Happy New Year! We are fueling the Foundation’s vision of a world where people with seizures realize their full potential in a number of ways in 2013:

- **EVENTS** - mark your calendar for these special events: “Light Up the Night” Gala on May 4, Stroll 2013 on August 8 and a new EFMN golf tournament on October 7. Help raise funding and awareness for epilepsy at these events. See page 13 for details.

- **SUPPORT** - advocate with us at the Capitol on February 26 (see page 7), connect with others in your area at a social event or “connect” group meeting or contact Information & Referral for help in navigating the challenges around epilepsy.

- **AWARENESS** – the Foundation’s epilepsy awareness campaign kicked off around the November 3 Gopher football game, with a flurry of media activity. This proactive effort will continue into 2013 - special thanks to Solve creative agency for donating their time/talent to EFMN!

In this newsletter, you’ll read about scholarship opportunities, Advocacy Day, Camp Oz, the Institute of Medicine’s recent epilepsy report and more. Your feedback is always welcome: vkopplin@efmn.org or 651.287.2314.

Vicki Kopplin
Executive Director
In January 2011, a committee of the Institute of Medicine (IOM) came together to address epilepsy. Over the next 12 months, the committee examined in-depth the state of what we know about epilepsy. Here are some of their insights and conclusions:

1) 1 in 26 people in the U.S. will develop epilepsy at some point in their lifetime. The most common times for epilepsy to begin are in childhood (including adolescence) and older adulthood (seniors).

2) Epilepsy is a spectrum disorder that includes at least 25 known epilepsy syndromes. The IOM report refers to this spectrum as “the epilepsies.” The epilepsies can be relatively benign or very severe and life-threatening. At least 30% of people with epilepsy have a refractory form.

3) Epilepsy is a common disease, the fourth most common disorder after migraine, stroke and Alzheimer’s disease, affecting at least 2.2 million Americans and 65 million people worldwide. There is a lot we don’t know about it.

Continued on page 4
What does the Institute of Medicine's Epilepsy Report Mean for You? (Continued from page 3)

4) Epilepsy is an expensive disease: direct costs are estimated at more than $9.6 billion dollars annually and indirect costs that are harder to measure.

5) The prevalence of epilepsy is increasing and we don’t know all the reasons why.

6) Having epilepsy significantly increases a person’s risk of death. Sudden Unexplained Death in Epilepsy (SUDEP) is the most common of the epilepsy-related causes of death. The risk of sudden death in people with epilepsy is more than 20 times greater than in the general population.

In March 2012, “Epilepsy Across the Spectrum – Promoting Health and Understanding,” was published. The report included 13 recommendations and 46 research priorities that are aimed at making the lives of people with epilepsy and their families better.

Let’s step back. What is the IOM and why should we pay attention to this report? The IOM was established in 1970 and is actually an outgrowth of the National Academy of Sciences, which was chartered under President Abraham Lincoln in 1863. Over the years, the National Academy of Sciences has expanded and today has four branches, known collectively as the National Academies. The IOM is one of the branches.

On the IOM website it states, “the Institute of Medicine (IOM) is an independent, nonprofit organization that works outside of government to provide unbiased and authoritative advice to decision makers and the public.” The committee that came together in January 2011 consisted of a cross-section of professionals (e.g. psychology, epidemiology, psychology, nursing and medicine) from a variety of academic, non-profit and other organizations.

The committee followed a rigorous process of inquiry in which conflicts of interest were avoided and objectivity was critical. In addition to meeting several times, the committee held public workshops in which they discussed topics such as health care quality, access to health care, education of patients/families/providers, research and data collection.

The 13 recommendations mentioned above fall into four key areas:

- Increasing the power of data and preventing epilepsy; this means identifying and using standard definitions when gathering data about epilepsy for government agencies such as the Centers for Disease Control (CDC) and the National Institutes of Health and looking for ways to prevent epilepsy in conditions such as stroke and traumatic brain injury;

- Improving health care to better screen and identify epilepsy early in people at high risk and work to ensure that those with difficult to control seizures have earlier access to an epilepsy specialist;

- Improving community resources and quality of life; this means ensuring that organizations such as the Epilepsy Foundation, CDC, and state health departments work more closely together to provide education to people with epilepsy and make sure they know what their resources are and how to use them, and

- Raising awareness and improving education; as we know, there is a great deal of misinformation about epilepsy and its consequences. The misinformation has contributed to stigma and prejudice, and does affect the quality of life for those with epilepsy.

