



# FOCUS ON EPILEPSY



THE NEWSLETTER OF THE EDMONTON EPILEPSY ASSOCIATION  
The Epilepsy Association of Northern Alberta - Our 53<sup>rd</sup> Year of Service

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

## Member Outings & Activities

### November

#### Fun BINGO for Prizes

Friday, November 1, 1:00 – 3:00 pm  
EEA Office

#### Christmas Craft Afternoon

Wednesday, November 20, 1:00-2:30 pm  
(pre-registration required)

#### Festival of Trees

Saturday, November 30, 1:00 - 4:00 pm  
Shaw Conference Centre  
9797 Jasper Avenue  
(registration deadline  
noon, Nov. 25)



### December

#### Annual Christmas Lunch & Social

Sunday, December 15<sup>th</sup>, 12:00-3:00 pm  
12456 - 126 Street  
(pre-registration required)

#### Christmas Craft Afternoon

Wednesday, December 18, 1:00-2:30 pm  
(pre-registration required)

#### Fun BINGO for Prizes

Friday, December 20, 1:00 – 3:00 pm  
EEA Office

Whichever Your Faith, We Wish  
Our Members and Friends Much  
Enjoyment During Your Holiday  
Celebrations!



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HANUKKAH



CHRISTMAS  
DAY

NEW  
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EVE



## FREE MEMBER ACTIVITY



### Festival of Trees

Saturday, November 30  
1:00 - 4:00 pm

Shaw Conference Centre  
9797 Jasper Avenue

Pre-registration required;  
deadline noon, November 25.

The Shaw Conference Centre is easily accessed by public transit, so transportation is not provided by the EEA to this event. Please contact the EEA Office if you need assistance with transit planning. Best DATS stop: Festival level (Exhibition level of the Shaw Conference Centre) westbound, half way down Grierson Hill.

## Annual Christmas Lunch and Social



Sunday, December 15<sup>th</sup>, 12 – 3 p.m.

Irish Sports & Social Society, 12546 - 126 Street

DOOR PRIZES/GIFT EXCHANGE

See [page 3](#) for details

## 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, November 13, 2013

No meeting in December

## Edmonton Epilepsy Parent Group

Please go to [eearentgroup@gmail.com](mailto:eearentgroup@gmail.com), or access "Edmonton Epilepsy Parent Group" on [Facebook](#), for more details on November's function and for the date, time, and location of the December function.





# 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  
**Past President ...**Laura Jurasek  
**Vice President...**Ann Gillie  
**Treasurer...**Yvonne Leonardis  
**Secretary...**David Cowan  
**Executive Director...**Gary Sampley

**Directors-at-Large:** Tammy Anast  
Alex Dolan  
Guy Doucette  
Kim Mahe  
Anna Pagliuso  
Joe Scalzo  
Anna Tymoszejko

## **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**

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

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

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



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



## **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.





## More News From the EEA Office



### Annual Christmas Lunch and Social

Sunday, December 15<sup>th</sup>, 12 – 3 p.m.  
Irish Sports & Social Society, 12546 - 126 Street  
DOOR PRIZES/GIFT EXCHANGE

In keeping with our tradition of a different ethnic theme each year, this year will have an Irish theme, with entertainment by the Mattierin School of Irish Dance.

**\$10.00** per person (remainder EEA subsidized)  
Full Subsidy Available For Those In Need

Call the EEA office, 780-488-9600,  
to book your seats (pre-registration required).

Assistance with transit planning available from the EEA Office.



### 2014 EEA Scholarship Awards

The Edmonton Epilepsy Association will fund two \$1000 Scholarships in 2014, for the purpose of assisting students to advance to or continue with College or University studies. Application for these Scholarships is open to Greater-Edmonton area students aged 17-29 years of age who are currently under a Canadian physician's care for epilepsy and are Canadian Citizens or who have permanent resident status.

Visa students are not eligible for this award.

**Deadline for applications is March 1st, 2014**

To download an application, visit our website: [www.edmontonepilepsy.org](http://www.edmontonepilepsy.org),  
or call our Office at 780-488-9600 if you wish to receive one by mail.



### We're Looking for an Achiever!



Do you know someone living with Epilepsy who has accomplished significant success in life, inspiring others in the process?

If you would like to nominate someone for the 2014 Award, please do so, in writing, to the EEA office by **March 1st, 2014**.

