

CLAE CONNECTIONS

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Canadian League Against Epilepsy

MESSAGE FROM THE PRESIDENT



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Dear members,

This is our first issue of 2018 and I would like to wish you the very best this year. There are a lot of activities happening in this year. We will be having the first North American (Canada, USA and the Caribbean) regional epilepsy meeting which will be held in Trinidad & Tobago from March 1st to the 3rd. This regional meeting provides an opportunity to start networking with our colleagues mainly from the Caribbean Chapter. Canada will be hosting the next Regional Congress, and we will provide enough time to plan your attendance and submit abstracts and proposals for scientific sessions.

Our chapter continues to be quite active, not only nationally but also abroad. With the support from UCB Canada, we will again be able to offer 3 epilepsy fellowship awards this year. The call for this competition is out, and I encourage all of you to spread the news and identify potential residents interested in doing a fellowship in epilepsy in Canada and invite them to apply.

In terms of fellowships, I have been in contact with all Canadian fellowship program directors, with the goal to create a committee dedicated to the creation of minimal standards in epilepsy education. The response has been great, and the idea has been well received. I hope to have something drafted before the end of my presidency. Perhaps in the future, we can join forces with the Canadian Society of Clinical Neurophysiologists, to enhance the training in epilepsy and EEG.

In the international arena, our members have been quite active and very involved in different initiatives. Under the leadership of Ms. Laura Jurasek from the University of Alberta, a survey assessing the involvement of our members in diverse initiatives to improve epilepsy care around the world was distributed and I hope all of you took the time to answer it. This will allow us to have a repository of different activities of our members abroad. This information will potentially be shared with the Commission on North American Affairs from the ILAE. Canadians have also been leaders in global health, and I hope this will continue

to be the case in the field of epilepsy.

Recently, you may have received a survey in an email to obtain your opinion on the current guidelines on driving and epilepsy from the Canadian Medical Association. Please take the time to answer, as the Driving Task Force is interested in completing their work on this issue.

I would also like to congratulate the website committee under the leadership of Dr. Kristin Ikeda, from Dalhousie University. The new website is up and running and provides much more information on our activities. It also provides information to the general public in many aspects of epilepsy. Please go ahead and start surfing through it (www.claegroup.org). Your feedback will be much appreciated.

At the CLAE we are all excited about our upcoming meeting in St John's, Newfoundland. Dr. Mark Keezer, our new Director of Education, and his committee, are working very hard to provide you with the best educational sessions, research informative sessions, and social experience. Mark your calendars with the dates: September 21st to the 23rd at the Delta Hotels St. John's Conference Centre.

The CLAE would like to congratulate the Canadian Epilepsy Alliance (CEA) on their 20th anniversary. The CEA has been our partner sharing the passion to improve epilepsy care in Canada.

Finally, please add to your calendars 'Purple Day', which will be happening on March 26th. The day is around the corner and is a great opportunity to increase awareness on Epilepsy. Wear purple and join thousands of people around the world in different educational activities on this day.

Cheers,

Jorge





RISING STAR



Dr. Kristin Ikeda is a neurologist and epileptologist who recently joined the Division of Neurology, Department of Medicine at Dalhousie University in Halifax, Nova Scotia. Dr. Ikeda is currently the junior member representative of the CLAE Board of Directors, and chair of the website development committee. Dr. Ikeda completed her undergraduate

education in Music at Wilfrid Laurier University in Waterloo ON. She worked as a music therapist for a couple of years with developmentally delayed adults and elderly people with dementia. It is through this work that she became interested in medicine, and subsequently completed her undergraduate medical training at McMaster University in Hamilton ON. Dr. Ikeda went on to complete her neurology residency and epilepsy fellowship at Western University in London ON. She was awarded the Canadian Society for Clinical Neurophysiologists National Fellowship for Epilepsy/EEG in 2016-2017.

Dr. Ikeda's research interests include functional connectivity analyses in people with epilepsy, and in particular after the first seizure, new-onset epilepsy and status epilepticus populations. While at Western, she also completed a Masters of Neuroscience under the supervision of Drs. Seyed Mirsattari and Ali Khan. She was able to make use of the only human ultra-high field MRI (7T) in Canada for her research.

