ART THERAPY — STUDIO E

Art therapy is a unique approach for helping individuals improve mental health, cognitive and communication abilities, sensory-motor functions and more. Studio E, an art therapy program sponsored by Lundbeck partnering with the Epilepsy Foundation brings the opportunity to offer art therapy programs to individuals with epilepsy in 50 locations around the country.

Art therapists in our Studio E sessions use art as well as verbal descriptions of the finished project to help children and adults increase self-awareness, resolve conflicts and achieve insight into how they perceive epilepsy and their world around them. Art therapy as it pertains to our programming is a way of communicating pain, worries, joy, stress and other emotions of living with epilepsy in a supportive environment.

We have been fortunate to be working with several art therapists, including Janice Havlena, Professor of Art Therapy and Art Therapy Program Coordinator at Edgewood College in Madison. Janice and her students facilitate the 8 week session in Madison culminating with an artists’ reception and exhibit. They facilitated an art therapy project at our 17th annual siblings event in Madison and along with Beth Sherwood, Child Life Specialist, University of Chicago, offered sessions for children with epilepsy as well as their siblings as a part of the “Educating Parents & Youth on Epilepsy” program this fall in Stevens Point. Froedtert Hospital invited us to participate in an 8 week session there facilitated by The Art Therapy House in Milwaukee.

For several years art therapy activities have been offered to our children at Camp Phoenix. Alison Heinz, Clinical Therapist with Clark County Community Services, brought the story of the Cracked Pot to camp this year. The story details how the cracked pot that couldn’t deliver a full pot of water to its destination did, in fact, water flowers along the path and made them flourish. The children made claycrete bowls and shared their thoughts. One camper, Jake, from LaCrosse stated “at first my bowl was cracked but then I put more layers on it”. The statement about his actual art project was a perfect example of the sessions’ theme of recognizing your potential, accomplishments and taking pride in who you are.

For additional information about Studio E go to (Lundbeck) at www.yourpartnerinepilepsy.com, or check the Epilepsy Foundation web sites www.epilepsywisconsin.org or www.epilepsy.com.

The national Epilepsy Foundation announced a new initiative to advance the awareness of SUDEP (Sudden Unexpected Death in Epilepsy). The campaign #AimForZero speaks to the need for understanding the risks of SUDEP and taking measures to ‘aim for zero’ seizures to reduce that risk.

Sudden Unexpected Death in Epilepsy is said to occur when a person with epilepsy dies unexpectedly when otherwise in good health. Researchers believe that SUDEP happens most often at night. A seizure may or may not be evident just prior to death. They believe there may be problems with irregular heart rhythm, breathing or brain function after a seizure.

The Epilepsy Foundation along with other medical organizations have created the SUDEP Institute and their 16 page report can be found at www.epilepsy.com. They report the greatest risk factor for SUDEP is frequent seizures, especially generalized tonic-clonic seizures. Other factors may include seizures beginning in childhood, not taking medications as prescribed and having nocturnal seizures. Young adults (ages 20—40) also appear to be at greater risk.

The #AimForZero campaign is dedicated to facilitating greater discussion of risk factors and to adopt four critical actions to reduce risk of SUDEP:

- Take medications as prescribed
- Get enough sleep
- Limit alcohol
- Do everything you can to stop seizures

For more information talk to your physician, visit www.epilepsy.com, or contact Epilepsy Foundation Heart of Wisconsin.

Adapted from www.epilepsy.com
MEDICATION AFFORDABILITY

When the Affordable Care Act became law it was met with enthusiasm for many individuals with pre-existing conditions such as epilepsy which in the past was a roadblock to obtaining health insurance coverage. It was and still is a highly charged political debate as there are so many facets of the law. Prescription medication is one area of concern, including insurance coverage gaps, high deductibles, copays, co-insurance and the cost of medications for uninsured.

We received calls regularly from people in a situation where their medications are not affordable. The Epilepsy Foundation Heart of Wisconsin works to help people in this type of crisis. Below are some resources we have found to be beneficial.

Pharmaceutical Companies have a variety of patient assistance programs, from receiving medications at no cost, to assistance with high co-pays.

Shop around! Make calls and research the price of your medications at different pharmacies in your area.

If you have prescription insurance choices—check the formularies for your particular medications. Comparison websites are available for Medicare Part D programs.

Use savings cards. Epilepsy Foundation Heart of WI has one such card that has saved some people money at the pharmacy. Many pharmacies have their own saving programs.

Check for on-line resources such as www.blinkhealth.com. You will be given the best price they can negotiate. You pay Blink Health for the medication on-line. Take the receipt to your pharmacy and have the prescription filled at no extra cost. Many retail pharmacies accept blinkhealth payments.