If you have any questions about the criteria for the award, please contact EEA Executive Director Gary Sampley at 780-488-9600 or [gary@edmontonepilepsy.org](mailto:gary@edmontonepilepsy.org)

### Christmas Crafts Afternoons

Would you like to join us to make some Christmas crafts? Members will enjoy time together as a group on two afternoons, creating seasonal cards and decorations.

Wednesday, November 20, 1-2:30 pm - cards and small decorations  
Wednesday, December 18th, 1-2:30 pm - wreaths or small trees

Please call the office at 780-488-9600 to register.  
Registration is limited to 10 participants each session.







# News From the EEA Office



## A Fond Farewell to an Old Friend



Photo by Ed Kaiser,  
The Edmonton Journal

Many visitors to the EEA office and participants at EEA events met Taffy, EEA Executive Director Gary Sampley's West Highland White Terrier.

Taffy passed away on August 17th at the age of 16 years and 6 months, 103 in human years.

Taffy was Gary's best friend and constant companion, and always went to work with Gary. Over the years, he met well over two thousand people and made many friends from all walks of life. As a personality in his own right, Taffy was in newspaper photos 8 times and on TV 7 times.

Taffy's picture and ashes sit on Gary's nightstand and wish Gary "good morning" and "good night" every day.



## Meet the New Kid on the Block



This is Gio, a just-turned one year old Shi-Tzu/Pomeranian cross who is in training as the new office greeter.

Gio has already met and entertained numerous visitors to the EEA office. He runs like the wind, jumps like a jackrabbit and eats like a horse.

His boundless energy and enthusiasm for life make every day interesting for Gary and the office staff.



## First Call for Next EEA Computer Training Program!

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 requested to register now.

- ♦ The training program will run for four consecutive Wednesdays, from 1:00-2:45 p.m., commencing February 5th;
- ♦ There is a maximum of 4 participants for the course;
- ♦ 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 Centre.



To register, call Wendy at 780-488-9600 or e-mail [info@edmontonepilepsy.org](mailto:info@edmontonepilepsy.org)

## Pocket Calendar & Seizure Record

The EEA has again produced a new 25-month pocket calendar style Seizure Record, which is available free for EEA Members from the EEA Office and is also being provided free to patients of the Glenrose, University of Alberta and Stollery Children's Hospital clinics.

Production and printing of this new publication was funded by a Sponsorship from UCB Canada Inc. If you'd like a copy please call our office at 780-488-9600 or stop by 11007-124 Street and pick one up!





## More News From The EEA Office

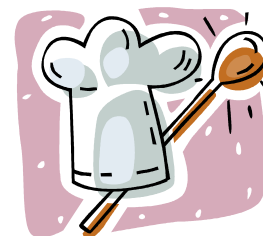


### Collective Kitchen Program Starting in January 2014

This is a combined support and training program to assist members living on a limited income who lack a knowledge of proper nutrition, as well of budgeting and cooking skills. Working collectively, course participants are guided into the world of nutrition and how it affects their seizures and overall health. The course also covers issues such as low cost cooking, food preparation, budgeting skills and planning ahead. A hands-on course, it has components of active teaching. Each participant gets to take home what they have cooked, usually four to six individual portions, in freezable containers capable of fitting into a fridge freezer compartment.

The next Collective Kitchen Project runs on January 17, February 14, March 14, April 11, May 16 and June 13, 2012. Interested members can phone the EEA Office at 780-488-9600 to register.

Registration is limited to **eight** participants.



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### Offerings In Our Broader Community



#### TRANSITION PLANNING FOR ADULthood

*"Planning Positive Futures"*

**Gateway Association** is a family resource centre that has provided education, family support and mentorship to individuals and their families since 1975. Gateway is widely renowned for our work with transition planning for youth with disabilities. We believe having a disability doesn't define or limit who you are. All individuals can live, work, love and play as valued and respected members of a community.

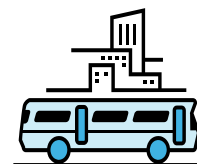
This fall, we are presenting our longstanding workshop series ***Transition Planning for Adulthood*** in five parts on Monday evenings beginning October 28<sup>th</sup>. This workshop is designed to assist families as they undertake the process of transitioning their teen to adulthood. Parents/Caregivers are lead through the process of visioning for the future and ensuring their teen has the opportunities and supports needed to succeed! Pre-registration is required.

