

NETWORK NEWSLETTER

A CHRONIC PAIN NETWORK UPDATE

INSIDE



A message from the Scientific Director

An update from
Dr. Norm Buckley

Page 2



The 2017 inaugural annual meeting

Highlights from our annual meeting,
held in Hamilton

Page 3



A Patient Perspective:

Patient Partner Rebecca Lee explains
why pain matters

Page 4

Strategy for Patient-Oriented Research

SPOR

Putting Patients First 



CIHR IRSC

Canadian Institutes of Health Research
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A message from the Scientific Director

Network updates from Dr. Norman Buckley



Many thanks to the Agenda Planning committee for a productive and enjoyable day and a half at our first Annual Meeting. The committee, made up of Patient Partners, Principal Applicants and Primary Investigators, first met in May, with the aim of structuring the meeting to provide face-to-face (in some cases for the first time) networking opportunities and information exchange - ensuring that issues relevant to both Patient Partners and researchers were covered. We wanted to maximize opportunities for dialogue amongst CPN participants, leading to further collaboration amongst stakeholders.

While generally well received, the Annual Meeting did highlight specific challenges that can arise when working in partnership with patients - chronic pain patients in particular. Travel can be exhausting, even for those without health issues. For those living with chronic pain, even the prospect of a quick car ride can be intimidating. Going forward we will continue to work with our Patient Partners to provide meaningful avenues to contribute and advance the discussion, while ensuring they leave mentally and physically invigorated. With both time constraints and financial constraints to consider, this proves to be quite a challenge. However, it is one

we strive to answer and an area we are dedicated to improving in.

Representatives from CIHR were impressed by our group, its accomplishments and energy. It was good to have the first (almost!) full representation of the Clinical Research Network (CRN) in a face-to-face sit down on Wednesday afternoon, and the evening reception was a good chance for networking.

Planning has already begun for our next meeting, likely to be held in late April or May. We are still working with the CPS executive and board to see if there is an opportunity to meld the meetings, but this may take time to put in place, as the CPS meetings are planned years in advance. We do have many congruent goals and common members.

Our Patient Oriented Research (POR) committee is now working through the process of mid-course review of projects underway and releasing funds as we do so. This is an opportunity to highlight opportunities for further patient engagement and link with Knowledge Translation activities as we check on milestones for each project.

We are working to establish the Network as a good source of collaborations with other groups, ensuring that pain research is well integrated into other networks.

Most of all, we realize that the Network funding is really only a beginning; we aim to have our members use the funds as seed-type grants to support larger funding applications and also demonstrate the value of the CRN and other network activities to support national pain research.

Thanks for your interest. ■

Coming Events

Who: Chronic Pain Network
What: Webinar: PAIN+CPN Tour
When: January 4, 2018, 2 p.m. EST
A virtual tour, led by Dr. Alfonso Iorio, that will allow you to explore and experience the new PAIN+CPN site and all its new features.

Who: Canadian Institute for the Relief of Pain and Disability
What: Webinar: Workplace Safety and Prescribed Medications in Chronic Pain Patients
When: March 8, 2018, 2 p.m. EST
Presented by Dr. Paul Farnan. For more information or to register, visit cirpd.org.

Who: Chronic Pain Network
What: Annual Meeting
When: April 24, 2018
Where: Hamilton, Ontario
Details to come.

Who: Canadian Pain Society
What: Annual Scientific Meeting
When: May 22-25, 2018
Where: Montreal, Quebec
Visit canadianpainsociety.ca for more information or to register.

Highlights from the 2017 Inaugural Annual Meeting

A quick recap and takeaways from September's meeting in Hamilton



Representatives from CPN committees took part in a panel session, answering questions about their involvement with the Network.

When Mario Di Carlo was only a year old, he was stricken with polio - a disease that left him with significant physical weaknesses. Over the years, he has been able to use his experiences to provide a unique perspective as a champion for causes close to his heart. His role as a Patient Partner with the CPN is just one example of how he has done this. On September 14, 2017, Mario shared his story with those in attendance at the Chronic Pain Network's (CPN) inaugural Annual Meeting.

From Squamish, British Columbia to Halifax, Nova Scotia, more than 100 CPN participants from near and far came together in Hamilton, Ontario to discuss the CPN's achievements, challenges and goals for the future.

Manager of Major Initiatives for the Canadian Institutes of Health Research (CIHR), Nancy Mason MacLellan discussed the guiding principles of SPOR and patient engagement. She also addressed what it

means to "develop capacity," explaining that the SPOR movement isn't just about training researchers. SPOR initiatives seek to ensure that everyone, at all levels of the research process, understand what patient engagement means and ensure patients are an integrated into the research team at the beginning of the project.

