From The President

WE’RE BUILDING

For people with epilepsy, access to the medication that works for them is crucial. We have been working to prevent the switching of epilepsy medication, whether that is from brand to generic or generic to a different generic manufacturer, without consent. While not a problem for everyone with epilepsy, it is a problem for some. Many have called us and shared stories of being switched at the pharmacy and the problems this has caused. Others have called about the problems they have had with insurance companies about keeping on or getting back on the epilepsy medication that works for them.

We are supporting House Bill 4408, introduced by Representatives Espinoza, Gregory, Lis, and Terry Brown, and Senate Bill 318, introduced by Senator Gleason. The legislation would prevent a pharmacist from changing an anti-epileptic drug to a different formulation without prior notification by the prescribing physician and the patient or the patient’s legal representative. Unfortunately, neither bill has had a hearing yet.

However, we have seen some progress on the issue. The Medical Letter on Drugs and Therapeutics reviewed the evidence that switching between brand and different generic medications may cause epileptic events requiring medical care. The letter went on to recommend “using one formulation (brand name or generic) consistently or, if consistency is not possible with generics, prescribing the brand name routinely”.

As a result of this and other studies, Wellmark Blue Cross Blue Shield of Iowa recently changed policy for people with epilepsy taking Topamax, Keppra, and Lamictal. Members do not have to pay the difference between brand name and the generic for the above listed medications. In addition, Wellmark Blue Cross Blue Shield of Iowa also maintains the same co-pay for older anti-epileptic drugs.

We applaud Wellmark Blue Cross Blue Shield of Iowa for this change in policy. We’re continuing to work on this issue, both at the legislative level and with health insurance companies in Michigan. But we cannot do it alone. I invite you to join us on May 4th at our 12th Annual Legislative Recognition Breakfast at the House Office Building in Lansing. Together, we can make a difference.
In late September of 2009, Susan Richardson approached the Epilepsy Foundation of Michigan with an interest in doing a presentation to a small class at Ferris State University. By November 11th, she had partnered with the Foundation to launch a campus wide awareness and third party fundraising effort.

During the process, Susan coordinated the talents and efforts of Foundation staff, FSU departments, faculty and students, and many others. The final program, Epilepsy in Our Own Words & Seizure Smart, was attended by 177 people. During the performance, faculty member Mindy Britton, Epilepsy Foundation of Michigan staff person, Cindy Handford, RN, students Corey Potter, Tina Westra (Calvin College) and Susan Richardson shared touching stories about how epilepsy had impacted their lives. Attendees then learned how to properly assist someone having a seizure.

Prior to, and during the event, volunteers also sold “Links of Love” to benefit the Epilepsy Foundation of Michigan. The paper chain that resulted was hung prominently in the campus library.

Says Susan, “What started as a small initiative to inform my class of thirty students about epilepsy has led to a campus-wide event – this truly shows that with dedication and confidence you can do the same! Never hesitate to share your biggest battles with others – you never know what type of emotional healing can occur along the way. I once felt that I was the only person on campus with epilepsy, and come to find out, I am not alone.”

Susan is now the President of the Epilepsy Foundation of Michigan’s Young Adult Leadership Council. In that role, she will be assisting others to launch similar collegiate awareness and fundraising efforts on college campuses all across Michigan in 2010.

If you would like more information about Epilepsy in Our Own Words, the Young Adult Leadership Council, or Seizure Smart, please visit our website http://www.epilepsymichigan.org or contact Tyler MacEachran at (800) 377-6226 option 1, ext. 211.

For information about doing other third party fundraising, please visit our website: www.epilepsymichigan.org or contact Brianna Romines at (800) 377-6226 option 1, ext. 217.
EPILEPSY FOUNDATION OF MICHIGAN: UPCOMING PROGRAMS & EVENTS

APPLY TODAY!
Dakota Pequeno Memorial Scholarship
deadline is March 24, 2010
Please visit our website to check if you are eligible and to download the scholarship application.

SAVE THE DATE
5TH ANNUAL PAUL NEU MEMORIAL GOLF CLASSIC
JUNE 28, 2010
Railside Golf Club
2500 76th Street, Byron Center, MI 49315
Want to Register, Sponsor, or have questions?
Please contact Johanne Neu at (616) 878 – 3889
or visit us at www.epilepsymichigan.org

Paul Neu was a man of honor and wit, a lover of music and golf. He bravely faced the challenges of epilepsy for 22 years without letting it stop him from experiencing the things and people he loved most. In June 2005, at the age of 38, Paul lost his fight with epilepsy, but his family and friends pledge to continue his support of the Epilepsy Foundation of Michigan and its goals.

