

NETWORK NEWSLETTER

A CHRONIC PAIN NETWORK UPDATE

INSIDE



A message from the Scientific Director

An update from
Dr. Norm Buckley.

Page 2



2019 Chronic Pain Network Annual Meeting

Find out what happened at the
2019 Annual Meeting.

Page 2



Network Profile: Meet Karen Smith

A Patient Partner who has spent
more than 20 years helping to bring
Chronic Pain to the discussion table.

Page 3

Strategy for Patient-Oriented Research



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A message from the Scientific Director

Network updates from Dr. Norman Buckley



The issue of chronic pain, and not just the opioid epidemic, has seen increased attention in both the media and from our own federal government – just one example being the Federal Minister of Health’s announcement of the Canadian Pain Task Force at the recent Canadian Pain Society Annual Scientific Meeting.

While this is very heartening recognition, the task of bringing chronic

pain out of the shadows and onto the policy making table has been a slow-going process, with the diligence and determination of many leading to this increase in momentum.

Congratulations to Network Patient Perspective Partners Jacques Laliberté and Linda Wilhelm on their appointments to the Canadian Pain Task Force, as well as Network Principal Applicants Manon Choinière and Maria Hudspith, and Network member Fiona Campbell. The task force will work with an External Advisory Panel which includes Christine Chambers and myself, to provide advice and information related to elements of the Task Force’s mandate.

The increased newsworthiness of chronic pain and added media attention has been a great way to carry us into Year Four of the Network. With some projects beginning to wrap up and moving into the publication stage, we begin to look towards strategic planning

and ensuring the continued viability of infrastructure put in place during the life of the Network. This was one of the main areas of discussion at the Steering committee meeting as part of the Chronic Pain Network’s 2019 Annual Meeting activities.

This year’s Annual Meeting was well attended, taking place in Toronto just ahead of the Canadian Pain Society’s Annual Scientific Meeting. Though committee members in our governance structure are used to meeting regularly through the magic of technology, there is something to be said for the productivity that face-to-face meetings can often foster.

Whether from the success of our own meetings or the awakening many Canadians are having to the issues facing those with chronic pain, the beginning of Year Four of the Network brings with it a sense of possibility.

Chronic Pain Network Annual Meeting

What happens when you give nine researchers five minutes and three slides to speak about their research projects and explain their impact? The answer is some pretty interesting presentations.

With more than 80 attendees, the Chronic Pain Network’s third Annual Meeting was held just prior to the Canadian Pain Society’s Annual Scientific Meeting. On April 2, in Toronto, the meeting saw Network Patient Perspective Partners, researchers, clinicians, as well as representatives from Health Canada and the Canadian Institutes for Health Research come together to discuss Network accomplishments and direction.

Following greetings and an update on the Strategy for Patient Oriented

Research (SPOR) from Nancy Mason MacLellan, Manager of Major Initiatives for CIHR-SPOR, Patient Perspective Partners Jacques Laliberté, Therese Lane and Linda Wilhelm led a session about continuing to grow the Network’s Patient Engagement efforts. The trio covered areas such as patient perspective partner participation in research, the development of resources and information sharing.

Julia Abelson, of McMaster University’s Department of Health Evidence and Impact, with her team, is performing an evaluation of the Network’s current Patient Engagement efforts. Julia provided an overview of the evaluation results to date and

[continued on page 4...](#)



Carley Ouellette (left) and Chitra Laloo (right) discuss the iCanCope project - an app to help young people manage persistent pain.

Network Profile: Meet Patient Perspective Partner Karen Smith

Working for more than 20 years to bring Chronic Pain to the discussion table



Karen Smith has been advocating for pain patients in Canada for more than a decade. She also sits on the Chronic Pain Networks Executive committee.

In 1986, Karen Smith was diagnosed with chronic pain and deemed unemployable for full-time or part-time work. Before that, Karen had worked for years in the field of public relations and held positions such as Director of Public Relations at St. Francis Xavier University and Director of Communications with the Metro Toronto branch of the Canadian Red Cross.

It was during her time at St. Francis Xavier that she developed serious back problems

that required a series of surgeries. Though she worked tirelessly with her medical team to get back to work at a job she loved, she was unable to.

Living in London, Ontario at the time of her diagnosis, Karen began volunteering at Information London, a community-based resource centre, handling media relations, promotions and publicity, as well as a number of other communications tasks. She also hosted a weekly cable television show called, "You Wanted to Know."

Volunteering gave Karen a sense of purpose. She went on to serve on the Board of Directors for the United Way of London and Middlesex and also spent time as the chair of their marketing committee.

Others soon took notice of Karen's altruistic nature, and she received volunteer recognition awards, not once, but twice for her work in the non-profit sector.