Research priorities for each area are also clearly spelled out.

What does all of this mean for EFMN and the programs and services it provides? It means that pooling our efforts with other agencies, such as epilepsy centers, that provide direct care to people with epilepsy is more important than ever. The IOM report is a strong mandate for the epilepsy community and provides “realistic, feasible, and action-oriented steps that a variety of stakeholders can take to enable short- and long-term improvements for people with epilepsy and their families.”

The Foundation, and each one of us, is a stakeholder. Let us continue this important work together. To learn more about the Institute of Medicine and to see the full report, “Epilepsy Across the Spectrum – Promoting Health and Understanding,” visit http://www.iom.edu.
Creative Arts Showcase

The 4th annual Creative Arts Program Showcase, hosted by Vineeta Sawkar of Five Eyewitness News, featured six talented performers, and allowed artists to shine in the face of adversity.

Thank You BP/Speedstop

BP/Speedstop provided a generous matching grant to help the Foundation raise money for programs and services. The check presentation was in St. Cloud.

Fargo Parent Connect Holiday Party

Fargo’s Parent Connect group gathered for a holiday celebration, with support from Pediatric Therapy Partners.
EFMN in Action
Community Events and Education

Seizure Smart Schools
The Seizure Smart Schools program spans across Minnesota and North Dakota. In this image, a classroom at Herbert Hoover Elementary School in Rochester learned about epilepsy and how to support their classmate with seizures.

Shining Star Annual Event
Over 200 youth with epilepsy gathered at Target Field for the annual Shining Stars celebration, in partnership with Gillette Children’s Specialty Healthcare.
Advocate with Us

Epilepsy Awareness Day at the Capitol
Tuesday, February 26, 2013

In collaboration with the national Epilepsy Foundation on legislative priorities, the Epilepsy Foundation of Minnesota (EFMN) will host 100+ advocates at the State Capitol to raise epilepsy awareness and educate legislators around the following:

- Improve access to medical care and treatment.
- Stop stigma and discrimination against people with epilepsy.

JOIN US!

2013 Epilepsy Awareness Day at the Capitol
Tuesday, February 26, 2013
8:30 AM – 2 PM
Great Hall, Minnesota State Capitol (transportation is provided from EFMN's office)

RSVP to Stephanie Kolari at 800.779.0777, ext. 2310 or skolari@efmn.org.
THERE’S AN APP FOR THAT

There is a free app for people with epilepsy to track seizure activity, appointments and medication schedules through a simple calendar interface from your computer, tablet or mobile device. Visit www.seizuretracker.com to get the app.

MRI AND EEG COULD IDENTIFY CHILDREN AT RISK FOR EPILEPSY AFTER FEBRILE SEIZURES: NIH-FUNDED STUDY IS FOLLOWING NEARLY 200 CHILDREN

Seizures during childhood fever are usually benign, but when prolonged, they can foreshadow an increased risk of epilepsy later in life. Now a study funded by the National Institutes of Health (NIH) suggests that brain imaging and recordings of brain activity could help identify the children at highest risk. The study reveals that within days of a prolonged fever-related seizure, some children have signs of acute brain injury, abnormal brain anatomy, altered brain activity or a combination.

“Our goal has been to develop biomarkers that will tell us whether or not a particular child is at risk for epilepsy. This could in turn help us develop strategies to prevent the disorder,” said study investigator Shlomo Shinnar, M.D., Ph.D. Dr. Shinnar is a professor of neurology, pediatrics and epidemiology and the Hyman Climenko Professor of Neuroscience Research at Montefiore Medical Center, Albert Einstein College of Medicine, New York City.

