The Modified Atkins Diet

The success of ketogenic diet therapy for treating seizures has led to the development of another diet-related option considered more manageable for adults: the Modified Atkins Diet (MAD). While the popular Atkins diet is ‘low carb’, MAD further reduces the amount of allowed carbohydrates, and increases the intake of fats. This produces the desired change in the body that has been shown to decrease the risk of seizures in some patients, but does not require the strict nutrient monitoring and fluid restriction required by the ketogenic diet. These changes allow for more variation in the diet, and fewer problems when eating outside the home.

Findings of two studies indicate that half the participants saw a 50% or greater reduction in their seizures. This diet is closely monitored by a neurologist as well as dietician and medications are usually left unchanged.

MRI-Guided Laser Ablation

A new minimally-invasive surgical alternative, MRI-guided laser ablation has given individuals with intractable epilepsy another surgical option. The technique called stereotactic thermal ablation involves inserting a laser fiber through the skull to the precisely targeted area of the brain causing seizures. Light energy from the laser heats the brain tissue effectively destroying it.

Thermal ablation, like Gamma Knife, is a minimally invasive procedure. As with any surgical technique used to treat epilepsy, extensive, precise pre-surgical studies of the epileptic focus are critical to its success.

Innovative Tools: “Shark Tank”

Three winners in the 2014 Epilepsy Foundation “Shark Tank” competition were awarded $200,000 to advance the most innovative ideas in epilepsy and seizure care.

First place: Oren Knopfmacher, PhD to develop a non-invasive device that monitors anti-seizure drug levels in saliva.

Second place: Jon Davis for developing “Shower Power”, a safely monitoring system that tracks and alerts others and shuts off the water valve when seizure events occur in the shower.

Peoples Choice award went to 13 year old Amir Helmy and his father, Ahmed Helmy for the development of “Seizaro”, a Smartphone app that detects and alerts loved ones when the owner is experiencing an emergency scenario.

“Epilepsy Foundation is working hard to fund the research that will accelerate new therapies and treatments”, commented Phil Gattone, CEO. Besides the annual “Shark Tank” competition the Foundation funds other medical research with grants awarded to medical professionals and clinics.

Visit the epilepsy.com website and click OUR RESEARCH AND IMPACT for information.

Update: Cannabidiol Studies

Continued on Page 4
A LOOK AT SOME OF OUR PROGRAMS

Seniors and Seizures Caregivers Trainings: Seniors over the age of 60 are the fastest growing group of individuals to develop epilepsy. Care facilities staff may contact us for a free specialized training program to recognize and respond to seizures.

Individual Services: Our core service is designed to address individual needs. Concerns ranging from employment, school, epilepsy self-management, financial, insurance, transportation, social/emotional as well as epilepsy education are addressed on an individual basis.

Camp Phoenix: Week-long summer camp for children with epilepsy.

Adult Retreat: Weekend of activities and camaraderie for adults with epilepsy.

Studio E: Art Therapy has proven to be a highly popular program with children at Camp Phoenix as well as with adults in a 6 week course.

Public Policy Institute, Teens Speak Up and National Stroll for Epilepsy: Three events in our nation’s capitol. Rally together for public policy changes, increased awareness and to raise funds for the national Epilepsy Foundation programs.

Support Groups: Support, camaraderie, education. Offered in nine communities we always welcome new participants. See schedule page 3.

PACE (Parent and Caregiver Education): Education and support sessions for parents who have children with epilepsy or other special needs.

FUNNE (Familias Unidas Con Ninos Con Necesidades Especiales): Spanish speaking support network for families with children with special needs.
Dear Friends,

We are blessed with a generous board of directors, a professional advisory board, and by volunteers and donors who support our mission and care about the needs of people with epilepsy. At year’s end, we ask you for your continued support of the Epilepsy Foundation Heart of Wisconsin.

Here are just a few programs you might be familiar with and costs that might surprise you:

- $1,200/year for the Seize Your Education Scholarship Fund, awarded every April.
- $4,000/year for emergency medication, helping patients who've lost their job or insurance bridge the gap while waiting for longer term assistance.
- $5,000/year for our adult retreat weekend including bus transportation for those who don’t drive.
- $7,500/year for Camp Phoenix, a week-long summer camp for kids with epilepsy, where they meet peers and share great experiences in a safe, fun environment.
- $20,000/year for peer self-help networks. Facilitated meetings for patient education, empowerment and improved self-management.
- $20,000/year for epilepsy research and development of new therapies.

Every year we provide epilepsy awareness and seizure education to about 5,000 people throughout Wisconsin and that means, from early childhood through their senior years, people with seizures have a better chance of staying safe and receiving appropriate first aid.

These programs need your help and support to continue. Please consider a financial gift to Epilepsy Foundation Heart of Wisconsin this holiday season!

Join our Founders Club and divide your gift throughout the year with small monthly payments.

Remember Epilepsy Foundation Heart of Wisconsin in your estate planning.

