal skills and autism, Michael is unable to completely share his emotions and feelings with his family. What's more, Michael recently battled Stevens-Johnson Syndrome, a serious allergic reaction that consists of a characteristic rash involving the skin and mucous membranes. SJS is due to a hypersensitive reaction to certain types of drugs and infectious agents. And to make matters more challenging, Michael fought through a severe adverse reaction last year to having his medication switched by his pharmacist. The switch to generic drugs from his usual brand name prescription was performed without notice or consent by Michael's parents or his physician. And perhaps the most painful episode of all to Hilary was the six month stretch three years ago when, due to severe illness, Michael never smiled. “I could deal with him being sick,” she recalls, “but I couldn’t deal with him not smiling. I wanted to see my baby smile.”

Hilary recently began participating in a support group for parents of children with Dravet Syndrome, and what she realized is that Michael's long-term prognosis is not promising. “Michael’s not going to get any better,” she says. “And we've yet to find a child with Dravet Syndrome that lives to adulthood.”

Through it all, however, Hilary and her family continue to forge ahead. She and husband Tom, a truck driver who has modified his schedule to remain home as much as possible, understand the limitations they live with as parents of a child with epilepsy. “There are things we can do as a family, and things we cannot,” she says. “But we find other ways to celebrate life and celebrate us as a family.”

“Living with epilepsy is not easy,” she continues. “But it’s brought another level of appreciation for life. And just celebrating the joy in all three of my children has given me a better appreciation for being a mother and enjoying my children and loving them more.”

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.

YOU CAN NOW FIND THE FOUNDATION ON FACEBOOK OR MYSPACE THROUGH THE CAUSES APPLICATION. CHECK US OUT!
In 1948, the first Polaroid camera was sold in the United States; Executive Order 9981 was signed, ending segregation in the U.S. Armed Forces; and the Epileptic Clinic (now known as the Epilepsy Foundation of Michigan) opened its doors.

It’s been 60 years since our beginning in that small, cramped office in Detroit. But during our six decades of advocating for those with epilepsy, we’ve made tremendous strides in the areas of epilepsy awareness, mental health parity, advocacy and a host of other initiatives. We’re proud of our accomplishments, and we’re aware that our longevity is due in part to the commitment and dedication of our consumers.

To commemorate our 60th anniversary, we’re taking a trip through the Epilepsy Foundation of Michigan time machine—a look back at how things were and how they formed to create the organization we have today.

**EPILEPSY FOUNDATION**

1948 Representatives from the fields of medicine, education and public health decide to serve the need in Michigan for an organization specializing in epilepsy; the Michigan Epilepsy Center opens its doors in January at 96 W. Ferry St.

1950 The organization is admitted to the Michigan United Fund (United Way of Michigan).

1951 Before electroencephalograph (EEG) equipment was standard in out-of-state hospitals, the Michigan Epilepsy Center provided a mobile diagnostic service, an “EEG laboratory on wheels;” it is the first of its kind in the world and served about 1,000 people during its summer operations.

1958 The Michigan Epilepsy Center changes its name to the Michigan Epilepsy Center and Association (MEC-A), following a merger with the Michigan Association for Epilepsy.

1958 The Foundation celebrates its 10 year anniversary; its income of more than $120,000 represents a 500 percent increase over its income in 1948.

1971 The organization’s name changes once more to the Epilepsy Center of Michigan.

1973 The Foundation develops a clinical chemistry laboratory, making the Epilepsy Center of Michigan a pioneer in the field of anticonvulsant determinations.

1975 The organization receives a grant from the State of Michigan Developmental Disabilities Planning Council that enables the Foundation to open a pediatric seizure clinic.

1991 The organization becomes an affiliate of the Epilepsy Foundation, a national epilepsy organization in Landover, Maryland.
1993 The Foundation moves from Detroit city limits for the first time into the Central Park Plaza office building in Southfield.

1994 An agreement is reached with Henry Ford Health System. With the agreement, Henry Ford Health System acquires the diagnostic and medical treatment functions of the Center. The Epilepsy Center of Michigan continues to provide psychosocial and nursing services, as well as individual and family support programs.

1996 The Foundation wins Best-Managed Nonprofit by *Crain's Detroit Business* for agencies with budgets less than $3 million.

1998 The organization changes its name to the Epilepsy Foundation of Michigan and adopts a new logo—an elegant three-branched flame. This change aligns the Foundation more closely with the national epilepsy organization.

