

MINNESOTA Epilepsy

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July 21, 2011



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A QUARTERLY PUBLICATION OF THE EPILEPSY FOUNDATION OF MINNESOTA

SUMMER 2011



Are Clinical Trials Right for You?

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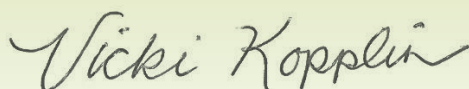
“We are deeply committed to providing opportunities to educate, connect and empower people living with seizures.”

- Vicki Kopplin

Epilepsy is more common than one would think, and can happen to anyone at anytime. Over three million Americans live with epilepsy – 60,000 of those people are right here in our community. Most people are able to get their seizures under control with medication, and yet 20 – 30% continue to struggle with seizures.

In this issue you’ll learn about clinical trials, a brave woman’s brain surgery journey, the latest in epilepsy news, and ways to get involved with EFM’s programs and services. From “Winning Kid” Ryan Walsh’s recent trip to advocate on Capitol Hill, to our expanded Information & Referral program, we are deeply committed to providing opportunities to educate, connect and empower people living with seizures.

The Epilepsy Foundation of Minnesota aims to be a one-stop shop for people with seizures to make connections with others, get reliable information/ resources and gain tools to manage their epilepsy. I’m always glad to hear from you, and can be reached at vkopplin@efmn.org or 651.287.2314.



Vicki Kopplin
Executive Director

THE EPILEPSY FOUNDATION OF MINNESOTA

is a nonprofit organization and one of fifty-five affiliates of the National Epilepsy Foundation. Serving Minnesota and Eastern North Dakota, the Foundation works to educate, connect and empower people affected by seizures.

1600 University Avenue West | Suite 300 | St. Paul, MN 55104
www.efmn.org | 800.779.0777

MISSION

The Epilepsy Foundation of Minnesota leads the fight to stop seizures, find a cure and overcome the challenges of living with epilepsy.

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CLINICAL TRIALS:

How you can help in the discovery of new epilepsy treatments

(excerpted from www.epilepsy.com)



The core element for all medical knowledge is derived from clinical trials. Clinical trials, in brief, are studies of possible new treatments or medications and are a segment of clinical research. Clinical research also can be used to look at other aspects of care, such as preventing disease, screening and or diagnosing health problems, and quality of life for people with chronic illnesses. Clinical trials often look at new medications or drugs, new combinations of drugs, new surgical procedures or devices, or new ways to use existing treatments.

However, before a new approach can be tested in humans, it must already have shown some benefit in laboratory testing, animal experiments, or in testing with a small group of volunteers. The goal of clinical trials is to determine if a new treatment both works and is safe. In fact, new medications cannot be sold in the United States until they have been through clinical trials. Therapies that prove effective during this research may go on to become approved and then widely available treatment options.

WHO CAN PARTICIPATE IN CLINICAL TRIALS?

Epilepsy researchers are often looking for individuals with chronic seizures with particular characteristics depending on the study. Some epilepsy trials are limited to people who haven't started treatment, such as new onset epilepsy or new seizures. Many others focus on people where treatment has failed, the drug-resistant or refractory epilepsy patient group. Even in some instances, healthy individuals are needed for some trials. The important point is that there are a lot of different options that can go into one's selection for a trial.

Many people volunteer for a clinical trial because it is an opportunity to help researchers find a new way to fight disease. Even though volunteering may help others in the future, there is no guarantee that the treatment will be effective for the patient at hand. Complicating this picture is that some of these trials use a placebo (a pill or liquid that looks like the treatment but has no active ingredients) as a comparison for the drug being tested. In a "blinded" trial,

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EFM in Action

Youth Programs

2011-2012 WINNING KID NAMED



Congratulations to 14 year-old Emily duSaire! Emily was diagnosed with epilepsy at age three. She was put on medication and remained seizure-free until age eight, when she began having seizures again. Emily deals with seizures weekly, and is currently on numerous medications to gain control.

Emily struggles in school due to the medications and effects of her seizures; she sees a tutor every day and on the weekends. Emily is determined to do well and move forward with her life, despite having seizures. Emily is a happy, positive, sweet girl who speaks both English and Spanish, plays piano and enjoys art and quilting. Emily lives in St. Louis Park with her parents, Martin and Kim, and her two younger siblings, sister Anna, 11, and brother Ryan, 6.

