

CLAE CONNECTIONS

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Canadian League Against Epilepsy

MESSAGE FROM THE PRESIDENT



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Dear CLAE members,

It is an honour to be writing to you as the new CLAE President and an honour to be part of a selected group of professionals who have shaped our League over the years. An honor, because I get to be the leader of those involved in the improvement of the lives of Canadians with epilepsy. An honor, because I will be representing and speaking on behalf of all Canadians whose common interest is to enable those with epilepsy and have a better quality of life.

Being Canadian has been a great experience, and my years of living in Canada and being a Canadian citizen have been the best because of all that my family has achieved. Being Canadian and an epileptologist in Canada has been as expected. This is the land where advances in epileptology have been made and have influenced the world. From the work of Jasper and Penfield, to the amazing contributions of Juhn Wada and Peter Gloor, to the influential work of Warren Blume and Fred Andermann and the most recent remarkable work of Carter Snead and Sam Wiebe, among others.

This legacy has continued over the years, and it will continue, in generations to come. I am very grateful to all of you for being part of this great community.

For my first action as President, I would like to recognize the tireless work of our

out-going President Nathalie Jette, whose work has allowed us to be more organized and recognized. The idea of creating committees has made all of our lives easier. The Canadian health community is now recognizing how influential we can be. A clear example is the work of the Therapeutics Committee who has done an incredible job in dealing with the shortage of AEDs, particularly with clobazam, a topic that was discussed in detail during the recent CLAE Scientific Meeting in Québec City. Thank you Nathalie. And, rest assure that we will continue with the committees and will get more members involved as we grow as an organization.

I would also like to recognize the work of my colleague Rajesh RamachandraNair. Thanks to him we have a newsletter that circulates on a regular basis and informs us of the activities of our League and the extraordinary work of our colleagues in research, clinical care, and community action. There is still more to do. Our focus should be to become more influential in Canadian society, in all that is related to epilepsy, as well as outside our borders. The world is becoming a small village thanks to the internet and social media. Twitter, Facebook, Instagram, snapchat, you name it, are in our phones and in the phones and computers of all Canadians, particularly those in the generations that follow us. This social media will continue to be very influential in what we do and how we learn what happens in the world. That is why I believe the CLAE should have a presence in social media. Jose Tellez did some work on

**PRESIDENT'S MESSAGE - CONTINUED**

Facebook, but we need to have a stronger presence. For that reason, I have created an account on twitter: @CanLeagEpilep. This will be our window to the outside. Start following us. We will inform the public of what we do through this social media ap.

It is important as well to start collaborative relationships with other Leagues outside our borders. The creation of the North American Regional Commission has not been successful in increasing liaisons with other commissions or among Chapters within the region. The PECA has allowed the creation of some relationships with Latin American countries, but they have not become solidified beyond visiting hospitals and universities to give lectures. It is important to recognize that we are not alone in this world and that the philosophy used to treat patients and do research may differ from country to country, and is different outside North America, despite the current similarities with our neighbors in the south. It is why the second objective of my mandate is to start interactions with other chapters. This can be in the form of workshops, conferences, visits, among other activities. For that, funding will be crucial, and our efforts should concentrate on that.

Partnerships within Canada are also extremely important and the financial support we receive from them is of great value. To mention some, UCB Canada has been supporting a fellowship in clinical epilepsy for the last few years. It is my pleasure to mention that UCB will provide support for the following 3 years for 3 fellowships per year. This level of educational support has not been seen before in Canada, and we thank you UCB for your interest in improving epilepsy care and research by supporting those fellowships. This support is a reflection on the recognition our society is giving to our institution. We are the leaders in the field and we should continue to do so. Sunovion and Eisai have also continued to support our meeting and I hope they become interested in

supporting some of the initiatives we hope to develop within the next 2 years.

The work the Education committee has been doing has been terrific. Our meetings have been much more organized and the science has been outstanding. Furthermore, the past failure to hold a National Residents Course has been resolved with the receipt of funding and it was a reality this year. We hope this will attract young residents into the field of epileptology.

