

# JULY - AUGUST 2015

## FOCUS ON EPILEPSY

THE NEWSLETTER OF THE EDMONTON EPILEPSY ASSOCIATION  
The Epilepsy Association of Northern Alberta - Our 55<sup>th</sup> Year of Service

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

### Member Outings & Activities

#### July

**Open House at new EEA Office**  
Saturday, July 18, 1:00 - 3:00 pm  
11215 Groat Road NW, Edmonton

**Fun BINGO for Prizes**  
Friday, July 31, 1:00 - 3:00 pm  
EEA Office

**Happy Canada Day!**



#### August

**Annual Members' BBQ, Games & Social**  
Saturday, August 15, 11:00 am - 2:00 pm  
Leaving EEA Office 10:40 am SHARP  
(note new EEA Office location)  
**(preregistration deadline August 12)**

**Fun BINGO for Prizes**  
Friday, August 28, 1:00 - 3:00 pm  
EEA Office



See [page 3](#) for details of new location and July 18<sup>th</sup> Open House.

### FREE MEMBER ACTIVITY

**Annual Members' BBQ, Games & Social**  
Saturday, August 15<sup>th</sup>, 11 am - 2 pm  
"Social Room" in ACT Centre, Rundle Park

See [page 3](#) for details.



### be your own boss

THE CHRONIC CONDITION SELF-MANAGEMENT PROGRAM FOR YOUTH

A free six-week youth & young adult workshop series on planning for everyday living.

See [page 4](#) for details

### "Celebrate the Grape"

Thursday, September 10, 2015

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

See [page 5](#) for details



### Adult Support Group Schedule

(Group meets from 1:00 - 3:00 p.m. in the EEA office.)

**Please call the Office to advise if you will be attending.**

Wednesday, July 8, 2015

Wednesday, August 12, 2015

### Support for Parents of Children with Epilepsy

No formal sessions are planned. See **"Free Member Activities"** for EEA's upcoming family-friendly activities. For individual questions or concerns, please contact the EEA office for support and information.



# Edmonton Epilepsy Association

The Epilepsy Association of Northern Alberta



**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](mailto:info@edmontonepilepsy.org)

## **BOARD OF DIRECTORS**

**President...**Don Risdon  
**Vice President...**Ann Gillie  
**Treasurer...**Anna Tymoszejko  
**Secretary...**Cameron Reid  
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Cheryl Renzenbrink  
Anne Starreveld  
Brian Wilkie  
Michel Zielinski

## **STAFF**

**Gary Sampley...** Executive Director & Chief Operating Officer  
[gary@edmontonepilepsy.org](mailto:gary@edmontonepilepsy.org)

**Sharon Otto...** Program Manager & Education Coordinator  
[sharon@edmontonepilepsy.org](mailto:sharon@edmontonepilepsy.org)

**Dr. Sunny Kim...** Counsellor  
[sunny@edmontonepilepsy.org](mailto:sunny@edmontonepilepsy.org)

**Wendy Sauve...** Asst. to the Executive Director  
[info@edmontonepilepsy.org](mailto:info@edmontonepilepsy.org)

## ***Edmonton Epilepsy Association***



### **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](mailto:gary@edmontonepilepsy.org)

## **Edmonton Epilepsy Association The Epilepsy Association of Northern Alberta**

11215 Groat Road NW  
Edmonton, AB T5M 3K2

(780) 488-9600  
(780) 447-5486 fax  
1-866-EPILEPSY

[info@edmontonepilepsy.org](mailto:info@edmontonepilepsy.org)  
[www.edmontonepilepsy.org](http://www.edmontonepilepsy.org)



## **Now you can Donate to the EEA online!**

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](http://www.edmontonepilepsy.org), and click on the [Canada Helps](#) Logo. This donation program gives you the ability to instantly print off a donation receipt.



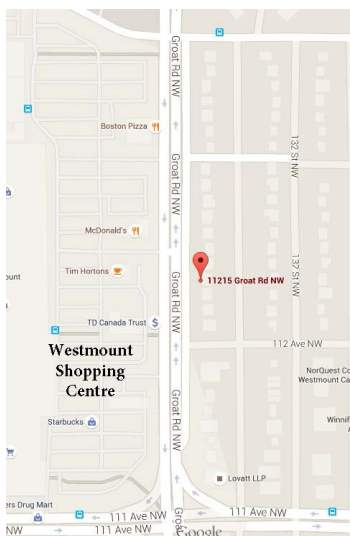


## The EEA has a new home!

Please Join us for an open house at our new location. Meet our staff and tour the new offices and yard space.