Emily kicks off her 2011-2012 term as Winning Kid with a free week at Camp Oz in June! EFM's Winning Kid (ages 10-16) represents youth at events, gets involved with their school and community and works to raise seizure awareness.

RYAN WALSH ON CAPITOL HILL



2010 Winning Kid Ryan Walsh traveled to Washington, D.C. as one of 42 selected youth ambassadors from across the country, to the national Epilepsy Foundation's "Kids

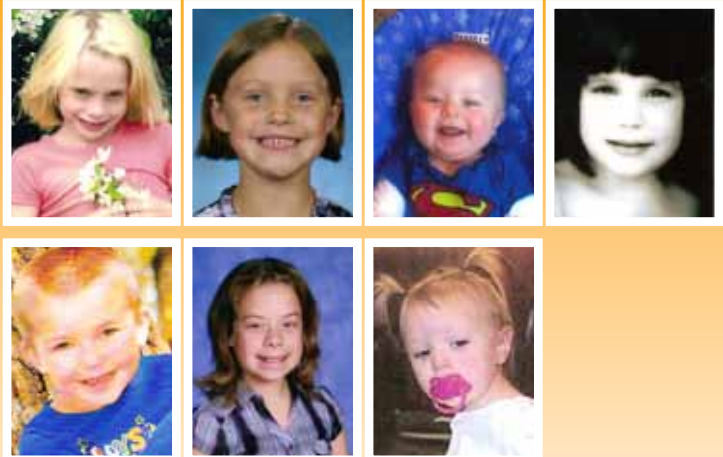
Speak Up!" conference for youth with epilepsy. This group of youth ambassadors petitioned congressional leaders for aid in assuring better access to care and more research toward a cure for epilepsy. Participants were trained to become advocates on behalf of the nearly 3 million people with epilepsy in the United States; 60,000 people in Minnesota and North Dakota.

"Minnesota was well-represented at the national events on Capitol Hill by the Walsh family. It's empowering for youth with epilepsy to advocate with their congressional representatives and meet others facing similar challenges created by epilepsy," said EFM Executive Director Vicki Kopplin.



**A PROGRAM OF THE
EPILEPSY FOUNDATION OF MINNESOTA
CELEBRATING CHILDREN WITH SEIZURES**

All kids are special, but we think kids with epilepsy are shining stars! At the Epilepsy Foundation of Minnesota, we celebrate kids with epilepsy by making them Shining Stars. The program is FREE and open to kids of all ages with epilepsy.



Please call us for a brochure at
651.287.2310 or
register online at **www.efmn.org**

EFM in Action

Community Events and Education

EFM Events: Connecting people living with seizures

Gala Film Premiere

Hollywood filmmaker Nathan Jones premiered his short film, which plunges viewers into the visceral experience of having a seizure. Host Leah McLean of Five Eyewitness News led gala guests through a fun-filled, red carpet evening. Nearly \$135,000 was raised to support programs and services for people with epilepsy.



Rochester Pizza Party

Teens gathered in Rochester with family and friends to learn about volunteer opportunities and connect with their peers.



EFM Day at Target Field

The rain held off for our annual Minnesota Twins game, where families enjoyed a ballgame and the opportunity to chat with others affected by epilepsy.



Epilepsy in the News



LINK FOUND BETWEEN EPILEPSY AND AUTISM

Researchers at the University of Montreal have discovered a gene that predisposes people to both autism and epilepsy. It's long been thought there is a connection between the two disorders, as about one-third of people with autism also suffer from epilepsy.

The team, led by Dr. Patrick Cossette, studied the genetics of a large French-Canadian family, all of whom have epilepsy and some of whom are autistic. The researchers found all members of the family had severe mutation in the synapsin gene (SYN1).

"The results show for the first time the role of the SYN1 gene in autism, in addition to epilepsy, and strengthen the hypothesis that a deregulation of the function of synapse because of this mutation is the cause of both diseases," said Cossette. "Until now, no other genetic study of humans has made this demonstration." Cossette believes these new findings will pave the way for better treatments for both epilepsy and autism.

LARGEST U.S. CHILD CARE PROVIDER ADOPTS NATIONWIDE SEIZURE CARE POLICY

Working in collaboration with the Epilepsy Foundation, the largest corporate child care provider in the U.S., Knowledge Learning Corporation, which operates KinderCare and Knowledge Beginnings child care centers, has adopted a comprehensive written policy on providing first aid to children with epilepsy.

