

CLAE CONNECTIONS

MARCH 25, 2015; VOLUME 3: ISSUE 1



Canadian League Against Epilepsy

MESSAGE FROM THE PRESIDENT



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Dear CLAE members,

It has been a real pleasure serving as your new president these past few months.

The CLAE meeting in London Ontario was a tremendous success. We had our largest attendance yet and witnessed the election of a new Executive Board made up of wonderful colleagues who, just like me, are eager to ensure our vision is met, and that we continue to help improve the lives of those with epilepsy in Canada. In this issue, you will learn a bit more about our newly elected President-Elect, Dr. Jorge Burneo who will take on his new role as President in October 2016.

I enjoyed catching up with colleagues and meeting new faces at Canada Night in Seattle this past December. There I had the opportunity see a room filled with enthusiastic CLAE members keen to collaborate and work together to advance the field nationally. I also had the honour of presenting Dr. O. Carter Snead III with the Wilder Penfield Award for Lifetime Achievement at Canada Night. You can find out more about Dr. Snead and his remarkable achievements in this newsletter.

We have been working these past few months on developing a number of new processes for the CLAE, including the development of formal committees and task forces. Please don't forget to sign up for these important committees! We depend on you for their success. We may call on you to join some of our committees. We hope you will accept our invitation.

A number of emerging issues are continuing to face Canadians with epilepsy and their health

care professionals, such as the dramatic increase in the cost of certain drugs (e.g. ACTH) recently or the loss of brand name coverage in certain provinces. Together with the Canadian Epilepsy Alliance we hope to setup a new therapeutics committee that will help us deal with these issues collaboratively to avoid duplication of efforts and ensure our efforts lead to national policy changes. If you are interested in serving on this committee, please let us know.

Soon we will be sending you a questionnaire, so we can find out more about your needs as CLAE members. We hope you will complete this questionnaire as it will also guide the development of our strategic plan.

Times have been tough but we have been working hard at fundraising these past few months to ensure that we can continue to offer an epilepsy research fellowship to a future leader in our field and to offer you other research and educational opportunities. More to come about these opportunities soon! ...but remember, we depend on you for your in kind support (participation in committees) and financial support (through membership dues, donations) to ensure we achieve our educational and research goals.

Nathalie Jette, MD, MSc, FRCPC





DR. CARTER SNEAD III WINNER OF THE 2014 WILDER PENFIELD LIFETIME ACHIEVEMENT AWARD



Dr. Carter Snead has had a long, distinguished and exemplary career in epilepsy, whose contributions are really self-evident and highly deserving of the Penfield Award. He is Professor of Pediatrics and Pharmacology at the University of Toronto. After a distinguished career in prestigious centers such as Birmingham Alabama and UCLA, in 1996 he took the position of Head of the Division of Child Neurology at Sick Kids Hospital in Toronto and essentially led the program to new heights. Not only that, but he had put epilepsy on the map in the most populous province in Canada and in times of fiscal constraint has engineered the largest provincially funded initiative for epilepsy in recent memory.

His research has been extremely influential, including his work on the use of ACTH to treat spasms in infant all the way to the development of animal models to enhance our understanding of these devastating consequences of epilepsy.

His contributions to the field of epilepsy surgery in children have also been tremendous – for example, he pioneered the use of MEG to improve surgical outcomes taking epilepsy surgery to the next frontier ,you might say.

He has mentored junior investigators and clinicians from around the world. But what is even most impressive, has been his caring approach to patients and their families, and to quote Dr. Appendino: “I remember one occasion when Dr. Snead, despite being the Chief of the largest Pediatric Neurology program in Canada and one of the most productive researchers in the field, got down on his knee to speak at eye-level with a mother, who only six days prior had delivered a baby with hemimegalencephaly. Dr. Snead explained the need for a Hemispherectomy with a combination of humility and conviction that this was the right treatment for that child. It was a lesson that I will take with me to the end of my days.

Finally, what truly sets him further apart from many, has been his tremendous ability to build new programs, new initiative and new institutions. The Canadian Epilepsy Academic community and most importantly people with epilepsy in Canada have benefited enormously by Dr. Snead’s enduring and still growing legacy.

Congratulations to our winner of the 2014 Penfield Lifetime Achievement Award, Dr. Carter Snead.