Dr. Ikeda's Masters thesis was on functional connectivity using resting-state functional MRI at ultra-high field in the first seizure population in the hope of developing a biomarker for predicting the development of epilepsy after a single seizure. This research was awarded the Canadian Neurological Society's Andre Barbeau Memorial Prize in 2017. She will be continuing research in this area through her work with the Halifax First Seizure Clinic.

Through her Masters research, Dr. Ikeda was exposed to advanced neuroimaging techniques and methods of visualizing neuroimaging data, and is interested in integrating these tools into clinical practice. She has participated in "hack-a-thons" or project weeks with other neuroimaging researchers to develop useful clinical tools that are accessible to clinicians.

Dr. Ikeda is establishing the adult epilepsy magnetoencephalography program at the Nova Scotia Health Authority in conjunction with Dr. Maher Quraan, scientist with BIOTIC at the IWK Health Centre, and location of the magnetoencephalogram. She plans on integrating multimodal imaging techniques to provide assistance in locating the epileptogenic zone in patients being investigated for epilepsy surgery.

In addition to her neuroimaging interests, Dr. Ikeda's clinical interests also include women's issues, management of medically refractory epilepsy, presurgical epilepsy evaluations, and transitioning pediatric patients to the adult epilepsy clinic.

MY VISION – FROM THE DIRECTOR OF EDUCATION



I was very excited to be elected Director of Education last fall. Assuming the role that Paolo Federico occupied before me was a humbling experience. I am fortunate to chair an Education Committee that includes both returning and new members, all of whom are working hard to help the CLAE carry out this core academic mission.

Planning for the 2018 CLAE meeting in Saint John's, Newfoundland is progressing well. We think that this year's program will be great. We continue to work to ensure that the program is interesting to not only clinicians (general neurologists, epileptologists, and neurosurgeons), but also researchers. The contribution of allied health professionals, such as nurses and neuropsychologists, is also important and we hope that this year's program will be of interest to a multidisciplinary audience.

One priority for this year's meeting is to continue to further engage CLAE members involved in basic science research. Their contribution enriches the academic environment for all meeting attendees.

Another priority is to find new ways to highlight the research presented at the meeting in the form of posters. It is important that contributors of posters feel that their work is seen, especially for trainees and junior investigators. The CLAE biennial meeting should serve as an opportunity for our most junior colleagues to interact with their peers and the rest of the Canadian epilepsy community.

The Education Committee is exploring new ways the CLAE can support the training of epilepsy fellows in Canada. We are working to see whether we can facilitate their participation in the J. Kiffin Penry Epilepsy Minifellow Network program in the USA or the ILAE-sponsored San Servolo Epilepsy Summer School in Italy. Another option is to develop content at the CLAE biennial meeting that targets epilepsy fellows. New initiatives to support epilepsy fellows ensures a higher quality training, as well as facilitates their involvement in our growing epilepsy community.

I am excited about my 2-year tenure as the Director of Education for the CLAE. I would be pleased to hear from CLAE members with any new ideas, and ways to continue to grow the educational aspect of the CLAE. This is work started by my predecessors that I hope to continue.

By Mark Keezer



**THE CANADIAN EPILEPSY ALLIANCE / ALLIANCE CANADIENNE DE L'ÉPILEPSIE
TURNS "20 YEARS OLD" IN 2018**



In 1998, ten community epilepsy agencies from across Canada identified a gap and started a movement which is still going strong 20 years later. Clients and families of persons living with epilepsy wanted a national voice to work on their behalf so that all Canadians would gain insight and education about what it is like to live with a seizure disorder.

These 10 agencies believed that as an alliance and working together would make them stronger than working alone – and so the Canadian Epilepsy Alliance/Alliance canadienne de l'épilepsie (CEA/ACE) was born.

The CEA/ACE is a partnership between grassroots epilepsy organizations Canada-wide dedicated to the promotion of independence, quality of life, and full community participation of persons with and affected by epilepsy, through innovative support services, advocacy, education and public awareness.

