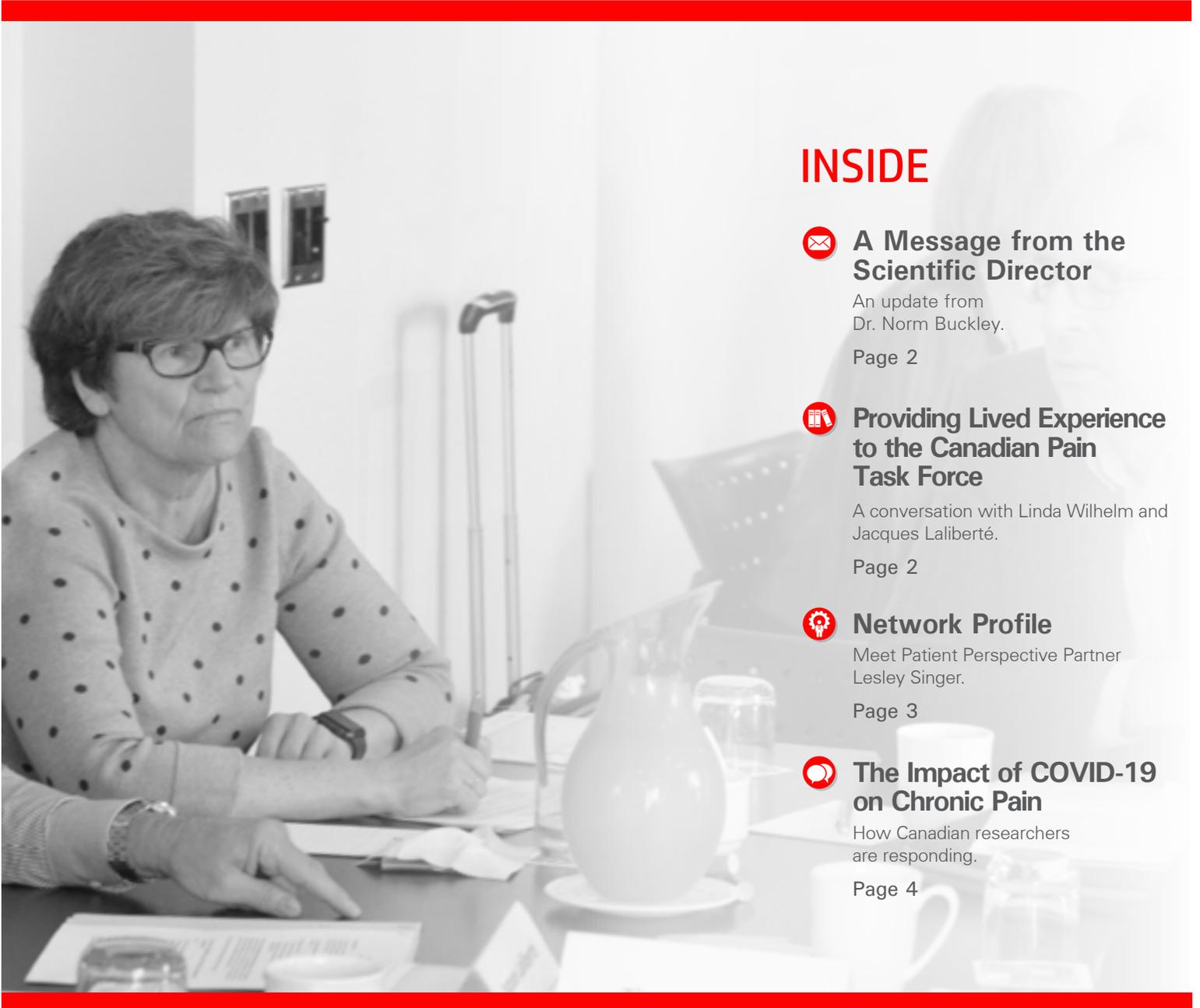


# NETWORK NEWSLETTER

A CHRONIC PAIN NETWORK UPDATE



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# A message from the Scientific Director

## Network updates from Dr. Norman Buckley



Though time may be a universal constant, our own frame of mind seems to be the biggest determining factor in how quickly a minute, a day or even a month will pass. It is hard

to believe that the Network is already well into its fifth year of operating. Many of the projects included in our initial application to CIHR have been completed, or are in the process of winding down, and data is being prepared for release.

