JULY - AUGUST 2014

FOCUS ON EPILEPSY

THE NEWSLETTER OF THE EDMONTON EPILEPSY ASSOCIATION
The Epilepsy Association of Northern Alberta - Our 54th Year of Service

(This Newsletter can be viewed in full colour on our website.)

FREE Member Outings & Activities

July

Prairie Gardens & Adventure Farm
Bon Accord
Saturday, July 19, 1:00 - 4:00 pm
Transportation leaves EEA Office 1:00 SHARP
(pre-registration required)

Fun BINGO for Prizes
Friday, July 25, 1:00 – 3:00 pm
EEA Office

August

Members' BBQ, Games & Social
Saturday, August 23, 11:00 am - 2:00 pm
Leaving EEA Office 10:40 am SHARP
(pre-registration required)

Fun BINGO for Prizes
Friday, August 29,1:00 – 3:00 pm
EEA Office

FREE MEMBER ACTIVITIES

Trip to Prairie Gardens & Adventure Farm, Bon Accord
Saturday, July 19, 1 - 4 p.m.

Annual Members' BBQ, Games & Social
Saturday, August 23rd, 11a.m. – 2 p.m.

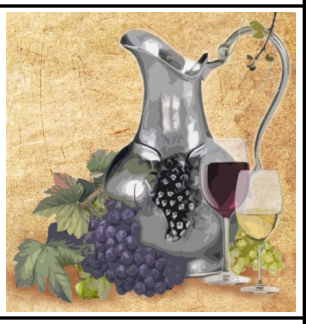
See page 3 for details on these outings.

"Celebrate the Grape"

Thursday, September 11, 2014

A Celebration of Greek-Themed Fine Food and Wine
In Support of Epilepsy Awareness

See page 5 for details



Nominate Your Employer as the EEA "Employer of the Year"

Do You Have Epilepsy? Do you have a great, supportive Employer that recognizes and encourages the many contributions people with Epilepsy offer their fellow employees and workplace?

Nominate them for the 2014 Edmonton Epilepsy Association Employer of the Year Award. Contact us to find out how: 780-488-9600 or gary@edmontonepilepsy.org

Nomination Deadline is September 1st

Adult Support Group Schedule

(Group meets from 4:00 - 6:00 p.m. in the EEA office.)
Please call the Office to advise if you will be attending.

Wednesday, July 16, 2014	Wednesday, August 13, 2014

Support for Parents of Children with Epilepsy

No formal sessions are planned during the summer months. **See page 3 for great summer activities for kids**. For individual questions or concerns, please contact the EEA office for support and information.

Focus on Epilepsy is published 6 times annually by the **Edmonton Epilepsy Association.** Articles appearing in **Focus on Epilepsy** do not necessarily reflect the opinions of the Association.

We welcome your contributions:

Do you have a poem or maybe a short story (1/2 page) that you would like to share with others. Or maybe you have read a book from our library and want to share a review with others. If you would like to share your wisdom, please submit your items to Wendy at our office or e-mail her at info@edmontonepilepsy.org

Edmonton Epilepsy Association

TD Canada Trust

EEA Partners with TD Canada Trust in Employability Program

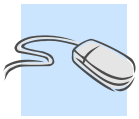
Through the initiative of EEA member Tim McCallen, a Branch Manager with TD Canada Trust, members who are potentially interested in part-time positions as a bank customer service representative (Teller) or full-time positions such as a Financial Service Representative have an opportunity to submit a resume directly through TD's Prairie Region Human Resources Counsellor

For Further information contact EEA Executive Director, Gary Sampley, 488-9600 or gary@edmontonepilepsy.org

Edmonton Epilepsy Association
The Epilepsy Association of Northern Alberta

11007-124th Street NW
Edmonton, AB T5M 0J5

(780) 488-9600
(780) 447-5486 fax
1-866-EPILEPSY
info@edmontonepilepsy.org
www.edmontonepilepsy.org



Find us on Facebook

Member Agency
United Way
Alberta Capital Region

E-Action
TAKING ACTION AGAINST EPILEPSY

Link to E-Action's On-line Epilepsy Resource and Community

Now you can Donate to the EEA online!

Donate Now through CanadaHelps.org

If you would like to make either a lump sum Donation or a monthly donation contribution to the Association by credit card, please visit our website, www.edmontonepilepsy.org, and click on the **Canada Helps** Logo. This donation program gives you the ability to instantly print off a donation receipt.

