

May 2014

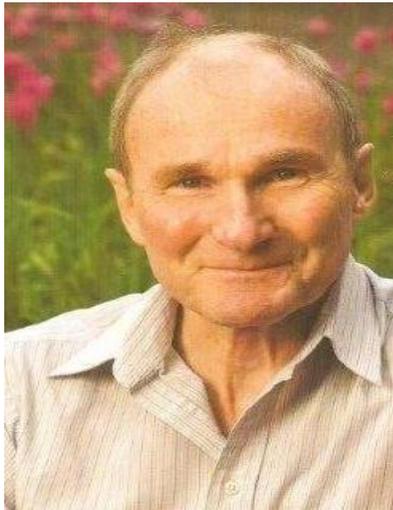
Spring Edition



EPILEPSY AND SEIZURE ASSOCIATION OF MANITOBA

Epilepsy Educator

In Memoriam



Picture reprinted with permission from HSC Foundation. Originally printed in "HSC Foundation 2007-2008 Annual Report".

On March 22 2014, a dear friend to the Epilepsy and Seizure Association of Manitoba lost his battle with cancer. Jim Cook was a man whose

inspirational spirit and hard work as a past President and Director lead a path ESAM continues to follow to this day. Jim always had a smile and an encouraging word for all. He

will be missed dearly. Our sincere condolences to to Jim's wife Morna and his family. May we all remember Jim as he lived his life and be inspired by his character.

-Board of Directors



Dr. Harold Peter Penner was born in Winkler, Manitoba on October 13, 1959. Harold was ten years old when he had his first epileptic seizure. That shaped the rest of his life. He would have multiple seizures almost every day and was on many medications, which had many side effects. In 1990, he had brain surgery at the University Hospital in Saskatoon.

He attended Providence College where he received his Bachelor of Arts, University of Winnipeg for his Master of Divinity and finally McGill in Montreal where he earned his Doctorate in the study of the Philosophy of Religion.

Recently he was again having more seizures and life became very difficult for him. He was found unconscious in his suite as a result of a seizure and was taken to Health Sciences Centre and admitted to the Intensive Care Unit. He did not regain consciousness and after two weeks, Monday, March 10, 2014, he was taken off life support and he passed away.

He was dearly loved and will be deeply missed. He is survived by his parents George and Marion Penner, two brothers: Brian and Robert; his sister Valerie and her husband Richard Markovitz; nephews: Yishai and Tobiah, and one niece Tavi.

Originally printed in Winnipeg Free Press, March 13, 2014.

Local man hopes for ambulance subsidy



Posted: 02/25/2014 3:59 PM— Keith Holden said his family members are often tasked with making choices other families don't have to make.

The Elmwood resident is an epileptic who says he suffered 300 seizures of varying intensities last year. He believes he will perpetually be in debt to the City of Winnipeg because of his ambulance transportation bills, which can run from \$500 for provincially-subsidized regional service to \$800 for basic, unsubsidized service.

"It's a big deal, because my (13-year-old) daughter is being put in the place to make the decision – can we afford it?" Holden said. "For my daughter to be put in that position, it's wrong."

Holden, 41, estimated he's taken over 100 ambulance rides but says he now feels he has to call his parents in Lorette to take him to the hospital if he needs a ride. He said he hadn't taken an ambulance since August. "I'm at the point where I can't do it anymore. I have to stay home, or phone a family member and get them to rush into the city and drive me to the hospital," he said. "It's a 25-minute drive, but it's still 25 minutes that mean the difference between life and death for me."

Holden is calling for an ambulance subsidy similar to one in place in Ontario. In that province, ambulance transport deemed medically necessary costs \$45, and even if the transport is not deemed medically necessary, the charge is \$240. Holden said he cannot afford health insurance. "I'm not thinking about this just for myself. Sure, I've paid \$40,000 in ambulance bills," he said. "There's a lot of old people out there who need this help. I have this one friend who broke his leg playing hockey — he was just at the city limits, and he had a \$635 ambulance bill."