For more information please contact Gateway at 780-454-0701 ext. 110 or [registration@gatewayassociation.ca](mailto:registration@gatewayassociation.ca)  
For further details: <http://www.gatewayassociation.ca/latest-news/140-transition-planning-for-adulthood-fall-2013-series>

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### Bus Tickets Available for Members in Reduced Circumstances

**Please note** that we now have our 2013 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.



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### 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

#### Central

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



#### Southside

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







# “Celebrate the Grape”



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# Fundraiser at Yiannis Taverna



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Photos Courtesy of [TJ Flexhaug Photography](#)







## New Approach for the Treatment of Epilepsy Authorized by Health Canada - FYCOMPA(TM) is Now Available as an Adjunctive Treatment for Adult Patients

### *First and Only Selective, Non-Competitive AMPA Glutamate Receptor Antagonist*

Eisai Limited is pleased to announce the Health Canada authorization and availability of FYCOMPA (perampanel) indicated as an adjunctive therapy in the management of partial-onset seizures, in adult patients with epilepsy who are not satisfactorily controlled with conventional therapy.

FYCOMPA is a first-in-class treatment authorized by Health Canada that selectively and non-competitively targets post-synaptic AMPA glutamate receptors, representing a new approach to seizure control.

Health Canada's authorization of FYCOMPA was primarily based on three Phase III studies (304, 305 and 306). These multi-centre, randomized, double-blind, placebo-controlled, parallel group studies evaluated the efficacy and safety of FYCOMPA compared to placebo given as an adjunctive therapy in patients with partial-onset seizures. The studies demonstrated that FYCOMPA significantly reduced seizure frequency in patients with partial-onset seizures with or without secondarily generalized seizures.

"FYCOMPA represents an innovative approach in the treatment of epilepsy and a much needed option for Canadian patients and physicians," says Dr. Neelan Pillay, Clinical Professor, Director Adult Epilepsy Program, EEG and Evoked Potentials, Department of Clinical Neurosciences, Foothills Medical Centre. "When added to their current treatment regimen, FYCOMPA is shown to significantly reduce seizures in patients."

In Canada, 300,000 Canadians currently live with epilepsy, and an estimated 15,500 are diagnosed each year. Despite the high epilepsy incidence, there still remains a relatively low understanding and awareness of this neurological disorder.

"Health Canada's authorization of FYCOMPA marks another important milestone for Canadian epilepsy patients with partial-onset seizures who now have a new option that is proven to control their seizures," says Oliver Technow, President and General Manager, Eisai Limited. "Eisai's human healthcare (hhc) philosophy centres around improving the health and quality of life for patients and their families and we are committed to improving these lives by providing innovative therapies that can have a positive impact."

"The epilepsy community celebrates the authorization of FYCOMPA as an additional tool to manage the disorder," says Gail Dempsey, President, Canadian Epilepsy Alliance. "Access to new options is key - every patient responds differently to a treatment and it is our goal as a community to ensure the tools are available, so that patients can live a fulfilling and rewarding life."

In the three clinical studies, most adverse events in all treatment groups were considered mild or moderate in severity. The most common adverse events (greater than or equal to 5 per cent) in patients treated with FYCOMPA were dizziness, somnolence, fatigue, irritability, nausea, ataxia and falls.

### **About Epilepsy**

Epilepsy is a medical condition that produces seizures affecting a variety of mental and physical functions. About 70 per cent of people with epilepsy have partial-onset seizures. In about 30 per cent of patients with epilepsy, seizures cannot be controlled with treatment.

### **About FYCOMPA (perampanel)**

FYCOMPA is an oral medication taken once-daily and is the first Health Canada-authorized selective and non-competitive post-synaptic AMPA (alpha-amino-3-hydroxy-5-methyl-4-isoxazolepropionic acid) glutamate receptor antagonist. AMPA receptors, widely present in almost all excitatory neurons, transmit signals stimulated by the excitatory neurotransmitter glutamate within the brain. Glutamate is the primary excitatory neurotransmitter in the central nervous system.

Discovered and developed by Eisai, FYCOMPA has been licensed in more than 30 countries including, the U.S., U.K., Germany, Sweden, Norway, Denmark, Austria and Switzerland.

FYCOMPA is supplied as 2 mg, 4 mg, 6 mg, 8 mg, 10 mg and 12 mg film-coated tablets.

Epilepsy is a therapeutic area of focus for Eisai. The company continues to make further contributions to help address the diversified needs of epilepsy patients and their families as part of its corporate human health care (hhc) mission.

