

MINNESOTA Epilepsy

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A QUARTERLY PUBLICATION OF THE EPILEPSY FOUNDATION OF MINNESOTA

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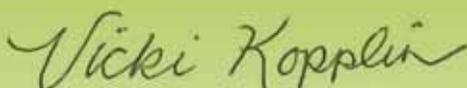
Stroll with us on August 7

“As we begin our next 60 years serving people with epilepsy, we celebrate the hopes and dreams of people with seizures.”

Our 60th anniversary year is making history:

- We had the most media coverage of “Rise Above Seizures” Day on May 15 in EFMN’s history!
- More than 12,000 balloons were distributed to 140+ cities across MN & ND to raise epilepsy awareness.
- Camp Oz hosted 109 campers and Coach Kill came for a visit, as we launch his “Chasing Dreams” fund to support kids with epilepsy this year.

In this issue, you will read about new medications for epilepsy, why families Stroll and find numerous ways to get involved with EFMN in our events calendar. We hope to see you soon!



Vicki Kopplin
Executive Director

THE EPILEPSY FOUNDATION OF MINNESOTA

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

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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Clinicians Corner

New Options in Treating Epilepsy

By Joanne Rogin MD

Midwest Center for Seizure Disorders, Minneapolis Clinic of Neurology



In spite of many antiepileptic medications now available, approximately one million Americans continue to have seizures, even while on several antiepileptic drugs. There is thus a need for new options. Two new antiepileptic medications, Aptiom and Fycompa, have recently been approved in the United States. Both have been used in other parts of the world for several years, and have been used in clinical trials by members of the Epilepsy Foundation of Minnesota's Professional Advisory Board. Both have improved seizure control in patients who continue to have seizures.

Aptiom (generic name eslicarbazepine acetate), made by Sunovion, is used to treat partial onset (focal) seizures with or without secondary generalization in conjunction with another

antiepileptic drug. Aptiom is a unique new medication which may be taken once daily and decreased seizures in individuals having seizures on other antiepileptic drugs. Although the precise way in which the antiepileptic drugs work is not fully understood, Aptiom works on the inactivated sodium channel, more prevalent when a seizure is likely to occur, and may thus result in reduced seizures.

The effectiveness of Aptiom was demonstrated in three clinical studies in which Aptiom was more effective than placebo in decreasing seizures in those having seizures while on one to three antiepileptic drugs. In the clinical studies, oxcarbazepine was not permitted as it shares a common metabolite with Aptiom. The use of the two medications together has thus not been studied. As with all

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New Options in Treating Epilepsy (Continued from page 3)

drugs, side effects may occur. The most common side effects were dizziness, sleepiness, nausea, headache and double vision, increased at higher doses, lower when starting at 400 mg compared to 800 mg, and similar to placebo at the end of three weeks in the studies.

Aptiom is available as 200 mg, 400 mg, 600 mg, and 800 mg tablets. It is taken once daily, with or without food, and may be crushed or chewed. Aptiom is started at 400 mg daily and increased to 800 mg daily after one week, which may be an effective dose. Aptiom may be further increased to 1200 mg if needed. Aptiom is a new medication with good tolerability and effectiveness. With once daily dosing and one week to an effective dose, Aptiom provides a good option in treating our patients with epilepsy.

Fycompa (generic name perampanel) made by Eisai, also was recently approved to be used with another medication to treat partial onset (focal) seizures with or without secondary generalization in individuals ages 12 years and older. It may be taken once daily and decreased seizures in individuals having seizures on other antiepileptic medications. Fycompa works in a unique way, only affecting the neurotransmitter glutamate, which decreases excitability and may thus decrease seizures, although the precise mechanism by which our drugs work is not entirely known.

Fycompa was shown to be effective in three clinical trials. It was significantly more effective than placebo in decreasing seizure frequency in people taking up to three antiepileptic drugs and continuing to have seizures. Side effects may occur with all medications, and most common side effects

seen with Fycompa were dizziness, sleepiness, fatigue, irritability, and unsteadiness, which increased with higher doses. Psychiatric and behavioral side effects including aggression, hostility and irritability have been reported very rarely. Monitoring with decreasing or stopping the drug is recommended should this occur.

Fycompa is available as 2 mg, 4 mg, 6 mg, 8 mg, 10 mg and 12 mg tablets, and is taken once daily at bedtime. The tablet should be swallowed whole. Fycompa is started at 2 mg daily and may be increased weekly to an effective dose from 4 to 12 mg. Fycompa is effective and well-tolerated with once daily dosing. It may be increased gradually over several weeks to an effective dose of 4 to 8 mg. With a unique mechanism of action, Fycompa offers the opportunity for improved seizure control.

Our two newest antiepileptic drugs both have been shown to be effective and generally well tolerated with few side effects in individuals still having seizures. Keep in mind that most individuals did not experience side effects in the studies and with use. Dosing may vary depending on other medications you may be taking. Talk to your doctor if you are still having seizures. These and our other antiepileptic drugs provide good options in improving seizure control and achieving our goal of no seizures and no side effects.