The first large national project the CEA/ACE launched was a Canada-wide survey on what people affected by epilepsy saw as their most pressing concerns. The survey results helped to direct the ongoing efforts and kept the CEA/ACE members agencies in touch with the real-life challenges of those living with epilepsy in Canada. Since then an additional survey was done to make sure our mandate and programs continue to address important issues for Canadians living with epilepsy.

The creation of the CEA/ACE also coincided with the International Postcard Campaign by the World Health Organization called "Out of the Shadows". This global campaign was supported by CEA/ACE, the International League Against Epilepsy and the International Bureau for Epilepsy.

From its humble beginnings in 1998, the Canadian Epilepsy Alliance has grown from the ten founding agencies to a twenty-seven community epilepsy agencies representing urban and rural communities from coast to coast.

More recently, the CEA/ACE has re-branded itself and launched a new website at www.canadianepilepsyalliance.org and provided up-to-date information on all aspects of epilepsy. The CEA/ACE is also increasing its presence on social media platforms like Facebook and Twitter in order to increase awareness and dispel myths about epilepsy. The CEA/ACE reposts activities and news from the twenty-seven local epilepsy agencies Canada-wide.

The CEA/ACE also developed and maintains a **1-866 EPILEPSY** toll free number accessible to all Canadians. This number links any caller to their nearest community epilepsy agency. Once connected, individuals can get the information and supports they need to help them not only cope with their diagnoses but live WELL with epilepsy.

The CEA/ACE recently hired a part-time social media staff that promotes our initiatives. The CEA/ACE has worked at the national level to help to manage the issue of drug shortages as well. In 2017 the CEA/ACE also issued a timely press release in response to incorrect steps of first aid for seizures that was contained in a viral news story on social media. Our goal was to state the appropriate steps in relation to first aid for seizures in order to help educate the public on what they should do if they witness someone having a seizure. <http://www.canadianepilepsyalliance.org/canadian-epilepsy-alliance-responds-to-viral-good-samaritan-story>.

It has developed, maintains and distributes an epilepsy booklet series in both official languages that is used by clinicians and community agencies across the country. The CEA/ACE continues to lead initiatives for Purple Day – March 26th to empower Canadians living with epilepsy.

Last year the CEA/ACE offered a Bursary to sponsor a CLAE member to attend an ILAE course for neuropsychology and leverages partnerships with national groups like CLAE, NHCC, IBE, Health Canada and the ILAE.

Despite some on-going challenges, we know that Canada is a much better place for persons with epilepsy because of the existence of the Canadian Epilepsy Alliance.

The Canadian Epilepsy Alliance is planning to celebrate our 20th anniversary milestone at the CLAE conference in Newfoundland this fall!

Here's to another great 20 years. **Happy Anniversary Canadian Epilepsy Alliance!**

By Paul Raymond





EXPERIENCE WITH CBD OIL IN A PEDIATRIC EPILEPSY CLINIC



In 2016, Dr. Andrade (Pediatric Epileptologists) developed a comprehensive epilepsy clinic for children with medically refractory epilepsy in Southwestern Ontario. Patients who have failed multiple medications will be approached by a multidisciplinary team that includes: pediatric epileptologist, pediatric N.P, social worker, community agency, psychologist, dietician, pharmacist and neurosurgery.

The clinic aims to introduce non-pharmacological therapies for epilepsy that could be beneficial for children with pharmacoresistant epilepsies. These therapies include epilepsy surgery, the ketogenic diet and the vagal nerve stimulator. In response to an increased demand by parents, we started a subsection of the clinic that aims to select children with epileptic encephalopathies who have failed to multiple medications and whose parents are willing to try CBD oil as an adjunctive therapy in very well selected patients on compassionate grounds. We have around 30 patients currently managed with CBD as an adjunctive therapy. All these patients are evaluated in a standardized fashion which includes an EEG and complete blood work pre-initiation, and a comprehensive explanation and written

information about the challenges encountered while on CBD oil (including the possibility of inconsistencies in the amount of active compound in the bottles received by the dispensaries, the challenges of travelling abroad while taking the oil given medical cannabis is still illegal in some countries, the still unknown interactions between the oil and traditional anticonvulsants, and the lack of coverage by government or private insurance making it hard for parents to afford the goal dosage to achieve seizure reduction).