MISSISSAUGA, ON, July 10, 2013 /CNW/

For full article with references:

<http://www.newswire.ca/en/story/1196681/new-approach-for-the-treatment-of-epilepsy-authorized-by-health-canada-fycompa-tm-perampanel-is-now-available-as-an-adjunctive-treatment-for-adult-pat>







## Physicians 'must educate parents' About Influenza Risks to Epilepsy Patients

According to the Centers for Disease Control and Prevention (CDC), the 2009 influenza pandemic revealed that children with epilepsy and similar disorders are more susceptible to life-threatening complications – some 146 of 336 paediatric deaths occurred in patients with underlying neurological conditions.

A follow-up survey suggests that vaccination rates are low among these individuals, leading the US federal agency to conclude it is “essential” for physicians to educate the families of patients about the heightened risk.

CDC worked alongside Family Voices and the American Academy of Pediatrics to determine vaccination rates in a sample of 1,005 children with neurological or neurodevelopmental disorders.

They found that just 59 per cent of epilepsy patients had been vaccinated against the influenza virus. Furthermore, just 52 per cent of their physicians understood that these individuals faced a higher risk of fatal complications than their counterparts without underlying neurological conditions.

“Further research ... is needed to identify barriers to influenza vaccination among families and healthcare providers of these children,” researchers commented.

<http://www.epilepsyresearch.org.uk/physicians-must-educate-parents-about-influenza-risks-to-epilepsy-patients/>

September 13, 2013

Posted by Steve Long

## Brain Maps May Aid Epilepsy Surgery Planning

Canadian scientists have developed a new way to help surgeons prepare to operate on patients with epilepsy.

Researchers at Simon Fraser University have been testing the potential of magnetoencephalography (MEG) technology to help pre-operative planning.

The technique produces detailed spatial maps of language functions, helping surgeons to determine whether or not a patient's language capabilities might be affected when treating the part of the brain responsible for seizure activity.

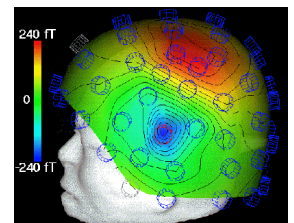
Areas of the brain involved in language activity show up in different colours on the images, revealing whether or not the patient's epileptic seizures originate in these regions.

Neuroscientist Dr Ryan D'Arcy explained: “When carrying out brain surgery it's imperative not only to determine where the areas are to treat, but whether the critical regions that carry out higher functions like language and memory will be affected.”

The researcher, whose findings are published in the journal Human Brain Mapping, is now continuing his brain mapping work with a view to improving imaging technologies for use by surgical teams.

August 1, 2013

<http://www.epilepsyresearch.org.uk/brain-maps-may-aid-epilepsy-surgery-planning-2/>



<http://simerg.files.wordpress.com/2009/06/datapict3.gif>

<https://encrypted-tbn1.gstatic.com/images?q=tbn:ANd9GcRWtfHRAJm9nGCMQWUHAeOwjgEOvlfW3RylQeZyQnMdnadO0Fhc>

## Surgery 'offers good outcomes' for Children with Epilepsy

Surgery offers children with drug-resistant epilepsy a good chance of improvement, according to a long-term follow-up study conducted in Sweden.

Researchers at the University of Gothenburg's Sahlgrenska Academy have reported long-term observations on the first 47 children to undergo epilepsy surgery at the University Hospital in Lund between 1991 and 2007.

Participants ranged in age from 0.5 years to 18.7 years, with a median age at the time of surgery of eight years.

All of the children underwent cognitive function tests before having surgery, and again at a follow-up appointment between five and 21 years later.

The researchers also looked at the children's medical records to obtain information on demographics and seizure-related characteristics.

Analysis revealed that almost half of the children (23 out of 47) were seizure-free at the time of their follow-up appointment, while a further six benefited from a greater than 75 per cent improvement in the frequency of their seizures.

Twenty-one of the children required a second surgical procedure in order to achieve a satisfactory outcome, but none of the youngsters experienced any increase in their seizure frequency.

(continued on page 10)





## **Surgery...** *(continued from page 9)*

In terms of cognitive function, epilepsy surgery did not seem to have any adverse effects.

Just over three-quarters (76 per cent) of patients saw their cognitive functional level progress as expected and there was a significant improvement in cognitive processing speed among those who became seizure-free.

