The new national health care program will be in effect January 1, 2014. The long awaited program may help many individuals with epilepsy who have been denied insurance or charged higher rates due to their pre-existing condition. Individuals are now able to compare plans and apply for coverage at the “Affordable Care Marketplace”.

There are several components of the program and Marketplace, some of the most common questions are addressed below.

**What is the Affordable Care Marketplace?** The Marketplace is set up to help uninsured people find health coverage. It may be accessed on-line at www.healthcare.gov or by calling 1-800-318-2596.

**How does it work?** There are many private companies and information about their plans and costs which can be compared side by side. You may compare and apply at the Marketplace.

Information about low cost measures, exemptions and other details can also be found.

**What are the low-cost measures?** You may qualify for lower cost insurance, eligibility will be determined by your household size, income and the state you live in.

**What about state aid programs?** Wisconsin has chosen not to expand their current Medicaid guidelines. You may, however apply for benefits at the current level through the Marketplace.

**What if I already have insurance?** If you have insurance through work, Medicare or state programs you do not have to do anything. You may check insurance options at the Marketplace if you have private insurance and want to check on lower cost options.

**Do I have to have health insurance?** Yes. Individuals who are not insured by March 31, 2014 will pay a penalty.

**What is the penalty?** The individual ‘shared responsibility payment’ (penalty fee) is 1% of your income or $95 per adult and $47.50 per child—whichever is higher. The most a family would have to pay is $285 in 2014. You make penalty payments when you file your 2014 income taxes on April 15, 2015.

**Are there exemptions from payment of the penalty fee?** Yes. You may qualify for an exemption if you are uninsured for only 3 months of the year or the lowest-priced coverage available to you would cost more than 8% of your household income. Other exemptions can be found at www.healthcare.gov.

**What about hardship exemptions?** There are many circumstantial exemptions. Examples include being homeless, recently evicted, had utility shut-off, a death in the family, domestic violence, high medical expenses and more.

For more information go to www.healthcare.gov or call 1-800-318-2596.
BOARD OF DIRECTORS AND STAFF RETREAT

Staff from all three Epilepsy Foundation Heart of Wisconsin offices and members of the Board of Directors met for a day-long meeting held in Madison October 5. It was an opportunity for staff and the volunteers that govern the organization to meet face to face and it proved to be an exceptional event.

Facilitated by Ted Izydor of Full Potential Coaching & Consulting, a strategic plan to maintain fiscal health was drafted after careful evaluation of trends, current strategies and new technology. The re-energized staff and Board of Directors look forward to the future of the organization and are committed to its mission:

Epilepsy Foundation Heart of Wisconsin leads the fight to stop seizures, find a cure and overcome the challenges created by epilepsy

Epilepsy Foundation Heart of Wisconsin
Executive Director: Arthur Taggart

Staff

Madison Office
Jane Meyer, Program Director
John Mirasola, Employment Specialist

Janesville Office
Jeanne Thompson, Program Director
Carolyn Parker, Administrative Assistant
Pattie Cleaton, Bookkeeper

Stevens Point Office
Ann Hubbard, Services Director
Anne Faulks, Community Outreach Director
Dennis Perkins, Development Director
Melissa Clark, Bookkeeper
Richard Glinski, Office Assistant

Outreach Office
Paul Toellner, Dodge Co. Respite Lifespan Coordinator

Contact Information

www.epilepsywisconsin.org
Toll Free: 800-693-2287

Madison: 608-442-5555
1302 Mendota St. Ste 100
Madison, WI 53714
info@epilepsywisconsin.org

Janesville: 608-755-1821
205 N Main St. Ste. 106
Janesville, WI 53545

Stevens Point: 715-341-5811
1004 First St. Ste. 5
Stevens Point, WI 54481
cne@epilepsywisconsin.org

Appleton: 800-693-2287
1800 Appleton Ave.
Menasha, WI 54952

Professional Advisory Board
Tom McCarrier NREMT-1
Naomi Arenson, MD
MaryEllen Gullickson, PharmD
Gary Jepsen, Capt.
Karen Lapp, NP
Scott Rifleman, EMT-P
Pat Trudeau, REEGT
Evan Sandok, MD
Sigan Hartley, PhD
Ann Hartwig, Atty
DeeDee Watson, Atty
Michael Hsu, PhD
Rama Maganti, MD
Paul Rutecki, MD
Janel Schneider, MD
Laura Skilton Verhoff, Atty
Veronica Sosa, MD
Training for School Nurses

Managing Students with Seizures (MSS) is a nationally accredited training developed in partnership with the Epilepsy Foundation, the CDC and National Association of School Nurses. Affiliates across the country have provided this valuable information to over 6,000 school nurses this past year. A group from south-central WI attended the MSS training on Saturday, November 2nd in Madison. They received the latest information about epilepsy and seizure management for school-aged children, resources to train teachers and staff and a better understanding of parent concerns and how to address them.

