Edmonton Epilepsy Association
The Epilepsy Association of Northern Alberta

EEA Focus on Epilepsy Monthly

Newsletter

Volume 3 | May-June 2020 | Focus on Epilepsy

EEA Celebrates 60 Years!

The EEA evolved from the Western Canada Epilepsy League (Edmonton Branch), that was founded in 1958. Twenty to 25 persons attended monthly meetings held in private homes before an office was established at Red Cross House in 1960. In the beginning, help in dealing with the effects of seizures, and education of the public, were aims of the group. The branch was incorporated as The Edmonton Epilepsy Association, serving Edmonton and District, in June 1960.

The agency was accepted as a member of the United Community Fund (now the United Way) in 1961, as a service organization of "tremendous potential for good work in the community".

In 1993, the services provided by the EEA were extended to Northern Alberta as well. There are currently over 23,000 people with epilepsy who live in our service area.

Over the years, the Association has evolved into an organization providing numerous and diverse programs and services.

Inside This Issue

Message from the EEA Board President

These have been challenging times for all of us. We've all been adapting to social distancing and the many changes in our regular routines to ensure we keep each other safe. In response the EEA office needed to pause in-person member activities. We are exploring ways to enable the delivery of support and advice to our members though digital and social media channels. If you have not yet had the chance, please visit our refreshed website at http://www.edmontonepilepsy.org/ it has a new look and feel to hopefully make it easier to navigate and find the information you are looking for.

Some of you may be struggling during these times of isolation. I would implore you to contact the EEA office to ask for help and support. We have virtual telephone counseling sessions available, mentors ready to provide support and numerous government resources are available to help those struggling financially and emotionally. You are not alone.

As you know, we are also going through a key transition of leadership at the EEA, our Executive Director and Chief Operating Officer, Gary Sampley, retired as of May 1st. I would like to thank Gary for his everlasting impact and dedication to the E.E.A over the last 15 years. Gary, on behalf of our members, we wish you a well-earned retirement… you will be missed!

I am excited to introduce to you our new Executive Director and Chief Operating Officer, Valeria Palladino. She comes to us with a passion for helping others as an educator and is an experienced leader from her time as a Chief Officer with the Alberta School Boards Association. She has a track record of expertise in project management, building collaborative relationships and effectively managing, leading and mentoring others. Please join me in welcoming Valeria to the EEA and I look forward to you meeting her at a future member activity! Stay safe everyone,

Colleen Matvichuk

Monthly Activities

All monthly activities have been cancelled for May and June due to the Covid-19 Virus.

Counselling sessions and the Monthly Support Group have also been cancelled. However, if you would like to speak to the EEA Counsellor, Dr. Sunny Kim, call the office and Sunny will return your call within 24 hours.

The Collective Garden will begin after the May Long Weekend, May 18th. Gardeners will be contacted individually to set up a planting time. Planting times will be staggered to maintain social distancing.

The EEA will not be holding any Garage Sales this year as the City has banned Garage Sales for 2020. We ask that you hold onto any items you wish to donate.

If you would like to visit the EEA Office, please call to set up an appointment.
Due to Covid-19, we are accepting limited in-person appointments. However, please do call us if you have any questions or just want to chat.

The Time Has Come

I joined the EEA as Executive Director on May 5th, 2005. I retired on April 30th, 2020; five days short of 15 years.

This was not my first retirement. My first one was in 2003, the year I turned 60. That lasted two years until one day I saw an ad in the Journal from a small charity looking for an Executive Director and then and there started the next chapter in my life, which has never been dull.

I have met with, worked with, and tried to assist so many people in my years with the EEA that the numbers boggle my mind. It has truly been a unique, interesting, and enjoyable major part of my professional life. I especially want to recognize the many Staff, Directors, Volunteers and Medical Professionals who helped me over these years to collectively grow the EEA into the success story it is today. I salute you all. Thank You!!

There are many fond memories I take with me from my EEA days. My most vivid EEA memory though is not so fond, but it did prove to me that a problem would be better looked at as an opportunity rather than a negative. In mid-2015, the EEA bought a house on 123rd Street in the Inglewood District to be our new home. On the very night before the day we were to take legal ownership of the property, some teenagers playing with fire set the house under construction next door to our place on fire. That house burned to the ground and so did most of ours. The rental store front we had been in had already been leased to a new tenant. Our lawyer told us that in over 30 years of practise, he had never heard of a similar situation anywhere. It was a month of scrambling for us, but we found another better property in a better location, all the while continuing to deliver our usual programs and services. I thank my old friend and EEA Treasurer David Cowan for teaching me that adversity can be its own problem solver.