**Saturday, July 18**  
**1 - 3 p.m**  
**11215 Groat Road NW**

Light refreshments will be served



## Annual Members' BBQ, Games & Social

Saturday, August 15, 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



## 2015 Collective Kitchen

The 2015 Collective Kitchen ended with a celebratory Potluck Luncheon on June 17th. This year's Kitchen started in January and was held monthly, from January to June 2015.

There were a total of six participants who were led by Sharon Otto and helper Cheryl Gillie. This year's focus was on learning how to cook and food safety. Each month we highlighted a different food type from the Canada Food Guide and prepared three to four recipes belonging to that food group. The 2016 Collective Kitchen will begin in January, 2016.



## Bus Tickets Available for Members in Reduced Circumstances

Please note that we now have our 2015 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. (Please note new EEA Office location.)



## Need Prescriptions Filled?

We recommend the following Pharmacists, who support the programs of the EEA. For all your Pharmacy needs,

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



Central  
**Royal Pharmacy**  
Ground Floor, 11010-101 Street





# News from the EEA Office



## be your own boss

THE CHRONIC CONDITION SELF-MANAGEMENT PROGRAM FOR YOUTH

If you are a youth or young adult aged 14-20 and live with one or more chronic conditions, you probably face many challenges. Alberta Health Services, in partnership with the EEA, is offering a free six-week workshop series on planning for everyday living.

September 17 & 24 and October 1, 15, 22 and 29      Thursdays, 4:30-7:00 pm.  
Edmonton Epilepsy Association, 11215 Groat Road NW

Supper Provided for All Participants

In a supportive environment with young people like you, you will learn:

- how to look after your condition and the various requirements associated with having a chronic condition
- how to carry on with school, homework, activities, social life, and relationships with friends and family
- how to handle the difficult emotions and stresses that come with living with a chronic condition

Contact 780-488-9600 or [info@edmontonepilepsy.org](mailto:info@edmontonepilepsy.org) to register.      [Detailed flyer](#) available on EEA website.

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## Next EEA Computer Training Program Begins in October 2015

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](mailto:info@edmontonepilepsy.org)

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## Nominate your Employer as the EEA Employer of the Year



Nomination Deadline is September 1st, 2015

## Do You Have Epilepsy???

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

Nominate them for the 2015 Edmonton Epilepsy Association Employer of the Year Award. Contact us to find out how:  
780-488-9600 or [gary@edmontonepilepsy.org](mailto:gary@edmontonepilepsy.org)

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## 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.edmontonepilepsy.org](http://www.edmontonepilepsy.org), or a hard-copy Application can be mailed to you on request to the EEA Office, 780-488-9600.







# Celebrate the Grape

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

Thursday, September 10, 6:30 p.m.  
Yiannis Taverna 10444 - 82 Avenue NW

Tickets: \$125 No Minors

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.

Our M.C for the evening:



Rob Christie,  
96.3 Capital FM

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

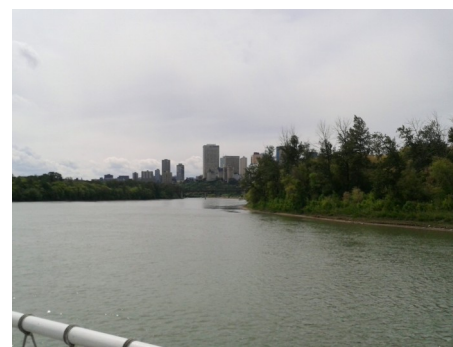
Edmonton Epilepsy Association,  
780-488-9600  
[info@edmontonepilepsy.org](mailto:info@edmontonepilepsy.org)







# Edmonton Queen Riverboat







# Great Volunteer Opportunity!



The Edmonton Epilepsy Association is partnering with Oxford Properties to provide a Christmas Wrapping Station at the Edmonton City Centre Mall. The Wrapping Station is entirely based on donations and 100% of all donations go directly to the EEA. We are looking for volunteers who love to wrap gifts and who have a few hours in December to share in this fun, festive opportunity to support our association.