The care we deliver to people with epilepsy has to be multidisciplinary, and our League has to be as well. We have welcomed a nursing representative to our Board committee calls, in addition to the presence of the Canadian Epilepsy Alliance. It is important to be more inclusive and I hope more neuropsychologists, clinical psychologists, and EEG technologist will become members of our League.

We live in difficult economic times and funding for all activities are not at ideal levels. Entities and those who call themselves funding agencies for epilepsy and whose members do not represent those caring for Canadians with epilepsy should stop fundraising, and those who donate to them, should consider donating to our League. That is why I will start a campaign to raise awareness of our League and the great work we do.

Thank you very much,

Jorge Burneo, MD, MSPH

President, CLAE



A POPULATION BASED STRATEGY FOR COMPREHENSIVE EPILEPSY CARE IN ONTARIO

Introduction: Prior to 2013 the care that the 95,000 Ontarians with epilepsy received was uneven, including access to surgical treatment. There were several reasons for this including a lack of awareness amongst primary care providers and neurologists of the value of epilepsy surgery for those 30- 35 thousand with medically refractory epilepsy, and a patchwork referral pattern for those patients with uncontrolled seizures. Further there was a major lack of understanding in government of the scope of the problem of epilepsy in Ontario about of the role of epilepsy surgery and its value in reducing the burden of illness and costs to the system of epilepsy. Finally, there was the problem of geography. The majority of people in Ontario live in the southern part of the province, so services are sometimes difficult to provide to the far flung regions of Northern Ontario. Since 2013, the Ontario Ministry of Health and Long Term Care [MOHLTC] has taken on these challenges and established the first population-based strategy for comprehensive epilepsy care in Canada and North America.

Comprehensive Epilepsy Care in Ontario: In response to an expert panel report on epilepsy care in the Province of Ontario in 2011, the MOHLTC, with the administrative help of Critical Care Services Ontario and the Provincial Neurosurgery Advisory Committee, regionalized epilepsy care with the establishment of Adult and Pediatric District Epilepsy Centers (DEC) and Adult and Pediatric Regional Epilepsy Surgery Centers of Excellence (RESCE) in 2013. During the course of this, the MOHLTC funded 21 additional protected EMU beds across the province. As well, the MOHLTC created an Epilepsy Implementation Task Force [EITF] to develop an integrated system for epilepsy care in Ontario. The EITF brings together senior clinicians and administrators from the epilepsy community across the province of Ontario to improve access by coordinating resources and wait lists, establishing standardized diagnostic and surgical protocols across centres and developing supports for primary care providers. As part of this mandate, the EITF has created a series of Provincial Guidelines for primary care providers and community neurologists. In addition, the EITF was asked to develop educational programs for primary care providers and community neurologists.

The Ontario EITF set the criteria for a comprehensive epilepsy program (CEP) of integrated care for the management of individuals with epilepsy within a multidisciplinary team. The CEP covers various aspects of care including medical (epileptologists), psychosocial (social workers and neuropsychologists) and skilled epilepsy nursing care (nurse practitioners). The CEP also covers nutritional management (dietitian) and appropriate neurodiagnostic investigations. The latter includes all hardware and personnel for neuroimaging and neurophysiology including an EMU with protected beds, capability for presurgical diagnostic evaluation, and established links to Community Epilepsy Agencies.

Full infrastructure is provided within the system for surgical management of appropriate candidates.

The District Epilepsy Centre (DEC) houses a CEP that provides all appropriate epilepsy related clinical services except for epilepsy surgery. A DEC provides basic investigations necessary to determine candidacy for epilepsy surgery including assessment by an epileptologist, and full EMU capability including neuropsychological evaluations. Adult DEC's are located in Hamilton, Ottawa, and Sudbury. Pediatric DEC's are located in Ottawa and Hamilton. We are hopeful that DEC's also will be established in Kingston and Thunder Bay. The Regional Epilepsy Surgery Centres of Excellence (RESCE) also house a CEP that provides all the services available in a DEC, with the addition of all necessary facilities for state of the art epilepsy surgery. Both Adult and Pediatric RESCE's are in London and Toronto.

