CPN
CHRONIC PAIN NETWORK

SUMMER
2017

NETWORK NEWSLETTER

A CHRONIC PAIN NETWORK UPDATE

INSIDE

Strategy for Patient-Oriented Research
SPOR
Putting Patients First

CIHR IRSC
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A message from the Scientific Director

Network updates from Dr. Norman Buckley

Sleep is known to help regulate mood, appetite and libido. Research also exists suggesting that aging adults perform better earlier in the morning. Knowing this, 7 a.m. AST seemed like an ideal time for the Chronic Pain Network to hold a plenary session at the Chronic Pain Society's (CPS) recent Annual Scientific Meeting.

The session provided updates from each committee in the Network's governance structure and looked ahead at sustainability beyond current SPOR funding. A special thank you to Patient Partners Mario Di Carlo, Dr. Richard Hovey, Jacques Laliberté and Carley Ouellette and Primary Applicants Drs. Ian Gilron, Margot Latimer, Patricia Poulin and Bonnie Stevens for presenting on behalf of their committees.

The Network was involved in many aspects of the CPS conference, attending the CPS Strategic Planning day prior to the meeting proper, supporting the Training & Mentoring social event and sponsoring the attendance of a number of trainees and patient partners.

At the Chronic Pain Network Coordinating Centre, a key activity this summer will be preparation for our Inaugural Annual Meeting. The Annual Meeting will take place on September 14, 2017, with a Welcome reception taking place the night before. Attendance is open to all Network members. We encourage those interested in attending to visit the Chronic Pain Network website (cpn-rdc.ca) for more information as details of the agenda are finalized.

The Inaugural Annual Meeting is just one of many exciting Network initiatives underway. With the recent launch of our website and creation of our Facebook and Twitter accounts, we are in the midst of creating a new social media strategy to both promote Network activities and increase general awareness of the issues facing those affected by chronic pain. Part of this strategy includes utilizing social media to promote a series of webinars hosted by the Network. Our Patient Engagement and Knowledge Translation committees have also employed webinars to provide mandated SPOR training to Patient Partners and leads of Network supported projects.

We hope that you will join us in the coming months to take part in a webinar and that you will attend our Annual Meeting, in September, as we reflect on the Network's accomplishments this first year and lay out the path ahead. ■

Coming Events

Who: Canadian Institute for the Relief of Pain and Disability
What: **Webinar:** Mindfulness for Cancer Survivors Living with Chronic Neuropathic Pain
When: August 8, 2017
2 p.m.

For more information, please visit www.cirpd.org

Who: Chronic Pain Network
What: **Webinar:** Your Involvement of Patients and Their Families in Your Research
When: September 7, 2017
1 - 2 p.m.

This webinar is part of the CPN Patient Engagement in Research Rounds series. For more information, please visit cpn-rdc.ca

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Who: Chronic Pain Network
What: Inaugural Annual Meeting
When: September 14, 2017
Where: Hamilton, Ontario

Save the date for the Chronic Pain Network's Inaugural Annual Meeting. More details will be available in the coming months.

Who: BC Children's Hospital, UBC, PainBC and the Arthritis Society
What: BC Provincial Pediatric Pain Management Symposium
When: September 22-24, 2017
Where: Vancouver, BC

For more information, please visit painbc.ca/pedspainbc2017

Who: Centre of Expertise in Chronic Pain ULaval, McGill, UdeM, UdeS (in collaboration with the Québec Pain Research Network)
What: 1st Provincial Symposium of the Table nationale des experts sur la douleur chronique (preceded by the annual retreat of the Québec Pain Research Network)
When: November 8-10, 2017
Where: Québec City, Québec

For more information, email rayonnement.ciussscn@ssss.gouv.qc.ca or visit colloquedouleurchronique.ca

Building Sustainable Partnerships with Patients and Families to Guide Pediatric Chronic Pain Research and Practice in Canada

Submitted by *Kathryn Birnie, PhD, Postdoctoral Fellow at the University of Toronto and the Hospital for Sick Children and Katherine Dib, Patient Partner from Halifax, Nova Scotia*

Chronic pain affects one in five children and teens. This means that approximately two million Canadian youth deal with pain that lasts months to years. Chronic pain can interfere with being active, sleeping, going to school and spending meaningful time with friends and family. Teens with chronic pain, as well as their families, are experts on what it's like to live with pain, but their voice is largely lacking when identifying priorities for future research. Dr. Jennifer Stinson and Dr. Kathryn Birnie are striving to address this through #PediatricPainPriorities, funded by a Canadian Institutes for Health Research (CIHR) Patient-Oriented Research Collaboration Grant.

The overall goal of the project is to improve pediatric pain research and clinical care by creating partnerships amongst youth with chronic pain, their families, healthcare providers and researchers. This means giving everyone a voice when deciding what we need to learn about pain, how we should learn it, and the best way to share what we learn with others.

We are doing this in three ways: (1) developing an online patient engagement registry of youth with chronic pain, and their families, who are interested in becoming research partners; (2) developing training materials in order for youth with chronic pain, their parents, healthcare providers, and researchers to learn how to effectively partner in research; and (3) identifying the top ten research priorities for treating pediatric pain in Canada.