Dates: **December 1st to December 24th**

Times: **Mall is open weekdays - 10:00am - 8:00pm daily,  
Saturday, 10:00am - 6:00pm, Sunday, Noon - 5:00pm**

**Shifts will be short (4 - 5 hours)**

We will have a variety of shifts available weekdays and weekends.

Location & Address: **Edmonton City Centre Mall – 10025 - 102A Ave**  
Wrapping Station will be behind Guest Services - Main Level

You can volunteer by calling the Edmonton Epilepsy Association  
directly at 780-488-9600 or by email at  
[sharon@edmontonepilepsy.org](mailto:sharon@edmontonepilepsy.org)

NOTE: All volunteers will be provided with vouchers for parking



The EEA will be conducting gift-wrapping classes for volunteers in November.

Further details will follow as our volunteer list is compiled.



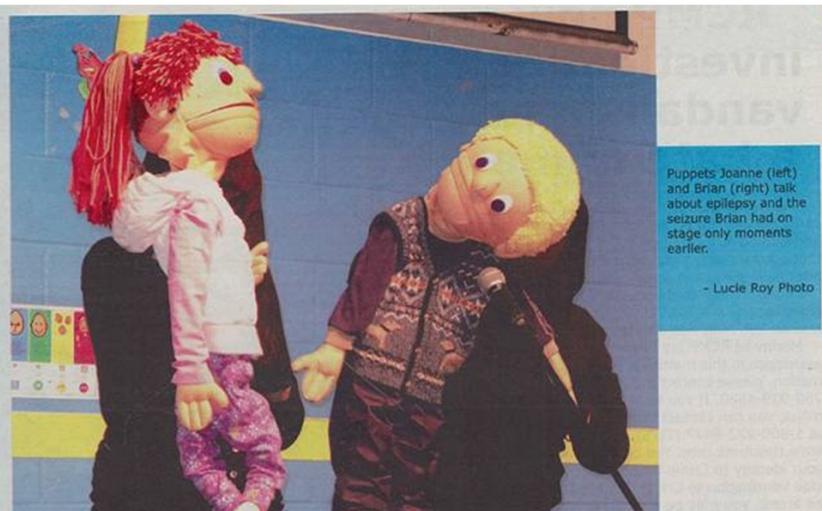


## EEA's "Kids on the Block" Puppet Show Gets Rave Review

"The presentation was fabulous and I thank you very much for arranging it for our students!! The local newspaper (Morinville News) was here to take a few pictures and reported on it in the weekly newspaper. I wanted to share this with you. Thanks again Lisa Kleparchuk (& the students of École Notre Dame School)"

Morinville is a town of approximately 8,600 and is located about 35km north of Edmonton.

Morinville News,  
Morinville, Alberta  
April 26, 2015



## Puppets educate about epilepsy

by Lucie Roy

Two members of the Edmonton Epilepsy Association presented the *Kids On the Block* puppet show to École Notre Students Thursday. The presentation educated students about epilepsy in an entertaining manner.

Puppet characters Brain, Joanne and Nam were moved through their story by puppeteers Darrel Stephenson and Demmi Connolly.

In Canada, one in 100 people is affected by epilepsy, which is a disorder and not a disease. Epilepsy can develop at any time in life and has nothing to do with mental health or intelligence, students were told.

Students learned hundreds of the world's greatest historical figures lived with epilepsy, including Julius Caesar, who was the subject of one of the puppet skits.

Stephenson and Connolly emphasized what to do when someone has a seizure. Students learned it is important to stay calm, move away from hard or sharp objects, and to not hold the person down or put anything in the person's mouth. If the person falls and is shaking - gently roll the person on their side, send for help and stay with the person.

The students also received an activity booklet to learn about epilepsy.

## Sisters' Journey to Healing and Health

It is been thought that Epilepsy is a condition that takes us nowhere. We deal with the condition with medications, lifestyle changes and learning whatever we can to enhance our lives.

I started having seizures along with depression and anxiety issues in 2002. During this time I had several hospitalizations and testing to finally diagnose me has having complex-partial lobe seizures in 2007. Although I was happy for a diagnosis I was nervous about the condition. Since then my seizures have been controlled by medication, routine lab work and a healthy lifestyle. As a result I have been able to keep working as an LPN, in acute care and homecare for 40 years!

