Dear Colleagues,

Summer has finally arrived! I hope that each of you will be able to enjoy some well deserved relaxing time over the next few weeks as another academic year comes to an end.

Thank you to everyone who voted in our recent elections. We had a great turnout! The votes will be tabulated and then reviewed by the election committee chaired by Dr. Nizam Ahmed. The term for these positions (President Elect, Treasurer and Junior/trainee) will begin in October 2016. It is also my pleasure to announce the election of Dr. Samuel Wiebe, past CLAE President, to the position of President of the International League Against Epilepsy (ILAE). We wish him all the best in this new and exciting endeavour and are proud that one of our fellow Canadians will be serving in this prestigious role.

Congratulations are also in orders to our trainee awards’ recipients. The competition was tough in every category (summer studentship, publication awards, fellowship award). Special congratulations to Dr. Syed Rizvi, the recipient of the CLAE Clinical Fellowship Award. We will soon be announcing our non-trainee awards. Please keep your well deserving colleagues in mind for these special awards.

Plans are also well under way for our upcoming Biennial meeting in Quebec City on October 14-16, 2016. Dr. Paolo Federico, our Director of Education, and the CLAE Education Committee have been hard at work planning a very exciting meeting for us all. Don’t forget our Fun Run for Epilepsy that will help us support our activities, especially those that benefit our members (awards, educational sessions, research activity, etc.). …and believe it or not, we are already starting to plan our next meeting in Vancouver, in 2017, where we will be celebrating the 40th anniversary of our organization.

In this newsletter, you will learn about the Ontario Provincial Standards of Care for Epilepsy from Dr. O. Carter Snead; the first adult diet therapy for epilepsy at the Toronto Western Hospital by Dr. Eduard Bercovici; and finally will see a write-up from one of our rising stars, Dr. Mark Keezer from the Centre Hospitalier de l’Université de Montréal (CHUM).

On a more sober note, there is still a significant widespread shortage of clobazam nationally. The CLAE Medical Therapeutics Committee and I are working closely with Health Canada and key stakeholders to address this serious shortage. It is recommended that clobazam be restricted to patients currently on this therapy to preserve the limited supplies until there is improved availability of this drug. I urge you all to read the regular statements that we are sending you regarding the important drug shortage issues. I want to thank the CLAE medical therapeutics committee and in particular Dr. Suzanne Nurse and members of the CEA drug shortage committee for their advocacy and efforts on behalf of patients with epilepsy who are affected by this shortage.

In closing, I also want to thank members of all of our other committees who have also been hard at work. Thank you everyone for your time and effort. Keep us posted regarding any important news or accomplishments by members of our organizations, and a big thanks to Dr. Rajesh Ramachandran and his publication committee for their work on our newsletter once again!

Sincerely,

Nathalie Jette, MD, FRCPC
CLAE TRAINING AWARDS

Undergraduate Summer Studentship Award - $5,000

Mr. Bertrand Leduc, supervised by Dr. Lionel Carmant of the Universite de Montreal for: The role of an underlying brain malformation in the pathophysiology of Rasmussen's encephalitis

Ms. Mayuri Mahendran, supervised by Dr. Kathy Nixon Speechley of Western University and Dr. Elysia Widjaja for: Systematic review of unmet health care needs in patients with epilepsy

Ms. Stellar Dongmin Lim, supervised by Dr. Liang Zhang of the Krembil Research Institute, University Health Network for: Role of the inflammatory process in epilepsy susceptibility of aged hippocampal circuitry

Ms. Tefani Perera, supervised by Dr. Paolo Federico of the University Of Calgary for: A novel MRI marker of the seizure onset zone

Publication Awards - $1,000


CLAE FELLOWSHIP AWARD: DR SYED RIZVI

A native of Saskatchewan, Dr. Syed Rizvi completed his medical school and residency training in Neurology at the University Of Saskatchewan College Of Medicine. Fruitful collaborations with Dr. Tellez-Zenteno, who helped launch the Saskatchewan Epilepsy program, and Dr. Krishna Kumar, a pioneer in neuromodulation, helped develop Dr. Rizvi’s interest in epilepsy. Dr. Rizvi recalls residency as an exciting time which fortuitously coincided with the expansion of clinical services in neurophysiology, epilepsy surgery, and neuromodulation. His research efforts to date have focused on determinants of care for patients with epilepsy, the role of neuromodulation for refractory epilepsy, and novel patient assessment techniques. He has also published on the efficacy and cost-effectiveness of various neuromodulatory techniques. Dr. Rizvi is co-author of 3 book chapters and has published 21 papers in peer-reviewed journals.

Dr. Rizvi’s long term research interests involve the development of a comprehensive Epilepsy program with an emphasis on promoting evidence-based approaches that resolve the issues of access to care and harness multimodal treatment options that enhance quality of life for people with epilepsy. Dr. Rizvi feels truly privileged to have been selected for this award as it helps lay the foundation for a future career as an epileptologist with an active clinical profile and strong research focus on improving timely delivery of care to patients with epilepsy.