To read more visit: http://www.ninds.nih.gov/news_and_events/news_articles/FEBSTAT_results_2012.htm

“SLASH THE ‘STACHE” CAMPAIGN RAISES OVER $1M FOR EPILEPSY RESEARCH

CURE Founder Susan Axelrod was a guest speaker at the Foundation’s 2012 gala. Axelrod’s husband, David, took a very public bet that he would shave his moustache if $1 million was raised for epilepsy research, via the CURE foundation. In December, Axelrod shaved his trademark moustache on live television when donations surpassed the million dollar mark! Visit www.cureepilepsy.org for the full story.

Free Information & Referral Services

According to the IOM report mentioned in this issue, “living with epilepsy is much more than seizures.” In practical terms, it can cause challenges in school, a heavy financial burden, uncertainties in employment/social situations, as well as possible limitations in driving. EFMN’s Information & Referral Service links people to community resources by identifying and delivering information to meet their needs. Contact Kelsey Ryan for more information at 800.779.0777, ext. 2303 or kryan@efmn.org.
No one likes to be told, “No…you can’t….you shouldn’t…be careful,” least of all a 17 year-old who has just experienced one the most terrifying and confusing moments of her life. I have never been one to let the word “no” rule my life, including as a child, (ask my parents) and this was no different. In fact, I think that possibly somewhere in my subconscious, even during the ER visit after my first seizure, I knew epilepsy wouldn’t stop me. I wouldn’t let epilepsy be the “no” that would stop me from living my life.

And it hasn’t, not for one day. Not when I was on my college swim team and the doctor told me I shouldn’t be swimming in water (in case I had a seizure). I just made sure my coaches and teammates knew what to do if I had a seizure.

Not when I moved to Boston to get my Master’s degree in child life and family-centered care. I always carry identification and information regarding my medical history. I also use my personal medical experiences to help me better relate to, and care about, the children and families that I encounter.

Not when I signed up for my first triathlon this summer, despite my doctor responding with a sideways look and, “really?” I had the word epilepsy written on my arms during the race so there would be no question in case I had a seizure (as well as an amazing support team along the way who knew my background).

Granted, I have had my share of ups and downs…doctor appointments and tests, medication side effects, hospitalizations, and yes, seizures. I have been and will always continue to be smart about taking care of myself and making sure those around me are aware of my epilepsy. However, I have yet to find something I can’t do and I’m not expecting to.

Through the past 18 years, and all those to come, there is no way I could handle all this by myself. It’s way too much for one person to comprehend and maneuver alone. I have been hugely blessed with amazing, supportive and loving people who are always there for me. I always thought of their support affecting my life and bringing encouragement to me each day, but little did I know that I’ve encouraged people:

“Through it all, she has persevered and kept her spirits up. She always bounces back when she is down. My daughter is my hero and has shown that living with epilepsy doesn’t have to slow you down, or place limits on your life.”

- quote from my dad

Overwhelming emotions come over me when I realize that epilepsy, which I initially thought of as a negative in my life, could also bring positive things into my life and those around me. I didn’t let epilepsy be the “no” that stopped me from living my life. I hope you are also enjoying your life and not letting any “no” stop you.
Scholarships, Creative Arts and Shining Stars

SCHOLARSHIPS

The Foundation announces the 2013 call for applications for the Elam Baer and Janis Clay Educational Scholarship program. Ten, $1000 scholarships will be awarded to students who have shown courage in dealing with epilepsy and seizures, commitment to their education and perseverance in eliminating the obstacles that seizures present.

Applications are due by April 1, 2013, and winners will be announced by May 1. The application form is available at www.efmn.org. Contact skolari@efmn.org with questions.

CREATIVE ARTS PROGRAM

Do you need a creative outlet to express living with a chronic condition? Are you interested in raising epilepsy awareness and education? Check out the Creative Arts Program!

There are many opportunities to get involved and raise awareness through creative expression. Share a piece of your artwork, poetry, short story or performance. The program runs year-round and we invite participants to consider a “Seizures Don’t Stop Me” theme when submitting work.

