

# NETWORK NEWSLETTER

A CHRONIC PAIN NETWORK UPDATE



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# A message from the Scientific Director

## Network updates from Dr. Norman Buckley



The first quarter of the calendar year is the final quarter of our third year of operation for reporting purposes- time is flying as we enter the fourth year of the Network. A new initiative arising from last spring's Annual Meeting was the recent Canadian Consensus Conference on Biomarkers in Pain Research. Held on February 5th at McMaster University, the conference came about as a result of conversation amongst researchers at the 2018 Annual Meeting.

The goals for the day included setting an overview of use of biomarkers in pain research, and learning about the logistics of biobanking from two large consortia currently underway- The Canadian Longitudinal Study of Aging (CLSA) and the Clinical Research laboratory and Biobank (CRLB). Presenters included Network members Luda Diatchenko, Nader Ghasemlou, Karen Davis and Postdoctoral fellow Jennifer Fazzari, in addition to Cynthia Balion and Parminder Raina from CLSA, Matthew McQueen and Shana Lamers from CRLB, Laura Stone of McGill University and Brian Meshkin of Profound Ventures and Benefit Health in California. Discussion focused on making the most of existing registries, databases and biobanks while developing a strategy for establishing a Canadian Pain Research focused biobank. More to come about this.

The Network's third Annual Meeting is also fast approaching. This year we will meet on April 2, in conjunction with the Canadian Pain Society's Annual

Scientific Meeting, taking place in Toronto, Ontario (April 2-5).

Our meeting will see the return of the well-received project blitz session, during which research projects use up to three slides to provide a quick summary of their work and answer questions from the audience. The meeting will also feature a panel presentation from Network participants, in addition to a poster session and update from CIHR.

Many CPN participants will also be visible at CPS, giving opening remarks, participating in panel presentations and presenting posters. The Network will also be presenting two of its own posters.

We look forward to seeing everyone in Toronto for what we know will be an informative and productive meeting. We hope that information will be forthcoming which will allow us to enter into discussions about renewal of the CPN.

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## Pain and Mental Health in Youth (PATH) Study

By: Melanie Noel, PhD, RPsych, Department of Psychology, University of Calgary; Janice Sumpton, RPh, BScPhm; and Allison McPeak, BSc, MPH

Chronic pain in children and adolescents is a rising public health problem, affecting approximately 25% of Canadian youth, and costing society more than childhood asthma and obesity. It has been referred to as a "modern public health disaster". However, pediatric chronic pain does not exist in a vacuum. In fact, we have discovered that many youth with chronic pain also have internalizing mental health issues, such as anxiety, depression, and post-traumatic stress disorder (PTSD). Youth who have both chronic pain and mental health issues are less likely to respond to conventional pain treatments (which

often do not address co-occurring mental health issues). What is more, we recently found that 50% of their parents have chronic pain and many have mental health issues themselves, which play a critical role in influencing their children's pain and functioning. What remains a mystery, is why chronic pain and mental health issues co-occur at such high rates and the ever-elusive chicken-egg question remains: Do mental health issues precede or follow the pain problem? Moreover, how do chronic pain and mental health issues 'get under the skin' to influence the next generation of offspring? And how can we better help

children and parents who have these co-occurring issues in treatment?

We are working to answer these questions with project funding from the Chronic Pain Network (CPN) and in close collaboration with patient partner Janice Sumpton, an individual who has lives with pain, has a child with pain, and who works clinically with youth who have chronic pain. In the Pain and Mental Health in Youth (PATH) Study, conducted at the Alberta Children's Hospital, SickKids, and the IWK Health Centre, we are assessing mental health and chronic pain, as well as a variety of proposed mechanisms that may account for these co-

# Network Profile: Meet Isabel Jordan

Parent, feminist and patient advocate



*While Isabel Jordan has stepped down from her role with the Chronic Pain Network, she is still active in many other initiatives, such as the Rare Disease Foundation, advocating for patient rights.*

“Patient engagement, to me, means respecting the patient voice as a colleague. Knowing that there is equal value in the knowledge brought, by patients and families, to that brought by researchers and clinicians,” says Isabel Jordan. “It means valuing patients for the work they do, as if they are real partners in work.”

