



Canadian League Against Epilepsy

MESSAGE FROM THE PRESIDENT



INSIDE THIS ISSUE:

EPLINK PROGRAM	2
SUNNY DAYS CAMP	3
GLOBAL OUTREACH	4
CLAE COMMITTEES	4
UPCOMING EVENTS	5
EDITOR'S PICK	6

Dear CLAE members,

I hope that you had a restful summer and that you are now ready to have a productive year that will include dedicated time to enhance epilepsy outcomes either through your research, teaching activities or the clinical care that you provide.

It is my last message as your president. It has been an honour serving as your CLAE President these past two years. I'm thrilled with everything that has been accomplished by our executive board members, CLAE members and our partner organizations (e.g. Canadian Epilepsy Alliance, Canadian Pediatric Epilepsy Network, Canadian Epilepsy Research Initiative, Canadian Epilepsy Nurses Group).

Once again, this newsletter highlights great initiatives led by CLAE members regionally, nationally and internationally, including EpLink, Sunny Days Camp, and work done to improve the care of patients with epilepsy in Vietnam. Thanks to our Editor, Dr. Rajesh RamachandranNair, and the publication committee for keeping us up-to-date with these important undertakings.

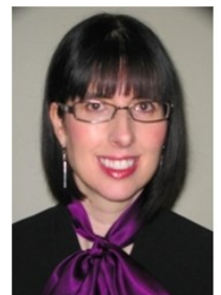
The Québec City CLAE meeting is just around the corner...we look forward to seeing you all there! The program is excellent, thanks to Dr. Paolo Federico and the Education Committee for their hard work planning this meeting. There will also be a fun walk/run for epilepsy on Saturday morning (October 15, 2016) which we hope to see you at!

A motion will be put forth at our upcoming Annual General Meeting also in Québec City to welcome our newly elected board members: Dr. Dang Nguyen, for President-Elect; Dr. David Steven, for treasurer and Dr. Kristen Ikeda for junior member representative. Congratulations to all of you! We had terrific members run for these positions, including four for President-Elect, all of whom were excellent candidates. Thank you all for putting your names forward.

Welcome to our new CLAE President, Dr. Jorge Burneo who will be starting his two-year term on October 14, 2016. We wish him the best of luck in his new position. I look forward to seeing more great things being accomplished over the coming months and years by our CLAE members and partner organizations to improve the lives of persons living with epilepsy in Canada and all around the world!

Warm Regards,

Nathalie Jette





EPLINK'S RESEARCH, PARTNERSHIPS & SUCCESSSES



EpLink is the Epilepsy Research Program of the Ontario Brain Institute (OBI).

OBI was first established in 2010 as a virtual research institute that would help transform the Ontario neuroscience research environment, improve brain health for Ontarians and make a positive impact on the province's economy. As part of this mandate, OBI requested and received 33 workshop proposals from neuroscientists across Ontario, which were then categorized into 7 formal proposals for funding. Shortly after, OBI announced the funding of 3 pan-Ontario programs in different areas of brain research.

Drug-resistant epilepsy was selected as one of the research areas to receive funding. The epilepsy-focused Integrated Discovery Program was formally established in October 2011 and has come to be known as EpLink – The Epilepsy Research Program of the Ontario Brain Institute. From its establishment to the present time, EpLink has been led by Co-Directors Dr. W. McIntyre Burnham at the University of Toronto and Dr. Jorge Burneo at Western University.

Research

EpLink's primary goal is to conduct translational research that will improve treatments and quality of life for people living with drug-resistant epilepsy. Working towards this goal, EpLink now has more than 35 principal investigators working on more than 40 research projects across Ontario. EpLink researchers include many well-known clinicians and scientists in Ontario. The affiliated institutions – eight in total – include all of Ontario's major clinical epilepsy centres. EpLink's researchers are working together to find new and improved ways to treat seizures. The areas of research that are currently ongoing include studies to improve drug therapy, diet therapy, seizure prediction and brain stimulation, surgery therapy, genetics and quality of life. The research in these areas are collaborative, integrative and multidisciplinary, thanks to key partnerships with non-profit and industrial advisors.

