

# NETWORK NEWSLETTER

A CHRONIC PAIN NETWORK UPDATE



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# A message from the Scientific Director

## Network updates from Dr. Norman Buckley



This summer, the Chronic Pain Network received an invitation to attend the 2018 Opioid Symposium in Toronto, on September fifth and sixth.

It featured panel discussions on a wide array of subjects, and the diversity of attendees was impressive. The CPN had the opportunity to display information at a booth, as well as participate in panel discussions.

One panel discussion, which took place on day one of the Symposium, was organized by Pain BC and featured CPN patient partners Linda Wilhelm and Billie Jo Bogden. The session was entitled “Unintended Consequences: The Impact

of the Opioid Response on People Living with Pain.”

Network members Lynn Cooper, Dawn Richards and Manon Chionière also participated in a panel discussion about the barriers of treating chronic pain.

Not to be left out, I was one of three members on a panel presentation, moderated by the Canadian Pain Society’s Fiona Campbell, on innovative treatment for chronic pain. Other members of the panel included UHN patient partner Paul Ross; Dr. Hance Clarke, Director of the Transitional Pain Program for the University Health Network; and Dr. Aliza Weinrib, a Clinical Psychologist with Transitional Pain Services at Toronto General Hospital. You can find links to all of the live webcasts here: <https://www.meetview.com/opioidsympo2018br2en/index.php?enter>

Also in September was the Canadian Academy of Health Science’s Forum and Annual General Meeting. Taking place in Vancouver, BC, there was once again a strong Network presence, both as panelists and attendees.

Network member Kathryn Birnie and patient perspective partner Carley Ouellette co-presented on co-producing

with patients and their families to move the agenda forward. Bonnie Stevens spoke on Knowledge translation and ‘using the data’ and I gave a talk about the progress towards a Canadian Pain Strategy.

The coming months will no doubt be just as busy for the Network. In November, we will be presenting posters at the SPOR Summit in Ottawa.

Even though it is sometimes hard to tell if we are coming or going, we look forward to each and every opportunity to educate others about the Network and its work. Every presentation, panel, interview, poster or lecture is used as a soapbox to ultimately further the mission of the CPN - to reduce pain and improve function, participation and quality of life for those affected, while alleviating the economic burden of pain over one’s lifespan.

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## Experts with Lived Experience: Dr. Dave Walton on patients as true partners

What is the value of partnering a patient perspective partner with a researcher?

For a researcher, the experience can provide a great deal of reassurance, or at least it does in the opinion of Dr. Dave Walton, a co-applicant with the Chronic Pain Network, as well as the lead on a Network-funded project.

His partnership with CPN patient perspective partner Curtis May provides him with the unique advantage of being able to consult someone with lived experience, who can confirm the value

of the work - from both the perspective of a patient with specific informational needs, as well as a technical perspective because of Curtis’s background in science.

Dave’s project, termed SYMBIOME, is a longitudinal databanking initiative in which a rich dataset is collected from people, starting within days to a few weeks of a non-catastrophic traumatic event (i.e. car crashes, work injuries, sports injuries, etc.) and following them for up to a year.

Data is collected at specific points - 1, 2, 3, 6 and 12 months after the event. Biological materials, such as blood, saliva, hair and stool; psychological variables, such as distress, pain, disability and expectations; and social data, such as education, income, living arrangements, work status and medicolegal involvement are providing invaluable information that will allow for conducting of advanced biopsychosocial analyses of the process and potential mechanisms of recovery or chronicity.

# Network Profile: Patients as Partners

## Curtis May



*Patient Perspective Partner Curtis May and Primary Investigator Dave Walton, at the Chronic Pain Network's 2018 Annual Meeting, discuss their experiences working together to enhance patient engagement on a Network project.*

It was at the age of 16, while out for a run one day, that Curtis May first felt a heaviness in his foot that turned out to be the onset of chronic pain.

The feeling stopped him in his tracks. When he attempted to continue, the feeling spread throughout his leg. "For two years afterwards, the heaviness transformed into a deep, intense pain, and gradually worsened to cover the entire right side of my body," said Curtis.

Over the next five years, Curtis would see more than twenty-five health care professionals for his chronic pain, ranging from seven physiotherapists and three counsellors, to many specialized medical and naturopathic doctors. It was ultimately through a yoga teacher, who taught Curtis about mindfulness, and working with his final physiotherapist that Curtis was able to find relief and management for his pain.