The Brainstorms Art Collection is open for entries January 1 – April 15 and will be making stops at the Federal Reserve Bank and the Mayday Café in 2013. Information is at www.efmn.org/creative_arts and you can apply to the program online. Contact 800.779.0777, ext. 2310 or skolari@efmn.org with questions.

There is no cost to be a Shining Star and ages 18 and under are welcome. Join Shining Stars at www.efmn.org and complete the registration form, or call 800.779.0777, ext. 2310. We’ll help you shine!

Shining Stars receive:

- A star medallion
- Program certificate
- Special invitations to EFMN events throughout the year
- BEST OF ALL – opportunities to connect and meet other Shining Stars and their families.

We think all youth with epilepsy are special – in fact we think they are Shining Stars! The Shining Star program, our largest youth program, recognizes youth with epilepsy, making them feel less isolated by connecting them with other youth with epilepsy.

We think all youth with epilepsy are special – in fact we think they are Shining Stars! The Shining Star program, our largest youth program, recognizes youth with epilepsy, making them feel less isolated by connecting them with other youth with epilepsy.
Planned Giving - leave a legacy for your community & maximize your impact

The Foundation provides opportunities for donors to support the mission, vision and core programs, while leaving a lasting impact on the community. Planned giving has many benefits, for the donor, their family, as well as the Foundation. A gift that may cost nothing now can make a difference in the future.

Consider designating EFMN as a beneficiary of your IRA or other retirement account.

Benefits: IRA gifts will pass directly to EFMN tax-free. If your family is provided for, this can also decrease the tax burden on any IRA assets family members will receive.

Consider designating EFMN as a beneficiary in your Will.

Benefits: Provides individuals another opportunity to express their values. Bequests are also revocable and can be changed at any time.

Consider making a gift of appreciated securities/stock.

Benefits: Individuals will avoid paying capital gains tax on these gifts and will also be eligible for a charitable income tax deduction.

Informing EFMN about your plans allows us to not only celebrate the difference you are making in the lives of people impacted by epilepsy, it also provides an opportunity to help direct your support toward areas that you are passionate about. If you have questions about planned giving at EFMN and the impact that it has, contact Hannah Baines at 651.287.2319 or hbaines@efmn.org.

EFMN recommends consulting and informing a financial planner or attorney about your intention to make a planned gift. Our staff is happy to assist with these conversations, if requested.

Mail this pledge form to: Epilepsy Foundation of Minnesota, 1600 University Ave. Ste. 300, St. Paul, MN 55104

Enclosed is my tax deductible gift of:  □ $1,000  □ $500  □ $250  □ $100  □ $50  □ Other Amount $ _________

Name(s) __________________________________________________________________________________________________

Address __________________________________________________________________________________________________

City ____________________________  State ___________________  Zip ____________

My gift is payable by:  □ Cash or Check (payable to: EFMN)  □ Credit Card  □ Visa  □ MasterCard  □ American Express  □ Discover

Designate my gift to  □ Educate  □ Connect  □ Empower  □ Other __________________________________________________________

Card # ___________________________________________________________________________  Exp. Date: __________  Security Code # _________________

Name on Card: _________________________________________________________  Signature: _____________________________________________

Email Address: _______________________________________________________________________________________________________________________

Making a difference by honoring or remembering someone special. This gift is:

□ In honor of __________________________  □ In memory of __________________________

Make an Impact – Leave a Legacy – Learn More About Planned Giving Opportunities

□ I would like more information
Welcome to Camp Oz 2013, as we celebrate our 30th year of providing a safe, educational and fun camping experience for youth affected by epilepsy. Located on a beautiful 400-acre site near Hudson, WI, YMCA's Camp St. Croix is an American Camping Association accredited camp.

Camp Oz, for boys and girls ages 9-17 with seizure disorders, combines the traditional camp experience with the security of medical staff: registered nurses are on-site 24 hours/day, as well as physicians, psychologists, a neurologist and pharmacists. Plus, siblings and friends who do not have epilepsy are welcome to attend Camp Oz.

The actual cost of Camp Oz is $1,400 per camper. To keep camp affordable for everyone, the Foundation charges a minimal $200 fee per camper and fundraises to cover actual costs. Additional financial assistance is available.