Where possible, anyone with new onset of epilepsy is referred by their primary care provider to a neurologist who will obtain an EEG and make first line treatment recommendations to be managed by their primary care provider. Those patients who fail to respond to a conventional first line anticonvulsant medication, or who have complex epilepsy from the onset such as multiple or frequent seizures or status epilepticus are referred to the DEC where appropriate medical management recommendations are developed, psychosocial support provided, and a connection with local community epilepsy agencies established. A preliminary evaluation of the patients' candidacy for epilepsy surgery is made at the DEC, and, if the patient is a candidate for surgery, he/she is referred to an RESCE for further evaluation.

At the time we began this initiative, less than 2% of patients with medically refractory epilepsy were being appropriately referred for epilepsy surgery. Since the creation and operationalization of regionalized epilepsy care in Ontario, the numbers of patients referred for epilepsy surgery and the numbers of epilepsy surgery performed in the Regional Epilepsy Surgery Centres of Excellence have increased. There has been a concomitant decrease in wait times for patients for EMU beds.

We are in the process of developing knowledge translation strategies targeting primary care providers, pediatricians, and community neurologists to make everyone in the Province aware of the Ontario Comprehensive Care Strategy for Epilepsy Care and the Provincial Guidelines for Epilepsy Care that we have created to date.

O. Carter Snead III, M.D.
Co-Chair, Ontario EITF





RISING STAR

Klajdi Puka is currently completing a Master's of Science degree in Epidemiology and Biostatistics at Western University in London, Ontario, and is supported by the Canadian Institutes of Health Research CGS Master's award and the Western Graduate Research Scholarship. Klajdi's research has focused on the cognitive and psychosocial comorbidities associated with pediatric epilepsy. In addition, he has become increasingly interested in evaluating the social determinants of health and identifying how family and parental factors impact outcomes in pediatric epilepsy.

Klajdi received his Bachelor's of Science in Psychology and Biology from the University of Toronto and received the I.M. Spigel Memorial Scholarship in Psychology for attaining one of the highest grades in the department. He completed his undergraduate thesis in conjunction with the Hospital for Sick Children in Toronto under the supervision of Dr. Mary Lou Smith. His thesis evaluated the cognitive functioning of young adults who had undergone epilepsy surgery in childhood. It was this experience, observing first hand the impact of chronic health problems in children, and the exceptional support by Dr. Smith that engendered Klajdi's career in epilepsy. Following graduation, Klajdi continued working at the Hospital for Sick Children where his research primarily focused on cognitive, behavioral, affective and quality of life outcomes associated with pediatric epilepsy and pediatric epilepsy surgery. He has published widely in *Epilepsia*, *Neuropsychology*, *Journal of Neuropsychology*, *Journal of Neurology and Epilepsy & Behavior*. He has also co-authored several book chapters on the cognitive and psychosocial manifestations of pediatric epilepsy, presented in numerous conferences and has been invited to give oral presentations at research rounds at the University of Toronto and Toronto Western Hospital.

While at the Hospital for Sick Children, Klajdi also worked closely with Dr. Cristina Go where he was further exposed to patients' experiences in navigating treatment options. He further learned of the process of treatment selection and of various treatment options and their side effects, including pharmacotherapy, epilepsy surgery, the ketogenic diet, and implantation of vagal nerve stimulator. Klajdi also worked closely with Dr. Elysa Widjaja evaluating health resource utilization among children with epilepsy across Ontario. These experiences and the guidance of Dr. Go, Dr. Widjaja and Dr. Smith furthered Klajdi's interests in pediatric epilepsy and further stimulated an interest in public health.

Klajdi continued to pursue his interest in public health through a Master's degree in Epidemiology and Biostatistics at Western University. Under the supervision of Dr. Kathy Nixon Speechley, Klajdi's Master's thesis will be focusing on identifying social determinants of health in children with epilepsy by evaluating the impact of family environment on patient and caregivers' quality of life and psychopathology. To this end, Klajdi is working on the Health-Related Quality of Life in Children with Epilepsy Study (HERQULES), a large, Canada-wide, prospective, cohort study of children with newly diagnosed epilepsy. Upon completion of his Master's degree, Klajdi plans to continue his research and clinical interests on the cognitive and psychosocial comorbidities of pediatric epilepsy by pursuing a MD/PhD.