If parents agree and understand all these limitations, then they sign a written consent and we initiate a slow titration with a close follow up and also another EEG and blood work at 3 and 6 months time. Our experience and initial observations have shown mixed results and the CBD oil behaves like another antiepileptic in children who are medically refractory and are not candidates for epilepsy surgery. We feel that giving the families a safe venue where they can try the oil under the supervision of a pediatric epilepsy multidisciplinary team has helped them to understand the still "unknowns" and challenges of CBD oil as an adjunctive therapy for children with epilepsy. We are certainly excited to get the results from the clinical trials that are currently ongoing that will help us to understand more the use, benefits and limitations of this new therapy.

A NEW DISTRICT EPILEPSY CENTER



As an early career epileptologist and the director of the epilepsy program and EEG laboratory at the Ottawa Hospital, I am committed to ensure The Ottawa Hospital becomes an epilepsy center of excellence over the next 5 years. The Ottawa Hospital serves the healthcare needs of 1.3 million people living in the Champlain LHIN and yet has never before provided its constituents with a dedicated epilepsy program. In 2014 The Ottawa Hospital became an Epilepsy district referral center and an integral part of the proposed provincial epilepsy strategy, which provided the funding necessary to create and grow an epilepsy program in the Nation's capital.

Since then Ottawa's burgeoning epilepsy program has started to thrive: we now have a functioning 2 bed epilepsy monitoring unit, new Neuropsychology services, a continuous EEG monitoring service for critically ill patients, an epilepsy OB clinic for pregnant patients, a

fully realized transition clinic for pediatric epilepsy patients transferring to the adult stream of care, as well as close links with colleagues in psychiatry to help our PNES patient population. Over the next 12 months, we will be adding PET capability, which will bring us one step closer to our long-term goal of achieving NAEC Level 3 accreditation and establishing a surgical center of excellence. Over the next 3 years we are looking at expanding our EMU to 4-5 beds as well as adding WADA and fMRI modalities. Our program has a bright future as the new Civic campus is currently being designed and built over the next 8 years, allowing for further expansion of our EMU and clinic services. Finally, we have built strong links with our community partners and are actively involved with Epilepsy Ottawa, our local patient advocacy group, striving to improve the lives of people living with epilepsy. None of this work would be possible without the program's dedicated team of physicians, nurses and EEG technologists, including Dr. Rajendra Kale, our epilepsy specialist, Gillian Reid McDonald, our advanced practice nurse, Sabrina Chang our epilepsy clinic nurse, Dr. Bryce Mulligan our neuropsychologist as well as Nikki Porter, the director of Epilepsy Ottawa.

By Tadeu A. Fantaneanu





PROJECT ECHO ONTARIO: EPILEPSY ACROSS THE LIFESPAN

DEMOCRATIZING EPILEPSY KNOWLEDGE: Educating Community Providers about Epilepsy Care

Each year over 6000 people in Ontario are newly diagnosed with epilepsy. Often, people who experience their first seizure will present either to the emergency room or their primary care provider, seeking treatment and support. The typical patient flow will be for the emergency physician or the primary care provider to refer to a neurologist. In urban areas, a referral may be addressed quickly, potentially mitigating future seizures. However, in many parts of the province, particularly in remote and rural areas, there is a lack of neurologists, which results in lengthy patient wait times for specialist care.

As part of a broad initiative to improve care for the 90,000 people with living epilepsy in Ontario, an Epilepsy Guideline Series (available at www.criticalcareontario.ca), was developed in conjunction with all of Ontario's Comprehensive Epilepsy Programs. The guidelines provide consensus recommendations on diagnosis, management and treatment options of patients with epilepsy. The series is targeted at a variety of providers who may provide care or counsel to people with epilepsy, including primary care providers, paediatricians, neurologists, pharmacists, social workers, and many others. Though the guidelines have been finalized and disseminated broadly, evolving practice towards guideline-concordant care requires efforts beyond simply distributing published content and hoping front-line providers will adopt the recommendations into practice. A new approach to engage all providers involved in caring for people with epilepsy is underway. Project ECHO (Extension of Community Health Outcomes), a knowledge translation approach gaining global traction, will be implemented across Ontario for epilepsy care, beginning in the spring of 2018.