Camp Oz is designed for youth affected by epilepsy to meet others, learn more about their seizures, have the opportunity to try new things and have a positive camp experience. We want each camper to feel safe and be able to thrive. It is a vital part of Camp Oz that campers must be able to do the following:

- understand and follow directions
- stay involved in camp activities (up to 2 hours)
- interact in a respectful way with other campers and staff
- move from different camp areas and activities, with limited supervision
- participate in mostly outdoor activities, within a hilly/wooded setting
- be capable of performing activities of daily living (e.g. showering, eating, etc.)
- IMPORTANT: Camp Oz requires children to function independently within a structured group setting.

Registration opens February 1 online at www.efmn.org and watch your mailbox for a brochure. Contact 800.779.8777, ext. 2310 or nbaker@efmn.org with questions.
Save the Date!
Mark your calendar for these special events

"Light Up the Night" Gala
Saturday, May 4, 2013 at 6 PM
Minneapolis Marriott Southwest

The Foundation envisions a world where people with seizures can realize their full potential! Enjoy a night of fine food, silent/live auctions and support people with epilepsy. World-renowned guitarist, composer, producer, Billy McLaughlin will speak and perform (Billy overcame a neuromuscular disease and relearned guitar left-handed). Billy has a teenage son with epilepsy and knows first-hand about the challenges created by seizures. Phil Gattone, CEO of the national Epilepsy Foundation is our special guest, and will share an update on the national epilepsy movement.
Tickets go on sale March 1.

The annual Stroll for Epilepsy is slated for Thursday, August 8, 2013.

The Foundation hosts its first-ever golf tournament on October 7 at TPC Golf Club in Blaine.
Help raise funds and awareness for epilepsy at this event and watch for more information.
Events Calendar

Twin Cities Area

TWIN CITIES EAST METRO ADULT CONNECT
Meets the 1st Thursday of each month
January 3, February 7, March 7
6:30-8 PM
EFMN Office
1600 University Avenue West, Suite 300, St. Paul
(16, 21, 50, and 84 bus lines)

Connect with other adults affected by seizures in St. Paul, or join us from the comfort of your own home via Go To Meeting. Please RSVP.

TWIN CITIES WEST METRO ADULT CONNECT
Meets the 2nd Thursday of each month
January 10, February 14, March 14
6:30-8 PM
Southdale Library
7001 York Avenue South, Edina

Join us in the Ethel Berry Room (EIB) to connect with other adults affected by seizures – some meetings include guest speakers. No RSVP required.

METRO PARENT CONNECT
Thursday, February 21
6:30-8 PM
Gillette Children’s Specialty Healthcare
200 University Avenue East, St. Paul

Karri Larson, a registered dietician from Gillette will share insight on nutrition and epilepsy in children. Meeting is in room Wallace Cole A/B. RSVP by February 18.

YOUNG ADULT MEET UP AT OPEN MIC NIGHT
Monday, February 18
7:30 PM
Acme Comedy Club
708 North 1st Street #G31, Minneapolis
Shake the cold with some laughter! Meet other young adults affected by epilepsy (ages 18-35) at this free event. Please RSVP.

ADULT BOWLING
Saturday, March 23
3-5 PM
Park Tavern Bowling & Entertainment Center
3401 Louisiana Ave., St. Louis Park

Join us for an evening of bowling and fun at The Park Tavern. Bring a friend and/or family member for an additional $2. Pizza and beverages are provided. Please RSVP.

YOUTH AND TEEN CONNECT FAMILY EVENT
Saturday, March 23
12-2 PM
PINZ Entertainment Center
7520 32nd Street North, Oakdale

Get your bowl on with other youth and teens! Cost is $5 per family - includes bowling, shoes, pizza and beverages. PINZ also offers arcade games and laser tag. Please RSVP by March 15.

Duluth

ADULT CONNECT
Meets the 2nd Thursday of each month
January 10, February 14, March 14
5:30-7 PM
Essentia Health - SMDC
400 East 3rd Street

Join us in the Minnesota Room across from the 1st floor cafeteria with facilitator Kyah Atiere, for conversation, support and connection. The January meeting is an open forum. February features a speaker from Essentia’s intensive care unit. A speaker from Essentia’s emergency room will join us in March. No RSVP required.