Paypal and all major credit cards are accepted. Call 800-693-2287 or email donate@epilepsywisconsin.org for more information.

Thank you for your support!

Arthur Taggart
Executive Director

Jennifer Benishek
President, Board of Directors

The Epilepsy Foundation Heart of Wisconsin is a 501(c)3 charitable organization and our federal tax ID is 39-1370658.
Partners Against Mortality in Epilepsy (PAME) met in Minneapolis June 19-20. It was a unique opportunity for epileptologists, basic scientists, advocates and families affected by SUDEP (Sudden Unexpected Death in Epilepsy) to understand new research and support one another.

Current research on this topic focuses on respiratory, cardiac, autonomic dysfunction and sleep arousal as possible underlying causes of SUDEP. An additional field looking at genetic underpinnings behind epilepsy and sudden death is also being explored.

The Epilepsy Foundation launched the SUDEP Institute in collaboration with CURE, SUDEP Aware, Danny Did Foundation, AES and leading epilepsy organizations and experts. Projects include a comprehensive, collaborative, nationwide program of:

- Awareness and Education about SUDEP and prevention methods aimed at the medical community, including medical examiners and coroners.
- Research into the causes and methods of preventing epilepsy mortality.
- Support of the North American SUDEP registry.
- Support Network providing counseling, socialization, and resources for people living with and bereaved by epilepsy.

NEWS: Wisconsin has been chosen to participate in the Centers for Disease Control and Prevention’s Sudden Death in the Young Registry.

Funding will be used to collect comprehensive data on sudden unexpected deaths among young people aged 19 years and younger in participating states. The objective is to develop standardized definitions and autopsy guidelines. It will also collect data to describe demographic and clinical characteristics in cases of sudden death in the young as well as provide information that will improve systems that serve families.

Update on Cannabidiol Oil

Lydia’s Law, the Wisconsin bill legalizing the use of cannabidiol oil (CBD), an extract from the cannabis plant, for the treatment of seizures, was passed by the legislature in April of 2014. The signing ceremony was attended by over 100 family members and advocates. Since April, those families have been frustrated in their attempts to obtain CBD or even find investigational studies close to home.

Federal law treats CBD, even without the psychoactive component of the cannabis plant (THC), as a Schedule 1 substance, a classification reserved for drugs that have no medical use and a high potential for abuse. The Drug Enforcement Agency is currently reexamining its position on CBD. In addition, doctors are concerned about the lack of regulation for marijuana-based products and the lack of pharmaceutical-grade quality and purity controls.

To that end, GW Pharmaceuticals has established a regulatory pathway for its purified cannabinoid, Epidiolex, with the FDA. They received approval for an expanded access study of 400 children as well as corporate-sponsored clinical trials for children with Dravet Syndrome or Lennox-Gastaut Syndrome. Insys Pharmaceuticals has received approval to begin the manufacture of synthetic CBD, chemically identical to the plant form, and expects to begin Phase I trials in early 2015.

In states that have passed more comprehensive medical marijuana bills, with licensed dispensaries, it might be easier to explore compassionate use of CBD with your physician, but it’s important to know exactly what you’re getting. CBD manufacturers can and should request laboratory testing of any product they offer for sale.

To insure patient safety, it will be important to know that CBD has undergone the same rigorous study that brings other new therapies to market. Part of the intention of Lydia’s Law was to help facilitate that study in Wisconsin.
FOX CITIES STROLL

10 year old Elson brings a team of 53 family and friends to the Stroll!

Team “Just Believe” — Winners of the Spirit/Wacky Walker Award

Teams Tille and Starfish Stroll thru Neenah’s Memorial Park

Next year:
August 2—7

CAMP PHOENIX

Jacob and Jerry excel in Archery

Jake enjoys boating activities including kayaking

JANESVILLE STROLL

Stroll participants enjoy a walk through Janesville’s Palmer park

Team Isabelle raises the most money at Janesville stroll

WAUSAU STROLL

“Hardee’s® Happy Star (Melia) leads the stroll thru Marathon Park

1st Place: Team SAS $4,950
2nd Place: Bela’s Backers $2,480
3rd Place: Meurett Family $1,130

Leah shows us her face and arm art.

The “Blocheads” enjoying after-walk conversation

FALL RETREAT

1st place kickball team

Expression through art

Hiking around beautiful Lions Lake

Volleyball — one of many outdoor activities

Saturday night dance
Seize Your Education Scholarship

Epilepsy Foundation Heart of Wisconsin awarded its first “Seize Your Education Scholarship” to Jayden Magee of Eland WI. As a student at Wittenberg High School, Jayden took part in community service projects and spoke with legislators at the state capitol to advance epilepsy awareness. Jayden plans to pursue a career in the woodworking trade and currently attends Northcentral Technical College.

Information about the 2015 scholarship including eligibility criteria and instructions is now available. Call our office at 608-442-5555 or visit our web site www.epilepsywisconsin.org.