MEET YOUR PRESIDENT-ELECT



Dr. Jorge Burneo is Co-Director of the Epilepsy Program at Western University and the London Health Sciences Center. He is also an Associate Professor of Neurology and Epidemiology at the Schulich School of Medicine at Western, Medical Director of the EEG Laboratory at the London Health Sciences Center, and the Co-Director of the EBN Program for Neurology Residents at Western.

Dr. Burneo held the position of Director of Education at the CLAE from 2012-2014. He has been a member of the Scientific Committee of the American Epilepsy Society (AES) Annual Meeting, AES Annual Course Committee, and AES Research Initiative Fund Committee. He is the Co-Leader of EpLink, a research initiative from the Ontario Brain Institute to support research in Epilepsy in the Province of Ontario and a member of the Provincial Epilepsy Strategy, an initiative from the Ministry of Health, Ontario to improve epilepsy care in the Province.

Dr. Burneo has more than 105 peer-reviewed publications, more than 200 abstracts, and has presented in different international forums including the AES Annual Meeting, ILAE International Epilepsy Congress and the CNSF Annual Meeting. He has delivered lectures around the world, and is currently involved in the development of Epilepsy Programs in his native country of Perú. In Perú, Drs. Burneo and Steven have helped develop the first comprehensive epilepsy surgery program at the Instituto Nacional de Ciencias Neurológicas, where the first temporal lobectomy for refractory epilepsy was performed in 2011.

Dr. Burneo has granting support from the Ontario Brain Institute, Western University, The Institute of Clinical Evaluativ Sciences (ICES) and UCB Canada. His research interests include Epidemiology of Epilepsy (he has been recently named an ICES Scholar) and neuroimaging assessment of epileptic malformations of cortical development in collaboration with the Neuroimaging group at the Robarts Research Institute.

RISING STAR



In this issue of CLAE Connections we introduce Dr. George Ibrahim, MD; University of Toronto

Dr. George Ibrahim is a senior neurosurgery resident at the University of Toronto. He received his B.Sc. (Hons) from Queen's University in 2005 in biochemistry, then returned to his hometown of Calgary, Alberta to pursue his M.D. at the University of Calgary. He subsequently entered the residency program in neurosurgery at the University of Toronto. He entered the Surgeon-Scientist program in the Department of Surgery under the auspices of the Royal College Clinician-Scientist program during his fourth year of residency and completed a Ph.D. as a CIHR Vanier Scholar at the Institute of Medical Science under the supervision of Drs. James Rutka and Carter Snead. His main research interest is the intersection of typical childhood development and intractable epilepsy, with an emphasis on novel network-based approaches to understanding the neural substrates of the comorbidities of epilepsy with a view towards devising individualized treatment strategies. Secondly, he is interested in the conduct, monitoring and evaluation of neurosurgery in low- and middle-income countries and the study of "neuroethics" as it pertains to childhood epilepsy.

George has been the recipient of various national and international awards. He received the American Association of Neurological Surgeons / Congress of Neurological Surgeons Pediatric Section Kenneth Shulman Award for the best paper presented at the annual meeting of the Joint Section of Pediatric Neurological Surgery on disrupted network development in children with epilepsy.

In addition, he was the recipient of the Canadian Neurosurgical Society K.G. McKenzie Prize for Clinical Neuroscience Research.

His work on studying ethical issues pertaining to epilepsy surgery in childhood was also awarded the Royal College of Physicians and Surgeons of Canada K.J.R. Wightman Award for Scholarship in Ethics. During his residency, George has authored or co-authored over 55 peer-reviewed papers and has presented his work at over 65 national and international conferences.

George's primary research interest is functional neuroimaging and electrophysiology in childhood epilepsy. Using tools such as functional MRI, magnetoencephalography and electrocorticography, he has studied dynamics within and synchrony amongst spontaneous neural oscillations and their disruption by epileptic dynamics such as seizures and interictal discharges. These phenomena were then related back to behaviour, cognition and clinical phenotypes. In addition to understanding the intersection of epilepsy and typical childhood development, he is interested in studying hierarchical organization of neural oscillations and the disruption of oscillatory regulation, as it relates the manifestation of electrophysiological markers of epilepsy, such as pathological high frequency oscillations (pHFOs). Such endeavours have already begun to elucidate novel insights for seizure prediction and presurgical mapping.