The policy will help ensure that children with epilepsy attending any of the company's 2,200 centers nationwide are administered, as needed, both routine and emergency anti-seizure medications.



FEDERAL COURT IN BALTIMORE GRANTS AWARD IN ADA DISCRIMINATION CASE

A federal court in Baltimore has awarded a police detective \$225,000 in an ADA employment discrimination case. William Blake brought a suit against Baltimore County, Maryland after a commanding officer ordered that he undergo a neurological testing to determine if he was fit for duty, ten years after he experienced a single seizure and received clearance to return to work.

Mr. Blake alleged that the testing was ordered in retaliation for his testimony in favor of a fellow officer who was forced into retirement because of epilepsy. The commanding officer provided no justification for the testing, and a co-worker testified that Mr. Blake was in no risk of endangering the Department or the public. The court found that the testing requirement amounted to disability-based discrimination, and an invasion of Mr. Blake's rights under the ADA.

MAN BIKES 10,000 MILES FOR EPILEPSY

Florida resident Glenn Fenster is currently on a 10,000 mile bike ride across the country to raise epilepsy awareness.

He started his journey in Miami and plans to pedal his way to New York and into Canada all the way to Fairbanks, Alaska. From Fairbanks, he'll travel the west coast and hopes to end in California by July.

Fenster's son suffers from epilepsy. "When he was nine, we were on the tennis court together and...he fell from a seizure. When I went to put my hand to pick him up, he pushed it out of the way. I said, 'Son don't you want help up?' He said no. I asked, 'How do you keep getting up?' He said, 'Dad, I've never seen you stay down,'" Fenster explained.

Living in a Brainstorm: Erica's Journey

Below is a series of blog excerpts (edited for length) from Erica Egge, a brave 25 year-old woman who wanted to share what it's like to live with simple partial epilepsy and share candid insight on her decision to undergo brain surgery to gain better control over her seizures.

OCTOBER 23, 2010

The realization/transformation in my life that made me quit my job and decide to have brain surgery has come at the same time that I've noticed more and more the things that I can't do because of my epilepsy. I'm over it. I'm done. I take fifteen pills a day, some of which give me side effects to the point where I can't stand up and walk straight for two hours. I'm on so many pills right now, but I'm still having seizures. Something needs to change. With surgery, there's a minimum 70% chance that I'll never have another seizure and won't have to take medicine anymore.

OCTOBER 29, 2010

I was 7 years old when I was diagnosed with epilepsy, and since that day, I've been determined not to let it dictate my life. I didn't see how much the epilepsy was taxing me until I found myself spending a fortune on handfuls of pills and carving out hours in a day to deal with side effects, but



still forgetting to record the number of seizures I was still having.

NOVEMBER 5, 2010

The line I hear every time is, "You have epilepsy? I didn't know that. You're so normal; I wouldn't have guessed." What does that say about the perception of epilepsy as a condition? The biggest problem, the smoke machine of rumors, is the abhorrent lack of awareness. Spreading awareness about epilepsy is a combined effort to chip away at it. Every time I tell someone that I have epilepsy and explain to them what that means I, one person, have chipped.

NOVEMBER 24, 2010

I just saw the doctor, who showed me a plastic model of a brain and pointed out where my seizures are. The short circuit occurs right between the motor (blue stripe) and sensory (red stripe) areas on the left side. Today is the MRI, and I'll come back Friday for an early morning EEG, followed by one to four

days of 24-hr monitoring. God, I really hope I'm a candidate.

NOVEMBER 27, 2010

In the same vane as there's no such thing as a free lunch, there's no such thing as an easy procedure to extricate myself from the state of epileptic. In my case, because of the placement of the origin point, I would have to have two surgeries. The first one would be to open my skull and place electrodes directly on the surface of my brain. I would then be closed back up for a day or two while more seizures were monitored and recorded. The next surgery, a couple days later, would be to remove the electrodes and subsequently remove the origin point of my seizures. Afterwards I would almost certainly be on medication indefinitely, though much less. I don't yet know if I am, in fact, a surgical candidate, but already I'm conflicted. Breaking my skull open twice. Is the prudent thing to run away? I really don't know if I am strong enough.

DECEMBER 9, 2010

I just got off the phone with my doctor. For the surgery where they put the electrodes on my brain, there's a 60% chance that they'd be able to find the exact spot where my seizures originate AND have it be in a safe place to operate so they'd be able to offer me the second surgery. The other two options are to adjust my medications, or to implant a device called the Vagus Nerve Stimulator. Those each have a 40% chance of greatly reducing my seizures. So for now, I'm going to go ahead with the evaluations for the surgery.

