

CLAE CONNECTIONS

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Canadian League Against Epilepsy



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Let me start with wishing all of you a very joyous holiday season and a happy new year. It was wonderful to see and connect with the Canadian colleagues at AES and Canada Night. Canada Night as usual was a great success and attended by more than 100 CLAE members.

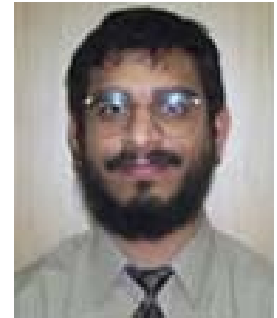
UCB has once again provided funding for fellowship for 2014-15. I am very thankful to UCB for their ongoing support. The announcement with deadlines for submission of application was circulated last week. Do encourage your residents

and fellows to apply. Please mark your calendars for the CLAE Biennial Meeting in London, Ontario from October 17-19, 2014. We have received a large number of submissions and proposals for the plenary sessions. We hope to have the applications reviewed and adjudicated by early spring.

I encourage all of you to get involved with CLAE and share your experience and expertise related to educational activities, advocacy, mentoring of junior colleagues and fund raising. Last but not the least I encourage all

of you to consider generously donating to CLAE, to help us continue running our league in the most organized way and help support research and fellowships in epilepsy care.

Thank you.



Best Regards,

S. Nizam Ahmed, MD, FRCP





RISING STARS

In this issue of CLAE connections, we introduce Dr Ali Khan



Dr. Ali Khan is a Postdoctoral Fellow at the Robarts Research Institute, Western University, in the Virtual Augmentation and Simulation for Surgery and Therapy (VASST) laboratory. Dr. Khan received his BSc (2006) and PhD (2011) in Engineering Science at Simon Fraser University, carrying out research in computational tools for assessing neurodegenerative brain diseases. He is the recipient of many national research awards including the NSERC Canada Postgraduate Scholarship (2009-2011), the Epilepsy Canada Postdoctoral Fellowship (2011) and the CIHR Fellowship (2012-2013). Dr. Khan has published widely, including papers in Human Brain Mapping, NeuroImage, IEEE Transactions on Medical Imaging, and IEEE Transactions on Biomedical Engineering.

The Virtual Augmentation and Simulation for Surgery and Therapy (VASST) laboratory, headed by Dr. Terry Peters, is concerned with the development and validation of tools that allow surgeons to make efficient use of images, produced by sophisticated 3-D imaging systems, during surgical procedures. This exciting area of research has attracted a multidisciplinary research team with specialized knowledge in fields such as, medical imaging, digital image processing, 3D visualization and computer-human interaction.

Dr. Khan's research is centred on the development and application of quantitative brain imaging techniques to improve understanding, diagnosis, and treatment of neurological disorders. His current work is evaluating new and emerging imaging techniques for better lateralization and localization of seizure onset in drug-resistant epilepsy patients. The unique study underway at Robarts Research Institute and in collaboration with clinicians at the London Health Sciences Centre involves scanning surgery patients in state-of-the-art MRI scanners,

including Canada's highest field-strength 7 Tesla MRI, using a number of complementary quantitative imaging techniques. By correlating these images with microscopic histology images of the resected temporal lobe after surgery, their team hopes to better understand the relationship between imaging and pathology, and ultimately decipher the MRI "signature" for the optimal detection of epileptogenic tissue. Dr. Khan's research has the potential to obviate the need for invasive monitoring with intracranial electrodes and improve surgical outcomes by providing a more accurate delineation of the epileptogenic zone pre-operatively. His work is especially relevant to non-lesional patients, or those with normal MRI findings, since the imaging techniques under investigation have greater sensitivity in detecting lesions, and could ultimately influence clinical management of these patients.

Another research interest of Dr. Khan's is the clinical application of diffusion tensor MRI. This technique precisely measures the degree and direction of water diffusion in the brain, and can be used to probe the complex microstructure of brain tissue. One application of diffusion MRI is tractography, whereby fibre bundles in the white matter are traced out by following the directionality of water diffusion throughout the 3-dimensional image. Dr. Khan has been involved in further development of this tool for surgical planning applications, specifically improving extraction of the cortico-spinal tract to avoid functional deficits in resective tumour surgery. Diffusion tensor tractography can be used to pre-operatively map the extent of the optic radiation and inform surgeons to either avoid this fibre bundle or better predict the potential post-operative deficits. Dr. Khan is also involved in research aimed at understanding the mechanism of post-operative recovery of functional deficits and how presentation and characterization of these fibre bundles can predict recovery. Dr. Khan's aspirations are to continue pushing the clinical validation and translation of novel imaging techniques, where they can have a positive impact on diagnosis and surgical treatment of epilepsy. He is looking forward to continued interaction and collaboration with epilepsy clinicians and researchers throughout the CLAE.