News from the EEA Office

Annual Members' BBQ, Games & Social

Saturday, August 23, 11– 2 p.m.
"Social Room" in the ACT Centre, Rundle Park

- Games
- Door Prizes
- Paddle Boat Rides
- Excellent Kids' Playground just out the door
- A free toy/gift of their choice for every child

(FREE transportation leaves the EEA office at 10:40 a.m. SHARP)
Call the Office to register! 780-488-9600

Trip to Prairie Gardens & Adventure Farm, Bon Accord

Saturday, July 19, 1 - 4 p.m.
Transportation leaves EEA Office 1:00 pm SHARP
Pre-registration required

A 35-acre family farm from the 1950s. Over 50 fun activities, including a petting farm, u-pick strawberries, kids' mazes, Pirates Cove kids zone, scarecrow band, tractor & wagon rides, haunted farm house, Chick and Cluck Ville, Outpost General Store, and much more.

"Team EEA" Participates Again in the Mayor's Walk for Charity

For the seventh straight year, Team EEA participated in St. Albert's *Roy Financial Mayor's Walk for Charity.* Our 17 enthusiastic team members collectively raised $7059 for EEA Programs and Services.

Congratulations to Cam Reid, who, for the seventh continuous year, was EEA's highest fundraiser! Cam was also the Participant Grand Prize Winner of a Gift Card from AMA, donated by Roy Financial Services.

EEA was co-sponsor of the event's bbq, partnering with the St. Albert Food Bank.

Thank you to all runners, walkers and sponsors!

News from the EEA Office

Next EEA Computer Training Program Begins in October 2014

EEA members who wish to learn the basics of how to use a computer and have the opportunity to purchase a low-cost computer with a slim flat screen monitor, keyboard and mouse package are invited to register now.

- The training program will run for four consecutive Wednesdays, from 1:00-2:45 p.m., commencing October 1st;
- Registration is limited to 4 participants;
- EEA Assistant to the Executive Director, Wendy Sauve, will deliver the training;
- This program is a partnership of the EEA and the United Way InKind Exchange.

To register, call Wendy at 780-488-9600 or e-mail info@edmontonepilepsy.org

New EEA Initiative: Edmonton Transit Mobility Training

Uncertain about how to use Edmonton's bus and LRT systems? Need a confidence booster? We have just the answer! Expand your horizons by joining us for an afternoon with a skilled Edmonton Transit travel trainer. Together in our own ETS bus we will learn about **safe travel, how to access buses and LRT trains and much more**. New and experienced transit users welcome.

Wednesday, September 17th, 1:00 - 3:30 pm
Starting at EEA Office
For more information or to register, call Wendy at 780-488-9600 or email info@edmontonepilepsy.org

Odd Fellows & Rebekahs of Edmonton Donate $3500 to EEA

91-year-old Eileen Tober, who has been a member of Jewel Rebekah Lodge #25 for 67 of its 100 years, presents the donation cheque to EEA Executive Director Gary Sampley during a June 7th dinner at the Odd Fellows Temple.

Odd Fellows & Rebekahs of Alberta

EEA sincerely thanks you!

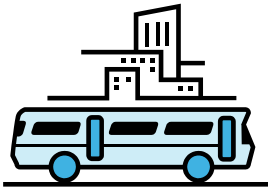
2014 Collective Kitchen

The 2014 Collective Kitchen was held once a month for a period of six months from January to June, 2014. It was wrapped up with a potluck luncheon on Friday, June 20th. Participants were presented with a recipe book from a previous session of Collective Kitchen.

This year's Collective Kitchen had a total of seven participants and was led by Sharon Otto and helper Cheryl Gillie. The focus for this year was recipes from different countries, with each month highlighting a country. The next session of Collective Kitchen will begin in January, 2015.

Bus Tickets Available for Members in Reduced Circumstances

Please note that we now have our 2014 allotment of tickets available in the EEA Office. These can be accessed by MEMBERS with limited financial resources who need help getting to medical appointments, EEA events, food shopping, etc., and who do not have an AISH bus pass. Call 780-488-9600 or drop by to pick them up.