Another resource - www.goodrx.com. This site will compare the prices of your medication at pharmacies in your local area and you can print out the savings card or coupon that would work the best for you.

You may call us and we will work with you through the maze of assistance programs if possible. We have a short term emergency medication program that in some situations can pay up to a two week supply of a medication. Our Becker Loan program allows you to take out a loan from us to pay for one month of medication and you pay it back to us with no interest. Once paid, you are eligible for another one month loan if needed.

We are always interested in information about programs that have helped people unable to pay for medications. If you have any such experience, let us know and we can possibly share it with someone else.
Dear Friends,

Thank you to those of you who support the work of the Epilepsy Foundation Heart of Wisconsin. We are truly grateful to have you on the team!

Donors – we absolutely could not expand our reach without financial support. Personal donations as well as pledges from friends and co-workers for our events are critical to our success. Reaching out to community members and businesses on our behalf raises funds as well as awareness of epilepsy.

Advocates – it is mid-November as I write this and I am amazed at your efforts to let the world know about and understand seizures during this “Epilepsy Awareness month”. Not a day goes by that someone hasn’t posted to Facebook or Twitter to educate with facts, share a personal experience or highlight the need for research and public awareness. Your voices are powerful and create a positive impact year-round.

Volunteers – Thanks to those of you who are passionate about epilepsy services and education. Event coordinators and worker-bees, our board of directors, our expert speaker panel and our office and clerical support are all critical to our mission.

In-kind – Non-financial gifts of merchandise or services are also donated to the cause of epilepsy. Radio promotions and television advertisements, interviews and newspaper articles are worth thousands of dollars each year. Local businesses support successful raffles and donations of food and drinks make our events fun. Patient educational events are held in many different locations and these restaurants waive room rental fees. In-kind support plays an important role in making these events successful and keeping our programs affordable for the families we serve.

Our ask – We continue to streamline our administrative overhead and to be careful stewards of our resources. As the holidays approach and while Epilepsy Awareness month is fresh in our minds we humbly ask for your financial support to continue this important work throughout 2017.

Use the form below and mail a donation to us directly, or use our web site to make on-line gifts. Thank you for your generous support and for being part of the team that is making a difference!

Arthur Taggart,
Executive Director

Please support the work of Epilepsy Foundation Heart of Wisconsin
Donations may be made on-line on our web-site www.epilepsywisconsin.org or detach and mail in enclosed envelope.

Name: ___________________________ Address _____________________________

Phone number: ___________ E-mail: _____________________________

Enclosed is a check for $_________________________ Charge my credit card $_________________________

CC# ___________________________ Exp. Date: ___________________________

Security Code: ___________ Zip Code: ___________________________

I would like my donation to go to a specific program or cause: _____________________________
ACCELERATING NEW THERAPIES

The mission of the Epilepsy Foundation Heart of Wisconsin mirrors that of the national organization: to lead the fight to overcome the challenges of living with epilepsy and to accelerate therapies to stop seizures, find cures and save lives.

Through its annual Epilepsy Pipeline Conference, Shark-Tank Competition, Epilepsy Therapy Project and Epilepsy Innovation Institute, the Epilepsy Foundation provides financial support and scientific and business direction to promising new therapies. The Epilepsy Therapy Pipeline is a listing of potential new therapies in various stages of research. The Epilepsy Foundation is currently involved in some manner in half of the current projects.

Two recent projects that the Epilepsy Foundation was involved with are now available to patients. SmartWatch is an Intelligent wristwatch that continuously monitors the user and alerts family members or caregivers of abnormal movement patterns like those caused by a seizure. Visulase® is an advanced MRI-guided laser ablation technology for epilepsy surgery. A third project, currently still in the pipeline, is the non-invasive stimulation eTNS System for drug-resistant seizures.

Research is ongoing in the areas of: new drug development, enhanced drug delivery, dietary supplements and devices for seizure detection, prediction, therapeutic intervention and safety.

Dr. Jacqueline French, the Director of Clinical Trials at New York University who serves as the chief scientific officer of the Epilepsy Foundation has said, “New therapies and new research have the potential to make a real difference in the lives of people with epilepsy in the foreseeable future, and the Epilepsy Foundation is poised to be at the forefront of realizing these exciting innovations.”

November is Epilepsy Awareness Month “DARE TO TALK ABOUT IT” All Year Round

EPILEPSY is a disorder of the central nervous system which results in recurring seizures.

One in ten people will experience a single seizure in their lifetime.

One in twenty-six people will develop epilepsy at some point in their lifetime.

The incidence of epilepsy is twice that of cerebral palsy, Parkinson’s Disease, muscular dystrophy and multiple sclerosis combined.