'CLINIC TO COMMUNITY' PROGRAM

MARY SECO



Parents of children and youth living with epilepsy in Southwestern Ontario were asked to share their opinions about the services and support they required to live well with a diagnosis of epilepsy. They spoke about timely access to a proper diagnosis and treatment plan but also reinforced the need for support in dealing with the non-medical aspects of the diagnosis. This included guidance on how to talk to others about this stigmatized condition, understanding when a seizure was a medical emergency and how to reduce fear in the entire family. Parents identified that they needed support with school advocacy and ways to cope with the unpredictability of the next seizure.

Development of the Program

The 'Clinic to Community' program was developed by the Epilepsy Support Centre in London, Ontario with input from stakeholders including adults, parents, neurologists, social workers, nurses and medical secretaries. In developing the program we recognized that the majority of health decisions are made by the individual within the context of his or her family and community and to make informed health decisions, persons with epilepsy require the education, skills, and tools to manage their condition day-to-day. The program is patient centred and is offered at the clinic after a family receives a new diagnosis of epilepsy.

How it Works

After receiving a diagnosis and treatment plan, the 'Clinic to Community' educator meets with the family at their clinic appointment to provide basic information about epilepsy and seizure first aid. This first meeting allows the family to talk about their personal experience and how the seizure has impacted them and to ask their questions about the diagnosis.

At this initial meeting the family is introduced to safety strategies, risk management and the services offered by the Community Epilepsy Agency. Connecting face to face is critical to gain the trust of the family and to customize the program to their individualized needs. One month after the initial contact, the 'Clinic to Community' educator phones the family to see how they are coping and to answer 'new' questions. The family is offered additional resources including classroom presentations, school support, recreation programs, peer to peer and support groups. The program is designed to provide knowledge that is personalized and offered at the time of need.

Research Project

With research funding from the Ontario Brain Institute we will evaluate the effectiveness of this intervention. We would like to determine if felt stigma and quality of life varies between individuals who participate in this early intervention program versus those that do not. We would also like to determine to what extent the rates of seizures, health care utilization and emergency room usage varies between families who receive this intervention and those that do not. We will also be documenting to what extent participating in the 'Clinic to Community' program improves collaboration between the patient, health care team and the Community Epilepsy Agency. Although we are at the pilot phase of our implementation we have also developed modules for this program to be used with youth and adults. The youth and adult modules place an emphasis on treatment compliance, lifestyle management, driving legislation, disclosure, relationships and employment.

EDITOR'S PICK: NOTABLE PUBLICATIONS FROM CANADA IN 2013 (JUNE-DECEMBER)

1. An D, Fahoum F, Hall J, Olivier A, Gotman J, Dubeau F. Electroencephalography/functional magnetic resonance imaging responses help predict surgical outcome in focal epilepsy. *Epilepsia*. 2013 Dec;54(12):2184-94. Montreal Neurological Institute, McGill University, Montreal, Quebec, Canada;
2. Ramachandranair R, Jack SM, Meaney BF, Ronen GM. SUDEP: what do parents want to know? *Epilepsy Behav*. 2013;29(3):560-4. Department of Pediatrics (Neurology), McMaster University, 1280 Main Street West, Hamilton, Ontario L8S 4K1, Canada.
3. Woodward KE, Gaxiola-Valdez I, Goodyear B, Federico P. Frontal Lobe Epilepsy Alters Functional Connections within the Brain's Motor Network: A Resting-state fMRI Study. *Brain Connect*. 2013 Dec 13. [Epub ahead of print] University of Calgary, Neuroscience, Calgary,