Celebrate the Grape

A Celebration of Fine Food and Wine
in support of
Epilepsy Awareness

Thursday, September 11, 6:30 p.m.
Yiannis Taverna 10444 – 82 Avenue

Up-scale entertainment, numerous and diverse silent auction items, 50/50 draw, wine-tasting contest (winner takes home a case of wine) and other attractions.

Tickets: $125
No Minors

Tickets are available through Yiannis,
780-433-6768 or

Edmonton Epilepsy Association,
780-488-9600
info@edmontonepilepsy.org

June Visit to Fort Edmonton Park

Breastfeeding Safe While Taking Epilepsy Medicine

A new study provides reassurance for new mothers with epilepsy, suggesting that breastfeeding while taking epilepsy medicine does not harm a baby's brain development.

What do we know already?
Breast milk is the best first food for babies, providing the nutrients they need along with antibodies from their mother's immune system to help them fight infections. Studies have shown that breastfeeding has other benefits as well, including a faster loss of pregnancy weight for women and possibly higher scores on intelligence tests for children, although researchers are still exploring this.

However, the benefits of breastfeeding have been less certain for babies whose mothers take medicine to treat epilepsy. Some of this medicine filters into breast milk, and there are concerns that this may be harmful for babies. This is based on studies showing that taking certain epilepsy medicines during pregnancy may affect a baby's brain development.

Not much research has focused on the effects of epilepsy medicine in breast milk, but findings so far have been reassuring. One study found that children whose mothers took epilepsy medicine had similar scores on intelligence tests at age 3, whether they had been breastfed or not. However, test results in younger children can't predict school performance and adult intelligence as reliably as test scores in older, school-aged children.

How was the new study done?
Researchers looked at 181 6-year-old children whose mothers took medicine for epilepsy. As babies, nearly half of the children had been breastfed for at least three months. The researchers gave tests to all of the children to measure their intelligence. They then compared the results, to see whether those who had been breastfed had lower scores.

What does the new study say?
The researchers found no harmful effects among children whose mothers breastfed them while taking epilepsy medicine. In fact, the breastfed children scored higher on intelligence tests than those who were not breastfed. Of particular note, breastfed children had better scores on verbal abilities.

These findings remained after the researchers took into account many things that might have affected the results, such as the mothers' ages and scores on intelligence tests, and what epilepsy medicines they took and at what doses.

How reliable is the research?
Taken together with previous research, this study provides compelling evidence that breastfeeding while taking epilepsy medicine is safe.

However, this study was fairly small, with only 181 children. We need further studies to confirm its findings, particularly those suggesting that breastfed children tend to score higher on intelligence tests. It's also worth noting that the study only included children whose mothers had also taken epilepsy medicine while they were pregnant. So we don't know if the findings would be similar for children whose mothers didn't take epilepsy medicine while they were expecting.

What does this mean for me?
If you take epilepsy medicine and would like to breastfeed, this study (along with others) shows that this is not likely to harm your child. If you have any questions or concerns about this, speak to your doctor.

June 17, 2014
http://www.webmd.boots.com/children/baby/news/20140617/breastfeeding-safe-epilepsy-medicine

Does Your Child or Teen Have Upcoming Sports, Arts, or Recreational Activities Costs?

The **Garry Hannigan Memorial Life Enhancement Scholarships for Youth**, to a maximum of $500 each, are available for Youths of any age, up to the age of 18, to assist them in participating in Sports, Cultural or Recreational Activities that will enhance their development as individuals.

Scholarship criteria, eligibility details and the current Application Form can be downloaded from www.edmontonepilepy.org, or a hard-copy Application can be mailed to you on request to the EEA Office, 780-488-9600.

Need Prescriptions Filled?

We recommend the following Pharmacists, who support the programs of the EEA. For all your Pharmacy needs, visit their friendly, helpful staff today

Southside
G & E Pharmacy
7326-82nd Avenue
780-469-7667

Central
Royal Pharmacy
Ground Floor, 11010-101 Street
780-426-0872

Teen's Epilepsy Service Dog Is Honored With Yearbook Photo

Texas middle school student Rachel Benke was lucky enough this year to have her seventh-grade yearbook photo appear right next to that of her best friend — a Labrador-golden retriever mix named Taxi. An epilepsy service dog who can predict the onset of seizures, Taxi has been by Rachel's side for four years, and her mom thought it only right that he be allowed to remain there in the yearbook, too.