DECEMBER 15, 2010

"On January 17th, you'll have a four-hour psych evaluation. On the 18th, you'll have an MRI, which will last at least two hours. You'll talk to the neurosurgeon on the 19th, and have your first surgery on the 20th." This is actually going to happen. On January 20th, 2011.

JANUARY 20, 2011

Erica went into Operating Room about 8:00 a.m. We are expecting her to be close to out of the recovery room roughly about 3:00 p.m. today.

JANUARY 21, 2011

Erica managed to have some small seizures this afternoon. The hope is that she'll have more seizures tonight so that her neurologists and surgeons can get the data they need to decide what comes next.

JANUARY 24, 2011

Erica rolled into the OR at approximately 2:45 CST. There is a 10-15% chance following surgery she will have facial numbness and/or some speech/recall issues and 55-60% chance of being seizure-free (with continued medication).

JANUARY 25, 2011

Erica is exhausted and in a lot of pain, but (as always) remains positive and thrilled to be on this side of the surgeries. She has a half-shaven head, where you see the large section of her head that was stapled back, and a drain tube.

JANUARY 29, 2011

It seems that being released from the hospital helped Erica turn a big corner in her healing process. She still needs to sleep a fair amount of the day, but when she's awake she is her old self. Correction: She's far better than her old self. Through her craniotomy left her with 60+ staples in her head and less-than-perfect use of her right hand, to me it represents the new life she fought so hard to get.

JANUARY 31, 2011

Yes, I am in pain. I'm exhausted. But by far, the dominating emotion is love. Love and gratitude. It all seems so surreal; the staples and the headaches remind me that it really happened. I'm still processing.

FEBRUARY 4, 2011

I began writing this in October, when I first decided to have surgery. It started as a way to keep a small handful of family and friends updated so I wouldn't have to repeat the same story over and over on the phone, but somewhere along the way, it changed. It's become bigger than me; an energy source bigger than any one person.

FEBRUARY 20, 2011

Recovery is kind of like spring: every day is wildly different, but even if it snows, you're still steadily on your way to summer.

FEBRUARY 24, 2011

In the past month - I can't believe it's already been a month - I've progressed

by leaps and bounds, but I still get terrible head rush almost every time I stand up. I know it's something that will take time. I'm still working on resigning myself to the "marathon, not a sprint" truth. I'll get there.

MARCH 20, 2011

Tomorrow I go to Mayo for the beginning of my follow-up testing. Tomorrow is the neuropsych exam, the results of which I'm not worried about. Tuesday consists of the test I'm most worried about: the EEG. The MRI is on Tuesday as well, but the EEG is the test that will show if there's still seizure activity going on in my brain. The EEG will show us if the surgery was successful.

MARCH 28, 2011

I still can't believe it. I'm seizure-free. The doctors were clear that a clean EEG didn't mean I was cured, but it's a good sign. The doctors also talked about the pathology report on the chunk of brain that they took out. Apparently it was a cortical dysplasia that had bothered me for so many years. What that means is that when my little fetus brain was forming, a few neurons missed the train and ended up growing in some incorrect fashion, causing me to have seizures. The neurologist said that in July, as long as I'm still seizure-free, I can start to wean off one of my three seizure meds, and if I'm still clean next January, a year from the surgery, I can get off another one! It hasn't sunk in yet. I have a new life.

To read Erica's entire blog, visit <http://livinginabrainstorm.blogspot.com/>. Epilepsy affects people in different ways and brain surgery results/options vary; consult your medical provider for more information.

Continued from page 3

neither the participant or the doctor will know who gets the placebo and who gets active treatment. This is to prevent either party from having preconceived ideas about the outcome. Often, however, at the end of the blinded period, there is an open period which is usually much longer, during which everyone gets active treatment. The treating doctor performing the study will explain exactly how the study will run before a volunteer makes a decision about participating.

HOW DO I FIND OUT ABOUT A CLINICAL TRIAL?

Sometimes the treating doctor may recommend a clinical trial for a given patient or an individual may actually find out about a trial and ask to participate. Oftentimes groups such as the Epilepsy Therapy Project, Epilepsy.com, and other advocacy organizations like the Epilepsy Foundation let people know about clinical trials. There may be some type of screening tests that are done prior to enrollment in order to make certain that the individual is appropriate for the trial.