Partnerships

Non-Profit Partners. EpLink was designed to work in partnership with the Community Epilepsy Agencies that represent and support people living with seizures. EpLink collaborates with Community Epilepsy Agencies, family and patient advocates that help to inform and guide EpLink's research priorities based on the needs of people living with seizures. These agencies and representatives also communicate EpLink's new discoveries and program goals to the epilepsy community, as well as assist with engaging participants for research studies and hosting collaborative educational and fundraising events.

One example of success from this integrative partnership is the ongoing public education events. EpLink teamed up with Epilepsy Toronto in October of 2015 to host a Medical Marijuana & Epilepsy Information Session for families and people with epilepsy hoping to learn more about the use of the medical marijuana extract, cannabidiol, for treating epilepsy. The success of this event sparked a similar event to be held in London, Ontario in partnership with Epilepsy Support Centre. EpLink is currently working towards hosting more partnered public education events, including those relating to the recently released clinical epilepsy guidelines.

Industry Partners. To ensure that epilepsy research done within EpLink leads to real-world healthcare innovations, EpLink collaborates with industry partners who help to bring new discoveries from bench to bedside. EpLink works closely with industry experts who help guide commercialization of new medical devices and drug therapies, which is essential to directly impacting healthcare and quality of life for people living with uncontrolled seizures.

For instance, both EpLink and the Ontario Brain Institute are supporting researchers within Avertus Inc., an Ontario-based company working on a wireless headset that monitors brain waves and detects when a seizure will occur. Based on this work, Avertus Inc. has now received approvals to start testing the device on people with epilepsy – as well to start selling headsets for clinical trial and non-medical uses – by the end of this year.

For more information about EpLink's research, partnerships and successes, please visit www.eplink.ca

Tiffany Scarcelli, M.Sc.
Knowledge Translation Lead, EpLink

SUNNY DAYS CAMP

epilepsy halton peel hamilton

For the past 7 years, Epilepsy Halton Peel Hamilton has provided the opportunity for parents to send their children to camp. "Sunny Days Camp" is a camp for kids living with epilepsy and their siblings, ages 5-12.

Sunny Days Camp is very important for us to run during the summer for numerous reasons. First and foremost, we provide an inclusive environment that reminds the campers that they are no different than anyone else. They are reminded that despite their epilepsy, they can engage in physical activity, games, crafts, and fun field trips! It is our goal for them to have fun and to be empowered. Every minute we spend with them is meaningful.

Sometimes, parents may be afraid of bringing their child to places such as Wild Water Kingdom or musicals (we've been to Wizard of Oz and Matilda!). Sunny Days Camp reminds parents that their children will be well taken care of and if they have a seizure, they will be more than okay! Providing an inclusive and safe environment helps take one thing to worry about off a parent's list.

Sunny Days Camp opens up their registration to siblings of kids living with epilepsy. Like most conditions, it is difficult for other siblings to feel recognized or important because epilepsy is a condition that the whole family lives with. Our camp allows our campers to meet other siblings who are going through the same thing. It allows them to create lasting relationships with one another. Our campers who are siblings are just as important as the campers who are living with epilepsy.

Epilepsy Halton Peel Hamilton opens registration in March and we officially begin to plan in May. Planning consists of booking transportation, booking field trips, and organizing training dates for our camp counsellors. It takes a lot of work to make sure everything is organized and well planned out. In July and August,



Sunny Days Camp 2016 at African Lion Safari

our camp counsellors reserve every Friday to plan, buy supplies, and organize crafts, games, and activities for the upcoming week.

Every Wednesday, we are able to give our campers the opportunity to attend a field trip. This past summer, we visited Ontario Science Centre, Wild Water Works, Adventure Village, African Lion Safari, Air Riderz, Classic Bowl, Matilda, and Adventure Works. Fun filled trips that have our campers complaining, "It's already time to go!?!?" Adventure Works was one of the biggest hits. This field trip gave the campers an opportunity to gain self-confidence in their abilities as an individual and within a team. It allowed them to recognize that even though they have epilepsy, they are capable of achieving success on fun and challenging activities.

I cannot stress the importance of continuing to provide this summer program for our families. It has a lasting positive impact on the family as a whole and the individual campers themselves. Epilepsy Halton Peel Hamilton would like to thank those who have kindly donated to keep Sunny Days Camp running.