July saw the publication of the Patient Engagement committee's paper "Guidance on authorship with and acknowledgment of patient partners in patient-oriented research." Though patient engagement itself is a concept that has been present for more than a decade, determining how and when to recognize that involvement has been an area in need of improvement for just as long.

The Network is in the final stages of adding new clinical research network

sites in Quebec. Once all contracts have been signed, this will bring the total number of sites within the CRN to 15 locations across Canada.

Our Patient EngagEment in Research (PEER) webinar series has seen interest from around the world. The webinars are aimed towards trainees in pain research, but all are welcome. Take a look at our website to learn more about the webinar series or to register. Recordings of past webinars can also be viewed (<http://cpn-rdc.ca/PEER>).

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## Providing lived experience to the Canadian Pain Task Force:

### A conversation with Linda Wilhelm and Jacques Laliberté

"An honour and a privilege." That is how Linda Wilhelm, a Patient Perspective Partner with the Chronic Pain Network and co-Chair of the CPN Steering Committee, describes what it's like to sit on the Canadian Pain Task Force representing people with lived experience in chronic pain. "But it's also a tremendous responsibility that weighs heavily at times," she adds. Linda is one of three lived experience voices on the Task Force. Her sentiments are echoed by Jacques Laliberté, another patient voice on the Task Force and co-chair of the CPN Executive committee.

"We are there, principally, to represent the patient views," said Jacques, "but each one of us also brings our own life experiences - private and professional." Those experiences help create discussion and influence decisions and strategies within the Task Force.

"There have been times when it is extremely difficult to relive some of my own traumatic pain experiences and to hear about the huge challenges facing people living with chronic pain when it comes to accessing the care they need while trying to cope with the ways pain impacts every aspect of their lives," said Linda. "In every meeting over the past year, I have done my best to educate my Task Force colleagues on what life is like for Canadians living with pain, speaking frankly about our daily struggles to live life with some quality while experiencing the challenges, stigma and guilt we face when we are unable to navigate the system."

Though the work of the Task Force can be difficult in many ways, it is also inspiring. "I am particularly proud to see the high level of positive engagement each one of the Task

Force members, including our Advisory Board and the Secretariat, have demonstrated so far," said Jacques.

"The Task Force has given a national voice to patients living with chronic pain and a platform to be heard. We have already seen impacts around the destigmatization on opioid prescribing and the changes to the regulations on telemedicine to assist patients during the COVID-19 pandemic. The Task Force has brought legitimacy to the voices calling for improved and expanded treatments for chronic pain," added Linda.

The inclusion of individuals with lived experience itself is also inspiring. "This is the first time, in my 16 years as a patient advocate, that I see this level of involvement from the government. I see it within the Task Force, as well as through research guidelines from the

# Network Profile: Patients as Partners

## Meet Lesley Singer

“Patient engagement means involving patients in all aspects, and at all levels, of chronic pain and its management. It means working alongside each other and making decisions together to make pain management better for others,” said Lesley Singer, Patient Perspective Partner with the Chronic Pain Network and co-chair of its Knowledge Translation committee, as well as its Training and Mentoring committee. “Patient engagement is so important because we are the ones living with the disease, and we are, collectively, the experts.”

“I think, if people could actually feel my pain for a minute, they would be surprised that it is as real as it is. I think people would also be surprised that you can still function, even though you might have a lot of pain.”

Functioning through pain is a concept Lesley is intimately familiar with. A physiotherapist by trade, Lesley grew up in Montreal, the youngest of six children. She went on to have four children of her own, but, following complications from a heart abnormality, her youngest child died at only seven months old. It was this event that ultimately led her back to school and her degree in physiotherapy.

“Life was tough when all the students were going out to pub crawls after working on group projects,” she said. “I had to go home and be a wife and mother.”

In 1999, she was diagnosed with a meningioma on her brain stem and had a craniotomy in 2000, followed by radiation. She developed chronic pain in 2002 and was then diagnosed with trigeminal neuralgia, affecting all three branches and beginning her longterm relationship with neuropathic facial pain.



Lesley Singer is the co-Chair of the Chronic Pain Network’s Knowledge Translation committee, as well as its Training and Mentoring committee. .