INFORMED CONSENT

It is important that you understand that you need to have as much information about the study and the treatment being investigated in order to make a well-informed decision. Facilitators for these studies provide what is called an informed consent document, which is read and signed by the participant before they enter into the trial. This informed consent document contains information that one needs to know about the study before deciding whether to participate. Some of the information on an informed consent document includes:

- What is going to happen during the trial, including the test you may be given
- Known risks and benefits of the experimental treatment
- How long you will be expected to participate in the trial
- Other treatments that might help you instead of the treatment being tested
- Whom to call with questions

This form needs to be explained in language that you can understand and no one should pressure an individual into signing up for a trial if there is some sense of hesitation. Signing this document means that one has agreed to participate in the trial, but it isn't a contract, and you can leave the study at any time. If your child is enrolled a clinical trial you also go through this informed consent process together, but you have to give permission for your child to participate.

QUESTIONS TO ASK

- Who is in charge of the study?
- Do the people running the study have a conflict of interest in the outcome?
- What is being found out; what is expected of me?
- Is it possible that I might receive a placebo?
- What benefits or risks can I expect?
- How long will the study last?
- What happens if my condition gets worse during the study?
- Can I see my own doctor during the study?
- Do I need to pay for any part of this study; who pays if I am injured in the study?
- How will participation affect my life?
- What happens at the end of the study; will I ever be told the results of the study and when?
- Who will know that I am participating?

PROTOCOLS: WHAT WILL HAPPEN?

The map for clinical trials follows an action plan that is laid out by the researcher called a protocol. The protocol explains what will be done in the study and outlines the following items:

- Who may participate
- How many people take part
- What will the treatment plan entail
- The type and frequency of tests
- How will the results be measured
- The reasons the study may be stopped
- The situation in which researchers may stop giving the treatment to patients
- Known or possible side effects
- Possible benefits of the treatment

SAFETY

To ensure the safety of people in the study the organization that sponsors the study, such as the medical center, clinic, or research institute must approve the protocol. There is a group mandated by the federal government called the Institutional Review Board (IRB) at each study site which reviews the protocol. The IRB includes people from the community as well as healthcare professionals. It reviews all protocols to make sure that participants are treated humanely and ethically. This committee also looks at issues, such as whether the likely benefit of the treatment is worth its risk. If the risks to the participants are found to be too great, the IRB can require changes in the protocol or reject the study. The IRB also checks to see if any of the researchers have significant conflicts of interest.

A clinical trial may also have another group called the Data Safety Monitoring Board overseeing it. This board is composed of people who aren't directly involved in conducting the study. The Data Safety Monitoring Board can stop the study at any time to see if the treatment isn't working or is causing too many side effects. A trial can also be halted by this board if the treatment is proven to be better than the standard treatment. It may be working so well that it should be made available to everyone outside of the clinical trials.

SO WHAT ARE THE TYPES OF CLINICAL TRIALS?

Phase 0

Phase zero trials are a relatively new type of study. They are designed to weed out treatments that aren't promising before they go on to what's known as Phase I research. These trials are small, typically less than 10 people, and usually focus on how a drug acts in the body and how the body reacts to it.

Phase I

This is typically the first step in testing in humans, and is often done in healthy volunteers rather than patients. At this point researchers study:

- How much of the treatment to give?
- When should it be given and how often?
- What is the highest dose that can be given safely?
- How the body reacts to the treatment?
- Any harmful side effects?

Earlier studies have often been done only in animals so the new treatment may pose some risk when first tried in humans. Researchers try to minimize these risks by starting with a very small dose and then increasing it only if there are no or few side effects. Phase I trials usually include a limited number of people, typically anywhere from 20 to 80 individuals. The number can vary depending on the goals of the research.

Phase II

This step focuses on determining whether a new approach works as intended. For example, does this drug actually seem to stop seizures? Researchers also monitor participants for common, short term side effects that occur with the therapy. Some things aren't yet known about the treatment so risks are still present. Several hundred people at many different centers may participate in a Phase II study.