Publishing their findings in the journal *Acta Neurologica Scandinavica*, the study authors concluded that epilepsy surgery during childhood “offers suitable candidates a good chance of significantly improved outcome and low

rates of complications”.

However, they noted: “Several children ... required a re-operation to achieve satisfactory seizure outcomes.”

The study authors also observed that improvements in children’s cognitive processing speed “appear to occur in parallel with seizure control and were even more pronounced in subjects with no anti-epilepsy drugs ... even after long-term follow-up”.

<http://www.epilepsyresearch.org.uk/surgery-offers-good-outcomes-for-children-with-epilepsy/>

June 13, 2013

## **Young Man Dies Due to Faith in Witchcraft Practitioner at Kuddupadav, State of Kamataka, India**

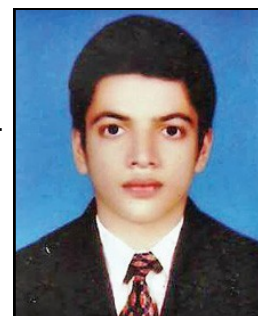
Bantwal, India, 22 Sep 2013 - An epilepsy student became a victim died owing to his family’s faith in superstitious belief, being reported from Kuddupadav in Kepu village near Vittal here.

The victim has been identified as twenty-one-year-old Mohammed Ashiq, son of Abdul Kunhi, a native of Kuddupadav and proprietor of Al-Badr Hardware in Vittal.

Mohammed Ashiq was affected by epilepsy since his childhood and has been treated by Dr Shankar at Vittal. Ashiq was able to lead a normal life with ongoing treatment of Dr Shankar.

Meanwhile, Abdul Kunhi has taken Mohammed Ashiq to a witchcraft practitioner who is known by the name Tangal a few days ago. Tangal has given Abdul Kunhi some powder and asked him to give that to Mohammed Ashiq by diluting in water. Tangal also reportedly said to Abdul Kunhi, to stop medication of Dr Shankar. As per the

instructions of Tangal, Abdul Kunhi abruptly stopped the medication of Dr Shankar and only gave medication that was given by Tangal to Mohammed Ashiq. However, the health of Ashiq deteriorated from the next day.



Abdul Kunhi called Tangal and informed the latter about the deteriorating health of Mohammed Ashiq, but Tangal assured him not to worry. Abdul Kunhi trusted Tangal and continued with the medication to Mohammed Ashiq whose condition reached critical stage that he had to be taken to a hospital in Mangalore. However, Mohammed Ashiq breathed his last en route to hospital. The family expressed anguish over Tangal, because of superstitious belief the youth died.

<http://www.bellevision.com/belle/index.php?action=topnews&type=7244>

## **Study Hopes to Identify Those Likely to Develop Epilepsy After a Stroke**

After a stroke, statistics show that some people are more likely to develop epilepsy, while some are not. It is not fully understood why this is. Now a new study hopes to help with this. This means that people who have had a stroke could receive early epilepsy treatment if necessary.

Every year around 150,000 people in the UK have a stroke. It is the most common cause of epilepsy in people over the age of 60. A stroke can cause brain injury because of bleeding or blockage of the blood supply. When a stroke happens, it can cause a seizure at the site of the damage. Seizures can also develop later.

The reasons why some people develop epilepsy after a stroke and other people don’t are not fully understood. Dr Beate Diehl and colleagues at University College London have been awarded some money to study this by Epilepsy Research UK. They will try to identify risk factors

for post-stroke epilepsy in a small group of people that have had strokes.

The research team will look at brain scans and other brain images as part of the study. By doing this they hope to better understand how the brains of people with and without post-stroke epilepsy are different. The study will be performed on a group of 500 patients.

By the end of the study, the researchers hope to be able to tell what to look for to show if somebody is likely to develop epilepsy after a stroke. Doctors can then check the brains of people who have had a stroke. Any signs that epilepsy is likely to develop could then be treated straight away, before the seizures themselves start.

July 19, 2013

<http://www.epilepsy.org.uk/news/news/study-hopes-identify-those-likely-develop-epilepsy-after-stroke-63266>







## Potential Epilepsy Drug Discovered Using Zebrafish

An antihistamine discovered in the 1950s to treat itching may also prevent seizures in an intractable form of childhood epilepsy, according to researchers at UC San Francisco who tested it in zebrafish bred to mimic the disease.