In July 2014 our family was devastated when my sister was diagnosed with Acute Myeloid Leukemia. She was immediately admitted to the U of A hospital in Edmonton where she underwent several months of testing, x-rays, consultations, PICC line insertions and Chemotherapy. She was also informed that if Chemo was not killing the cancer cells, that a stem cell transplant would be a further option. The wonderful, professional staff at the U were so helpful in taking care of my sister and informing her every day of her condition and its status with positive visits and suggestions. She also met so many others in the same situation and has made many friends through her journey. In Sept, it was evident that Stem Cell transplant would be the next option and testing would be done first on my sisters siblings (being my brother and I) and if there was not a match, a request would be put into the stem cell bank. I was cautioned with my Epilepsy condition and medication it was unlikely that we would match. There are 10 components in the blood that are needed for a match and 8 of them need to be met in order to consider it a positive match. 2 weeks later I was delighted to

receive the news that despite my epilepsy, I was a 100 % match and would be given the opportunity to save my sisters life!!

In Sept. my sister was transferred to the Tom Baker Centre in Calgary where the transplant would be done. More testing, consults and of course, chemo and radiation to kill all the good cells, to enable her body to accept the new cells from me! I was able to have the pre-testing done at our local hospital in Viking, which was nice and on Oct 10 I headed to Calgary to join my sister on our journey. For 5 days I was given a hormone to increase the amount of stem cells my body produced. This was done on an outpatient basis via 2 subcutaneous injections. 2 days later I was admitted to hospital and placed in a special Apheresis unit. One IV was put into each arm and the process started to collect the 410 million stem cells that my sister needed. I had to lie still for the 7 hours that it took, while hospital staff carefully monitored the number of stem cells as they were taken from me. The blood was taken from one arm, spun through a machine that separated the stem cells from the whole blood, warmed the blood up and returned it to me via the other arm. It was virtually a painless procedure other than lying still that long and told not to move!

Two days later following radiation, my sister was able to receive my stem cells. Her infusion took only 1 hour and following that she was kept in strict isolation so that she was not exposed to any bad "bugs" that may inhibit her adjusting to her new cells.

(continued on page 9)







## Sisters' Journey....

(continued from  
page 8)

We both recovered very well and I am so thrilled to say that on Jan 14<sup>th</sup> my sister was released from hospital Cancer Free. She is so thankful that I was a match that saved her... but I am more thankful than ever to be able to have the opportunity to do so !

Thank you for the opportunity to tell me story. During my sister's illness, I started a

facebook page called Sisters Journey and it was appreciated by all to keep up with all the progress and happenings along with pictures!

Submitted by  
Linda Lusk,  
Viking, Alberta

*Linda is a long-time EEA member. Thank you, Linda, for sharing your story with us!*



## Epilepsy News From Around the World

### Childhood Absence Epilepsy 'Linked With Cortical Connectivity Deviations'

A new Australian study has identified structural connectivity changes in the brains of childhood absence epilepsy patients.

Carried out by the Florey Institute of Neuroscience and Mental Health Austin Campus, the study compared cortical thickness measurements for 30 subjects with childhood absence epilepsy in young adulthood with 56 healthy controls.

The epilepsy patients were shown to have overall increased connectivity, with focal increased connection strength in anterior regions including the anterior cingulate and the insula and superior temporal gyrus bilaterally, the right orbito-frontal and supramarginal regions, and the left entorhinal cortex.

Meanwhile, decreased connection strength in the childhood absence epilepsy group was found in the left occipital lobe, with a similar trend in the right occipital lobe.

This could go some way to explaining why neurocognitive deficits can persist after resolution of the epilepsy among those with this condition.

The researchers concluded: "We interpret this as evidence of a developmental difference in childhood absence epilepsy that emphasises these frontal lobe regions, perhaps driven by frontal lobe epileptiform activity."

Posted by Anne Brown May 29, 2015

<http://www.epilepsyresearch.org.uk/childhood-absence-epilepsy-linked-with-cortical-connectivity-deviations/>

### World Health Assembly Closes, Passing Resolutions on Air Pollution and Epilepsy

26 MAY 2015 | GENEVA The World Health Assembly closed today, with Director-General Dr Margaret Chan noting that it had passed several "landmark resolutions and decisions". Three new resolutions were passed today: one on air pollution, one on epilepsy and one laying out the next steps in finalizing a framework of engagement with non-State actors.