We are currently living in troubled times and maybe even more so for people who live with epilepsy. I encourage you to keep your heads high and your hearts strong. This too will pass.

I am not a young man anymore and I am lucky to have a large family wanting more of my time. I want to give it to them while I can.

With that said,

Goodbye, Good Luck, God Bless!!

Gary

Welcome Valeria Palladino

Hello everyone,

My name is Valeria Palladino, and I am proud and honoured to be the new Executive Director and Chief Operating Officer of the Edmonton Epilepsy Association (EEA). I look forward to meeting you all in some capacity, and to serving all our members in the mission and values of the EEA, to better the lives of those who live with Epilepsy.

As a fervent believer in serving leadership, I have contributed to community-building, fascinating projects and initiatives in the education and non-profit sectors for the last three decades. These include my years as Executive Director of the International and Heritage Languages Association (IHLA), leading international projects and initiatives with Alberta Education and NorQuest College, and as a subject matter expert presenter at language conferences around the globe.

My passion for non-profit governance matters led me to work as the Chief Officer, Online Learning, Research and Events for the Alberta School Boards Association (ASBA). I also count a five-year tenure with the City of Edmonton, as Supervisor of the Hiring and Training Centre for Edmonton Transit Services (ETS). I am a certified member of the Association of Translators and Interpreters of Alberta (ATIA). I hold four university degrees, including a Masters in Secondary Education (MEd) and a Masters in Arts Communications Technologies (MACT) from the University of Alberta. I am proud to call myself a "forever-learner".

A passion for service, innovation, and creativity in respect of traditions and a love for people are values I proudly infuse in everything I do. I am a convicted book lover, I adore pets and walking, while perfecting my cooking skills for family and friends, engaging in exciting trips around the world, and always open to trying new things. As a proud Italian mamma to two grown boys and married to a wonderful husband, I immigrated to Canada over two and a half decades ago and I adore my adoptive country while maintaining close ties with family and friends back home.

I look forward to working together with the Board of Directors of the EEA and honouring the important work and services the association has built its legacy on for the past 60 years, and bringing new ideas and innovation, while building strong relationships with the community we serve and all our members.

Feel free to reach out to me at valeria@edmontonepilepsy.org.
Thank you for the privilege of serving you,

Valeria

EEA Annual Gala

The 60th Anniversary Gala of the EEA is temporarily on hold due to Covid-19. We hope to reschedule it for the Fall of 2020.

2020 EEA Continuing Education Scholarship Awards

The EEA is still accepting applications for two $1000 Scholarships, to be used to assist students to advance or continue with College of 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 extended to June 30, 2020.** To download an application, visit or website: www.edmontonepilepsy.org or call the Office at 780-488-9600 to receive one by mail.

EEA 60

Edmonton Epilepsy Association

The Epilepsy Association of Northern Alberta

FROM GIO TO CLEO

As we say goodbye to Gio, Gary's faithful friend and the association mascot, we say hello to Cleo, Valeria's lovely and faithful companion.
The two pets have already met and shared their doggy's thoughts and important information. Cleo is looking forward to meeting all EEA members when the office will officially reopen. For now, she is content barking at the mail-carrier and making friends with the office staff.

Epilepsy News

New Technique Could Revolutionize Treatment For Alzheimer's, Epilepsy, Brain Tumors

University of Virginia researchers are pioneering the use of focused ultrasound to defy the brain's protective barrier so that doctors could, at last, deliver many treatments directly into the brain to battle neurological diseases.

The approach, the researchers hope, could revolutionize treatment for conditions from Alzheimer's to epilepsy to brain tumors - and even help repair the devastating damage caused by stroke.

Richard J. Price, PhD, of UVA's School of Medicine and School of Engineering, is using focused soundwaves to overcome the natural "blood-brain barrier," which protects the brain from harmful pathogens. His approach aims to breach the barrier only where needed, and only when needed, and then deliver treatments in exquisitely precise fashion.

The blood-brain barrier is one of the greatest, if not the greatest, challenge to drug delivery for the central nervous system, Evolution gave us this barrier because the central nervous system needs to be protected. The problem is now we want to deliver something to those cells and evolution has had millions and millions of years to optimize a solution to stop it. ... So I'm attempting to circumvent biology with physics."