Joanne B. Rogin, M.D.
Midwest Center for Seizure Disorders
Minneapolis Clinic of Neurology
Professional Advisory Board, EFM

Help with Medications

There are many different medicines that can prevent or stop seizures. Some tend to work better for certain kinds of seizures than others, and if one medicine fails another may work better. EFMN's Information & Referral Program offers information on the different anti-epileptic medications, as

well as resources on how to access them. To request an anti-epileptic medication guide or to learn about the different prescription assistance programs available, please contact Information and Referral at 800.779.0777, ext. 2303 or kryan@efmn.org.

Seizures Don't Stop Me

By Sonny Chase



I was born in 1967 and after only six months I had a high fever. After convulsions, they kept me for a couple of weeks taking tests, with no answers. During my kindergarten year, signs [of seizures] began to show with daydream stages becoming frequent. Doctors said medications were needed. The very first medication was Dilantin and I tried many others.

Throughout life, epilepsy kept me from moving ahead with future jobs. I always supported myself and felt good about it, but not driving held me back. Depression had slowly started and also with more medication. Nobody really noticed this, because it had a snowball effect.

In 2011, after years of many different neurologists one finally said "you're out of my course of care" and it was wonderful. So he sent me to another clinic and within six months of testing I qualified for brain surgery.

On April 12, 2012 I went into surgery and have been seizure-free since then. Now driving gives me the freedom I have never had. I'm working full time again, and can take my 12 year-old daughter to simple things like seeing a movie. I rise above seizures.

Dealing with epilepsy throughout the school years was difficult. My grade average was low and I always wondered why. Not being able to get a driver's license made high school difficult, so I second guessed myself for going to college.

Shining Stars

The Foundation's largest youth program celebrates youth with epilepsy, connecting them with others to reduce isolation. Join the 300+ Shining Stars across MN and ND at efmn.org or call 800.779.0777, ext. 2310.



EFMN in Action

Proudly serving people across MN and ND



Nick Winge

Nick Winge, a Shining Star, is pictured here with his go kart that he uses to raise epilepsy awareness in Northwest MN.



Camp Oz

Camp Oz welcomed 109 campers this year and fun was had by all, especially the day Coach Kill and his family came for a visit.



Art Therapy

The third year of art therapy, sponsored by Lundbeck, was recently completed. The program serves both youth and adults.



Families Connect in Duluth

Families Connect in Duluth had 30+ people together this spring making crafts, playing games and sharing their epilepsy journeys over dinner.

Stroll With Us on August 7!

Jeanne and Jeff Theis got an epilepsy diagnosis for their son, Benjamin, at age two months. Many EEGs and MRIs, countless doctor's visits and different medications later... Benjamin is a busy first grader who reads stories to his mom and learns in school with the help of an aide.



"Each day he amazes us with something new," said Jeff Theis.

2014 marks the Theis family's seventh consecutive year strolling with EFMN in St. Cloud as Team Been Walking for Benjamin.

"We appreciate the support of our friends and family over the years to help our Stroll team raise money and awareness to hopefully find a cure for everyone affected by seizures," said Jeanne Theis.

Benjamin still struggles with seizures on a daily basis. Sometimes testing a new medication actually increases his seizures and it feels like taking steps backward. But that's why the Theis family feels so strongly about their Stroll efforts. They are making an impact for their son, and helping the 60,000 people with epilepsy in MN and ND.

The Foundation salutes the Theis family, and encourages others to join us on August 7 at Strolls in Duluth, Fargo/Moorhead, Rochester, St. Cloud and the Twin Cities.

Register at efmn.org/stroll today!

Epilepsy in the News

- Democratic Gov. Mark Dayton signed legislation in May that sets up a medical marijuana program with tight controls on the way it is administered, joining 21 other states where it's legal. If all goes as planned, the drug will be available in pill, oil and vapor form in mid-2015, with two manufacturing facilities and eight dispensaries permitted statewide.
- Congratulations to the 2014 recipients of the Elam Baer and Janis Clay educational scholarships (\$1,000 each): Barrett Bukowiec, Mitchell Floura, Adrienne Hester, Mariahna Jorgenson-Rathke, Amy Marquette, Elizabeth McGraw, William McMillan, Colton Menk, Rachel Stych and Alex Suszko.
- Welcome to EFMN's 2014/2015 Winning Kid, Katelyn Woehner! Katelyn is 15 years-old, in 9th grade and lives in Cottage Grove with her parents and younger brother. Katelyn has had a challenging journey with epilepsy beginning at age of four. She has had three brain surgeries, and has been seizure-free since her surgery last year. She enjoys horseback riding, traveling, shopping and more. Read about Katelyn on efmn.org.
- A recent study from the National Center for Biotechnology Information shows that 1/3 of people with autism also have epilepsy. The connection between the two conditions often makes headlines and more information can be found on Huffingtonpost.com, "The Connection Between Autism & Epilepsy."



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Join the Chasing Dreams Team!

On May 15th's "Rise Above Seizures" Day, Coach & Rebecca Kill announced the creation of the "Chasing Dreams" Coach Kill Fund. The fund will make a difference in the lives of children with epilepsy by supporting two of our most impactful programs for youth: Camp Oz and Seizure Smart Schools.

Coach Kill and EFMN are working to raise \$500,000 by August 2014! To be part of the "Chasing Dreams" Team, make your gift today:

- Send a check payable to EFMN (include "Chasing Dreams" in the memo)
- Give online at www.efmn.org/giving (designate your gift to Chasing Dreams)
- Give by phone (credit card) 651.287.2324