#### Strengthening care for epilepsy

Delegates endorsed a resolution urging Member States to strengthen their ongoing efforts in providing care for people with epilepsy. Although affordable treatment for epilepsy exists, up to 90% of people with the condition may not be properly diagnosed or treated in resource-poor settings. The resolution highlights the need for governments to formulate, strengthen and implement national policies and legislation to promote and protect the rights of people with epilepsy. It also stresses the need to reinforce health information and surveillance systems to get a clearer picture of the burden of disease and to measure progress in improving access to care.

Delegates emphasized the importance of training of non-specialist health-care providers as key to reducing the epilepsy treatment gap. In low- and middle-income settings, strategies to improve access and affordability of antiepileptic medicines should be a priority. Countries are encouraged to undertake public awareness activities to reduce misconceptions about epilepsy and encourage more people to seek treatment. The research capacity of low- and middle-income countries should be built through expanded academic collaboration and establishment of centres of excellence.

The resolution calls on the WHO Secretariat to continue to lead and coordinate support to Member States in addressing the global burden of epilepsy so that people with epilepsy can receive timely treatment and can benefit from educational and occupational opportunities, free from stigma and discrimination.

<http://www.who.int/mediacentre/news/releases/2015/wha-26-may-2015/en/>



World Health  
Organization

### Therapeutic Misconceptions 'Can Hinder Epilepsy Drug Trial Standards'

New research from Finland has underlined the importance of educating epilepsy patients and addressing misconceptions among those eligible to take part in clinical trials of new therapies.

Led by the University of Eastern Finland and Kuopio University Hospital, the study aimed to assess knowledge of and attitudes

toward clinical drug trials among patients with epilepsy, along with factors that motivate them to participate in such studies.

A 45-item questionnaire on the views of patients with epilepsy about clinical trials was developed for this purpose, which was mailed to a random sample of 1,875 members of the Finnish...

(continued on page 10)





**Therapeutic misconceptions....** (continued from page 9)  
...Epilepsy Association aged 18 years and older. A total of 342 questionnaires were returned, with 325 being accepted for the review.

According to results published in the medical journal *Epilepsy & Behavior*, the general attitude of epilepsy patients toward clinical trials was positive, with most acknowledging the fact that their participation in these studies plays a crucial role in new treatments being developed and becoming available.

However, retired respondents and persons who had developed epilepsy during their youth were largely shown to have inadequate knowledge of general issues related to clinical trials, with education levels and the number of antiepileptic medications used being significant predictors for failure to understand the nature and purpose of clinical research.

Additionally, a strong correlation was found between these

therapeutic misconceptions and respondents' willingness to participate in clinical trials, underlining the necessity of providing better education for these patients.

The researchers concluded: "Clinically, it may be worthwhile for the investigators to be able to recognise vulnerable individuals and pay special attention to the information provided on the purposes and methods of the trial, to contribute to high-quality antiepileptic drug (AED) studies."

There remains a strong need for new AED therapies, given that current option are only effective in 70 per cent of patients. Clinical trials play an essential role in validating the efficacy of new drugs and supporting manufacturers' efforts to secure regulatory approval for these treatments.

June 4, 2015

<http://www.epilepsyresearch.org.uk/therapeutic-misconceptions-can-hinder-epilepsy-drug-trial-standards/>

## GW Pharmaceuticals Initiates First Phase 3 Pivotal Trial for Epidiolex in Dravet Syndrome

GW Pharmaceuticals plc, a biopharmaceutical company focused on discovering, developing and commercializing novel therapeutics from its proprietary cannabinoid product platform, announces it has initiated the Phase 3 part of a Phase 2/3 clinical trial of Epidiolex® (cannabidiol or CBD) for the treatment of Dravet syndrome, a rare and catastrophic treatment-resistant form of childhood epilepsy. GW anticipates that top-line data from this trial will be available around the end of 2015.