Phase III

If a treatment is shown promise in Phases I and II, it can move on to this phase. Participants are often randomly

assigned, meaning neither the patient nor the doctor can choose which treatment is received, the experimental treatment or the standard treatment, or even the placebo. Randomization helps to avoid bias in the study and in doing so, improves the likelihood that the results are correct. Phase III trials provide more information about the safety of the experimental treatment and determines whether the standard or the experimental treatment has better outcome rates and fewer side effects. These trials usually include several hundred to several thousand people. Large trials make it easier to estimate what would happen if the experimental treatment were available to everyone with a condition. If a treatment performs well in a Phase III trial, the researchers may submit an application to the Food and Drug Administration (FDA), asking permission to make it available to the public. The FDA approval process generally takes about a year. The process is quicker for priority drugs, drugs that provide a significant advance in treatment for a life threatening condition. The FDA tries to rule on these within six months. In other cases it can take a few years in order to hear the final ruling.

Phase IV

In some cases research continues even after the FDA has approved a treatment. This research, sometimes called post-marketing research, tracks side effects in people receiving the newly approved treatment. Phase IV studies aren't required for every treatment, but the FDA can ask a manufacturer to conduct a Phase IV trial to further evaluate long term safety and effectiveness. This has been done for epilepsy drugs (i.e. Felbamate) Companies may also choose to do Phase IV research to compare their product with a competitor. Studies may also be done in new populations or seizure types that were not tested in the initial trials. Several hundred to several thousand people may take part in a Phase IV study.

SHOULD I PARTICIPATE IN A TRIAL?

Researchers need volunteers for clinical trials, healthy people, as well as those at risk or diagnosed with epilepsy. By participating, you help researchers find new ways to stop epilepsy. Volunteering is also a way to access treatment that otherwise isn't available. If you're considering a clinical trial because you've been diagnosed with epilepsy, it is important to take time to learn about seizures and epilepsy and your options. It is essential that you talk with your physician, other healthcare providers, and discuss your options with those that are close to you.

Learn more about research at our Midwest SEIZURE SMART Conferences July 21 and October 15.

Spotlight on Education

2011 Midwest SEIZURE SMART Summer Conference



Midwest SEIZURE SMART Conference

Thursday, July 21

9:00 a.m. - 3:00 p.m.

Duluth Entertainment Convention Center

350 Harbor Drive Duluth, MN

Registration is \$30; scholarships are available
Register online at www.efmn.org or call 800.779.0777.

Twice a year, our Midwest SEIZURE SMART Conferences bring together national/local experts in the field of epilepsy, and people living with seizures. Connections are made, educational materials are shared and the latest developments in seizure management are discussed. The summer conference features keynote speaker Dr. Kimford Meador, Director of the Emory Epilepsy Center and Professor of Neurology at Emory University in Atlanta. Mark your calendars for our fall Midwest SEIZURE SMART Conference: October 15, 2011 in Minneapolis.

GOLD EVENT SPONSORS



EXPANDED INFORMATION & REFERRAL PROGRAM

Our Information & Referral is expanding to meet the needs of people who need guidance and resources about epilepsy. We strive to help improve the quality of life of people affected by seizures, meeting the individual needs of the wide spectrum of epilepsy care needed. The program is:

- A CONNECTOR OF SERVICES – helps locate the appropriate services for clients.
- RELIABLE REFERENCE – refers clients to organizations that meet individual needs.
- EDUCATED INFORMER – dispenses current seizure education and resources surrounding epilepsy.
- BROKER OF INFORMATION – allocates literature/DVDs/other media to clients and identifies the most suitable resources.



Genna Maxwell, EFM's new Information & Referral Coordinator, is a licensed social worker who has experience with 'Care & Share', a homeless shelter in Crookston, MN and a day program for adults with disabilities. Contact Genna at gmaxwell@efmn.org or 651.287.2303 with your questions. We're at your service!

SCHOLARSHIP WINNERS ANNOUNCED

EFM is pleased to announce the 2011 recipients for the Elam Baer and Janis Clay Educational Scholarship program, \$1,000 to students with epilepsy. This program is in its sixth year and is made possible through the generosity of Elam Baer and Janis Clay.