Wellness & Epilepsy
REGIONAL CONFERENCE
An Epilepsy Today Feature Program

November 12–13, 2010
Rock Financial Showplace, Novi, MI 48374

Please visit our website, www.epilepsymichigan.org or contact Russ Derry at (248) 351-7979, option 1, ext. 302 to learn more about this educational, networking opportunity.
Over 1,400 people joined us last year in Midland, Kalamazoo, Metro Detroit, and Grand Rapids and helped to form over 78 teams! Because of your support, the Summer Stroll for Epilepsy™ helped to raise over $120,000! Join us for the 2010 Summer Stroll for Epilepsy™ so that we can continue to provide many of our programs and services to people in Michigan who are touched by epilepsy.

JOIN THE FIGHT THIS YEAR!

May 22 - Dow Diamond, Midland
June 5 - Celery Flats, Kalamazoo County
June 12 - Detroit Zoo, Metro Detroit
June 19 - Riverwalk, Grand Rapids
Anywhere, Anytime - Virtual Stroll

www.epilepsymichigan.org/stroll
(800) 377-6226 option 1, ext. 236

The only specialized camp in Michigan for youth with epilepsy June 27, 2010 through July 1, 2010

Sherman Lake
YMCA Outdoor Center
Augusta, MI
(NE of Kalamazoo)

For more information, visit our website, www.epilepsymichigan.org or contact Sheryl Darroch at (800) 377-6226, opt. 1, ext. 231
Epilepsy interpreted through Art

FOR ALISON

Created by local artist: A. Forand

“I envisioned this rainfall of neurons, and dendrites, repeatedly dumping water into the puddle. This image made me reflect about how beautiful and powerful the human body could be. Until I made this image, I wasn’t fully aware of how dispiriting epilepsy can be. I hope this image can empathize visually how I interpreted what it’s like to suffer from epilepsy. A conceptual pattern shown through my work, is taking an object or idea that is ugly, and to morph beauty into it. By doing this, the change in perspective suddenly became expressive, and stimulated my need to nurture those touched by epilepsy. I hope you see the beauty that others have achieved!”

A. Forand
EPILEPSY FOUNDATION OF MICHIGAN:
CALENDAR OF EVENTS

MARCH
March 24 Dakota Pequeno
Memorial Scholarship deadline
March 30 Epilepsy in Our Own Words
Eastern Michigan University

APRIL
April 21 Southeast MI Meet & Greet Open House
April 29 West MI Meet & Greet Open House

MAY
May 4 Legislative Breakfast & Michigan Kids Speak Up!
May 22 Summer Stroll for Epilepsy™ (Midland)

JUNE
June 5 Summer Stroll for Epilepsy™
(Kalamazoo County)
June 12 Summer Stroll for Epilepsy™ (Metro Detroit)
June 19 Summer Stroll for Epilepsy™ (Grand Rapids)
June 27-July 1 Camp Discovery
June 28 5th Annual Paul Neu Memorial Golf Classic

JULY
July 24 Epilepsy Entertainment Gathering
Whitecaps Game, (Star Wars Night). West MI

AUGUST
August 19 West MI Meet & Greet Open House
August 25 Southeast MI Meet & Greet Open House

SEPTEMBER
Sept. 24-25 Adult Camp Retreat
Sept. 30 Southeast MI Flame of Hope

OCTOBER
October 7 West MI Flame of Hope
October 2 Epilepsy Entertainment Gathering
Pankiewicz Cider Mill, Southeast MI

NOVEMBER
Nov. 12-13 Wellness & Epilepsy Regional Conference
Nov. 20 Epilepsy Entertainment Gathering – West MI

www.epilepsymichigan.org

Bursting with Joy

Recently released by Michigan author, Joan Broggi.
“Bursting with Joy” recounts the parental struggles and emotions experienced in raising a child with epilepsy and special needs, as well as the life lessons her son, Alex, taught her along the way. Even though Alex will never learn to read, ride a bike, drive a car, or go to college, his profound innocence and unique ability to do the right thing teaches those around him every day. Adapting some of the chapter headings from Elisabeth Kübler-Ross’s groundbreaking book, On Death and Dying, and adding her own chapter entitled Joy, Joan Broggi recounts how her family and community embrace Alex’s extraordinary gifts. Purchase this book and a portion of the proceeds will benefit the Epilepsy Foundation of Michigan!

Visit www.joanbroggibooks.com and purchase your copy 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

….how future generations can benefit from your generosity.

Consider leaving a bequest or beneficiary designation in your will for the Epilepsy Foundation of Michigan. Leaving a legacy gift will help assure 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, option 1, ext. 217.

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.