"Dravet syndrome is a rare and catastrophic form of pediatric epilepsy in which there is a substantial unmet need and for which there are no specifically approved medicines in the United States," stated Orrin Devinsky MD, Professor of Neurology, Neurosurgery, and Psychiatry at NYU School of Medicine, and Principal Investigator of the trial. "This Phase 3 clinical trial of Epidiolex in Dravet syndrome is the first ever rigorous placebo-controlled trial of pure pharmaceutical cannabidiol (CBD) in the field of epilepsy and, as such, a trial of significant interest for the entire epilepsy physician and patient communities."

"GW is dedicated to developing Epidiolex for Dravet syndrome as rapidly as possible. As such, the start of the first Dravet syndrome Phase 3 trial is a significant milestone for our Company and we are on track to start the second Phase 3 trial very shortly," stated Justin Gover, GW's Chief Executive Officer. "We look forward to working with epilepsy physicians across the United States to execute this program with the objective of submitting a New Drug Application for Epidiolex to the FDA in mid-2016."

The Phase 3 trial is the second part of a two-part randomized double-blind, placebo-controlled parallel group safety, tolerabil-

ity, pharmacokinetic and efficacy trial of Epidiolex to treat Dravet syndrome in children who are being treated with other anti-epileptic drugs. Part one completed in February 2015 and comprised the pharmacokinetic and dose-finding elements of the trial in a total of 34 patients over a three week treatment period. The dose for part two has been determined as 20mg/kg by a Data Safety Monitoring Committee (DSMC) after assessment of the part one safety and pharmacokinetic data.

Part two is a 14-week comparison of Epidiolex versus placebo in a total of 100 patients to assess the safety and efficacy as an adjunctive antiepileptic treatment. The primary measure of this trial will be the percentage change from baseline in convulsive seizure frequency during the maintenance period of the study in patients taking Epidiolex versus placebo. Several additional efficacy and safety secondary outcome measures will be analysed. Part two will recruit an entirely new group of patients who did not participate in part one. Following their participation in the study, all patients are eligible to receive Epidiolex under a long term open label extension study.

GW anticipates commencing the second pivotal Phase 3 trial in Dravet syndrome soon after this first trial, which will run in parallel with this Phase 2/3 trial. The Company also expects to commence two Phase 3 clinical trials in Lennox-Gastaut syndrome early in the second quarter of 2015. These additional pivotal trials are all expected to complete recruitment in 2015.

To obtain information about this clinical trial or eligibility criteria, the treating physician should contact: [medicaldirector@gwpharm.com](mailto:medicaldirector@gwpharm.com)

2 April 2015

<http://www.medicalnewstoday.com/releases/291824.php>

## Genetic Research Increases Understanding of Ketogenic Diet

A new study has highlighted the need to explore further genetic factors which may increase our understanding of why some people with epilepsy respond to ketogenic diet therapies while others don't.

Ketogenic diet therapies are high in fat and low in carbohydrate and switch the body's energy fuels from glucose to 'ketone bodies'. This is particularly beneficial for those with glucose trans-

porter type-I deficiency syndrome (GLUT1-DS) where glucose is unable to cross the blood-brain barrier into the brain. This deficiency is caused by mutations in the gene SLC2A1.

Reports have shown that people with mutations in this gene tend to have a more favourable response to the ketogenic diet therapies with some achieving complete seizure freedom. Only...  
(continued on page 11)







## Genetic research.... (continued from page 10)

...rarely do people without mutations in SLC2A1 achieve seizure freedom although they may see a significant reduction in seizure frequency of 50 per cent or more.

### Epilepsy Society leads research

Now, however, the latest study led by Epilepsy Society's geneticist Professor Sanjay Sisodiya, has shown that mutations in the gene SLC2A1 may not be the only explanation for a positive response to the ketogenic diet therapies.

Working with researchers from the UK, Netherlands and Australia, he has shown that there are other genetic factors involved which may help to predict who is likely to benefit from ketogenic diet therapy treatment.

The research team set out to discover whether people without GLUT1-DS who achieve seizure freedom on ketogenic diet therapies, may in fact have undiagnosed GLUT1-DS. They looked at 246 individuals who were following a ketogenic diet therapy but who had not been diagnosed with the syndrome. Their seizure frequency was recorded at regular intervals over a period of up to 24 months and researchers looked at the gene SLC2A1 in each individual.

Results showed that after three months, more than half of participants had a 50 per cent or more reduction in seizure frequency while nine of them (four per cent) were seizure free. The majority of these participants were children.