"Last year when their yearbooks came out, I said, 'Hey, where's Taxi's picture?' But I was kind of joking," Rachel's mom, Teresa Benke, tells Yahoo Shine. This year, Teresa — who attends picture day every year with her daughter, because Rachel's condition makes it difficult for her to make eye contact and smile for the camera — really made it happen. "After Rachel's picture, I said, 'OK, Taxi's turn,'" she says. And lo and behold, the photographer went for it, taking a quick snap of the handsome dog.

The subsequent attention has been a welcome distraction for Rachel, who had a portion of her brain removed at age 6 to quell the hundreds of seizures she was having daily.

Rachel and Taxi at school a few years ago. Photo: Courtesy Teresa BenkeBecause of her early seizures, 14-year-old Rachel is developmentally more of a 6- or 7-year-old, her mom explains. And while she can sometimes go months without a seizure, she can also suffer up to several in one week. It's why Taxi — who flunked out of Seeing Eye training because of a "cat-distraction problem," Teresa says, only to be retrained as an epilepsy service dog — has been such a godsend.

Epilepsy service dogs can work in various ways: by alerting people when a seizure is about to occur, assisting during and after a seizure, or by helping to protect the person from injury, according to the Epilepsy Foundation. And though the foundation's stance on seizure predicting is that more research is needed before people can truly understand or even count on the innate skill of service dogs, Taxi, who has been Rachel's protector since she was 9, appears able to do it all. He was exactly what Rachel's parents had hoped to find ever since learning about the dogs' existence many years ago on the news program "20/20."

"I can't tell you how many times she's just dropped on the pavement," Benke says through tears. "She's been bruised up her whole life. But you've also got to let her live. So when we got Taxi, it was just such a relief."

Once, when Rachel was swimming , her mom explains, Taxi jumped in the pooland started splashing. Teresa was able to get her daughter out of the water just minutes before the onset of a grand mal seizure. Another time, while Rachel was waiting for her turn on a trampoline at a birthday party, Taxi stood on his hind legs and placed his paws on her shoulders, stopping her just moments before another seizure.

It's been similar to the situation of another recent headline-making student-dog combo: Jessica Hayes, of Lubbock, Texas, whose service dog, Shawnee, joined her in donning a cap and gown and striding across the stage for her Roosevelt High School graduation. The yellow Lab, who senses Jessica's oft-violent seizures 10 to 15 minutes before they occur, was honored at the ceremony with a special treat and a certificate for "outstanding service, loyalty and companionship" to Jessica.

For Rachel, though, having Taxi by her side in school in San Antonio's Northside Independent School District has not always been smooth sailing. Her mom says Rachel's elementary-school principal complained frequently about the dog being a distraction, leading the Benkes to file a grievance against the school. It's why Rachel's entrance into middle school has been such a welcome relief, Teresa notes, and why the side-by-side yearbook photos have been a particularly joyous end-of-school-year send-off.

"It's been so much fun watching her," Teresa says of her daughter, who's been tickled to see their story picked up as far away as Japan. "She's eating it up. It's so cute."

Jun 9, 2014
https://shine.yahoo.com/parenting/teen-s-epilepsy-service-dog-gets-honored-with-yearbook-photo-184410172.html

Rachel and Taxi in the yearbook. Photo: Courtesy Teresa Benke

MRI-guided laser procedure provides alternative to epilepsy surgery

For patients with mesial temporal lobe epilepsy (MTLE) that can't be controlled by medications, a minimally invasive laser procedure performed under MRI guidance provides a safe and effective alternative to surgery, suggests a study in the June issue of *Neurosurgery* , official journal of the Congress of Neurological Surgeons.

"Real-time magnetic resonance-guided stereotactic laser amygdalohippocampotomy (SLAH) is a technically novel, safe and effective alternative to open surgery," according to the new research by Dr. Robert E. Gross of Emory University School of Medicine, Atlanta, and colleagues.

MRI Guides Precise Laser Destruction of Area Causing Epilepsy…

The researchers report their experience with MRI-guided SLAH in 13 adult patients with epilepsy mapped to a part of the brain called the mesial temporal lobe. The patients, median age 24 years, had "intractable" seizures despite treatment with antiepileptic drugs.