It was around this time that Karen decided to return to the east coast. Though she'd spent 26 years living in Ontario, she felt

Nova Scotia calling to her. "I never stopped loving it," she said, "the people, the ocean, my love of fishing."

In 2009, she packed up her things and moved to Halifax. Once there, she began working with Mary Lynch, then director of the Pain Management Unit at the Queen Elizabeth II Health Sciences Centre.

Karen continues to work diligently in the area of chronic pain advocacy. She currently serves as member of the Chronic Pain Network's Executive committee, providing a integral patient perspective, and, most recently, is the patient co-applicant, with Karen Davis and Daniel Buchman, on a successful grant application for CIHR, entitled "The Ethics of Pain Research, Management, and Policy: A Planning and Knowledge Exchange Meeting."

The intention of the meeting, at which Karen will be a speaker, is to develop a pain neuroethics and bioethics research network.

Canadian Pain Society Annual Scientific Meeting Recap

"Chronic pain is a real and significant health issue affecting the physical and mental health and well-being of millions of Canadians. Through the Canadian Pain Task Force, we hope to learn more about the impacts that chronic pain has on individuals and within specific communities, and to identify and share best practices that will improve the prevention and management of chronic pain in Canada," said Federal Minister of Health Ginette Petitpas Taylor. The Minister, who announced the formation of a National Pain Strategy Task Force at the Canadian Pain Society's Annual Scientific Meeting, was definitely a highlight of the week. The task force, which includes two CPN Patient Perspective Partners, as well as several Network Principal

Applicants and members, will work with an independent advisory panel to assess how chronic pain is currently addressed in Canada, identify best practices to prevent and manage chronic pain and disseminate findings to facilitate the implementation of these practices across Canada. Network members were engaged in many aspects of the meeting, displaying scientific posters as well as participating in symposia. Dawn Richards represented the Chronic Pain Network in a session entitled Time for a PEP talk: Building the evidence for Patient Engagement in Pain. Network members Carley Ouellette, Christine Chambers and Kathryn Birnie also participated in the panel, though they were representing other organizations.



Minister of Health Ginette Petitpas Taylor announces Canadian Pain Task Force at the Canadian Pain Society's Annual Scientific Meeting.

Chronic Pain Network Annual Meeting - Continued



Patient Perspective Partner and Network Steering Committee Co-Chair Linda Wilhelm contributes to the discussion at the Chronic Pain Network's 2019 Annual Meeting.

discussed next steps.

The general meeting concluded with a panel discussion on Network challenges and solutions that featured representatives from each committee.

Following the conclusion of the main meeting, several committees in the governance structure were also able to convene in-person. The Patient Oriented Research committee, the Patient Engagement committee, the Indigenous Health Research Advisory committee and the Knowledge Translation committee took advantage of the opportunity to hold a joint meeting. Members in attendance discussed congruencies amongst committees and possible areas of collaboration. In addition to the joint

meeting, the Registry Working Group was also able to meet face-to-face to discuss their latest efforts.

Research coordinators and site leads for the Network's Clinical Research Network reconvened later that evening for a dinner meeting where they were able to brainstorm ideas for potential projects.

The Network's Steering committee met bright and early on April 3, with guests from Health Canada and CIHR in attendance, to further discuss current Network initiatives and their viability beyond the life of the five-year SPOR grant.

Coming Events

Who: Ontario SPOR SUPPORT Unit
What: Virtual Masterclass
When: May 23 - August 1, 2019
September 9 - November 25, 2019
January 6 - March 3, 2020

A virtual masterclass on the conduct and use of patient-oriented research in Ontario's health system. All sessions will be conducted online using Webex. Runs for 11 weeks.

Visit <http://ossu.ca/events/upcoming-events/> for additional details.

Who: KT Canada
What: Scientific Meeting
When: May 30 - 31, 2019
Where: Winnipeg, Manitoba

Visit <https://ktcanada.org/event/kt-canada-scientific-meeting-2019> for additional details.

Who: Trillium Primary Health Care
What: 2019 Annual Research Day
When: June 5, 2019
Where: Toronto, Ontario

Visit <https://ossu.ca/2019/04/2019-trillium-primary-health-research-day> for additional details.

Chronic Pain Network National Coordinating Centre Contacts

Dr. Norman Buckley
Scientific Director
905-525-9140, Ext 22413
buckleyk@mcmaster.ca

Kimberly Begley
Managing Director
905-525-9140, Ext 22959
begleyk@mcmaster.ca

Megan Groves
Communications Coordinator
905-525-9140, Ext 27724
grovem2@mcmaster.ca

Donna Marfisi
Administrative Assistant
905-525-9140, Ext 27359
marfisi@mcmaster.ca

Mailing Address
MDCL-2101, McMaster University,
1280 Main Street West,
Hamilton, Ontario L8S 4K1

Email: cpn@mcmaster.ca
Website: cpn-rdc.ca