Meaningful integration of patients was also a theme discussed during a panel presentation that followed the keynote speakers. CPN committee representatives discussed their own experiences with patient engagement, as well as some of the challenges their committees faced when determining how to ensure patient participation was not merely tokenism.

The morning concluded with a poster session that served as an opportunity to for attendees to interact with project leads and learn more information about Network-affiliated projects. It also allowed for Network committees to provide an

overview of their own roles and most recent achievements.

Following lunch, attendees broke into huddles to allow for networking and the discussion of key topics influencing the direction of the Network. Groups tackled ideas ranging from new avenues of pain research, such as medicinal marijuana and new technologies, to how to address and improve representation of vulnerable populations in research.

The Annual Meeting concluded with presentations from Associate Director of the Québec Pain Research Network, Nicolas Beaudet; Assistant Director of CIHR's Institute of Gender and Health, Krystle van Hoof; and President and CEO of The Arthritis Society, Janet Yale. ■

CLINICAL RESEARCH NETWORK



The Chronic Pain Network's Annual Meeting was preceded by a half-day meeting of the Clinical Research Network (CRN), one of the 'infrastructure' elements of the Network. Local Primary Investigators and Research Coordinators from the 10 sites across the country attended for a presentation by Dr. Ralph Meyer,

Vice President of the Juravinski Cancer Centre, in Hamilton. Dr. Meyer spoke of his experience with multi-centre networks in cancer clinical trials research. An overview of several projects utilizing the CRN were presented for discussion, to begin the process of getting the network running. ■

A Patient Perspective: Why Chronic Pain Matters

A submission from Rebecca Lee



Patient partner Rebecca Lee is an active member of the Patient Engagement committee. Rebecca also serves as a spokesperson for The Lions Foundation of Canada Dog Guides.

It wasn't my own pain that broke me, but the sound of someone else's. The hospital curtain was no barrier to the woman's anguished sobbing. I wanted to reach out from my own hospital bed to reassure her that everything would be ok. How could I though, when all I had to offer was empty platitudes for comfort? I had no miracle treatment - no one-pill wonder to give her back the life she'd lost to pain. The distance between dreams and reality had never seemed so vast. So we lay there, side-by-side, in unspoken communion of all the vagaries of chronic pain. Passing ships in the night, I never saw that woman again, but her desperate need for relief stayed with me.

Suddenly, I was seeing chronic pain everywhere – at the pharmacy, at the physiotherapist's, and spanning across all age groups and genders. The one

commonality was that the confession of chronic pain was always quietly worded, almost shamefully disclosed. I couldn't wrap my head around why chronic pain was somehow less legitimate than other conditions when it wasn't merely a symptom, but a disease in its own right. Sure, it isn't lethal; instead, its more insidious, Sisyphean nature slowly wears away at the soul.

Empathy is the bedrock of humanity, and yet it's as rare as holding a diamond in your hand. In all my years in and out of doctors' offices, I have yet to become inured to the suffering of others. And I'm glad. It's what sets me marching ever-forward against the rising tide of chronic pain and the powerful misconceptions that bar the way to timely treatment. When I say treatment, I don't just mean healing in the medical sense. I also mean healing in the way that happens when a network of people evade the doubting Thomas trap of failing to believe what can't be seen.

That's where we come in. People living with chronic pain, chronic pain researchers, health care policy-makers and medical professionals. The single most powerful phrase you can tell someone in pain is "I believe you." We can't fight this battle alone, though we certainly do our part to manage our health. So when my local

hospital's donation form comes in the mail, with the areas in need of funding listed sequentially, I despair when chronic pain is omitted.

Part of my healing process has been crafting beauty from despair - finding light in darkness and becoming part of a movement that's bigger than myself. There are days when the climb seems endless and I want to take cover, close the blinds and escape to a place where pain has no hold over my body. But then I remember; I am needed. My experience with pain is needed to stir apathy to action. Until chronic pain finds its place among other chronic illnesses, until chronic pain receives steady funding for research, for health care, my voice is needed. And so is yours. I can't think of anything more powerful, or more important, than being able to change the course of a life. To be able to give someone hope that circumstance would otherwise deny them. Thank you for joining me in my journey in supporting the advancement of chronic pain care on all fronts. Your research and your advocacy matters. ■

Chronic Pain Network National Coordinating Centre Contacts

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

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

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

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

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

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