2003 The Foundation moves into its current location at 20300 Civic Center Drive in Southfield.

2007 The new Web Site www.epilepsymichigan.org is launched, giving the Foundation complete control over its internet content, donations and consumer compilation capabilities.
The 10th Annual Legislative Recognition Breakfast

by Sarah Kahn

The 10th Annual Legislative Recognition Breakfast was held on May 6, 2008 in Lansing. There were 52 constituents in attendance, as well as 37 Michigan legislators, including Representative Dave Hildenbrand, Senator Martha Scott, and Representative Tonya Schuitmaker. The purpose of this year’s breakfast was to educate consumers and legislators on the Epilepsy Patient Safety Legislation (House Bill 5077 and Senate Bill 926), sponsored by Representative John Espinoza and Senator John Gleason. If passed, this legislation would require a pharmacist to obtain consent from a patient and his or her physician before making any medication changes.

Also in attendance was Brien J. Smith, M.D., who spoke of the eminent dangers associated with changing medications from either brand name to generic, generic to brand name, brand name to brand name, or generic to generic. These changes can be especially detrimental to epilepsy patients, potentially causing seizures in people who have been seizure-free for years.

Hilary Robinson, mother of 7-year-old epilepsy patient Michael Robinson, shared her riveting and emotional story regarding her experiences with changes that were made in her son’s medications. Robinson’s story provided a concrete example of why the Patient Safety Legislation would benefit epilepsy patients in particular.

While the adults enjoyed the breakfast, the kids attended Michigan Kids Speak Up!, led by Cindy Hanford, RN, Education Specialist at the Foundation. Participants enjoyed a guided tour of the Capitol Building and learned about the legislative process. They were also able to meet with either their State Representative or a member of their staff.

The Legislative Breakfast is an important event, as it is the only time during the year that the Foundation and constituents are able to speak directly to the legislators. This year’s breakfast was successful, with more people in attendance than ever before. If the Patient Safety Legislation is passed, it will certainly help to improve the quality of life for people living with epilepsy in Michigan.

We at the Epilepsy Foundation of Michigan recently modified our Mission Statement in an effort to align our organizational goals with those of the national Epilepsy Foundation. Our new Mission Statement reads:

The Epilepsy Foundation of Michigan will ensure that people with seizures are able to participate in all life experiences; and will prevent, control and cure epilepsy through services, education, advocacy, and research.

Our former Mission Statement will be retained and used as the Vision Statement of the Foundation. It will read:

The Epilepsy Foundation of Michigan values all people with epilepsy. We commit our resources to empowering their independence and inspiring productive lives. To the extent of our capabilities, we offer our services to every individual without regard to artificial barriers.

BE A MENTOR

Youth Leadership Council Recruiting Young Adults

The Epilepsy Foundation of Michigan is recruiting young adults, ages 18-25, for its Youth Leadership Council. Having epilepsy is not a condition of membership. However, applicants MUST be passionate about taking active leadership roles in their communities to further the mission of the Foundation.

Youth Leadership Council President Christina Westra says: “Our big goal during our first year is to actively work with the Foundation to improve employment prospects for youth and young adults with epilepsy. We’re looking for positive and dynamic young leaders that are excited to take on the biggest challenges out there.”
RESEARCH IN PROGRESS:
Epilepsy Treatments: New Targets, New Mechanisms

Current antiepileptic drugs reduce seizure frequency through a number of different mechanisms. The primary mechanisms of action are blocking neuronal sodium and calcium channels, which inhibits high-frequency neuronal firing or spike-wave bursts; enhancing the action of gamma-aminobutyric acid (GABA), the brain’s primary inhibitory neurotransmitter; and blocking the action of glutamate, the brain’s primary excitatory neurotransmitter. Some AEDs have one mechanism of action, some have more than one, and some have unknown mechanisms of action.

Current animal and human research has identified a number of new molecular targets and new agents to act on those targets. In some cases, these agents act, as current AEDs do, to prevent seizures by promoting neuronal inhibition and limiting excitation. In other cases, agents act to slow or halt the neurochemical processes that lead to new-onset epilepsy or intractable epilepsy.

The rapid growth in new targets, mechanisms, and drugs can be attributed in large part to the complexity of the brain and the diversity of epilepsy types and causes. The following is just a sample of new therapeutic avenues:

Researchers at the University of Minnesota identified a protein, P-glycoprotein, that increases as a result of seizures and limits free passage of antiepileptic drugs into the brain. This may explain why some people with frequent seizures do not respond to antiepileptic medications. Potential targets for preventing this include the protein itself, glutamate (which initiates a cascade leading to increased P-glycoprotein), or COX-2 (which signals increased production of the protein). This study showed that a COX-2 inhibitor could reduce levels of the P-glycoprotein, but did not establish that this could actually reduce seizures.