School nurses interested in the training may also take the web-based program for 3.2 credit hours at www.epilepsy.com/school-nurse-training.

Dear Friends

During this holiday season we thank you for your support of the Epilepsy Foundation and ask you to please remember us and the work we do at year’s end with a contribution.

The Epilepsy Foundation has had a strong presence in Wisconsin for over 30 years thanks to the support of our Boards, event and agency volunteers and generous donors. Your previous contributions have enabled us to reach out to people with epilepsy with our core programs and services as well as new and innovative programs.

If you would like to designate your donation, cut out this section and return with your contribution.

Our sincere thanks,

Executive Director

Support Groups:

Madison, every Thursday
Stevens Point, 3rd Friday
Wausau, 2nd Monday
Appleton, 4th Tuesday
Green Bay, 1st Wednesday
Wisconsin Rapids, 3rd Wed.
Antigo, 1st Thurs. bimonthly

UPCOMING EVENTS

2014

February 6  An Evening of Chocolate Decadence
Stevens Point
March 22  National Walk for Epilepsy, Washington DC
March 23-24  Public Policy Institute Kids Speak Up
Washington DC
April TBA  Sib’s Day, Madison
April 11  Advances in Epilepsy Treatment Conference
Marshfield
May 17  Stroll for Epilepsy Janesville
May TBA  Bowl-a-thon, Madison
August 3-8  Camp Phoenix at WI Lions Camp, Rosholt
August 16  Stroll for Epilepsy Wausau
September 12-14  Adult retreat Rosholt
September  Stroll for Epilepsy Appleton

Our sincere thanks,

Executive Director

All Programs and Services

Educational Programs

_____ All Education Programs
_____ Police, EMS
_____ School Nurses & Staff
_____ Epilepsy Update
_____ Dinner Meetings
_____ Annual Conference
_____ Other

Service Programs

_____ All Client Services
_____ Kids Camp
_____ Adult Retreat
_____ Emergency Medication Fund
_____ Support Groups
_____ Other

Credit cards accepted by phone or enter information below and mail

Amount: ___________________

Name and Address: ___________________________________________________
____________________________________________________

Credit card number: __________________________________________________

CVV Code: _______________ Expiration Date: ________________________

Your e-mail address for a receipt: ______________________________________

Managing Students with Seizures (MSS) is a nationally accredited training developed in partnership with the Epilepsy Foundation, the CDC and National Association of School Nurses. Affiliates across the country have provided this valuable information to over 6,000 school nurses this past year. A group from south-central WI attended the MSS training on Saturday, November 2nd in Madison. They received the latest information about epilepsy and seizure management for school-aged children, resources to train teachers and staff and a better understanding of parent concerns and how to address them.

School nurses interested in the training may also take the web-based program for 3.2 credit hours at www.epilepsy.com/school-nurse-training.
NEW CLINICAL TRIAL EXPLORES CANNABIDIOL FOR TREATING EPILEPSY

A study being conducted by four pediatric epilepsy experts and GW Pharma is now underway to investigate the safety and tolerability of Cannabidiol (CBD), the non-psychoactive compound of cannabis (marijuana), as a treatment for children with difficult to control seizures. Cannabidiol is extracted from specific chemotypes of the cannabis plant. Dr. Maria Roberta Cilio at the University of California, San Francisco; Dr. Orrin Devinsky at New York University; Dr. Elizabeth A. Thiele at Massachusetts General; and Dr. J Helen Cross at Great Ormond Street Hospital in London are the chief investigators.

The research will provide important, objective data on the safety and tolerability of increasing doses of CBD in children with treatment-resistant epilepsy. The studies will better define the maximally tolerated dose and potential side effect profile of CBD, while studying its efficacy in two well-defined childhood epilepsy syndromes – Dravet and Lennox-Gastaut.