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A UNIVERSITY-COMMUNITY PARTNERSHIP FOR EPILEPSY AWARENESS

During the first week of January 2017, an enthusiastic group of students at the University of Toronto Mississauga launched a new initiative, the Debate League Mississauga. The purpose of the Debate League Mississauga is to encourage students to engage in informed discussion and the exchange of ideas across traditional academic discipline boundaries. At its launch, the Executive announced a unique community partnership with Epilepsy South Central Ontario (formerly Epilepsy Halton Peel Hamilton). The idea for this partnership was initiated by Matthew Halsall, the Director of Public Relations for the Debate League. Matthew, now in his second year of studies in Criminology, History and Political Science, began to have seizures just before he entered grade 9, and he has become a passionate advocate for epilepsy. He has been highly involved with Epilepsy South Central Ontario through participation in their Youth Empowerment Program (YEP), and in his work as a counsellor with their Sunny Days Camp program (see CLAE Connections, 4 (3), October 2016). Under this partnership, Epilepsy South Central Ontario will provide printed informational materials at each of the debates, and will host workshops about epilepsy on campus.

Key staff members from Epilepsy South Central Ontario (Cynthia Milburn, Executive Director; Jasmine Morante, Program Manager; Andrea Dent, Manager of Youth Services) shared their enthusiasm for the new connection with the Debate League Mississauga. Their vision is that the workshops will alleviate the stigma surrounding epilepsy by unravelling myths and having open discussions about the potential effects of epilepsy on mental health (i.e., depression,

anxiety, social isolation). They hope that the partnership will allow them to reach out to more youth and young adults living with epilepsy. They see that the partnership can help them grow the YEP which now provides resources to build life skills, and opportunities for social outings and fun activities within the community. With this partnership, current YEP members can potentially build more connections and friendships and develop peer mentorship. Furthermore, it supports their mandate of positively impacting the community of people with epilepsy, increasing quality of life to those living with epilepsy and their families, advocating on their behalf and ultimately empowering them to advocate for themselves.

Matthew's hope is that these educational efforts will help educate people on proper response to seizures, combat the stigma of epilepsy and increase awareness of epilepsy and appropriate safety measures on campus. He sees these initiatives as being beneficial to people with epilepsy and to students who now do not have deep knowledge or understanding of epilepsy. There is no debating the need for those initiatives!

By Mary Lou Smith

Matthew Halsall (far right), Director of Public Relations for the Debate League Mississauga, shown with other members of the Epilepsy South Central Ontario Youth Empowerment Program.



CLAE 2017

SCIENTIFIC MEETING

2ND - 6TH SEPTEMBER

BARCELONA 2017

32ND INTERNATIONAL EPILEPSY CONGRESS

Celebrating

40

YEARS

OCTOBER 13 -15 VANCOUVER, BC

ABSTRACT SUBMISSION IS NOW OPEN!

The Scientific and Organising Committee of the 32nd International Epilepsy Congress encourages all researchers and practitioners to consider contributing to the programme by submitting abstracts for poster or platform presentation.

Please [click here](#) to enter the abstract submission system.
 Abstract submission deadline: February 24, 2017.

Registration for the 32nd IEC is now available



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 the CLAE Newsletter (April 21, 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 (mair@mcmaster.ca) before April 5, 2017.

Thank you.