(Dr Rizvi’s one year clinical fellowship training in epilepsy under the supervision of Dr. Tellez-Zenteno begins in July 2016)
The adult epilepsy diet clinic at the Krembil Neuroscience Centre (KNC) is designed to provide an alternate treatment path for those with difficult to control epilepsy. The clinic uses a modified version of the Atkins diet that, along with medication and supplements, has the potential to help epilepsy patients reduce the frequency of their seizures.

"It’s important for patients to understand that this is a medically supervised diet. This is not a fad diet," says Dr. Bercovici. "Just like any treatment there are side effects and that’s why the diet needs to be supervised by a dietitian and a doctor." The new clinic at KNC is modelled on a similar facility at Johns Hopkins Hospital in Baltimore, which has successfully reduced the number of seizures for patients with refractory epilepsy. "The statistics tell us that more than one third of patients will have 50 per cent fewer seizures than when they started," says Dr. Bercovici. "The numbers also tell us that between five and 10 per cent of those patients will end up being seizure free."

While similar epilepsy diet clinics exist for children at pediatric facilities, the Krembil clinic is a first in Canada designed specifically for adult patients. The clinic has not been open long enough to determine the degree to which the diet is helping patients, but Dr. Bercovici says early anecdotal feedback is encouraging. In the meantime, he is trying to get the word out about the clinic's existence to patients, patient groups and doctors. "So far we have seen some very positive signs," says Dr. Bercovici. "What we need now is awareness among patients and doctors in the epilepsy world."

Source: wwwuhn.ca corporate news
Major shortages, or Tier 3 shortages, of antiseizure medications have impacted patients with epilepsy this year. The most serious have been the shortages of divalproex sodium and clobazam tablets. There has also been a domino effect on the valproic acid supply, primarily the capsules, as people unable to get their prescriptions for divalproex refilled were switched to valproic acid instead.

The divalproex sodium and valproic acid supply have not fully recovered yet, although there were some improvements during May and June.

Clobazam shortages have become increasingly more serious throughout the spring. The clobazam supply may be tenuous for a while. It is hoped that recent steps taken by Health Canada, in collaboration with pharmaceutical manufacturers to improve the supply situation will be effective in reducing the severity of the shortage. Due to the limited supply, it is recommended that clobazam be restricted to patients currently on therapy until there is improved availability of this drug.

The CLAE Medical Therapeutics Committee, in partnership with the Canadian Epilepsy Alliance Drug Shortage Committee have been working with Health Canada, the provincial health authorities, plus a wide range of other stakeholders to address the divalproex and clobazam shortages. Continued engagement on the clobazam shortage is expected throughout the summer.

The Medical Therapeutics Committee has developed clinical management suggestions for the divalproex and clobazam shortages. These documents have been shared with CLAE members and more broadly with the healthcare community through the network of organizations involved in the drug shortage response (neurologists, epilepsy nurses, primary care physicians, pharmacists, etc.). The management documents can be downloaded from the resources section of the CLAE member website and we encourage you to share them with your colleagues.

There is still residual supply of clobazam remaining at some pharmacies and distributors. Patients with epilepsy and their caregivers may need advocacy assistance to help them locate and obtain supply if their pharmacy is out-of-stock and if the pharmacist has exhausted all avenues to obtain generic clobazam and Frisium. Contact the CLAE office (clae@secretariatcentral.com) for further information or call the Canadian Epilepsy Alliance at 1-866-EPILEPSY (1-866-374-5377) for assistance identifying supply.

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**CLAE COMMITTEES**

**Awards Committee**
- Nathalie Jette (Chair)
- Francois Dubreau
- David Steven
- Mary Connolly
- Thomas Snyder
- Aylin Reid

**Education Committee**
- Paolo Federico (Chair)
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- Mary Pat McAndrews
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- Richard Desbiens
- Linda Huh
- Matt Wheatley

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- Paula Brna
- Gail Dempsey
- Lionel Carmant

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- Juan Pablo Appendino
- Danielle Andrade
- Richard Desbiens
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**Publication Committee**
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- Aylin Reid
- Luis Bello-Espinosa
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**Medical Therapeutics Committee**
- Carter Snead (Chair)
- Suzanne Nurse (Co-Chair)
- Lionel Carmant
- JP Appendino
- Susan Rahey
- Laura Wang
- Manouchehr Javidan
- Cyrus Boelman

**Driving Task Force**
- Jeff Jirsch (Chair)
- Richard McLachlan
- Chantelle Hrazdil
- Lysa Boisse Lomax
- Karen Legg
- Pierrettee Cloutier
- Martin Veilleux
Dr Mark Keezer recently joined the epilepsy group at Hôpital Notre Dame (CHUM) and the Université de Montréal as Neurologist and Assistant Professor. Dr Keezer received his BA from Georgia State University, and his BSc and MD,CM from McGill University. He completed his post-graduate neurology training at the Montreal Neurological Institute and Hospital before moving on to his MSc in Epidemiology at McGill University, supported by a training bursary from the Fonds de Recherche Santé Québec and under the supervision of Dr Christina Wolfson. He was subsequently awarded the International Sponsorship Scheme by the Royal College of Physicians of London and, under the supervision of Prof Josemir Sander, completed a clinical research fellowship in epilepsy and epidemiology at the National Hospital for Neurology and Neurosurgery, Queen Square, and the Institute of Neurology, University College London. Dr Keezer is completing a PhD in translational neuroscience, under the supervision of Prof Michel Ferrari, at Leiden University, the Netherlands.