Project ECHO Ontario: Epilepsy Across the Lifespan is a continuing medical education program designed for family doctors, paediatricians, nurse practitioners and other community providers in remote, rural and underserved communities. Originating from the University of New Mexico to enhance early diagnosis and treatment of patients with Hepatitis C, the Project ECHO model endeavors to reduce barriers to continuing professional education (such as geography and time) and community provider self-efficacy for the management of specific conditions and diseases.

The model relies on technology to connect community providers and specialists at the regional academic centre via video-conference on a repeating interval (e.g., once a month). The specialist team is interdisciplinary, and includes an epileptologist, epilepsy nurse practitioner, pharmacist, social worker and a representative from the community epilepsy agency.

The format of the session is case-based learning followed by a short didactic presentation to reinforce clinical pearls. Rather than using standardized cases, de-identified patient cases from the community provider's practice are presented and discussed. As a result, the presenting provider leaves the session with a care plan for their patient and all participants benefit from a collaborative review and discussion of the case. Through ongoing participation, the long-term goal of each Project ECHO is to establish and foster ongoing regional communities of practice between the academic centres and referring community providers and to enhance the self-efficacy of providers in the community to co-manage patients.

Project ECHO Ontario: Epilepsy Across the Lifespan will run two separate curricula. Epilepsy in childhood and youth, and Epilepsy in adulthood. Each of Ontario's comprehensive epilepsy programs will be offering this program within their catchment:

- Hamilton: Hamilton Health Sciences and McMaster Children's Hospital
- Kingston: Kingston General Hospital
- Ottawa: The Ottawa Hospital and the Children's Hospital of Eastern Ontario
- London: London Health Sciences Centre and Children's Hospital
- Thunder Bay: Thunder Bay Regional Health Sciences Centre
- Toronto: Hospital for Sick Children and University Health Network

For more information, visit www.echoontario.ca or contact the Program Manager, Anastasia Vogt at anastasia.vogt@sickkids.ca

CLAE 2018 SCIENTIFIC MEETING

September 21-23, 2018

CLAE
CLCE

DELTA HOTELS ST. JOHN'S
CONFERENCE CENTRE



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 (June 15, 2018) 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, 2108.

Thank you.

Rajesh Ramachandran Nair, MD, FRCPC

Editor-in-Chief, CLAE Connections

EDITOR'S PICK

Development and assessment of the Quality of Life in Childhood Epilepsy Questionnaire (QOLCE-16). Goodwin SW, Ferro MA, Speechley KN. *Epilepsia*. 2018 Jan 28. doi: 10.1111/epi.14008.

Spike-related haemodynamic responses overlap with high frequency oscillations in patients with focal epilepsy. González Otárola KA, Khoo HM, von Ellenrieder N, Hall JA, Dubeau F, Gotman J. *Brain*. 2018 Jan 18. doi: 10.1093/brain/awx383.

Update on Minimal Standards for Electroencephalography in Canada: A Review by the Canadian Society of Clinical Neurophysiologists. Dash D, Dash C, Primrose S, Hernandez-Ronquillo L, Moien-Afshari F, Ladino LD, Appendino JP, Mazepa L, Elliott C, Mirsattari SM, Federico P, Bui E, Hunter G, Ramachandran Nair R, Sharma R, Melendres P, Nikkel J, Nguyen DK, Almubarak S, Rigby M, Téllez-Zenteno JF. *Can J Neurol Sci*. 2017 Nov;44(6):631-642.

CLAE FELLOWSHIPS

This year CLAE is pleased to offer 3 separate awards of \$64,000 each.

Funding for post-graduate epilepsy training has been offered by UCB for the 2018-2019 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.

Application Deadline Friday March 30, 2018 11:59 PM EDT ([contact CLAE@secretariatcentral.com](mailto:contact.CLAE@secretariatcentral.com))