Curtis, who grew up on a farm in Richmond, British Columbia, graduated from the University of British Columbia

(UBC) Kinesiology programme, in 2014. "I wanted to be in a program where I could potentially learn more about my pain condition. However, I realized that little around chronic pain was known," said Curtis.

After graduating, uncertain of his next steps, Curtis decided to follow his gut instinct and continue to pursue his interest in chronic pain - which led him to the CHANGEpain Clinic. A community-based clinic, led by an interdisciplinary team specializing in pain, it was at the CHANGEpain Clinic that Curtis finally started to learn the latest around chronic pain.

"I experienced a fun, expanding, innovative medical team that was unafraid to critique their own practice and pursue challenging endeavours, such as a research program I was involved with," said Curtis. The positive encounter sculpted the vision Curtis had for his future and inspired him to enroll in medical school at UBC in 2016.

Curtis soon began volunteering with Pain BC that Curtis, through which he heard about the Chronic Pain Network. "They asked me if I'd like to join, and I said yes."

Within the Network, Curtis is part of the Pain Registry committee, its Adult subcommittee, and he also works as a patient perspective partner on a Network-funded research project with Dr. Dave Walton. The two co-presented at the CPN's 2018 Annual Meeting, in Hamilton.

"Curtis was able to offer some alternative views on how the results drawn from our data could be interpreted from a more person-centric perspective," said Dave when touching upon the benefits of having a patient perspective partner. Curtis was even included as

a collaborator on Dave's last grant application to CIHR.

It is the emphasis on the equal importance of the experiences and perspective of patients in research that, in part, interested Curtis in the Network. "Outcomes that directly affect patients should have past and/or present patients, with and without research expertise, involved - from research funding to knowledge translation," he said.

The idea of a network connecting experts across the country, including patient partners, also appealed to Curtis. "Even a trans-disciplinary chronic pain care practice, involving a few dozen experts within a single city, is siloed if we don't build ongoing connections with others, in other cities or provinces, to know what others are doing," he said.

Going forward, Curtis would like to see the continued involvement of patients in research - as lived experience experts rather than patients - using their unique perspective to advance research being done. "I'd also like to see some permanent infrastructure that, even without CPN funding, keeps connecting new patient perspective partners with existing and new pain scientist partners. With this, I hope there is a concomitant cultural shift in general to see the value of including more patients in all fields of research."

## Continued: Experts with Lived Experience



*Patient Perspective Partner Curtis May and Primary Investigator Dave Walton, at the Chronic Pain Network's 2018 Annual Meeting, discuss their experiences working together to enhance patient engagement on a Network project.*

"With the support of the CPN, we have completed the first phase of data collection on 112 participants, through up to 12 months, and are now working on getting our data assayed and analysed before embarking on phase two," said Dave.

The addition of a patient partner was a new experience for Dave. "There was that sense of trepidation, at not knowing how, or how to find out, the best way to involve a patient as a partner," he said.

So how did they overcome hesitations on both sides? They held their first few meetings intentionally at a slower pace.

"We spent time getting to know one another and establishing some

shared values and expectations," Dave explained. "I was concerned that Curtis would either be disinterested in what we were doing or feel overwhelmed." This approach helped tremendously.

"Seeing the value and having that very unique perspective involved in my research program has led me to a position where I will continue to actively seek patient partners in my ongoing research and teaching projects. It was also personally very exciting for me to include Curtis as a collaborator on my last CIHR grant, which, while not successful, was reviewed generally well. I felt Curtis's input in the most relevant areas really strengthened the final product."

## Coming Events

**Who:** CIHR Institute of Musculoskeletal Health & Arthritis  
**What:** Webinar: Research Priorities in Pain  
**When:** October 3, 2018  
12 noon EST  
<http://bit.ly/PainPriorities>

**Who:** Chronic Pain Network  
**What:** 2019 Annual Meeting  
**When:** April 2, 2019  
**Where:** Toronto, Ontario  
Details to come.

**Who:** Canadian Pain Society  
**What:** 2019 Annual Scientific Meeting  
**When:** April 2-5, 2019  
**Where:** Toronto, Ontario

Visit <http://canadianpainsociety.ca> for additional details.

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