Holden receives a pension from when he worked as a truck driver, as well as other subsidies for housing and recreation, and says his annual income is approximately \$9,000, with between one-quarter to one-third of that allocated to paying off his ambulance bills. Holden has applied for social assistance, but with income of approximately \$900 per month, he said he was told he does not qualify. "I'm using (the subsidies) properly, so I can just get by, but with the ambulance bills, I can't do it," he said. "I worked until the day I got sick."

Holden was diagnosed in 1999 and says he suffers from six different types of seizures. He said that due to a lack of understanding surrounding his condition, he has met resistance getting employment insurance and other benefits. Holden said that, as of Feb. 12, he had a payment plan for \$150 per month and owed the City approximately \$700 for ambulances. Because he'll keep having seizures, he doesn't expect to get out from under the debt anytime soon.

A spokesperson for the City of Winnipeg said in an email that ambulance service rates are determined using a funding formula in which 50% of the cost is shouldered by users, with the other half split evenly by the city and Winnipeg Regional Health Authority. Rates are reviewed annually by city council and adjusted when needed. In Brandon, the base rate for an ambulance trip is \$455, while life support fees (\$100 to \$200 depending on severity) and out-of-community surcharges (\$150) may be applicable. In the Assiniboine Regional Health Authority, a primary call is \$530 and waiting time is \$75 per hour.

Source: <http://www.winnipegfreepress.com/our-communities/herald/Local-man-hopes-for-ambulance-subsidy-247136061.html>



Purple Day Events 2014



On Purple Day-March 26th, I wanted to help spread awareness of epilepsy here in Winnipeg, MB.

I rented a table at Health Sciences Centre and gave out purple cake along with information on epilepsy as well as pins and bookmarks. I have an eight year old daughter, Ava, who has a severe type of epilepsy called "Dravet Syndrome". It has been and continues to be a very difficult and challenging disorder to live with.

I have come to realize just how common epilepsy is and also how people who have it are reluctant to tell others. Many people came up to my table on Purple Day and not one person had ever heard of Dravet Syndrome. Even people living with epilepsy themselves did not know about it. It is time the silence is broken about epilepsy.

My hope is that a cure can be found one day but this won't happen until people are more educated about how common and devastating epilepsy is.

I will keep spreading the word as much as I can and ask Manitobans to join in my mission.

Nicole Mastaler, Purple Day 2014

Purple Day Events and Fundraisers

Purple Day Bunny Hop 2014

Daycares from across Manitoba participated in the Purple Day Bunny Hop. Funds raised go directly to ESAM. A big thank you to all staff, students and parents who participated in the Bunny Hop!



Purple Day Fundraising



The Doreen Bissett School of Dance Ltd. Facilitated Purple Day events the week of Purple Day.

Thank you to everyone who participated and contributed towards Purple Day 2014!

Purple Day Awareness

Sheena Ford, facilitator of the Brandon Support Group sent in a picture of herself sporting purple scrubs in honour of the Day. Great job in helping to raise awareness, Sheena!



ESAM Participates in Epilepsy Australia EpiArt Contest

ESAM participated in Epilepsy Australia's online EpiArt contest in honour of Purple Day 2014. We asked people via FaceBook, email and phone calls what they thought of when they heard "Manitoba" and based on the answers compiled a wall art project to enter the contest.



ESAM EpiArt Entry

Thank you to our volunteers who helped with the wall art project. We didn't win but we received a lovely participation prize in the mail. We had a lot of fun working on the project and it was a great way to spread awareness, support a fellow epilepsy agency and celebrate Purple Day.



Our participation prize.

New study shows benefits of intravenous epilepsy drug lamotrigine

May 6, 2014-Bob Jones

New research has demonstrated the benefits of a new intravenous version of lamotrigine, an established treatment for epilepsy.