Dr Keezer’s research to date has focused on the development and validation of diagnostic instruments and prognostic models in epilepsy. His MSc thesis centred on screening questionnaires and algorithms meant to identify individuals with epilepsy in the general population. The product of this research, the CLSA-Epilepsy Algorithm, was formally incorporated into the Canadian Longitudinal Study on Aging and is currently in use to screen 50,000+ study participants for epilepsy.

He has additionally carried out work examining the diagnostic accuracy of the diagnostic accuracy of electroencephalography as well as the prognostic potential of comorbidity indices in epilepsy. During the course of Dr Keezer’s fellowship and now his PhD, he has concentrated on issues related to the comorbidities of epilepsy, how these facilitate a deeper understanding of the mechanisms of epilepsy, as well as how they are associated with premature mortality. He played a key role in the development of clinical practice guidelines for the treatment of mental disorders in people with epilepsy, as part of the World Health Organization’s Mental Health Gap Action Programme (mhGAP).

As part of his desire to remain a part of the greater academic epilepsy community, Dr Keezer is co-founder and co-director of the National Epilepsy Review Course, a 3-day nationwide seminar designed to help prepare senior neurology residents for the Royal College Examination. He is a member of the editorial board for Epilepsia.

Presently, Dr Keezer is laying the foundation for his career in epileptology and clinical epidemiology. He is working to use population-based databases, both clinical and administrative, as vehicles to explore the relationship between comorbidities and a number of neurological conditions, including epilepsy, and how these may relate to etiology and disease burden, as well as healthcare utilization. He is also interested in the use of epilepsy surgery in Canada, how it compares to international standards, and how the Canadian experience may shed light on the potential underutilization of epilepsy surgery which has been described around the globe.

MESSAGE FROM DR. O. CARTER SNEAD: PUBLISHED PROVINCIAL GUIDELINES FOR EPILEPSY CARE IN ONTARIO

To all,

As many of you know, for the last three years the Ministry of Health and Long Term Care in Ontario has been working on a strategy for comprehensive care for those Ontarians, adults and children, who suffer from epilepsy. To this end the MOHLTC has established and funded five District Epilepsy Centres and four Regional Epilepsy Surgery Centres of Excellence, each with protected EMU beds and each with a full comprehensive epilepsy program. The Regional Centres also have full capability for all presurgical diagnostic procedures and full capabilities for all epilepsy surgery techniques.

As part of the epilepsy strategy, the Ministry also established an Epilepsy Implementation Task Force, of which I am co-chair, to improve access to epilepsy care in general and epilepsy surgery in particular across the province as well as to do performance management of the Centres. As well, we have been mandated to establish standardized diagnostic and surgical protocols across Centres. To this latter end, the EITF has issued a number of Guidelines:

Critical Care Services Ontario is the agency that is providing all of the infrastructure support for the Provincial Epilepsy Strategy. The CCSO has just built a new webpage for our Provincial Guideline series. PDFs of all the published guidelines are there. We of the EITF believe that it might be useful to CLAE members across Canada to have this link.

https://www.criticalcareontario.ca/EN/Library/Epilepsy%20Guideline%20Series/Pages/default.aspx

This Governmental effort by the Ontario Ministry of Health and Long Term Care on behalf of citizens of our Province with epilepsy is unique in North America. The Guidelines are pretty amazing in their breadth, depth, and age trajectory. They represent a multidisciplinary effort by what Peter Cambridge has called our small army of advocates in Ontario for the epilepsy strategy.

There are two more Guidelines coming that will be posted when they are officially released this year, one Provincial Guideline for Regional Epilepsy Surgery Centres of Excellence and one Provincial Guideline for Transitional Care for Epilepsy. I will let everyone know when they are released. The Guidelines for Transitional Care, written by Danielle Andrade and a large working group, is remarkable.

So, tell everyone you know about what is going on here in Ontario. We are quite proud of our Ministry and of CCSO for making this happen. The wider distribution we get the better.

Sincerely

O. Carter Sneed, MD, FRCP C
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 (September 2016) 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 September 10, 2016.

Thank you.

Rajesh Ramachandran Nair, MD, FRCPC
Editor-in-Chief, CLAE Connections

EDITOR’S PICK

NOTABLE PUBLICATIONS FROM CANADA IN 2016


UPCOMING PROGRAMS

2016 Canadian League Against Epilepsy Meeting
Quebec City, October 14-16, 2016
Registration Opening! Monday July 4, 2016

4th Halifax International Epilepsy Conference & Retreat
White Point Beach Resort, Nova Scotia, Canada, September 21st to 24th, 2016
Epilepsy as a Network Disorder: What can we learn from other disorders such as autism, depression, dementia and schizophrenia?