WOMEN CONNECT
Meets the 4th Wednesday every other month
January 23, March 27
6:30-8 PM
St. Luke’s Hospital
915 East 1st Street

Women of all ages - join us for an evening of conversation and connecting. If you or someone you love has epilepsy, then this evening is for you! We will meet in conference room 337. Take east elevators to 3rd floor, turn right down the hall. No RSVP required.

WINTER WONDERLAND
Saturday, February 16
11 AM-1 PM
LC’s Sleigh & Hay Rides
5672 River Lane

Join us for a sleigh ride through the beautiful balsam woods along the Cloquet River. Enjoy the bonfire for roasting hot dogs and toasted marshmallows for s’mores. All ages invited! Ages 3 and up are $3, people with epilepsy are free. Please RSVP by February 14.

RSVP:
800.779.0777, ext. 2310 or rsvp@efmn.org

Nikki Baker - Twin Cities Senior Program Manager nbaker@efmn.org 651.287.2308

Stephanie Kolari - Twin Cities Program Manager Adult Programs skolari@efmn.org 651.287.2312

Amanda Pike - Twin Cities Program Manager Education apike@efmn.org 651.287.2313

Mary Giese - Duluth Outreach Coordinator mgiese@efmn.org 218.624.1330
St. Cloud

ADULT CONNECT
Meets the 1st Thursday of each month
January 3, February 7, March 7
7-8:30 PM
Great River Regional Library
1300 West St. Germain Street

Connect is open to all adults affected by epilepsy who are looking for support/info on living well with epilepsy. Please RSVP.

BOWLING AND PIZZA PARTY
Saturday, February 9
1:30-3:30 PM
Great River Bowl
208 2nd Street South, Sartell

Enjoy an afternoon of bowling and fun with family and friends. Adults and children with epilepsy are free, $5 each for family members. Open to all ages. Please RSVP by February 1.

THUNDER BOWLING
Friday, April 19
4-6 PM
Recreation Bowling Lanes
2810 North Broadway

Join us in experiencing the thrill of bowling with sound effects and music! Pizza and soda are included in admission. Price is $6 and people with epilepsy are free. Please RSVP by April 2.

ADULT CONNECT
Meets the 3rd Tuesday of each month
January 15, February 19, March 19
6:30-8 PM
Rochester Area Family YMCA
709 1st Avenue Southwest

Dr. Marietta Hoogs from the Mayo Clinic will attend and answer questions at all meetings. No RSVP required.

Fargo

PARENT CONNECT
Meets the 1st Tuesday of each month
No January meeting, February 5, March 5
7-9 PM
Pediatric Therapy Partners
2846 Brandt Drive South

Parents of children living with epilepsy can join us for support and resources. February topic is siblings of children with epilepsy. Pam Gallagher, RN and Coordinator for Sanford’s Health’s Pediatric Medical Home Program will speak about your child’s health care needs in March. No RSVP required.

CONNECTION BOWLING EVENTS
Saturday, January 26
2-4 PM
Red Ray Lanes
2105 S. Washington St., Grand Forks

Join us for an afternoon of bowling and pizza. It’s a fun way to get to know others in the Grand Forks community living with epilepsy. People with epilepsy are free, $5 for all others. Open to all ages. Please RSVP.

Saturday, February 23
3-5 PM
Stars and Strikes
434 Sheyenne Street, West Fargo

Enjoy an afternoon of unlimited bowling and a pizza buffet. People with epilepsy are free, $5 for all others. Open to all ages. Please RSVP by February 18.

RSVP:
800.779.0777, ext. 2310 or rsvp@efmn.org

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Connect with us!

Sign up for an email version of this newsletter and to receive the latest news and information from the Epilepsy Foundation of Minnesota. Visit www.efmn.org today to connect with us via email.

pot·ten·tial

A World Where People With Seizures Realize Their Full Potential

Light Up the Night Gala

save the date

Saturday, May 4, 2013 | 6 pm