The Epilepsy Foundation, in conjunction with its Epilepsy Therapy Project initiative, is providing $50,000 in funding to support this study. “The Epilepsy Foundation was proud to provide funding for this important new clinical trial to help young children living with intractable seizures improve the quality of their lives,” said President & CEO Philip M. Gattone. “We are dedicated to making sure all people living with epilepsy and seizures have the best treatments available.”

For more information about this study, go to http://www.gwpharm.com/Phase1Epilepsy.aspx

MEDICAL MARIJUANA

The Cannabidiol study mentioned above, although uses part of the marijuana plant, is not to be confused with “medical marijuana”.

Twenty states in the US have legalized the controlled use of marijuana to treat a variety of conditions including epilepsy. Although still not legalized federally, these states are allowing possession of a limited amount of specially cultivated marijuana to individuals with medical verifications, proof of residency and other criteria. Wisconsin is not among the states to allow the medical use of marijuana.

ADVANCES IN EPILEPSY TREATMENT

XXXIII

April 11, 2014 is the date for our 33rd annual conference. Evan Sandok MD, Epileptologist at the Marshfield Clinic’s Epilepsy Clinic is chairman of the event. Speakers will include epilepsy specialist from around the country. Watch our web site for information.

WE STAND WITH COACH KILL

ATHLETES VS. EPILEPSY

Coach Jerry Kill of the University of Minnesota’s football team had a seizure on the sidelines of the Western Illinois game on Saturday September 14, 2013. Seizures are unpredictable but are also part of the routine for too many people who live with epilepsy. Coach Kill’s team has been there before and knew how to respond. They stayed calm, stayed focused and stayed with Coach’s game plan, going on to a 29-12 victory.

Coach Kill’s determination, courage and leadership have become an inspiration for his players, staff and school, college football and sports fans and more than 2 million people in the U.S. -- who, like Coach Kill, live with epilepsy and seizures.

Coach Kill has been a leader not only in college football but in the epilepsy community. At the Epilepsy Foundation of Minnesota's Camp Oz, Coach Kill invited more than 300 kids with epilepsy to a spring practice with the Gophers where he spoke out with epilepsy to a spring practice with the Gophers where he spoke out about his seizures.

Coach Kill and other accomplished athletic heroes are leading a new Epilepsy Foundation initiative, "Athletes vs. Epilepsy," to increase awareness and inspire people with epilepsy to reach their potential. For many, Coach Kill’s example helps them stand tall against negative perceptions, school bullies and the real challenges of seizures. Coach Kill embodies strength, determination and character. We applaud Coach Kill for his example and leadership.
**ANNOUNCING COLLEGE SCHOLARSHIP OPPORTUNITY**

Epilepsy Foundation Heart of Wisconsin with the assistance of Sara White has created the “Seize your Education Fund”. The first college scholarship of $1200 will be awarded to an individual with epilepsy in 2014. **Applications are due by April 1, 2014.** Eligibility criteria includes: diagnosis of epilepsy, current resident within the Epilepsy Foundation Heart of Wisconsin service territory, high school graduate, current student at a university or technical college, or professional needing to further education and a GPA of 3.0 or higher. Applications, further eligibility criteria and instructions are available by calling our office at 608-442-5555 or visit our web site at www.epilepsywisconsin.org.

**NOVEMBER IS EPILEPSY AWARENESS MONTH**

**LOTS YOU CAN DO:**
- Watch some “Now I Know” videos posted to the Epilepsy Foundation facebook page. Then record your own “Now I Know” video and post to www.epilepsywisconsin.org
- Add the awareness month message to your e-mail signature
- Visit talkaboutit.org and see what celebrities are doing to create awareness
- Wear purple to honor epilepsy awareness
- Stay informed about what is going on in the epilepsy community—sign up for the E-Newsletter at www.epilepsyfoundation.org
- “Like” the foundation on facebook, national as well as Heart of Wisconsin
- Attend a local epilepsy support group

**EPILEPSY IN KOREA**

Thank you to Yunjung Yangandl, a graduate student at Indiana University who was born and raised in S. Korea. Below are excerpts from her personal account of living with epilepsy in Korea.

Most Korean adults are familiar with epilepsy. However, interest in learning about the disorder is slight and public knowledge and awareness is limited, although its impact on individuals, and their families and friends, is significant.

Lack of public awareness, knowledge, and interest foster misconceptions about epilepsy. For example, some of the most common misconceptions of epilepsy in Korea is that it is a type of psychiatric illness and mental retardation. Even people with epilepsy, especially children, do not have sufficient knowledge of their condition. The public’s misconceptions of epilepsy could be attributed to their attitude toward the disorder.