In the SLAH procedure, a saline-cooled fiberoptic laser probe was precisely targeted to the area of the brain—the "amygdalohippocampal complex"—responsible for the procedures. Using real-time MRI guidance, the neurosurgeon was able to pinpoint the area of the brain responsible for seizure activity and destroy (ablate) by computer-controlled laser energy, without harming neighboring brain tissue.

The technical aspects of the procedure were successfully carried out in all patients. Using thermal imaging and MRI guidance, …

(continued on page 9)

MRI-Guided Laser… (continued from page 8)
the surgeons were able to see the area of laser ablation as treatment proceeded. The average laser exposure time was just under ten minutes.

On average, 60 percent of the amygdalohippocampal complex was destroyed in the SLAH procedure; the average length of the ablated area was 2.5 centimeters. Median time spent in the hospital was just one day—compared to a typical two to five-day stay after conventional temporal lobe surgery, and SLAH patients did not have to be admitted to the intensive care unit.

…With Good Control of Seizures at Follow-Up
Most important, the procedure was effective in reducing or eliminating seizures in patients with MTLE. At a median of 14 months after SLAH, ten out of thirteen patients achieved meaningful seizure reductions, while seven were free of "disabling seizures." This included six out of nine patients whose epilepsy was caused by an abnormality called mesial temporal sclerosis. Although some complications occurred, none were directly caused by laser application. Two patients had an additional SLAH procedure to control seizures, and another patient underwent standard open surgery.

Open brain surgery is the standard treatment for patients with intractable MTLE. Surgery has a high success rate, but carries a significant risk of neurological and cognitive (intellectual) impairment. Minimally invasive approaches like the new MRI-guided laser ablation technique might produce similar seizure control with lower risks than surgery.

The new study shows "technical feasibility and encouraging results" with the minimally invasive MRI-guided SLAH technique for patients with MTLE. Effectiveness in relieving or eliminating seizures approaches that of surgery—perhaps especially among patients whose seizures are caused by mesial temporal sclerosis. "These are promising results considering that this reflects our initial experience, and results may improve with greater experience with this novel technique," notes Dr. Gross.

"Such minimally invasive techniques may be more desirable to patients and result in increased use of epilepsy surgery among the large number of medically intractable epilepsy patients," Dr. Gross and colleagues conclude. They note that a larger, longer-term study of SLAH is underway, including assessment of the effects on cognitive function as well as seizures.

June 2, 2014
http://medicalxpress.com/news/2014-06-mri-guided-laser-procedure-alternative-epilepsy.html

Brooklyn Might Make it to P.E.I. After All

A B.C. teen with autism and epilepsy who missed out on an exchange trip to P.E.I. will get to travel to the province after all thanks to some help from Islanders.

Jeff Himelman, president of the Autism Society of P.E.I., said as a lot of Islanders became aware of Brooklyn Mavis's situation, it left a bad taste in their mouths.

"As Islanders we certainly pride ourselves on being welcoming and inclusive to all people and visitors alike," he said.

Mavis, 15, was supposed to take part in a Society for Educational Visits and Exchanges in Canada (SEVEC) trip to P.E.I. this spring but wasn't allowed to after having a complex seizure during an outing with Island students in B.C.

SEVEC said steps were taken to accommodate Mavis. The incident led to allegations of discrimination, harassment and bullying against Mavis.

Since she didn't come to P.E.I. through SEVEC, local community groups and the City of Charlottetown have organized a fundraising effort to bring her to the province.

Himelman said the organizers have been in contact with Mavis's family about her coming to P.E.I.

"We're very hopeful that we'll see a very positive outcome to this in the near future," he said.

On Thursday, fundraising partners Parkdale Sherwood Lions Club, the autism society, the City of Charlottetown and the Stars for Life Foundation held a barbecue at the Charlottetown Fire Department's station on Kent Street.

Although Mavis won't be part of the educational experience of the exchange, Himelman said she will still get a unique Island experience so the family leaves with a positive impression of P.E.I.

"We just didn't want it to end on the note that it did," he said. Paul Gauthier of the Lions Club said Mavis wanted to come to P.E.I. and the organizers wanted to help her fulfil that dream. "We have done that."

The fundraisers' goal is to have Mavis in P.E.I. next month.