George is committed to pursuing a career as a pediatric neurosurgeon with a view towards developing novel surgical strategies for childhood epilepsy, guided by better awareness of network disturbances. He is interested in collaborating with the global community to expand the provision of neurosurgical and epilepsy care to the most vulnerable populations of children in low- and middle-income country. To this end, he has completed a certificate in global health education at the Dalla Lana School of Public Health in Toronto and has spent time at a pediatric neurosurgical centre in Uganda.



THE FIRST EPILEPSY BRAIN BANK IN CANADA

What is an epilepsy brain bank?

An epilepsy brain bank is a storage source for pieces of brain tissue from epilepsy surgery resections. The tissues are donated by the patients undergoing brain resection for the treatment of their medication refractory seizures. The tissues are kept in Flash frozen in liquid nitrogen and stored at -80°C . As per current standard of care in most epilepsy centers, the brain tissue obtained from temporal lobectomies or other types of temporal resections is fixed in formaldehyde to undergo routine pathological screening. Therefore, no further research studies are performed on the specimen as the formaldehyde-fixed tissue is not suitable for most advanced research methods. It is extremely crucial to perform further studies on brain samples using advanced methods such as v molecular biology, proteomics and genomics to answer important questions about mechanism of seizures to find new treatment targets.

Background of the project

In December of 2011, DR. Tellez and Dr. Moien approached the college of medicine in order to establish the first Epilepsy Brain Bank in Canada. On November 13, 2012 the college of medicine approved the project and provided seed funding to develop the bank (\$250,000). An application to the Research Ethics Board (REB) of the U of S to develop the first Epilepsy Brain Bank in Canada was approved on Oct 29, 2013.

Core group who developed preservation of the first samples



Our group has created a methodology to preserve samples. The following group has provided equal intellectual ideas and work to preserve the first four samples; from left to right, Jose Tellez-Zenteno (neurologist-epileptologist), Adam Wu (neurosurgeon), Mark Hiken (Neuropathologist), Farzad Moien (neurologist-epileptologist), Lizbeth Hernandez (master of sciences student-U of S).

Need of a multidisciplinary team

In January of 2014, the Saskatchewan Health Research Foundation (SHRF) provided a team grant to establish the group (25,000 dollars). The mission of the Saskatchewan Epilepsy Research Initiative Team is to synergize clinical and basic science expertise at the University of Saskatchewan.

The following is the group that forms the epilepsy research initiative:



From left to right (lower part), Frank Cayabyab (Associate Professor-Department of Physiology), Huma Aftab (Psychiatrist-Saskatoon Health region), Mirna Vrbancic (Neuropsychologist-Saskatoon Health Region), Mark Hiken (Neuropathologist-Saskatoon Health region), Lisa Kalynchuk (scientist), Adam Wu (Clinical Assistant professor-College of Medicine), Lizbeth Hernandez Ronquillo (Master student-community health sciences and epidemiology), Marla Mickleborough (Assistant professor- College of Arts and Sciences). Not in the picture but part of the group, Dr. Richard Huntsman (Assistant professor-University of Saskatchewan).

Upper part, left to right, Gary Hunter (Clinical assistant professor- College of Medicine), Ron Borowsky (Professor-College of Arts and Sciences), Noel Lowry (Professor- College of Medicine), Farzad Moien (Assistant Professor-University of Saskatchewan), Jose Tellez Zenteno (Professor- College of Medicine), Changiz Taghibiglou (Assistant Professor- Department of Pharmacology)

How the samples will be used to help patients?

The basic research on tissues saved in the bank combined with clinical knowledge may provide vital information about some of the unanswered questions in epilepsy including finding new targets for antiepileptic drugs. A few of the potential uses are as follows: 1) To detect the chronic differences in regions of the brain prone to seizures using proteomics, immunohistochemistry, and molecular biology; 2) To identify biomarkers of refractory epileptic activity by identifying the common abnormal pathways shared by many patients with temporal epilepsy; 3) These biomarkers will be translated into therapeutic targets, which will be tested in animal models to determine efficacy prior to clinical trials; 4) Target binding of these compounds in humans at therapeutic doses will be assessed using the PET scan with specific molecules



CANADIAN EPILEPSY ALLIANCE WELCOMES DRUG SHORTAGES ANNOUNCEMENT

Vancouver, February 10th 2015- Canadian Epilepsy Alliance members joined Federal Health Minister Rona Ambrose today as the Minister announced that Canadian pharmaceutical manufacturers will now be required to provide notice of shortages of their drugs. Currently the drug shortage notification is voluntary.