DEPRESSION AND EPILEPSY

Depression is a state of mind characterized by feelings of sadness, loneliness, despair and low self-esteem, and often includes withdrawal from social contact, loss of appetite, weight changes and insomnia. It is the most frequent type of mental health problem experienced by people with epilepsy.

Brain research studies have found that seizures can be associated with changes in brain chemicals called neurotransmitters, which are also believed to be a factor in depression. It may also result from the challenges related to having epilepsy – frequent seizures, financial pressures, relationship problems, job discrimination, and a lack of control over one’s life or future. Seizure medications may cause depressive symptoms as well.

For people with epilepsy, depression goes unrecognized and untreated when:

- Doctors may not ask and patients may feel uncomfortable talking about their feelings
- Patients and doctors assume that symptoms of depression are ‘normal’ in people with epilepsy
- There are concerns that antidepressant drugs may cause more seizures

The treatment of depression includes re-evaluation of the current seizure medications, counseling therapy and cautious use of antidepressants. There is evidence that some epilepsy treatments also have antidepressant effects and therefore could be useful in treating both problems.

When an antidepressant is prescribed, negative side effects and drug interactions must be evaluated. Finding the best and most effective medication will take time, but it is important that depression be recognized and addressed. Counseling and getting help with the other aspects of dealing with epilepsy are essential too. If you are struggling with symptoms of depression, be certain to mention it to your health care provider.

“ADVANCES IN EPILEPSY TREATMENT”

Mark your calendar: April 17, 2015 is the date for our 34th Annual conference, “Advances in Epilepsy Treatment” to be held at Marshfield Clinic. Specialists will share their expertise on research, developments, and understanding of epilepsy and related concerns. It is an opportunity for patients and family members as well as professionals who work with people with epilepsy to learn.

Evan Sandok MD, Epileptologist at Marshfield Clinic’s Epilepsy Clinic is chairman of the event. Watch our web site or call for further information.
**Community Awareness and Outreach Events**

**Epilepsy Update Dinner Programs Come to Eleven Heart of Wisconsin Cities**

Dr. Rama Maganti, neurologist and epilepsy specialist at the University of Wisconsin Hospitals and Clinics will be giving a series of talks throughout the Epilepsy Foundation Heart of Wisconsin’s service area. The first two programs will be offered in Madison and Stevens Point this November, recognizing it as Epilepsy Awareness Month. During 2015 an additional ten programs will be offered around the state.

Dr. Maganti will be presenting on the need for patients to seek more aggressive/specialized treatment for intractable or difficult to control seizures. When are seizures considered intractable? What are Tertiary Epilepsy Centers? What treatment and testing options are available?

For more information on when a program will be in your area, contact the Epilepsy Foundation Heart of Wisconsin.

**United Way Blackhawk Region “Day of Caring”**

The annual “Day of Caring”, sponsored by the United Way Blackhawk Region invites business and their employees to give back to their community. This year over 725 people from 27 business volunteered to work on over 83 different community projects.

Volunteers from Kerry Ingredients of Beloit spent an entire morning cleaning and re-organizing the combined storage room of several non-profit organizations that rent space at the United Way Blackhawk Regions office building, including our office in Janesville.

Jeanne Thompson from Epilepsy Foundation Heart of Wisconsin said “it was a day of fun, but more so, a day of giving. We would like to thank the employees of Kerry Ingredients for their time and energy and the United Way Blackhawk Region for providing a great day for the community to give back.”

**Epilepsy Foundation Heart of Wisconsin Takes Part in the “Public Policy Institute” and “Teens Speak UP” in Washington DC**

Mom Shonda Crapp, Executive Director Arthur Taggart, Rep. Mark Pocan (D-WI), Jarin Crapp from Lancaster and John Mirasola, Epilepsy Foundation Heart of Wisconsin.

**Driver, Kenny Mathews (center in back) and the Kimmel Racing team were at Madison International Speedway “Racing for Epilepsy Awareness”. Pictured with Kenny are Wausau Stroll participants who attended the event.**

**Best Advantage Credit Union in Brillion holds a “Purple Day” fundraiser for the Epilepsy Foundation Heart of Wisconsin**

**Driver, Kenny Mathews (center in back) and the Kimmel Racing team were at Madison International Speedway “Racing for Epilepsy Awareness”.” Pictured with Kenny are Wausau Stroll participants who attended the event.**

**Heart of Wisconsin takes part in the “Public Policy Institute” and “Teens Speak UP” in Washington DC. Pictured left to right, mom Shonda Crapp, Executive Director Arthur Taggart, Rep. Mark Pocan (D-WI), Jarin Crapp from Lancaster and John Mirasola, Epilepsy Foundation Heart of Wisconsin.**
Epilepsy Awareness Month: November

International Day of Epilepsy Awareness: March 26

Wear your purple, tell your story, raise money for epilepsy services and research...

#DaretoTalkAboutIt!

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