June 6, 2014
http://www.journalpioneer.com/News/Local/2014-06-06/article-3753285/Brooklyn-might-make-it-to-P.E.I.-after-all/1

© Photo special to The Guardian by Global News

Melanie Bowen, right, looks on as her daughter, Brooklyn Mavis, sheds tears during an interview with Global News in British Columbia. Brooklyn was told she was not allowed to attend a students exchange in Prince Edward Island because of her autism and epilepsy.

Recognising When Epilepsy is Linked to Alzheimer's Disease

Alzheimer's disease (AD) carries a significantly increased risk of seizures, and it is estimated that 10-22% of people with AD develop unprovoked seizures at some point (the higher rates being associated with hereditary/early-onset AD). People who have AD in combination with a seizure disorder suffer greater cognitive decline and more rapid progression of symptoms than those with AD alone; and it is important to treat their seizures early so that their prognosis can be improved. However, little is currently understood about the nature of seizures that are linked to AD, and they are therefore difficult to identify (especially as seizures themselves can also cause cognitive problems). In addition it is reported that more than half of the seizures experienced by people with AD are non-convulsive, meaning that they can easily go unrecognised. Researchers in California have recently been investigating seizures in AD and they have made some important findings.

In their most recent study the team recruited 54 people who were treated at the Memory and Ageing Centre, at the University of California, between 2007 and 2012. All had either mild AD (42 people) or a condition known as amnestic mild cognitive impairment (described as a very early stage of AD – 12 people). The participants who had amnestic mild cognitive impairment, and 35 of the 42 those with AD, also had epilepsy; and the remaining seven people with AD had previously had epileptic activity recorded in their brains but they did not experience seizures (this will be referred to as subclinical epilepsy). Having identified the study participants, the scientists examined all of their medical records, and collected a range ofinformation including: their ethnicity; their economic status; their seizure type(s); the nature/timing of their cognitive decline, and their response to antiepileptic drugs (AEDs). They also looked at the medical records of a similar group of people who had AD but no history of seizures/epileptic activity, to find out if having seizures had an impact on the rate of cognitive decline.

When they analysed their data, the researchers found that both AD and epilepsy, and amnestic mild cognitive impairment and epilepsy, were linked to an earlier onset of cognitive decline than AD and amnestic mild cognitive impairment without epilepsy. According to the records the people with AD and epilepsy presented with cognitive decline approximately 5.5 years earlier than those with AD alone (at an average age of 64.8 years as opposed to 70.3 years), and the difference was even more marked for the people with amnestic mild cognitive impairment (those with epilepsy presenting 6.8 years earlier than those without epilepsy – at an average age of 64.3 years as opposed to 71.1 years). Interestingly, subclinical epilepsy was associated with a particularly early onset of cognitive decline – at an average age of 58.9 years.

Examining the nature of the seizures experienced by the subjects, the team noted that over half (55%) had non-convulsive seizures, and that complex partial seizures were the most common. They also observed that the majority of seizures arose in the temporal lobe, on one side of the brain. The onset of seizures was found to vary greatly amongst the participants; however it often coincided with the start of their cognitive decline. Importantly, of the most commonly prescribed AEDs, the subjects appeared to respond better to lamotrigine or levetiracetam than to phenytoin.

These findings are significant, because they highlight several characteristics that might help doctors to recognise when seizures are associated with underlying AD or amnestic mild cognitive impairment. These include: unusually early age of cognitive decline; seizures beginning around the onset of cognitive decline and arising from the temporal lobe on one side, and a good response to lamotrigine and levetiracetam. The results also suggest that prompt control of seizures can help to slow the progression of cognitive impairment, and this could be of significant benefit to people's quality of life.

This study was small, and it included only one centre; however it will hopefully form the basis for a much larger investigation, leading to official guidelines for the diagnosis of epilepsy associated with AD/amnestic mild cognitive impairment. In the meantime, the current results will hopefully make neurologists more alert when treating people with (what appears to be) late-onset epilepsy.

August 14, 2013
http://www.epilepsyresearch.org.uk/recognising-when-epilepsy-is-linked-to-alzheimers-disease/

Potential Association Between Soy Formula, Seizures in Children with Autism

A University of Wisconsin-Madison researcher has detected a higher rate of seizures among children with autism who were fed infant formula containing soy protein rather than milk protein. The study found excess seizures among girls and in the total sample of 1,949 children. The soy-seizure link reached borderline significance among boys, who comprised 87 percent of the children described in the database under study.