Rajesh Ramachandran Nair, MD, FRCPC

Editor-in-Chief, CLAE Connections

EDITOR'S PICK

NOTABLE PUBLICATIONS FROM CANADA IN 2016

1. Camfield C, Camfield P, Smith B. Poor versus rich children with epilepsy have the same clinical course and remission rates but a less favorable social outcome: A population-based study with 25 years of follow-up. *Epilepsia*. 2016; 57(11):1826-1833. doi: 10.1111/epi.13576.
2. Fiest KM, Sauro KM, Wiebe S, Patten SB, Kwon CS, Dykeman J, Pringsheim T, Lorenzetti DL, Jetté N. Prevalence and incidence of epilepsy: A systematic review and meta-analysis of international studies. *Neurology*. 2017; 88(3):296-303.
3. Massot-Tarrús A, Steven DA, McLachlan RS, Mirsattari SM, Diosy D, Parrent AG, Blume WT, Girvin JP, Burneo JG. Outcome of temporal lobe epilepsy surgery evaluated with bitemporal intracranial electrode recordings. *Epilepsy Res*. 2016; 127:324-330

2017 CLAE Fellowship Awards : Call for Proposals

The Canadian League Against Epilepsy in conjunction with UCB is pleased to announce [the Call for Proposals for the 2017-2018 Epilepsy Post-Graduate Training Fellowship Award](#) (with a research component). This year we are pleased to offer 3 separate awards.

Background/ Specific Objectives

Funding for post graduate epilepsy training has been offered by UCB for the 2017-2018 academic year. These fellowship awards will be administered under the auspices of the Canadian League Against Epilepsy (CLAE). The purpose of these scholarships is to bring increased epilepsy expertise to the Canadian Epilepsy Community. The CLAE will accept applications for a clinical epilepsy or epilepsy surgery fellowship in Canada, which encompasses elements of both clinical experience and research. Fellows must complete a research project during their fellowship.

Eligibility

- Canadian Citizen or Landed Immigrant
- Neurology or Neurosurgery trainees with expected finish of their residency training no later than June 30, 2017
- Enrolled or accepted in a clinical epilepsy or epilepsy surgery fellowship program at an accredited university or a post-graduate training program in Canada with a focus on epilepsy clinical care and research.
- Anticipated start of the fellowship program should be between July 1, 2017 and December 31, 2017
- Post-training fellowship practice to be located in Canada. Fellowships based outside Canada will not be funded.

Criteria for applications

1. Quality of the applicant: Academic excellence, previous relevant clinical and research experience, letters of recommendation.
2. Quality of the clinical research and training environment: Academic excellence of the supervisor/co-supervisors in the relevant area, resources available for the candidate, collaborators, etc.
3. Quality of the training program:
 - a. Specific aims of the training: Will they effectively achieve a specific skill set for the candidate? Are they clear?
 - b. Training program design: Is the program achievable for the candidate over the proposed time period? Provide a detailed description of the training program, including an outline of any planned clinical projects.
4. Significance of the research: Is this an important area of epilepsy research? Is the study justified? Are the objectives/hypotheses clear?

Amount of Award

Three scholarships of \$64,000 will be awarded for the 2017-2018 year.

Application Deadline

Friday March 31, 2017 11:59 PM EDT is the application deadline. Candidates will be notified by April 21, 2017 if their application was successful.

Please [click here](#) for an application

CLAE Meeting: Call for Proposals

You are invited to submit proposals for a plenary session or workshop for the 40th Anniversary of the CLAE Scientific Meeting to be held in Vancouver, B.C. from October 13-15, 2017. The deadline for submission is March 12, 2017.

The proposal should be organized under the following headings:

Session outline (maximum 250 words)

Learning objectives (maximum 5)

Target audience

Learning format: Lectures or workshops

Name of the chairperson (including affiliation and contact information)

Name of each speaker with a title of the talk and affiliation

Please note the following:

Session Chairs and speakers will be offered a discounted rate for registration. Registration is required to participate.

Speakers and chairs will not be provided with travel or accommodation expense reimbursement.

Sessions are limited to a maximum of 5 speakers, are 1 hour 45 minutes in duration and must include a minimum of 25% interactivity.

Preference will be given to topics relevant to the broader community that include multidisciplinary speakers from different Canadian regions/centers.

The CLAE Education Committee will review all proposals and send decision notifications the week of April 17, 2017.

Please submit your proposals electronically to:

Dr. Paolo Federico

c/o CLAE Secretariat

events@secretariatcentral.com