The researchers said their unexpected discovery offers a glimmer of hope for families of children with Dravet Syndrome, a rare genetic disorder that manifests in early childhood with disabling, lifelong consequences. These include dozens, if not hundreds, of daily seizures, as well as profound cognitive and social deficits.

"It is very unfortunate for these children and families, as they often live from seizure to seizure," said Scott C. Baraban, PhD, lead author of the article, UCSF William K. Bowes Jr. Endowed Chair in Neuroscience Research and professor of Neurological Surgery.

Small, translucent and easy to breed, zebrafish are increasingly being used in place of rodents to screen drugs for rare genetic disorders. But no one had used them for epilepsy drug screening until Baraban's team found zebrafish with a genetic mutation identical to the one that causes Dravet Syndrome.

Baraban said his method of drug discovery could be used to screen drugs for any form of epilepsy caused by mutations in a single gene – a number of which were recently discovered in another UCSF study on epilepsy. The finding is described in a paper published online in [Nature Communications](#) on Sept. 4.

Dravet Syndrome usually develops because of mutations in the *SCN1A* gene, which codes for proteins in sodium ion channels. These channels act as pores that allow charged ions to pass through the membranes of neurons and regulate how they fire. In Dravet Syndrome, these channels let in too many ions and the neurons fire excessively, causing seizures. Other forms of genetically-caused epilepsy involve similar problems in potassium and calcium channels.

While some adult forms of epilepsy can be treated by surgically removing small areas of electrically malfunctioning brain tissue, genetic forms of epilepsy cannot, because they involve neurons all over the brain. Instead, researchers are focusing their efforts on finding effective drugs.

Baraban's team discovered the efficacy of clemizole, which had previously been used only as an antihistamine and an antiviral drug, by accident. Since antihistamines can make seizures worse, it's unlikely he would have focused on the drug if he hadn't used a study design intended to circumvent bias about which drugs might work. Instead of beginning with a hypothesis based on previous findings, Baraban used a random assortment of 320 compounds in a chemical library of drugs that had already been approved by the Food and Drug Administration. He did not look to see what the drugs were until after he had his results.

Why clemizole works is still a mystery. Baraban's group tried 10 other antihistamines, four mentioned in the paper and six others

since then, and none blocked seizures. Baraban concluded that the antihistamine itself was probably not the mechanism of the drug's anti-seizure effect and plans future studies to try to figure this out.

This study used mutant zebrafish discovered a few years ago by then-UCSF neuroscientist, Herwig Baier, PhD, now at the Max Planck Institute of Neurobiology in Germany. By chance, one strain of the fish had a mutation in the same sodium channel gene as the one implicated in Dravet Syndrome.

Just like people with Dravet Syndrome, the fish with this mutation had spontaneous seizures that did not respond to many drugs used to treat epilepsy. But they did respond to a form of the ketogenic – or high-fat – diet, which also often helps reduce seizures in children with Dravet Syndrome. The mutant fish also showed the same developmental pattern as children, whose seizures do not begin until after their first year. In fish, seizures began three days after fertilization. The fish typically died at 10 or 12 days. People with Dravet Syndrome are also vulnerable to sudden unexpected death in epilepsy, or SUDEP.

In these studies, Baraban and colleagues worked with larvae no larger than a human eyelash. They measured their brain activity with a micro-electrode just 1 micron in diameter and tracked their tiny, convulsive movements with special software. He said the seizures in these mutant fish closely resembled those in humans with Dravet Syndrome. Since the larvae are so small and easy to work with, they can screen five times as many drugs in his small laboratory as a much larger lab can do with rodents.

Baraban said that it's important to use whole animals in screening drugs for epilepsy, since it arises from the activity of neural circuits containing many thousands of cells. Even so, his team plans to conduct lab studies to test clemizole's effect on individual neurons generated from patients with Dravet syndrome. They'll use induced Pluripotent Stem Cell (iPSC) technology, which involves generating individual neurons from patients with Dravet syndrome, as a preliminary step before testing the drug in people.

September 3, 2013

[http://www.sciencecodex.com/potential\\_epilepsy\\_drug\\_discovered\\_using\\_zebrafish-118587](http://www.sciencecodex.com/potential_epilepsy_drug_discovered_using_zebrafish-118587)



Scott C. Baraban, Ph.D., is the lead author of the article and UCSF William K. Bowes Jr. Endowed Chair in Neuroscience Research and professor of Neurological Surgery.

(Photo Credit: UCSF)



# 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*

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