Seizures -- caused by uncontrolled electrical currents in the brain -- occur in many neurological disorders including epilepsy, Alzheimer's disease, Down syndrome and autism.

About 25 percent of infant formula sold in the United States is based on soy protein.

Study author Cara Westmark, a senior scientist in the UW-Madison department of neurology, says her investigation was sparked by mouse studies of a drug that, it was hoped, would inhibit seizures by blocking signals that excite nerve cells. "It was pure serendipity that we happened to look at soy," she says.

To simplify the mouse study, she replaced the standard lab chow, which had a variable composition, with a diet containing purified ingredients. Unexpectedly, that diet reduced the rate of seizures by 50 percent compared to standard chow, Westmark says.

"We were intrigued that a dietary alteration was as effective as many medicines in reducing seizure incidence and wanted to pursue that finding," she says. "We foundthat the main difference between the diets was the protein source. The standard diet was soy-based, while the purified diet was casein, or dairy, based."- The mechanism of action is unknown, but Westmark points to the high level of plant-derived estrogens in soy products as a possible cause of the excess seizures.)

People eat a lot of soy products, and when Westmark began to look for the effect in people, she decided to focus on infants, who may consume nothing but formula.

(continued on page 11)

Potential Association… (continued from page 10)
Knowing that people with autism have a higher rate of seizures, Westmark turned to a database from the Simons Foundation Autism Research Initiative.

And that led to the new study, published in the journal *PLOS ONE*, which showed that children with autism who were fed soy formula had 2.6 times as many febrile seizures as the children fed non-soy formula in the database. That means 4.2 percent of the soy group had a seizure associated with a fever, compared to 1.6 percent of the others.

To put it another way, the vast majority of both groups did not have seizures. "This is not saying that all autistic children who eat soy-based formula are going to develop seizures," says Westmark.

And yet that increase is worrying, Westmark says. "The prevalence of autism is increasing and currently affects one American child in 88. Soy is a widespread ingredient …. in many food products and 25 percent of infant formulas are soy based, so this is something that needs to be studied. If the child is lactose intolerant, there are alternatives that a pediatrician can recommend."

The study, Westmark says, was not the kind of randomized clinical trial that can prove causation. "We can say that we have a potential association between the use of soy-based formula and seizures in autistic children; we can't say that this is cause and effect. We were fortunate to be granted access to the SFARI database, but it was not set up to answer the questions we were asking."

Although it's possible that seizures could also be more frequent among children who consume soy formula but do not have a developmental disability, "There is no data available at this time to support that," Westmark says. Still, the study raises concerns, since seizures cause neurological damage and repeated seizures -- epilepsy -- can develop into a lifelong problem.

"This needs to be studied more thoroughly," Westmark says. "If soy formula is lowering the threshold for seizures or increasing the incidence of seizures, we need to know that."

The above story is based on materials provided by University of Wisconsin.

March 13, 2014
http://www.sciencedaily.com/releases/2014/03/140313153937.htm

New Epilepsy Treatment May Prevent Seizures with a Pill

There may be a new way for those with epilepsy to suppress seizures. Researchers may have created a new treatment for drug-resistant epilepsy that allows someone to take a pill in order to keep a seizure at bay.

Epilepsy affects around 50 million people worldwide. Unfortunately, around a quarter of these cases are resistant to conventional treatments. Yet this new treatment method could provide some relief to those who cannot be treated conventionally.

So how does the new method work? It combines genetic and chemical approaches to suppress seizures without disrupting normal brain function. The technique was demonstrated in rodents, but could potentially be used in humans with the use of a simple pill.

"First, we inject a modified virus into the area of the brain where seizures arise," said Dimitri Kullmann, one of the researchers, in a news release. "This virus instructs the brain cells to make a protein that is activated by CNO (clozapine-N-oxide), a compound that can be taken as a pill. The activated protein then suppresses the over-excitable brain cells that trigger seizures, but only in the presence of CNO."

In fact, CNO could be given as a pill in the event that patients could predict when seizures were likely to occur. For example, many people with treatment-resistant epilepsy experience a cluster of seizures; severe seizures are preceded by smaller ones. In theory, a person could take a pill as a preventative measure.

CNO has a half-life of only about a few hours. It also only impacts the pre-treated epileptic parts of the brain.