For the next 15 years, Lesley would undergo a series of medical and psychosocial interventions, including the implantation of a motor cortex stimulator, to help treat her pain. “It’s been a tough, but very educational, journey for me,” she said. This journey also led her to McGill University, where she is currently a course coordinator with the School of Physical and Occupational Therapy’s Graduate Certificate in Chronic Pain Management program.

It was through a casual conversation with a coworker that Lesley first learned of the Chronic Pain Network. “He knew I loved being the patient who taught about pain through the eyes of the patient and thought I would have something of value to offer the Network by having three separate perspectives: patient, educator and clinician,” she said. “I applied for a place in the Network and have been involved since 2016.”

From providing a much valued lived experience perspective on research projects to rating papers available through the CPN Pain+ platform, Lesley’s role within the Network has grown and evolved over the years. “I’ve co-authored papers, led Knowledge Translation initiatives and presented at webinars.” Even more exciting, according to Lesley, is how much she has learned.

“The years have flown by. It’s taken me until now to better grasp what we can do with a network like the CPN,” said Lesley. “I can only imagine what we can achieve if we continue.”

Lesley will be co-presenting the Chronic Pain Network’s next webinar in the Patient EngagEment in Research (PEER) series. The webinar will take place October 22, 2020.

*To learn more, visit: [cpn-rdc.ca/PEER](http://cpn-rdc.ca/PEER)*

Canadian Institutes for Health Research and initiatives like the Chronic Pain Network.” said Jacques.

“There is improved communication among the Federal, provincial and municipal jurisdictions about the prevalence and impact of chronic pain and its cost to society. Change won’t happen overnight, but with education and knowledge will come results and improved treatments and outcomes,” said Linda.

“For people living with chronic pain, I’d

like them to know that they have been heard. Action is taking place now. There are areas of improvement throughout Canada,” said Jacques. “The future is brighter, but don’t expect short term miracles. Lasting changes takes time.”

*You can learn more about the Canadian Pain Task Force and its work by visiting:*

<https://www.canada.ca/en/health-canada/corporate/about-health-canada/public-engagement/external-advisory-bodies/canadian-pain-task-force.html>

## The impact of COVID-19 on chronic pain

### How Canadian researchers are responding

For many scientific researchers, COVID-19 meant the abrupt cessation of work on projects. Recruitment for studies was put on hold, and lab work, if still permitted to continue, was severely diminished. However, for some researchers, a unique opportunity presented itself.

Network Principal Applicant Manon Choinière and her team began working on an online survey on the impacts of the COVID-19 pandemic on Canadians living with chronic pain. The results of this study are now awaiting publication.

In Manitoba, Network Co-Applicant Renee El-Gabalawy began an online survey-based study to learn more about what factors may predict or

prevent post-traumatic stress and growth following the pandemic so that we are better equipped to meet needs if faced with a similar situation in the future.

Network Principal Applicant Jennifer Stinson, Co-Applicant Melanie Noel and Kathryn Birnie also began work on a study to examine stepped care solutions to reduce the impact of the COVID-19 pandemic on mental health, substance use, and functioning in youth living with chronic pain.

Visit the Chronic Pain Network’s COVID-19 page ([cpn-rdc.ca/COVID-19](http://cpn-rdc.ca/COVID-19)) to learn more about COVID-19-related research currently in the works. The page also provides links to COVID-19 resources from the government of Canada.

## Coming Events

**Who:** Canadian Journal of Pain  
**What:** Qualitative Research and Pain: Current Controversies and Future Directions - A Special Issue Webinar  
**When:** Friday, October 2, 2020  
**Time:** 2 - 3:30 PM ET  
**Where:** Online

To register or learn more, visit: [qualresearchpain.eventbrite.ca](http://qualresearchpain.eventbrite.ca)

**Who:** Chronic Pain Network  
**What:** Patient EngagEment in Research (PEER) Webinar Series  
**When:** October 22, 2020  
**Time:** 2 PM ET  
**Where:** Online

The fourth webinar in the PEER series will be hosted by Nader Ghasemlou and Lesley Singer. These webinars are geared towards trainees, but all are welcome to attend.

**Visit:** [cpn-rdc.ca/PEER-Registration](http://cpn-rdc.ca/PEER-Registration) to register today.

**Who:** IASP  
**What:** IASP World Congress  
**When:** June 27 - July 1, 2021  
**Where:** Amsterdam

For additional details visit: <https://www.iaspworldcongress.org/attend/registration-rates>

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