## Genetic factors in response to ketogenic diet

The number of participants remaining on ketogenic diet therapies fell during each interval. At 12 months, 89 of 111 people (80 per cent) had a 50 per cent or more reduced seizure frequency with seven (six per cent) seizure free: at 24 months, 37 out of 46 people (80 per cent) had an equivalent reduced seizure frequency and three (seven per cent) were seizure-free.

Out of all the 246 participants, three people were found to be seizure-free at every interval, but only one had an SLC2A1 mutation thought to be undiagnosed GLUT1-DS. The other two people achieved seizure freedom at every interval although they had no mutations in the gene SLC2A1, suggesting other genetic factors may be involved. All three were weaned off their anti-epileptic medication.

Professor Sanjay Sisodiya commented: 'Although the percentage of people achieving seizure freedom without mutations in SLC2A1 is less than eight per cent, our study shows that a favourable response to ketogenic diet therapies cannot be solely explained by this gene. It highlights the need to find other genetic factors so that we can identify those who are most likely to benefit from these diets, particularly those who may achieve seizure freedom.'

Nicola Swanborough  
May 18, 2015

<http://www.epilepsysociety.org.uk/Genetic-research-ketogenic-diet-18-05-2015#.VXCpq89Viko>

## Epilepsy Drug Could Protect Eyesight of MS Patients

Sometimes solutions can seem to come from the unlikeliest of places. In this case, researchers have found that a drug commonly taken to prevent seizures in people with epilepsy could protect people with multiple sclerosis from the effects of an associated eye condition.

The findings of the study are due to be presented at the American Academy of Neurology's (AAN) 67th Annual Meeting in Washington, DC, by Dr. Raju Kapoor, of the National Hospital for Neurology and Neurosurgery in London, UK.

Acute optic neuritis is the name of the eye condition in question - an inflammation of the nerve that carries visual information from the eye to the brain. The condition is experienced by around half of people with multiple sclerosis (MS) at some point in their lives.

"The condition can cause sudden total or partial blindness, foggy or blackened vision and pain," explains Dr. Kapoor. "Even though eyesight can recover eventually, each attack still damages the nerve and the eye."

Acute optic neuritis, like many relapses of MS, is typically treated with steroid medications to hasten vision recovery. According to the study authors, however, these do not improve its final extent. As a result, there is presently an unmet need for therapy to prevent further disability caused by MS relapses.

Phenytoin is an anticonvulsant, or antiepileptic, drug that is used to control seizures by slowing down impulses in the brain that are responsible for them.

**Findings could lead to treatment 'serving a major unmet need' of people with MS**

For the study, a group of 86 participants with acute optic neuritis were randomly prescribed phenytoin (4 mg/kg/day) or a placebo within 2 weeks of having symptoms. The participants then took either the phenytoin or placebo for a period of 3 months. Using optical coherence tomography, the researchers measured the thickness of the retina - the layer of nerves at the back of the eye - both at the beginning of the study and 6 months afterward. In addition, the researchers also assessed the participants' eyesight, including color perception and sharpness.

On average, the researchers found that the participants who received phenytoin experienced 30% less damage to their retinal nerve fiber than those who received the placebo. The most light-sensitive part of the retina, the macula, had a volume 34% higher on average among participants who received phenytoin.

After the episodes of acute optic neuritis had resolved, the participants' vision returned to normal as expected. The researchers did not observe any significant differences in long-term visual outcomes between the group that received phenytoin and the control group. Five participants were lost to follow-up.

"If this finding is confirmed by larger studies, it could lead to a treatment that may prevent nerve damage and blindness in MS, and could help other attacks of MS, serving a major unmet need," suggests Dr. Kapoor.

The importance of eyesight - often fundamental to working, social activities and driving - can be overlooked. Should further research support these findings, the results could have real positive implications for people with this debilitating inflammatory disease.

James McIntosh April 19, 2015

<http://www.medicalnewstoday.com/articles/292521.php>





# 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 for members;
- ◆ 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;
- ◆ 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;
- ◆ Monthly group sessions geared toward Adults with Epilepsy and concerned family members;
- ◆ Information and support for Parents/Caregivers of Children with Epilepsy;
- ◆ 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, free ETS Bus Training, 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*

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Edmonton, AB T5M 3K2

*Place address label here*

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so that we can continue to ensure that you get your newsletter...*