Our project team includes patient, family, clinician and researcher representation from five specialized multidisciplinary pediatric pain clinics across Canada, including the Hospital for Sick Children in Toronto (Dr. Jennifer Stinson and Dr. Kathryn Birnie – project co-leads; Carley Ouellette and Kimberly Nelson), the IWK Health Centre in Halifax (Dr. Jill Chorney, Katherine and Mary Anne Dib), the Alberta Children's Hospital in Calgary (Dr. Melanie Noel and Matthew Dawson), the Saskatoon Health Region (Dr. Krista Baerg and Nikki Cooke), and the Children's Hospital of Eastern Ontario in Ottawa (Dr. Paula Forgeron and Dr. Christine Lamontagne). Additional team members include Dr. Patricia Poulin and collaboration with the Canadian Pain Coalition, the ILC Foundation, PainBC and the Ontario Ministry of Health and Long Term Care.

By enhancing pediatric patient and family engagement in pediatric chronic pain research, we believe that research will be more effective, efficient and meaningful to pediatric patients and families. This will increase the likelihood that research will be taken up in clinical care, lead to better patient outcomes, and avoid wasting research funds or effort in areas that are not of importance to patients. It also directly benefits patients and their families to be engaged in research, as it provides them with a deeper understanding of what we are learning about pediatric chronic pain. This reflects the underlying philosophy of the CIHR's Strategies for Patient Oriented Research.

Stay tuned in the coming months for updates about this project and opportunities to contribute your voice! ■

This project particularly involves network members including: Dr. Jennifer Stinson; Carley Ouellette; Dr. Melanie Noel; Dr. Krista Baerg; and Dr. Patricia Poulin, and also utilizes the Chronic Pain Network's pediatric clinical research sites.

UPCOMING WEBINARS

Webinars are an increasingly popular means of knowledge translation due in part to the convenience they offer users of being able to log on from anywhere in the world. Because of this, the Chronic Pain Network has been utilizing the webinar format to offer patient engagement training to Network members.

The Chronic Pain Network's Patient Engagement in Research Rounds webinar series sees Network members sharing their own experiences in patient oriented research, allowing others to benefit from their knowledge. The title of the series was inspired by the concept of hospital rounds, where case histories are shared for learning purposes.

This September, Network Primary Investigator Dr. Jennifer Stinson and Patient Partner Carley Ouellette will be presenting the third webinar in this series, entitled Your Involvement of Patients and Their Families in Your Research. We plan to offer them on a monthly basis. ■

Network profile: Carley Ouellette

Combining lived experience with clinical knowledge

Patient partner Carley Ouellette is co-chair of the Chronic Pain Network's Training & Mentoring committee, as well as a member of the Pediatric Registry Working Group.

Patients as equal partners - *that* is what first drew Carley Ouellette to the Chronic Pain Network; it was an opportunity to collaborate with leading researchers, clinicians and stakeholders, in a meaningful way, to address chronic pain in Canada.

Carley has a vested interest in chronic pain; she spent many of her adolescent years at Toronto's Hospital for Sick Children as a patient of the Chronic Pain Clinic. It was there that she began participating in pediatric chronic pain research, with Dr. Jennifer Stinson, as a patient panelist and knowledge user.

"The silver-lining of my pain experience has been the opportunity to work with such incredible pain leaders," says Carley. She credits work alongside leaders in pain research with helping to shape who she is today. "[The doctors] really had an impact on my life for the better," she adds.

Joining the Chronic Pain Network as a Patient Partner, Carley took on the role of co-chair of the Training & Mentoring committee. With the committee, Carley assists in seeking out opportunities for high quality, innovative patient-oriented research training within the Network; and creating and cultivating linkages between trainees and mentors, and between clinicians, consumers and researchers.

As a recent graduate of Western University's nursing program, the Training & Mentoring committee is a perfect fit for Carley. She is able to provide a patient perspective as well as explore her interest in the Network from a professional standpoint.

This fall, Carley will be starting classes at McMaster University, where she is enrolled in the graduate nursing program. After that, she aspires to complete a PhD in pain-related research.

Carley's involvement with the Chronic Pain Network has created opportunity to foster growth, both personally and professionally, and reflect on her pain journey. "To me, patient engagement means that all patients, families, healthcare providers, policy makers, researchers and advocacy bodies are equal contributors in identifying health priorities and areas of importance," she explains. "All voices are heard and appreciated."

This September, Carley will be helping to further emphasize the importance of patient engagement when she delivers a webinar with Dr. Jennifer Stinson. The webinar is part of a series that has members sharing their own experiences in patient oriented research, allowing others to benefit from their knowledge. They are intended to help researchers and Patient Partners better identify meaningful opportunities to collaborate throughout the research process.

"I think patient engagement allows patients to be field experts and lend their insights as to what is important and valued," Carley says. While doctors and researchers possess a wealth of clinical knowledge, there is no question that pain patients possess very valuable lived experience. "Both [researchers and patients] need to be more widely accepted as [having] complementary expertise," she says. "I think that is why patient engagement is so crucial in developing a national pain strategy and why the development of SPOR and the Chronic Pain Network is such a ground-breaking step." ■

Chronic Pain Network

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