"After the one-off injections into affected areas of the brain, our new technique would require nothing beyond CNO, administered as an injection or a pill, to suppress seizures when required," said Kullmann in a news release. "This makes it more attractive than alternative forms of targeted therapy such as surgery to remove the brain region where seizures arise, or gene therapy that permanently alters the excitability of brain cells."

The findings could be huge for those suffering from epilepsy. That said, more research will have to be conducted before scientists begin to conduct human trials.

June 2, 2014
http://www.scienceworldreport.com/articles/15129/20140602/new-epilepsy-treatment-prevent-seizures-pill.htm

Epilepsy patients 'could be at an increased risk of stroke'

Epilepsy patients may need to be monitored for an increased risk of stroke, according to new research from Taiwan.

The study, which was published in May 2014 edition of the medical journal Seizure, investigated the incidence and risk of stroke in patients with epilepsy using Taiwan National Health Insurance claims data.

Researchers identified 3,812 patients newly diagnosed with epilepsy in 2000 to 2008, comparing the findings to those of 15,248 people without epilepsy, before searching for subsequent stroke diagnoses in both cohorts until the end of 2009.

It was found that patients with epilepsy exhibited a threefold higher incidence of cerebral stroke than the general population, with the risk shown to be highest among those aged between 20 and 39, or among patients who took high doses of antiepileptic drugs.

Strokes are serious medical events that occur when the blood supply to part of the brain is cut off. Epilepsy is recognised as a common condition among post-stroke patients, but prior to this, studies investigating the association between epilepsy and a risk of subsequent stroke have been limited.

May 7, 2014
http://www.epilepsyresearch.org.uk/epilepsy-patients-could-be-at-an-increased-risk-of-stroke/

Our Programs and Services

- Free "Kids on the Block" puppet presentations that educate children (and their teachers, administrators, caregivers, and group leaders) about kids with Epilepsy in an entertaining manner;
- Free specially-tailored In-services about Epilepsy to schools, businesses, group homes, Public Service bodies, Colleges, etc. (includes annual training for NAIT EMT students and ETS Supervisors and Security Personnel, and on-line information about Epilepsy on the EPS Training System)
- Twice-yearly no-cost Epilepsy Educational Forums, and a bi-annual weekend specialized Educational Conference, all of interest to Health Care Professionals as well as the General Public;
- Free provision of our series of 12 Epilepsy Education Information booklets to Members, Hospitals, Clinics, Neurologists' Offices and Pharmacies;
- Website, print and video information about Epilepsy, and a free lending library;
- A bi-monthly newsletter for Members that includes the latest current medical information available about Epilepsy, as well as current news about the Association and our services and events;
- A Scholarship Program for Post-secondary Students with Epilepsy (minimum two scholarships a year);
- Garry Hannigan Memorial Life Enhancement Scholarships for Youth, to assist young people (up to the age of 18) to participate in sports, arts, cultural or recreational activities that will enhance their development as individuals;
- No-cost Counselling on Epilepsy-related problems for people with Epilepsy and Families of people with Epilepsy, with referrals to other supporting Agencies as needed;
- Two group sessions a month, one geared toward Adults with Epilepsy and concerned family members, and one for Parents/ Caregivers of Children with Epilepsy, plus an Epilepsy Experiences Group;
- No-cost provision of assistance/advice on diverse matters, including, but not limited to, finding employment, driving and Epilepsy, potential side-effects of medication, and dealing with the complexities of Government forms and applications (AISH, Disability, housing subsidy, etc);
- No-cost advocacy on behalf of people with Epilepsy experiencing discrimination or other problems;
- No-cost social and recreational activities for Members that help reduce social isolation, and free "Donate-a-Ride" Program bus tickets for Members in need;
- An annual no-cost in-house Collective Kitchen Cooking Training Program and annual in-house Computer Training Programs for Members;
- Ongoing recruitment and screening of quality Volunteers, annual recognition of all Volunteers, and annual award of Member-nominated Volunteer-, Achiever-, and Employer-of-the-Year Awards.

Edmonton Epilepsy Association

Edmonton Epilepsy Association
11007-124th Street NW
Edmonton, AB T5M 0J5

Place address label here

If you are planning to move in the near future please inform our office so that we can continue to ensure that you get your newsletter...