The University of Minnesota-led study involved the creation of a stable-labeled intravenous formulation of lamotrigine for studying pharmacokinetics in epilepsy patients. This administration method is useful in treating patients where oral administration is not possible.

A 50 mg dose of this new therapy option was given to 20 people with epilepsy, replacing their regular morning oral dose of the unlabeled, commercially available formulation of the drug.

It was shown there were no significant

changes in blood pressure, heart rate or adverse events – including rash – associated with the intravenous lamotrigine formulation.

The researchers concluded: "Our results show that lamotrigine base that is complexed with 2-hydroxypropyl-beta-cyclodextrin and stable-labeled can be given safely as a tracer replacement dose."

The drug is currently used to treat partial epilepsy, bipolar disorder, generalised epilepsy, Lennox-Gastaut syndrome and absence seizures. It helps to control electrical activity in the brain, thus reducing the chances of seizures.



Source:
<http://www.epilepsyresearch.org.uk/new-study-shows-benefits-of-intravenous-epilepsy-drug-lamotrigine/>

SEEG: New Hope for Severe Epilepsy

Pinpoints seizures' origins for more effective surgery

By [Brain & Spine Team](#) | 5/6/14 6:01 a.m.

One of the major challenges of using [surgery](#) to treat epilepsy has always been finding the place in the brain where the person's seizures begin. The more precisely doctors can pinpoint this area, the better they can focus efforts for surgical treatment. This is especially important in the delicate landscape of the brain where surgeons work to remove as little tissue as possible.

Now, a relatively new procedure called [stereoelectroencephalography \(SEEG\)](#) is significantly boosting success rates of epilepsy surgery. It allows doctors to be much more precise in targeting the origin of seizures, and gives hope to people with severe epilepsy. Before SEEG, the chances of eliminating [seizures after epilepsy surgery](#) were low — only about 20 to 30 percent. But now, SEEG has brought the rates of long-term success up to 55 to 60 percent. “This is truly a breakthrough,” says epileptologist [Jorge Gonzalez-Martinez, MD](#). “In the last 20 years, we've found new imaging technologies, new treatment tools and new medications, but there was really no change in the outcomes. That's because we were always missing the localization.”

Before and after SEEG

About 70 percent of people with epilepsy respond to treatment with medication. The other 30 percent who don't respond to medication consider surgery. In the past, doctors used a type of [invasive electroencephalography](#) that involved removing large portions of a person's skull and placing electrodes on the surface of the brain. This allowed for tracking seizure activity in a [monitoring lab](#). But the information is incomplete. “These superficial electrodes cannot pick up on seizures coming from the deep areas of the brain,” says Dr. Gonzalez-Martinez. With the less invasive [SEEG procedure](#), doctors create small incisions in the skull, just 2 millimeters in diameter. They then pass about 10 to 15 tiny probes into the areas deep in the brain where they believe seizures are originating.

A road map for surgery

Patients stay in the hospital for about a week after the procedure when the electrodes are implanted. Doctors monitor seizure activity as each probe detects it. This creates a road map for a more precise — and effective — surgery several weeks later. During this period of monitoring, doctors also use small electrical pulses to identify the portions of the brain that control speech, motor skills, facial movements and other functions. “Once we know where the seizures are originating and where these functional areas are located, we know what we can remove and what we must preserve for a person to be seizure-free without any neurological deficit,” Dr. Gonzalez-Martinez says.

New hope for those with epilepsy

A variation of SEEG has been used in Europe for more than 50 years. However, the procedure was highly complex with multiple stages over several days.

In 2009, Dr. Gonzalez-Martinez was the first to bring the technique to North America, simplifying it to only a two-hour surgical procedure. Since then, doctors from several epilepsy centers across the U.S. have traveled to Cleveland Clinic to learn more about SEEG from Dr. Gonzalez-Martinez.

“We can now offer hope for patients that once had no hope,” he says. “My dream is that one day we can do noninvasive tests, localize the seizures and then stop them without resection.”