Kelsey Busch	Crosby, ND
Julie Curley	Maplewood, MN
Abigail Dunham	St. Paul, MN
Jami Friday	Rush City, MN
Abdirahman Hussein	St. Paul, MN
Michael Scardigli	Andover, MN
Jillian Steen	Eden Prairie, MN
Ryan Stenzel	New Richmond, MN
Mackenzie Watson	Waconia, MN
Patrick Zimmer	Litchfield, MN

Thanks for Your Support

Honorariums

Jeremy Amundson
Becky Amundson

Jane Bale
Mark Bale

Travis Boyum
Troy Hanisch

Ashley & Michael Clapp
Robert Jones

Kendahl Cowmeadow
Tacy Stocking

Erica Egge
Peter Egge

Hayla Foss
Jillian Hiscock

Michele Frankfurth
Thomas Frankfurth

Ryan Gallagher
Tim Gallagher

Jacob Humpal
Mike Humpal

Taylor Mueller
Merchants Bank

Erin Ponto
Joseph Freund

Nolan Rock
Susan Glander
Jessica Hack
Leann Stephans

Sybil Rubin
Nancy Strauss

Andrea Samsten
Lynn Samsten

Whitney Steege
Mark Steege

Brady Stevenson
Matt Stevenson

Brenna Suchla
LaRayne Kupietz

John Thompson
Carol Johnson

Fionnula Tyler
Patrick Tyler

Memorials

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Peter Angelo
Patricia Fredericks
Elizabeth Galin
Jennifer Gonzalez

Sarah Margaret Carlson
William Keefer

Father of Charles Breitsprecher
Jerome J. Keating Branch Nine
National Association of Letter
Carriers

Shawn Garlinghouse
Neil Grunberg

Aubrey Gjerswold
Minnesota Epilepsy Group

Marcus Hertz
Nancy Strauss

Thomas P. Hoffman
Byron Crews

Marvin Hoppe
Guy Hoppe

Tony King
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Tracy Gulliver

Maxine Stengrim
Richard Stengrim

Marv Winslow
Alice Blomquist



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Events Calendar

Twin Cities Area

ADULT PEER SUPPORT GROUP

**Meets the 1st Thursday
August 4 & September 1
6:30 – 8 PM**

EFM's conference room
1600 University Ave. West, Suite 300
St. Paul, MN

Connect with adults affected by seizures, get new resources and enjoy a speaker around a topic about epilepsy.

PARENT CONNECT

EAST METRO

**Tuesday, July 12
7 – 9 PM**

Sun Ray Public Library
2105 Wilson Avenue
St. Paul, MN 55119

PACER Center guest speaker
Jody Manning shares insights and information with our group.

PICNIC FOR ADULTS WITH EPILEPSY

**July 14
6 – 8:30 PM**

Minnehaha Falls Regional Park
Park Area 2
Look for RED balloons
Picnic food and beverages provided!

All adults with epilepsy and their guests are invited. The picnic area is north of Godfrey Road and south of Nawadaha Blvd and 43rd Avenue South. RSVP by calling 651.287.2310.

WOMEN'S DISCUSSION GROUP

**September 8
6:30 – 8 PM**

Southdale Library
7001 York Avenue South
Edina, MN

Share stories of hope and strength with other women affected by epilepsy. Join us at the picnic on July 14 and at the Stroll on August 11!

PARENT CONNECT

WEST METRO

**Tuesday, September 13, 2011
7 – 9 PM**

Brookdale Library
6125 Shingle Creek Pkwy.
Brooklyn Center, 55430

Julia Doss, M.D., of the Minnesota Epilepsy Group (MEG) addresses the topic "More than just seizures: epilepsy, psychological and social issues."

EPILOGUES WRITING

**COLLECTION: Call for Entries
September 1 – October 31**

Any person affected by seizures is invited to submit written work before October 31, 2011. Up to three entries per person, per year (original work by submitting author). Entry must be typed (12-point font) or clearly printed with a prose maximum 2,500 word count. Recognition of entries will be in November, National Epilepsy Month, and may include: public readings, newsletters, website, and Epilogues book collection.

Rochester

HONKERS BASEBALL GAME

Sunday, July 24 at 1 PM
Mayo Field

We're taking you out to the ball game! Two free tickets for individuals or families affected by seizures. Additional tickets available for \$3 each. RSVP to Sue Ringhofer.

PARENT CONNECT – 3 GROUPS IN ONE!

Monday, Sept 19 | 6:30 PM

Quarry Ridge Club House
1823 Quarry Ridge Place

Choose from three separate "breakout" sessions for parents of children with epilepsy. Breakout sessions will be held for: Parents, Parents of Teens & Young Adults, Parents of Children on the Ketogenic Diet. RSVP to Sue Ringhofer.