Jasmine Morante

Camp Director

Visit www.ehph.org



IMPROVING THE CARE OF PATIENTS WITH EPILEPSY IN VIETNAM

Vietnam is a developing country in Southeast Asia with a population of over 90 million people. The care of patients with epilepsy is suboptimal due to insufficient resources, poor infrastructure, lack of education (among patients and physicians) and limited access to standard medical and surgical treatment options for epilepsy. Since 2010, the epilepsy team from the Université de Montréal has worked hard to improve the care of patients with epilepsy in the central provinces of Vietnam in collaboration with the Hue University of Medicine and Pharmacy. This work includes a) the training of local Vietnamese physicians in Montreal at Hôpital Notre-Dame (Dr. Tran -2 year epilepsy fellowship; Dr. Truong -3 year epilepsy surgery fellowship) or Sainte-Justine Hospitals (Dr. Son and Dr. Ton -3 month EEG training electives); b) an annual epilepsy course, each spanning over three days (March 2013, March 2014, August 2015, June 2016); c) and the donation of a video-EEG machine and a regular EEG machine.

This initiative is led by Dang Nguyen with the generous help of Anne Lortie, Sylvain Chouinard, Stéfanie Tran, Alain Bouthillier, Patrick Cossette and especially Lionel Carmant. Some financial support was provided by the Ministère des Relations Internationales du Québec, the Fondation Savoy, the Direction des Relations Internationales de l'Université de Montréal and UCB World.



Drs. Chouinard, Carmant, Nguyen and Lortie (front row, 4th, 5th, 7th and 8th from the left, respectively) and some of the students, paediatricians, psychiatrists and neurologists who attended the 2015 Hue Epilepsy Course.



First patient recorded with the video-EEG machine donated to the Hue University of Medicine and Pharmacy Hospital.

CLAE COMMITTEES

Awards Committee

Nathalie Jette (Chair)
 Francois Dubeau
 David Steven
 Mary Connolly
 Thomas Snyder
 Aylin Reid

Education Committee

Paolo Federico (Chair)
 Neda Bernasconi
 Peter Carlen
 Mary Pat McAndrews
 Bernd Pohlmann-Eden
 Gordon Cam Teskey
 Richard Desbiens
 Linda Huh
 Matt Wheatley

Fundraising Committee

Jose Tellez-Zenteno (Chair)
 Paula Brna
 Ms. Gail Dempsey
 Lionel Carmant

Nomination Committee

Jorge Burneo (Chair)
 Juan Pablo Appendino
 Danielle Andrade
 Richard Desbiens
 Mark Sadler

Publication Committee

Rajesh RamachandranNair (Chair)
 Aylin Reid
 Luis Bello-Espinosa
 Eliane Kobayashi
 Minh Dang Nguyen

Medical Therapeutics Committee

Carter Snead (Chair)
 Suzanne Nurse (Co-Chair)
 Lionel Carmant
 JP Appendino
 Susan Rahey
 Ms. Laura Wang
 Manouchehr Javidan
 Cyrus Boelman
Driving Task Force
 Jeff Jirsch (Chair)
 Richard McLachlan
 Chantelle Hrazdil
 Lysa Boisse Lomax
 Ms. Karen Legg
 Ms. Pierrette Cloutier
 Martin Veilleux



UPCOMING EVENTS

Annual Epilepsy Day -

"Epilepsy and Neuroinflammation"

Montreal Neurological Institute, McGill University

Thursday, April 6th 2017

In the morning symposium, speakers will discuss the basics of neuroinflammation, mechanisms of injury and repair (C. Moore, PhD, Memorial University, NL, Canada), compare neuroinflammatory mechanisms in MS and epilepsy (Dr A. Bar-Or, MD PhD, McGill/UPenn), and present the most recent data on PET imaging of inflammation in epilepsy (W. Theodore, MD PhD, NIH). The symposium will be preceded by the morning communications from students and fellows. The scientific activities of the day will end with the Pierre Gloor Lecture by Dr A Vezzani, PhD (Mario Negri Institute, Milano, Italy), who will present her seminal work in inflammation and epilepsy.

Epilepsy and EEG in Clinical Practice 2016

10-12 November 2016, Hard Rock Hotel Universal Orlando

Orlando , FL 32819, United States

<https://ce.mayo.edu/neurology-and-neurologic-surgery/node/20041>

1st International Training Course on Neuroimaging of Epilepsy

McConnell Brain Imaging Centre

Montreal Neurological Institute, McGill University

May 18-21, 2017

The course (sponsored by the International League Against Epilepsy) will provide clinicians and scientists working in epilepsy with an understanding of fundamentals and

practical skills related to neuroimaging. The course welcomes both individuals with and those without prior expertise in neuroimaging. In addition to offering methodological insights, emphasis will be placed on clinical decision-making and translation.