The ketogenic diet’s mechanism of action remains unclear; however, researchers at the University of Wisconsin-Madison suggested that, because carbohydrate restriction is a key part of the diet, and the brain metabolizes carbohydrates through glycolysis, an expected effect and possible therapeutic mechanism of the diet would be inhibition of glycolysis. With this hypothesis, the team wanted to find out if 2-Deoxy-D-glucose, a glycolytic inhibitor, could effectively suppress seizures in rats. The compound was found to have potent anticonvulsive and antiepileptic effects, both by inhibiting glycolysis and by blocking the expression of seizure-related genes. This provides hope that anti-glycolytic compounds may become a new class of antiepileptic drugs. Also, as a follow-up to this study, the research team is now investigating the potential antiepileptic qualities of Metformin, a widely used diabetes drug.

Astrocytes are star-shaped cells in the brain that perform a number of functions. Once thought to be of limited importance, astrocytes are now thought to play many key roles, including possible roles in the development of epilepsy. In addition to other functions, astrocytes form scar tissue when neurons are injured, aid in the release and reuptake of several neurotransmitters (including GABA and glutamate), and regulate ion concentrations. Increasing evidence is pointing toward numerous astrocyte-related targets for new antiepileptic drugs. Such drugs may target potassium imbalance, glutamate release from astrocytes, and the metabolic enzyme ADK which leads to a astrogliosis, a common condition in people with epilepsy.


3rd Annual Paul Neu Memorial Golf Classic

The 3rd annual Paul Neu Memorial Golf Classic, honoring the late Paul Neu, will be held on June 30, 2008 at the Railside Golf Club in Byron Center, Michigan. Paul died in his sleep from a seizure in June, 2005. His family, friends, and business associates developed the idea of this event at his funeral, and since its inception, it has raised more than $45,000 for the Epilepsy Foundation of Michigan. It was the perfect opportunity to create an event that included Paul’s love of golf, family, friends and the Epilepsy Foundation of Michigan.

EVENT DETAILS:
JUNE 30, 2008
1:00 P.M. SHOTGUN START
Railside Golf Club
2500 76th Street
Byron Center, MI 49315
$100 per person
Includes 18 rounds of golf, cart, prizes and barbeque dinner
All proceeds go to the Epilepsy Foundation of Michigan, and are tax deductible.

www.epilepsymichigan.org
CALENDAR OF EVENTS

JUNE
June 7 Summer Stroll for Epilepsy™ (Kalamazoo County)
June 14 Summer Stroll for Epilepsy™ (Detroit)
June 21 Summer Stroll for Epilepsy™ (Petoskey)
June 25 H.U.G.S. – Living Well Special Workshop (Kalamazoo)
June 25 L.E.G.S. – Living Well Special Workshop (Lansing)
June 26 Grand Rapids Group – Living Well Special Workshop (Grand Rapids)
June 28 Summer Stroll for Epilepsy™ (Grand Rapids)
June 29 Camp Discovery
June 30 3rd Annual Paul Neu Memorial Golf Classic

JULY
July 8 L.E.G.S. – Open Discussion Night (Lansing)
July 18 EEG – Summer Hot Dog Bash (West Michigan)
July 25 EEG – Summer Hot Dog Bash (West Michigan)
July 30 H.U.G.S. – Open Discussion Night (Kalamazoo)
July 31 Grand Rapids Group – Open Discussion Night

AUGUST
Aug. 12 L.E.G.S. – Living Well Special Workshop (Lansing)
Aug. 16 Teen EEG – C.J. Barrymore’s (S.E. Michigan)
Aug. 21 EEG – Bowling at Holiday Lanes (West Michigan) Open House - Grand Rapids office
Aug. 23 EEG – West Michigan Whitecaps (West Michigan)
Aug. 27 – H.U.G.S. – Living Well Special Workshop (Kalamazoo)
Aug. 28 – Grand Rapids Group – Living Well Special Workshop (Grand Rapids)

SHARE OUR MOMENT

The Epilepsy Foundation of Michigan is celebrating its 60th Anniversary this year, and we’d like you to commemorate this accomplishment with us. We’re looking for individuals to share with us their stories of battling and overcoming epilepsy.

Those with epilepsy and family members affected by epilepsy are free to participate. Our 60th Anniversary is as much about you as it is about us. You share in this moment with us, and we’d like to hear from you.

Share your story today at www.epilepsymichigan.org

No Limits
TELEMENTORING

Are you a young adult with epilepsy (18-25 years old) who’s ready to start a great career? Are you an employed adult who understands epilepsy and is willing to share your advice, support and expertise?

If so, contact Cindy Handford at the Epilepsy Foundation of Michigan today at (800) 377-6226, option 1, ext. 234, or visit our Web site at www.epilepsymichigan.org for more information.