Nikki Baker
Senior Program Manager
nbaker@efmn.org
651-287-2308



Amanda Van Wyhe
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Sue Ringhofer
Outreach Coordinator
sringhofer@efmn.org
507.287.2103

Duluth

HUSKIES BASEBALL GAME

Sunday, July 31, 2011
Game starts at 5:05 PM

Meet Mary at entrance after 4 p.m. to pick up tickets. (Mary's cell 218.343.0171) Shining Stars, kids and adults with epilepsy are free. Additional tickets are \$4 per person - Kids 3 and under free. Tickets include a reserved seat and \$5 HUSKYBONZ.

Call Mary Giese to reserve your tickets by July 28.

St. Cloud

RIVER BATS BASEBALL GAME & PICNIC

Tuesday, June 14
Picnic at 5:45 PM | Game at 7:05 PM

Joe Faber Field at Municipal Athletic Complex (MAC)
5001 Veteran's Drive, St. Cloud, MN


Bring the whole family for a night of baseball and fun! Meet in the Plaza Picnic area and meet River Bats mascot "Earl Batty, Jr." Tickets are \$5 and free to people with epilepsy. An RSVP to Lori Braegelmann is required.

PARENT CONNECT

Tuesday, June 21 | 6:30 – 8 PM

EFM Office
2229 Roosevelt Road, St Cloud

Have a child with seizures? Connect with other parents facing similar issues and get connected to resources in our newly-formed parents group. RSVP to Lori Braegelmann.



Lori Braegelmann
Outreach Coordinator
lbraegelmann@efmn.org
320.203.9722

CONNECTIONS SUPPORT GROUP

Meets the 2nd Thursday
each month
July 14 at 6 PM

Potluck picnic at Lincoln Park Shelter at 25th Avenue West and 3rd Street. Sloppy Joes provided and bring a dish to share. RSVP to Mary Giese.

August 11 – Connections joins everyone at the Stroll for Epilepsy at Park Point.

September 8 – Join us at Essentia in the Minnesota Room across from the first floor Cafeteria with facilitator Kyah Altieri. Brette Garnatz will present a program from the American Lung Association.

WOMEN'S GROUP

Meets the 4th Wednesday
of every other month
Wednesday, July 27 | 6 PM

Picnic at Lincoln Park Shelter 25th Avenue West and 3rd Street. Sloppy Joes provided and bring a dish to share, games for the kids included! RSVP to Mary Giese.

Wednesday, September 28
6:30 to 8:00 PM

St Luke's Hospital

Facilitator Lesa Raihala leads this support group especially designed for women affected by epilepsy. Take the East elevators to the third floor to reach Conference Room 3E.

PARENT CONNECT

Join the Women's Group Picnic on Wednesday, July 27 at the Lincoln Park Shelter, 25th Avenue West and 3rd Street. RSVP to Mary Giese.



Mary Giese
Outreach Coordinator
mgiese@efmn.org
218.624.1330

Fargo

PARENT CONNECT

Meets the 1st Tuesday of each
month
July 5, August 2, September 6
7 – 9 PM

Pediatric Therapy Partners
2846 Brandt Drive South, Fargo, ND

Parents of children living with epilepsy join us for a time of support and resources. Meeting includes time for sharing as well as topical speakers, suggested by participants. Childcare not provided.

ADULT CONNECT

SUPPORT GROUP
Meets the 1st Monday
of every month

August 1 & September 5 (no July
meeting) | 6:00 – 8:00 PM

Sanford South University Campus
Conference Room 1A-3 (look for signs)


Adults living with epilepsy join us for support, a discussion of pertinent health topics and living with epilepsy. Watch for emails with more specific information!

EFM DAY AT THE REDHAWKS

Sunday, August 28
Noon Picnic & 1:00 PM Game

FM Redhawks Stadium
1515 15th Avenue North, Fargo, ND

Calling all baseball fans...let's celebrate the success of the Stroll and watch some baseball! We have 50 tickets for this game and they will go fast, so reserve yours today! One free ticket for adults and children living with epilepsy, all others are \$5. RSVP required to Amy Beecher.



Amy Beecher
Outreach Coordinator
abeecher@efmn.org
701.429.1165



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Stroll for Epilepsy

A walk to benefit people affected by seizures



August 11, 2011

It's not too late to Stroll with us! Join us for the largest fundraising and awareness event in MN and ND to benefit people with seizures on August 11, 2011. All Strolls are approximately two miles and feature post-Stroll festivities.

Register at www.efmn.org or call 800.779.0777 for an entry form.

Twin Cities St. Cloud Duluth Rochester Fargo