- Richard J. Price, PhD, School of Medicine and School of Engineering, University of Virginia Health System

Focused ultrasound focuses sound waves inside the brain much like a magnifying glass can focus light, letting doctors manipulate tissue without cutting into the skull.

Magnetic resonance imaging (MRI), meanwhile, lets them watch what's happening inside the brain in real time. While Price, a biomedical engineer, is developing his techniques in the lab, doctors are already using the technology to treat conditions such as Parkinson's tremor.

Price marvels at the approach's specificity. "With MRI, we can look at the target, whether it's a brain tumor or maybe it's a part of the brain we want to do gene therapy on, and we can select it - we can actually make a treatment plan and say, We only want to open the [blood-brain] barrier there. The other 95% of the brain, we don't even touch," said Price, the research director at UVA's Focused Ultrasound Center.

"Then, when we apply the focused ultrasound, it opens the barrier there for a few hours. It lets us get the gene therapy across, and then it closes naturally."

Gene therapy introduced via focused ultrasound would essentially reprogram faulty cells.

For brain tumors, Price is exploring the potential of using focused ultrasound to deliver gene therapy via "deep-penetrating nanoparticles."

The nanoparticles, designed by Price's collaborators at Johns Hopkins University, "are specifically engineered to penetrate the tissue extremely well," he said. The problem has been transporting them where they're needed, often deep inside the brain, and Price says focused ultrasound holds the answer.

His solution is to use the focused soundwaves to open spaces between cells in the tissue. "It doesn't help us if you can't get to the neuron that's 50 microns away," he said. "So that becomes an engineering transport problem."

In addition to delivering the therapy, focused ultrasound can "precondition" targeted tissue to enhance the effectiveness of the gene delivery up to fivefold, Price has found. The preconditioning represents a "simple and effective strategy" to boost the benefits of the nanoparticles, he and his colleagues report in a scientific paper.

For stroke, a condition that is often debilitating when it's not deadly, Price aims to help the brain heal itself. He would do this by using focused ultrasound to put "homing molecules" inside damaged areas to recruit neural stem cells to do repairs. For this, his team has developed an innovative technique called "sonoselective transfection" that avoids opening the bloodbrain barriers in brains that are already compromised.

New Technique Could Revolutionize Treatment For Alzheimer's Epilepsy, Brain Tumors (cont.)

"With stroke, there's a lot of effort to try to salvage as much neural tissue as possible by doing things like gene therapy," he said. "In our lab, we thought, well, maybe we can deliver treatment right to the cells that need it, without breaching the blood-brain barrier. And my students basically figured out how to do that."

That notion of helping the body heal itself, of using focused ultrasound to activate an immune response, could be useful in cancer treatments as well.

"We would love to be able to put something into those [tumor] cells that will then allow them to start recruiting immune cells into the tumor," he said. "We have a lot of evidence that we can do some interesting things with focused ultrasound with respect to the internal landscape of those tumors."

Price, of UVA's Department of Biomedical Engineering, emphasizes that his work is still early, but he is excited to be creating new techniques that could change how many major diseases are treated in the not-too-distant future.

"We've had good results [with the research] so far. But what I, as an engineer, get excited about are all these tools we have made," he said. "You can use these tools for all these different applications. We think there are a lot of really exciting possibilities."

May 7th, 2020
Reviewed by James Ives, M.Psych. (Editor)
https://www.news-medical.net/health/Mechanisms-Behind-Epileptic-Seizures.aspx

Antibodies In The Brain Trigger Epilepsy

Certain forms of epilepsy are accompanied by inflammation of important brain regions. Researchers at the University of Bonn have now identified a mechanism that explains this link. Their results may also pave the way to new therapeutic options in the medium term. They have now been published in the scientific journal Annals of Neurology.

Epilepsy can be hereditary. In other cases, patients only develop the disease later in life: as a result of a brain injury, after a stroke or triggered by a tumor. Inflammation of the meninges or the brain itself can also result in epilepsy.

Particularly dangerous are inflammatory reactions affecting the so-called hippocampus, which is a brain structure that plays an important role in memory processes and the development of emotions. Doctors call this condition limbic encephalitis. "However, in many cases it is still not clear what causes such inflammation," explains Prof. Dr. Albert Becker, who heads the Section for Translational Epilepsy Research at the University Hospital Bonn.

Researchers have now identified an autoantibody that is believed to be responsible for encephalitis in some patients. Unlike normal antibodies, it is not directed against molecules that have entered the organism from outside, but against the body's own structures -- hence the prefix "auto," which can be translated as "self." The researchers discovered it in the spinal fluid of epilepsy patients suffering from acute inflammation of the hippocampus. The autoantibody is directed against the protein Drebrin. Drebrin ensures that the contact points between nerve cells function correctly. At these so-called synapses, the neurons are interconnected and pass on their information.