“This is a major step forward for people living with epilepsy, and other diseases and disorders who require ongoing access to their medications,” said Deirdre Floyd, President of the Canadian Epilepsy Alliance. “It’s terrifying when someone living with seizures goes to the pharmacy to refill their prescription only to find out there is a shortage. It has happened too often in recent years to too many people who can’t miss their medication, and hopefully this will help to address shortages in the future.”

“On behalf of the 300,000 people across Canada living with epilepsy, I want to thank Minister Ambrose for implementing this change to the Federal health regulations. I also wish to thank the Members of Parliament, from every party, who have supported past efforts to ensure the safety of people who require ongoing medications.”

“Today’s announcement won’t end drug shortages,” continued Floyd. “That will require further efforts on the part of government and industry to react when a shortage is anticipated. What today’s announcement does mean is that individuals and families have a real opportunity to prepare in times of anticipated crisis.”

Minister Ambrose’s announcement comes after years of work on the part of the Canadian Epilepsy Alliance and other organizations, raising the issue of drug shortages with Federal regulators and Parliamentarians.

The voluntary notification system, where manufacturers may provide information on an industry administered website, has often seen shortages not reported until patients discover the shortage on their own.

This is especially dangerous for individuals living with epilepsy where an interruption in their medication can result in serious adverse effects or even death. It is hoped that with mandatory notification, individuals can work with their physicians and pharmacists to ensure an adequate supply of the medication they require.

Nathalie Jette, President of the Canadian League Against Epilepsy, was also encouraged by the announcement and congratulated members of the Canadian Epilepsy Alliance for their efforts in bringing this important healthcare issue to government. “Mandatory reporting of drug shortages is critical for those with epilepsy as it is unsafe to stop antiseizure medications abruptly. This new policy will enhance the likelihood of ongoing safe care for those with epilepsy who already have to deal with so much uncertainty related to their conditions.”

Said Floyd, “This is an important decision for Canada’s epilepsy community.”

For more information contact:

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“I want people around the world to come together and teach others about epilepsy.”

Cassidy Megan,
Founder of Purple Day Canada



Photo credit: www.thetoronto.ca



Show your support for epilepsy awareness.

Wear purple on March 26th

www.epilepsymatters.com



1-866-EPILEPSY (1-866-374-5377)



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.

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NOTE FROM YOUR EDITOR

The next issue of CLAE Newsletter (June 2015) 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 June 5, 2015.

Thank you.

Rajesh Ramachandran Nair, MD, FRCPC

Editor-in-Chief, CLAE Connections

EDITOR'S PICK

NOTABLE PUBLICATIONS FROM CANADA IN 2014-2015

1: Ferrari-Marinho T, Perucca P, Mok K, Olivier A, Hall J, Dubeau F, Gotman J.

Pathologic substrates of focal epilepsy influence the generation of high-frequency oscillations. *Epilepsia*. 2015 Mar 5. doi: 10.1111/epi.12940.

2: Widjaja E, Zamyadi M, Raybaud C, Snead OC, Doesburg SM, Smith ML. Disrupted

Global and Regional Structural Networks and Subnetworks in Children with Localization-Related Epilepsy. *AJNR Am J Neuroradiol*. 2015 Mar 5.

3: Roberts JI, Hrazdil C, Wiebe S, Sauro K, Vautour M, Wiebe N, Jetté N.

Neurologists' knowledge of and attitudes toward epilepsy surgery: a national survey. *Neurology*. 2015 Jan 13;84(2):159-66.

4: Ferro MA. Risk factors for health-related quality of life in children with epilepsy: a meta-analysis. *Epilepsia*. 2014 ;55(11):1722-31.

UPCOMING PROGRAMS

50th Canadian Neurological Sciences Federation annual meeting,

June 9-12, 2015 Toronto

<http://congress.cnsfederation.org/>

31st International Epilepsy Congress

Istanbul; September 9-12, 2015

<http://www.epilepsyistanbul2015.org/>

American Epilepsy Society 69th Annual Meeting - December 4-8, 2015, Philadelphia

https://www.aesnet.org/meetings_events/annual_meeting/general_info