The attitude is generally negative, which is likely to lead to social stigma, discrimination, and poor mental health as well as a low quality of life for people with epilepsy. For example, some people believe that persons with epilepsy are not capable of performing certain tasks or participating in certain activities. Some parents are reluctant to let their children play with peers with epilepsy. Educational programs and media campaigns that raise awareness of epilepsy for the public as well as interventions for parents of children with epilepsy are in great need in S. Korea.

Because my paternal grandfather died fighting in the Korean War before my father was born, the burdens of supporting the family shifted onto my father very early in his life. By the time my father had overcome the ravages of the war and begun his own family, like the majority of Koreans, we found ourselves in a serious financial crisis that brought with it great emotional distress. Despite these severe hardships, not only was I outgoing and well-liked, but I also learned how to read all by myself and did well in school with few resources. I had high self-esteem as well as good leadership potential and always believed that there was nothing I could not do as long as I was persistent. During second grade all of this completely changed; I became a sad, withdrawn, and isolated child right after I had a seizure during class. Doctors diagnosed me with epilepsy. My peers teased and shunned me.

*Continued on page 7*
Community Awareness and Outreach Events

Epilepsy Day at the Capitol

October 23, 2013 over 40 individuals met with their WI State Legislators to increase their understanding of the impact of epilepsy on their lives; including employment, transportation and access to health care. They also advocated for increased state funding for epilepsy services.

Rockman’s Catering created a beautiful display and delicious treats “An Evening of Chocolate Decadence” in Stevens Point

Bowl-a-thon in Madison “Tomee’s Team” Traveled all the way from Upper Michigan to take part in the Stroll for Epilepsy in Janesville.

Wittenberg High School “Teens Against Disease” raised over $3000 for the Epilepsy Foundation Heart of Wisconsin during their annual week-long community fundraising project.

The art of face painting at the Stroll for Epilepsy in Wausau

Hardees sponsors and event volunteers make the Appleton and Wausau Strolls for Epilepsy fun with a top-notch picnic.

The Hembrook Family showed their support for several members of their family with epilepsy. Their team was one of many who participated in the Stroll for Epilepsy in Janesville.
not only because it was such a frightening scene for them, but also because many feared my condition was contagious.

I often wept and did not want to go to school, which led to a severe drop in my academic performance. My parents had no expectations of me because they believed that the disorder would prevent me from achieving my fullest potential. There was no one to talk to about what I was going through because I thought nobody would understand.

Thankfully, a wonderful teacher of mine, Mrs. Kim, was compassionate, and supportive. She gave me a book about the life of Helen Keller and challenged me to surmount the obstacle that epilepsy posed for me as Helen overcame being deaf and blind and became a highly influential figure.

“Hard times will always reveal true friends.” One of the most frustrating moments of my life is when I had a seizure after 18 years seizure free. There were times I would rather have been dead, but transforming my challenges into a positive contribution to society became one of the primary purposes of my life.

My difficult childhood, the impact of that wonderful teacher, and true love shaped my dreams. Facilitating children with epilepsy in order for them to live to their fullest capacities, and to have the quality of life they deserve while being challenged by this chronic illness is my passion. No matter what kind of challenge or struggle you are going through, whether you let it destroy you or use it as your stepping stone and overcome it to make yourself stronger is up to you.
Epilepsy Foundation Launches 24/7 Help Line

The Epilepsy Foundation Heart of Wisconsin is your source for information and services related to epilepsy. We have put several options into place so that you may reach us when it is convenient for you. After hours visit our website at www.epilepsywisconsin.org and click on the ‘contact us’ tab, e-mail us directly at addresses listed on page 2 or there is always the conventional phone voice mail.

The Epilepsy Foundation’s national office has now launched another option for you to get information: In response to your needs and a recommendation from the Institute of Medicine’s 2012 Report on Epilepsy, the Foundation has expanded its Helpline and is now available 24 hours a day, 7 days a week. Trained information specialists are standing by to answer your questions about epilepsy and seizures, first aid, treatment options, or to locate an epilepsy specialist and resources in your area.

Helpline does not provide individual medical advice. It is an information and resource helpline. However, the information provided may help you work with your health care team more effectively.

To contact the Helpline: Call 1-800-332-1000 or in Spanish: (en Espanol) call 1-866-748-8008.