Morning sessions will consist of lectures given by a faculty of world-class neuroimagers and epileptologists. In the afternoon, participants will benefit from hand-on sessions guided by a team of experienced tutors, including image acquisition in the MRI suite, quality control procedures, visual MRI analysis, functional MRI, together with established and cutting-edge diagnostic techniques.

For more information and to register: <http://neuroevents.mcgill.ca/index.php?page=1st-international-training-course-on-neuroimaging-of-epilepsy>

Andrea Bernasconi, MD




AES ANNUAL MEETING
 DECEMBER 2 - 6, 2016 | HOUSTON TEXAS

70th Annual Meeting
 George R. Brown Convention Center
 6th Biennial North American
 Regional Epilepsy Congress



Canadian League Against Epilepsy

The Canadian League Against Epilepsy is an organization of medical and basic sciences professionals including physicians, basic scientists, nurses, neuropsychologists, neuroradiologists, students and other healthcare professionals.

NOTE FROM YOUR EDITOR

The next issue of the CLAE Newsletter (January 16, 2017) will include meaningful and relevant information to CLAE members, including but not limited to the following:

1. CLAE Stars: A member who has received local, national or international recognition for his/her research, teaching, innovation or advocacy.
2. Innovative new programs and services (clinical, research or advocacy). These include, but are not restricted to: new major regional/ institutional or provincial clinical programs, new research themes, platforms, consortium and networks, outreach programs in vulnerable/ marginalized communities, innovative educational programs and advocacy initiatives/projects.
3. Major publications by Canadians in the field of epilepsy during the last six months.
4. Information on epilepsy meetings, and epilepsy related social events.
5. Information on recruitment of patients for research studies and opportunities for research, educational and clinical collaboration.
6. Success and success stories in major grant competitions.
7. Colleagues we recently lost /an In Memorium section.

If you are interested in contributing and providing content to the CLAE Newsletter, please contact Rajesh Ramachandran Nair (rnair@mcmaster.ca) before January 5, 2017.

Thank you.

Rajesh Ramachandran Nair, MD, FRCPC

Editor-in-Chief, CLAE Connections

Board of Directors

President

Nathalie Jette

President-Elect

Jorge Burneo

Secretary

Mary Lou Smith

Director of Education

Paolo Federico

Treasurer

Jose Tellez-Zenteno

Past President

Nizam Ahmed

Junior Member Representative

Colin Josephson

CEA Representative

Gail Dempsey

CERI Representative

G. Campbell Teskey

ILAE Representative

Samuel Wiebe

CPEN Representative

Kathy Speechley

EDITOR'S PICK

NOTABLE PUBLICATIONS FROM CANADA IN 2016

Knowledge and Attitudes About Epilepsy Surgery Among Family Doctors in Ontario. Cothros N, Burneo JG, Steven DA. Can J Neurol Sci. 2016 Sep;43(5):672-7.

Magnetoencephalographic signatures of insular epileptic spikes based on functional connectivity. Zerouali Y, Pouliot P, Robert M, Mohamed I, Bouthillier A, Lesage F, Nguyen DK. Hum Brain Mapp. 2016 Sep;37(9):3250-6.

Correlates of health-related quality of life in children with drug resistant epilepsy. Conway L, Smith ML, Ferro MA, Speechley KN, Connoly MB, Snead OC, Widjaja E; PEPSQOL Study Team. Epilepsia. 2016 Aug;57(8):1256-64.

016/2018 CLAE Board of Directors Slates

Dr Nizam Ahmed, Chair, Election Committee announced the slate for the vacant CLAE Board of Director positions for the 2016/2018 term (beginning October, 2016).

Candidate for President-Elect

Dr. Dang Nguyen, University of Montreal

Candidate for Treasurer

Dr. David Steven, University of Western Ontario

Candidate for Junior Member Representative

Dr. Kristen Ikeda, University of Western Ontario

A motion will be put forth at the Annual General Meeting of Members (October 14, 2016 at 5 pm EDT), during our 2016 Scientific Meeting in Quebec City, QC, to approve this slate.