When the autoantibody encounters a Drebrin molecule, it knocks it out of action and thereby disrupts the transmission of information between nerve cells. At the same time it alerts the immune system, which is then activated and switches to an inflammatory mode, while simultaneously producing even more autoantibodies. "However, Drebrin is located inside the synapses, whereas the autoantibody is located in the tissue fluid," says Dr. Julika Pitsch, who heads a junior research group in Prof. Becker's department. "These two should therefore normally never come into contact with each other." The autoantibody seems to use a back door to enter the cell. This is actually intended for completely different molecules: the so-called neurotransmitters.

Antibodies In The Brain Trigger Epilepsy (cont.)

Into the nerve cell by Trojan horse

Information processing in the brain is electrical. The synapses themselves however communicate via chemical messengers, the aforementioned neurotransmitters: In response to an electrical pulse, the transmitter synapse emits transmitters that then dock to certain receptors of the receiver synapse, where they in turn also generate electrical pulses.

The synaptic vesicles -- the packaging of the neurotransmitters -- are absorbed again and recycled. "The autoantibody seems to use this route to sneak into the cell, as with a Trojan horse," explains Becker's colleague Prof. Dr. Susanne Schoch McGovern.

In cell culture experiments, the researchers were able to show what happens next: Shortly after the addition of the autoantibody, the neurons in the Petri dish begin to fire machine gun-like rapid bursts of electrical impulses. "We know that this form of electrical excitation is contagious, so to speak," emphasizes Prof. Becker. "With nerve cells, which are interconnected to form a network, all the nerve cells involved suddenly start firing wildly." This may then result in an epileptic seizure.

The results also give hope for new therapeutic approaches. For instance, active substances such as cortisone can suppress the immune system and thereby possibly also prevent the massive production of autoantibodies. It may also be possible to intercept and incapacitate them specifically with certain drugs. But there is still a long way to go before treatment becomes available, stresses Prof. Dr. Rainer Surges, Director of the Department of Epileptology at the University Hospital Bonn. Moreover, it would primarily benefit patients with this particular form of the disease. For them, however, the benefit would probably be huge: In contrast to congenital epilepsies, those based on inflammation may possibly be cured in the future with the appropriate therapy.

University of Bonn. "Antibodies in the brain trigger epilepsy: Study may enable new therapies against certain forms of the disease." ScienceDaily. https://www.sciencedaily.com/releases/2020/03/200324113414.htm (accessed May 7, 2020).

Chronic Medical Conditions May Place Youth At An Increased Risk For Anxiety Disorders

Washington, DC, May 4, 2020 - Youth who report one of the seven chronic medical conditions (CMCs), including asthma, congenital heart disease, diabetes, epilepsy, inflammatory bowel disease, juvenile idiopathic arthritis, and sickle cell disease, are often diagnosed with an anxiety disorder. A new systematic review in the Journal of the American Academy of Child and Adolescent Psychiatry (JAACAP), published by Elsevier, examines the prevalence of anxiety disorders and the impact of anxiety on disease-related outcomes for children and adolescents with CMCs.

The research team based in Australia and the Netherlands found the prevalence of anxiety disorders in youth with CMCs was higher than that in the general population. Anxiety may also be associated with adverse disease-related outcomes for children and adolescents with these conditions.

"The issue of 'mental-physical comorbidity' (i.e., meeting diagnostic criteria for least one mental illness and one physical disease) is critical, with the combination of anxiety disorders and physical disease appearing to be particularly prevalent among youth, said lead author Vanessa Cobham, PhD and clinical psychologist at the University of Queensland and Children's Health Queensland's Child and Youth Mental Health Service, Brisbane, Australia.

Chronic Medical Conditions May Place Youth At An Increased Risk For Anxiety Disorders (cont.)

"Associated with significant implications, the combination of anxiety disorders and a physical disease presents the potential for worsened physical disease outcomes. Health professionals working with children and adolescents with chronic medical conditions should routinely screen for the presence of anxiety disorders in order to provide the best possible care to these youth."

The review based on 53 studies included the examination of prevalence of anxiety disorders and disease-related outcomes across seven different CMCs in children and adolescents with an average age of 18-years or younger.