OUR STORY: SASKATCHEWAN EPILEPSY PROGRAM

Jose Tellez-Zenteno , MD

For many years Saskatchewan did not have an epilepsy program. Neurologists had a difficult time treating patients with intractable epilepsy and many patients were referred to other provinces. Epilepsy monitoring and surgery were performed intermittently primarily in pediatric and some adult patients by Dr. Lowry (Pediatric Neurologist) and Dr. Griebel (Neurosurgeon). In 2007, Dr. Tellez-Zenteno arrived in Saskatoon, which is the largest city in the province and the location of the University of Saskatchewan. Prior to his arrival, Dr. Tellez had four years of training at the Epilepsy Programs of the University of Western Ontario and the University of Calgary. Dr. Tellez started organizing a resource centre for the province where patients with complex epilepsy could be assessed and treated, including the option of epilepsy surgery. Over the years the program has been incorporating highly motivated people interested in epilepsy. Presently, our team is composed of two adult epileptologists, one ICU Specialist with EEG expertise, seven EEG technologists, one neuropsychologist, two epilepsy surgeons, a nurse coordinator, an epilepsy fellow, a research coordinator and administrative staff.

In 2009 the program received the first donation (100,000) to acquire new video-EEG telemetry equipment through The Royal University Hospital Foundation. This equipment was shared between pediatric and adult patients. In the same year the program received a second donation from people in the community (90,000) that was used to purchase a portable EEG for adult patients and to support research projects. A historical moment occurred in 2011 when the first dedicated Saskatchewan Epilepsy Unit bed was established as a result of the third donation (100,000)

by generous people in the Saskatoon community allowing the purchase of a second video-EEG equipment. The capacity of the program to engage people in the community of Saskatchewan has been key to the success of our program. Currently the program is very active in the pre-surgical evaluations and epilepsy surgery. Since 2007 the program has investigated one hundred and eighty patients (video-EEG telemetry) and ninety candidates have been operated. Our experience showed a seizure free rate of 70%, which is in agreement with the international standards. The program covers 1.1 million (population in Saskatchewan) and is the only service available in the province.

Our program offers the following services a) epilepsy monitoring and surgery, b) implantation of vagal nerve stimulators, c) implantation of depth electrodes, d) electrocorticography and brain stimulation, d) a Single Seizure Clinic, e) 3-tesla MRI, f) PET scan and g) fMRI

The program has been involved, since the beginning, in clinical research. The program, has delivered more than sixty peer reviewed articles, presented more than sixty five abstracts in national and international meetings and nine book chapters since 2007. The most successful research in our program has been related to the exploration of outcomes after epilepsy surgery, epidemiology of epilepsy and the assessment of different clinical outcomes in patients with drug resistant epilepsy. The Program also started an epilepsy fellowship program in 2012 to enhance research activity. It has received more than two millions dollars in donations and grants for clinical research.

The significant waiting time to have a

video-EEG telemetry investigation (three years) with only one established bed brought the necessity to consider a second permanent bed to perform video-EEG telemetry investigations. The program organized a fundraising campaign in March 26 of 2013 (Purple day). In three months we were able to raise 100,000 dollars to buy a third video-EEG equipment and a second portable EEG. To promote this campaign we opened a website in Facebook which has been used to educate patients with epilepsy and inform the various activities of the program. As per our knowledge we were the first epilepsy program to open a Facebook page in Canada .

The program has plans for the future. We are in the process of establishing our first transition clinic. We are also developing a program to offer deep brain stimulation for selected cases with intractable epilepsy. We would like to establish strong collaborations with basic epilepsy scientists at the University of Saskatchewan. Finally the program will continue collaborating in clinical research with other epilepsy centers in the country.





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 (March 2014) 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 February 15, 2014.

Thank you.

Rajesh Ramachandran Nair, MD, FRCPC

Editor-in-Chief, CLAE Connections

UPCOMING PROGRAMS

4th Course on Epilepsy Surgery (EPODES), 13-17 January, 2014 Brno, Czech Republic

An advanced interactive course on surgically remediable epilepsies, presurgical evaluation, scalp and intracranial EEG, neuropsychology, imaging and psychiatric issues of surgical patients before and after surgery.

<http://www.ta-service.cz/epodes2014/>

5th SEEG Course on Seizures of the Motor System, SEEG 2014,

Venice, Italy

4 - 8 February, 2014

More information: seeg@ant-congres.com

4th North American Regional Caribbean Congress on Epilepsy

May 22-24, 2014

The luxurious Bay Gardens Resort in St. Lucia will be the venue for the 4th NARCC.

<http://www.epilepsycaribbean.org/narce-2014-registration.html>



The next CLAE Biennial Meeting will be held in London, Ontario from October 17-19, 2014. This would be a joint meeting with the Canadian Epilepsy Association. Please mark your calendars.