Source: <http://health.clevelandclinic.org/2014/05/seeg-new-hope-for-severe-epilepsy/>

Brandon and Area Support Group

The Brandon Epilepsy and Seizure Support group meetings run September through May in Brandon from 7:00PM-8:30PM.

We are a place for people with epilepsy or seizures to share their feelings and we're also open to family members who are affected by epilepsy/seizure disorders.

We have had speakers attend our meetings to discuss topics including medications and healthy eating.

Our group has also participated in many ESAM fundraisers such as the Healthy Living Marathon, Chuck-A-Puck night at the Wheat Kings hockey game and recently we helped to sell gladioli corms.

Contact Sheena Ford at sheenaforrn@gmail.com for more information on how you can join the group. We welcome everyone and look forward to meeting new people.



ESAM Receives Support



Wow! Thank you Tache Game and Fish for your support!

Your donation will be used to help keep our doors open and ensure that there is a place for people living with or affected by epilepsy/seizures disorders to turn to in their time of need.



Note from the Executive Director

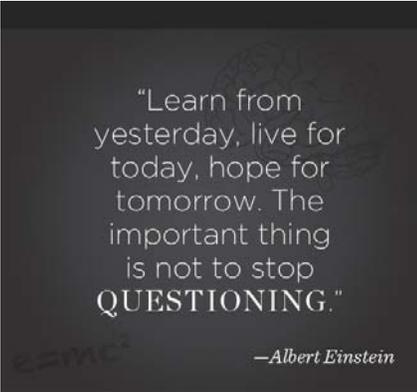
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Toll Free: 1-888-780-3726
Fax: 204-784-9689
Email: esam@manitobaepilepsy.org

I just wanted to take a moment and say thank you to everyone for their overwhelming show of support. To everyone who has called the ESAM offices to welcome me to the Association, to those who have journeyed to the offices so that we may meet in person and to those who have emailed to say hello and welcome, thank you. Your support and encouragement are truly appreciated.

Membership Renewal Reminder



"Learn from
yesterday, live for
today, hope for
tomorrow. The
important thing
is not to stop
QUESTIONING."

—Albert Einstein

Are you interested in continuing to receive our newsletter? Please let us know! We are trying to update our membership list.

Just a reminder....if you haven't already done so, memberships from 2013-2014 expired at the end of March 2014 and need to be renewed.

Paid members in good standing may vote at our AGM.

Call for Interest in Support Group(s)

We have received numerous phone calls in the last few months asking about support groups in the evenings and targeted support groups for youth and for parents.

Would you be interested in attending a support group in the evenings?

Are you a youth or person in their late teens, early twenties who would be

interested in attending a support group?

We would like to explore the option of moving our support group to the evening and adding another group.

If this is something you would be interested in, please let us know.

If we can generate

enough interest, we will change our groups and add more!

Email:

esam@manitobaepilepsy.org

Phone:

204-783-0466

Annual General Meeting

The date and location for the Annual General Meeting has been booked!

Date: Thursday September 18, 2014

Time: 6:30PM

Location: Church of Central Christ

170 St. Mary's Road

Winnipeg, Manitoba

Are you interested in attending the AGM?

RSVP and let us know!

Phone: 204-783-0466

Email:

easm@manitobaepilepsy.org

Guest Speaker: To Be Announced



AGM
Annual General Meeting



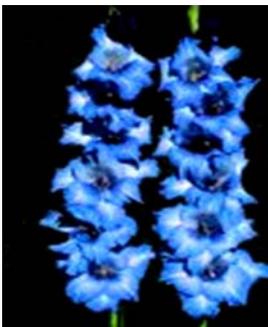
Gladioli Corms

We ordered more gladioli corms!

In our fundraising fervor, we ordered a second batch of gladioli corms. We have some available for sale.

Gladioli corms are \$5.00 a bag. Each bag contains 5 Blue Sky and 5 Royal Sea corms.

If you are interested in purchasing gladioli corms, please contact ESAM offices.



Blue Sky



Royal Sea