Twenty-nine studies investigated the occurrence of anxiety disorders and found that more-than-half of the identified studies relied on only one informant (either the youth themselves or parent) in determining whether or not the youth met the criteria for an anxiety disorder. This was seen as the most significant limitation regarding the pervasiveness of an anxiety disorder.

While it is likely these studies underestimate the occurrence of anxiety disorders, the authors did find however that across all CMCs the anxiety prevalence rates were high: affecting approximately 20 percent to 50 percent of youth. In studies that included a healthy control group, rates of an anxiety disorder were substantially higher among patients with all CMCs. Across all CMCs, the rate of anxiety disorder was higher than the global prevalence rate of 6.5 percent as previously reported by Polanczyk and colleagues1.

The remaining 24 studies examined the impact of anxiety on disease-related outcomes. No studies were identified for disease-related outcomes for epilepsy or congenital heart disease, however the authors reported that anxiety was associated with:

- poorer symptom control, school absenteeism, and higher rates of smoking in youth with asthma;
- increased disease activity in youth with inflammatory bowel disease;
- greater pain in youth with juvenile idiopathic arthritis; and
- longer lengths of hospitalizations in youth with sickle cell disease presenting in vaso-occular crisis.
-

The most significant and common limitations in relation to the question of the impact of anxiety on disease-related outcomes were the cross-sectional design of most studies and the fact that almost all studies relied on one informant only in assessing both anxiety and disease-related outcomes.

The evidence for youth with diabetes was inconsistent, with some studies reporting a negative impact of anxiety on metabolic control and treatment adherence and other studies reporting a positive association between elevated anxiety and treatment adherence.

While evidence that anxiety is associated with adverse disease-related outcomes in these youth, more longitudinal research is needed to delineate the impact of anxiety on child outcomes, Dr. Cobham and her team concluded. It is recommended that health services routinely assess for anxiety disorders among youth with CMCs. Psychometrically validated anxiety questionnaires.

May 4th, 2020
https://www.eurekalert.org/pub_releases/2020-05/e-cmc050420.php

EEA ACTIVITIES

Gary and Sharon open a special gift for Gary's retirement from the EEA office staff and volunteers.

This light depicts Gary with his companion Taffy when he first started with the EEA and Gary with Gio when he retired.

While the EEA office has been closed for regular business since March 15, 2020 due to COVID-19 provincial and national restrictions, office staff and volunteers have remained busy with a number of activities, initiatives, and programs to ensure continuity of services.

Listed below are the highlights of tasks and activities we engaged in that we want to inform you about. Please contact us with ideas on how to reach out to you and support you in these extraordinary times.

- **Leadership Transition**
  As you know by now, Gary Sampley, Executive Director and COO of the EEA for the past 15 years, retired on April 30, 2020. He has been leading the transition of leadership with the new Executive Director, Valeria Palladino, guiding her through the important work of the association.

- **Epilepsy Booklets**
  EEA continues to provide online and in-print access to the Epilepsy booklet series, sponsored by UCB. We are in the process of an important update of all new publications with the most current epilepsy terminology. Many volunteer hours go into the managing of this file, under the leadership of Cam Reid. Thank you Cam!

AND UPDATES

- **Counselling**
  Our association counsellor, Dr. Sunny Kim, has continued to provide essential individual counselling sessions over the phone in these past months, and she is open to support all our members who wish to reach out. Contact the EEA office to set a phone-call session with her.

- **Ongoing Members Support**
  EEA remains available for individual support to all members who reach out to us. While focus groups, team activities, garage sales and other social events are currently on hold, we remain available for any other individual needs from our members.

- **Video Sessions**
  Keep your eyes on the EEA website for upcoming video productions. The first one will be a farewell from Gary Sampley and a beautiful tribute to all that the EEA has meant for him, his family, the community and everyone who has been working together for the mission and values of the association.
  Contact us with ideas on topics we can explore for future video productions.

Gary's Farewell Luncheon was a small gathering with appropriate physical distancing.

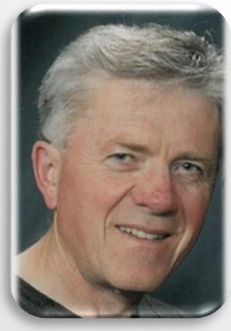
Life Enhancement Scholarship Program For Youths

The Brittany Hughes 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 Arts, Music, Dance and/or Ethnic Identity Cultural Programs 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.

Does Your Child or Teen Have Upcoming Sports 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 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.

Edmonton Epilepsy Association

11215 Groat Road
Edmonton, AB T5M 3K2

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...