Born in Lisbon, Portugal, Isabel moved to Ottawa, with her family, when she was five years old. She stayed in Ontario through university before moving to British Columbia after visiting the province with her boyfriend, who would go on to become her husband.

A former Patient Perspective Partner with the Chronic Pain Network, who recently stepped down from the Network’s Knowledge Translation committee, Isabel is well-known in

the world of patient advocacy. In 2018, Isabel was the recipient of the BC Patient Safety & Quality Council’s Quality Award for Leadership in Advancing the Patient Voice.

Isabel first became aware of the Chronic Pain Network through Maria Hudspith, of Pain BC. “She knew of my history with my son,” says Isabel. Though she had lived with chronic pain herself, in the form of migraines, since the age of nine, it was the birth of her son, and his subsequent health issues, that spurred Isabel into action and saw her take on the role of advocate.

“At about a year and a half, we knew that there was something going on with him that was different from other kids,” says Isabel. “We spent three years alternately being told we were worried about nothing and being bounced from doctor to doctor, test

to test, trying to figure out what was going on.”

The healthcare system can often be confusing and frustrating for those trying to navigate it. “The uncertainty and lack of prognosis weighs on us, as parents, like a lodestone around our necks. Not knowing how to help our son is the most miserable feeling in the world. The lack of supports for the patient impacts the whole family. The whole family experiences trauma, mental health effects and can spiral down a path of fear and worry. Society needs to support the patient; society needs to support the family,” says Isabel.

It wasn’t until 2017 that Isabel’s son finally received a diagnosis: Ehlers Danlos Syndrome, hypermobility type. “[It’s] a diagnosis that doesn’t exactly fit, but it come close,” she says.

Through her strong social media presence and participation in conferences across the continent, Isabel has established herself as a force to be reckoned with in the world of patient advocacy. “People with chronic pain and illness can’t will or wish it away,” she says. “They can’t power through; it will literally make them worse.”

When asked what drew her to the Chronic Pain Network, Isabel replied, “I want to be the voice of the paediatric community; not just the patient, but their siblings. There are far reaching familial effects.” Thank you, Isabel, for being that voice in our Network for the past three years. We are so proud to have had you as part of our team and wish you all the best in the future.

## Continued: Pain and Mental Health in Youth (PATH) Study



Melanie Noel recently received the Ulf Lindblom Young Investigator Award for Clinical Science, from the International Association for the Study of Pain, at the 17th World Congress on Pain.

occurring issues, in youth and their parents who are referred to the chronic pain clinics. These include cognitive (attention, memory and interpretation biases), behavioral (responses to pain), physiological (sleep disturbances), and neurobiological (genetics, epigenetics, brain structure and function) factors. We have also recently partnered with our basic science colleagues to more clearly identify the temporality of these relationships and the underlying neurobiological mechanisms through translational studies.

With the support of the CPN, as well as our national and international collaborators and partners, we have made excellent progress in meeting our goals. At the Alberta Children's

Hospital, we have successfully recruited 109 youth with chronic pain and their parents. Recruitment at SickKids has begun and will launch at the IWK Health Centre early this year.

Rates of pediatric chronic pain continue to rise, and we are increasingly realizing that mental health is a major, under-addressed concern for many of these youth and their parents. Through the PATH study, and with the combined efforts of an interdisciplinary group of clinical and basic scientists, patient partners, dedicated trainees, and the CPN, we hope to shed light on why chronic pain and mental health issues co-occur in families and how we can prevent this problem from affecting individuals across generations.

## Coming Events

**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.

**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.

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