Epilepsy is not a mental illness or developmental disability.

Epilepsy is not contagious.

Epilepsy affects children, adults, men and women and people of all ethnic backgrounds.

Epilepsy can be caused by head injury, infection of the brain, stroke, brain tumor, Alzheimer’s disease and genetic factors.

About 70% of people with epilepsy have seizures controlled with medication.

Other possible treatments for epilepsy include: brain surgeries, nerve stimulation and dietary therapies.

EPILEPSY UPDATES and CONFERENCES

Thanks to generous expert medical providers and grants from clinics, pharmaceutical companies and interested parties we have been able to offer 12 Epilepsy Update dinner and educational meetings throughout our service area this past year.

Barry Gidal Pharm.D, R.Ph, from University Hospital in Madison, Dr. Gregory Pupillo from Mayo Clinic Health System in LaCrosse, Dr. Janel Schneider from Wheaton Franciscan Comprehensive Epilepsy and Seizure Care Center in Racine, Dr. Kelley Parnell of Neuroscience Group of Northeast Wisconsin in Neenah, Dr. Kurt Hecox and Dr. Christopher Inglese from Children’s Hospital in Milwaukee, and Dr. Kristin Seaborg, Group Health Cooperative, Madison, have presented programs on new medication options, CBD oil research progress, mental health, family issues and how to best work with your medical team.

Sincere thanks to sponsors of these programs: the Sokaogon Medicinal Corporation a Wisconsin based developer in making CBD oil available for research, and Lundbeck and Sunovion Pharmaceutical companies. Their interest in the Epilepsy UpDate programs and the financial support offered ensured the success of these patient and family focused educational opportunities.

Continued. See Updates on page 5
Michelle Christensen of Neenah is the 2016 recipient of EF HOW’s “Seize Your Education” college scholarship. Since her diagnosis in middle school she has made talking about epilepsy a priority. She believes the more people know about epilepsy the more comfortable they will feel around her. Now in her second year at UW Eau Claire, Michelle talks to each of her professors, letting them know how epilepsy affects her, what accommodations she might need and what to do if she has a seizure in class.

She said “I have dealt with my epilepsy in a positive way: by educating myself and others about epilepsy, taking care of myself and by setting goals and challenging myself to succeed rather than using epilepsy as a reason to fail.” She does what is necessary to have the best seizure control possible, avoiding things that might trigger a seizure, gets plenty of sleep, and maintains a healthy diet and exercise routine and a well-balanced schedule of social and academic activities.

Besides school Michelle is active in many campus organizations, she organized a 200 person walk in her high school and participated in Strolls for Epilepsy in Neenah and Eau Claire.

EXCELLENCE IN EDUCATION FOR STUDENTS WITH EPILEPSY

Many children with epilepsy face unique challenges in school. There are ways to minimize the impact of epilepsy and other disabilities through provisions of the Individuals with Disabilities Act (IDEA) and Section 504 of the Rehabilitation Act. When a disability significantly affects educational performance, as measured through federal and state educational standards, IDEA provides for multi-disciplinary accommodations and an Individual Education Plan (IEP) is developed. This plan will address educational goals as well as accommodations to minimize the impact of epilepsy. The student will receive special education and accommodating services.

Some children with epilepsy do not qualify for services under the performance guidelines of IDEA. In this situation, children with epilepsy often qualify for a 504 Plan because their disability “limits one or more major life activity”. A 504 plan will allow for special services and accommodations even if they do not need special education.

A 504 plan (and a section of the IEP) is developed to manage the medical, social and academic impact of epilepsy. The school nurse should meet with the parents to design a seizure action plan for the student that contains specifics on seizure type (s), triggers, current treatment plan and actions to be taken in the event a seizure occurs, including the possible need for emergency medication.

Parents may be the first to see the social and emotional impact of epilepsy and may request accommodations. Educating classmates about epilepsy, giving friends a role, such peer mentoring or making accommodations so the student is able to safely participate in field trips are a few of many possible ideas to reduce any negative social concern.

The academic impact of epilepsy may be subtle. Be aware of issues of memory, attention, and cognitive function. Creative scheduling or adjusting teaching methods may reduce the concerns. Note if the academic impact of epilepsy is or becomes a significant concern, the child may then qualify for an IEP, which would include any 504 accommodations.

Updates Continued from page 4

Other educational events sponsored by Epilepsy Foundation include a visit from Dr. Lisa Bateman from Columbia and Cornell Hospitals, New York who presented Grand Rounds at the University Hospital on the latest research on SUDEP. She also presented a SUDEP Awareness program for community members in Madison.

The annual “Advances in Epilepsy Treatment” conference sponsored by Marshfield Clinic Neurosciences focused on Safety and Daily Living this year. Featured was Dr. Joseph Drakowski Mayo Clinic in Phoenix, Dr. Kathryn Pollovitz, Neurology of the Rockies in Colorado, Jana Jones Ph.D and Barry Gidal PharmD. of University Hospital in Madison as well as Dr. Evan Sandok, Angela Brenner PharmD. of Marshfield Clinic Epilepsy Clinic and Dr. Phiroze Hansotia, retired from Marshfield Clinic.

Over 500 individuals participated in these educational opportunities.

Epilepsy Foundation Heart of Wisconsin thanks all these professional experts in the field of epilepsy for giving their time and support to help educate and keep all of us up to date with the world of epilepsy care and treatment.
THINGS TO DO IN 2017

An Evening of Chocolate Decadence

Enjoy savory hors d’oeuvres, fabulous desserts from the areas most creative chefs. The chocolate truffle raffle features elegant and fabulous prize baskets. Not into chocolate or elegance? Our sports den silent auction makes sure there is something for everyone.

Thursday February 9, 2017

FALL RETREAT

for adults with epilepsy.
Meet others, share experiences, give each other support and encouragement and have lots of fun: ropes course, crafts, pontoon, camp fire, dance, kickball and so much more.

September 15—17, 2017

Camp Phoenix

A week-long camp for children with epilepsy. An opportunity to meet other kids with epilepsy and experience all the fun of summer camp with plenty of medical and well trained staff.

Contact us in April for your registration information.
2017 session is August 6—11, 2017

Take a Stroll for Epilepsy! Each event is filled with activities, food, raffles, music—fun for the whole family. And thanks to very generous and enthusiastic individuals and families, we raise the money necessary to provide services.

Please join us in 2017

Janesville: May 20
Neenah: August 19
Wausau: August 26

National Walk for Epilepsy

Washington DC
Saturday March 25, 2017
Siblings Day
Siblings of children with special needs gather for a special day of their own. It culminates with a program and pizza for their families.

Contact us to be sure your child is on the “Sibs” mailing list.

Next program Spring, 2017

Follow us on the web and social media
www.epilepsywisconsin.org
info@epilepsywisconsin.org
Epilepsy Foundation
Heart of Wisconsin
@EFHOW

Advances in Epilepsy Treatment Annual Conference
This 2016 session was presented by Dr. Evan Sandok of Marshfield Clinic, chairman of the annual event. Experts from across the country volunteer to come, offering a full day of education.

Mark your calendars:
May, 5, 2017

In Madison the annual BOWL-A-THON is held in the spring. Participants get together for fun and fundraising.
Spring 2017

The “Moms On A Mission” from Lancaster along with Phil Gattone, CEO of Epilepsy Foundation, and Art Taggart gather at this year’s event: WALK FOR A CURE.
Join them again next spring for the Walk and Casino Night to raise money for Epilepsy Research.
April 2017

Siblings Day
Siblings of children with special needs gather for a special day of their own. It culminates with a program and pizza for their families. Contact us to be sure your child is on the “Sibs” mailing list.

Next program Spring, 2017

Do your on-line shopping and support Epilepsy Foundation Heart of WI
amazon smile
You shop. Amazon gives.

ANSWERS TO CROSSWORD PUZZLE BACK PAGE
Across
2 Awareness
5 Friend
6 Spike
7 Partial
10 Tonic Clonic
12 Epileptologist
14 MRI
16 EFHOW
17 Camp Phoenix
19 Surgery

Down
1 Brain
3 Research
4 Stroll For Epilepsy
8 Achievement
11 Art Therapy
13 Impulse
15 Ictal
18 Aura

Details on our web site
Across
2. Teaching others about epilepsy
5. A person to rely on for support
6. Formation detected on an EEG
7. A category of seizure types where the seizure focus is in one part of the brain
10. Term that replaced Grand Mal (two words)
12. A medical specialist in epilepsy care
14. Magnetic Resonance Imaging
16. The abbreviation for the Epilepsy Foundation serving 46 counties in WI
17. Camping program for children with epilepsy in Wisconsin (2 words)
19. One treatment option for seizures

Down
1. Seizures originate here
3. Scientific process to further understanding of epilepsy treatment
4. Fundraising and awareness event held in many cities in the USA (3 words)
8. Accomplish one's own goals
9. Animal often trained for seizure response
11. Creative and therapeutic expression of feelings (two words) (hint: Studio E)
13. Brain sends messages/energy from one cell to another
15. Medical term referring to seizures
18. Simple partial seizure that precedes another seizure