

NETWORK NEWSLETTER

A CHRONIC PAIN NETWORK UPDATE

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#SeePainMoreClearly

Thomas Hadjistavropoulos is on a mission to increase awareness about untreated pain in people living with dementia.

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Strategy for Patient-Oriented Research

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A message from the Scientific Director

Network updates from Dr. Norman Buckley



There is a saying that goes “if you don’t know where you come from, then you don’t know where you are. And if you don’t know where you are, you don’t know where you’re going.” As we try to map out what the future of the Chronic Pain Network looks like, we must first stop and take inventory of where we started and our progress to date.

We know that pain research has historically been under-funded. It is decades behind other diseases, like cancer, in terms of effective treatments.

We know that some of the greatest names in pain research and advocacy, not only in Canada but around the world, are part of the Chronic Pain Network. They bring with them their knowledge and experience, but, most importantly, they bring with them their passion.

We know that the perspective of those with lived experience, and the priorities of those with lived experience, need to play a continued role in pain research. Researchers may be the experts in the science of pain, but those with lived experience, and their families, are the experts in way it impacts their lives and day-to-day activities, how it can affect their relationships, their moods and their overall quality of life.

We also know that the formation of the Network and its work have created positive change in these areas - that its efforts and activities have created increased awareness on a national level.

As we enter into the final year of its five years of SPOR funding, we now look towards a vision of the legacy of the Network - what we want its lasting impact to be. This was the central focus of September’s strategic planning meeting and will continue to be an area of focus in the coming weeks and months.

With 2020 looming on the horizon, it is a great time to take stock of our successes and aspirations - in both the Network and our own lives.

Have a safe and happy holiday season.

#SeePainMoreClearly: Creating Awareness

Dr. Thomas Hadjistavropoulos and his team are on a mission. Their goal? To ensure people affected by dementia, their friends and families, and health professionals are familiar with the problem of pain undertreatment and its dire consequences for this vulnerable population.

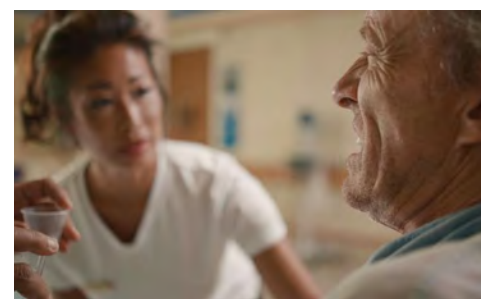
Pain in those living with dementia can sometimes cause challenging behaviours that may be mistaken for psychiatric problems and treated with psychiatric medications rather than pain medications. Psychiatric medications may sometimes increase the risk of earlier death among these patients.

Even so, pain is still underassessed in those with dementia. As pain is both complex and subjective, healthcare professionals often rely on

their patients to verbalize their pain. However, those with dementia may not be able to communicate, leaving them unable to express their discomfort.

On October 1, 2019, the team at the Centre on Aging and Health, based out of the University of Regina, launched the #SeePainMoreClearly campaign. The campaign seeks to increase awareness of the underassessment of pain in dementia and to disseminate evidence-based practices. They are tracking their success and impact through questionnaires and analytics, such as YouTube views, hashtag mentions, media stories and tweet impressions.

Only 24 hours after its launch, the campaign had already received 500,000 tweet impressions from



Dr. Thomas Hadjistavropoulos and his team and his #SeePainMoreClearly team are looking to raise awareness about pain in those living with dementia.

418,414 unique users, and the hashtag #SeePainMoreClearly had been used in Canada, the USA, the United Kingdom, Sweden, Australia and New Zealand.

While the reach continues to grow and the impact has been exciting to watch, the campaign is far from over.

Learn more or share your story at: www.seepainmoreclearly.org

Notes from the Strategic Planning Session

Looking to the Future



Attendees at the Strategic Planning Session worked in small groups to develop mission statements for the next iteration of the CPN. The mission statement exercise was developed in response to comments made during Strachan-Tomlinson's consultation.

Identifying Network assets and potential sources of funding for renewal - those were the two main objectives of the Chronic Pain Network's strategic planning session, held in Toronto on September 25, 2019.

Prior to the meeting, Strachan-Tomlinson, a Toronto-based consulting company specializing in process consulting and training and development, reached out in confidence to Network stakeholders through either phone interviews or an online survey. The purpose of this contact was to gain insight into how the Network's progress and impact to date we viewed, and to identify components of the Network that were seen as valuable legacy items going forward.

A report was synthesized from the findings of the interviews and presented by Mike Tomlinson, who facilitated the day's meeting on behalf of Strachan-Tomlinson. Mr. Tomlinson highlighted several quotes from report, which noted the strong leadership found within the Network, but also brought up uncertainties surrounding the funding of future iterations of the CPN.

One day prior to the strategic planning

session, on September 24, 2019, the Network's Patient Engagement committee met for an in-person meeting. Committee members were asked to review the committee's terms of reference and generate a list of accomplishments they felt had been achieved to date under each area.

Committee members were also asked to create aspirations for the PE committee, both within the Chronic Pain Network and beyond it. They then discussed strategic options to continue and grow patient engagement going forward. These scenarios were ranked by feasibility and alignment with the prioritized functions of the committee, then committee members were able to vote on their favoured options to bring up as topics of discussion at the strategic planning session.

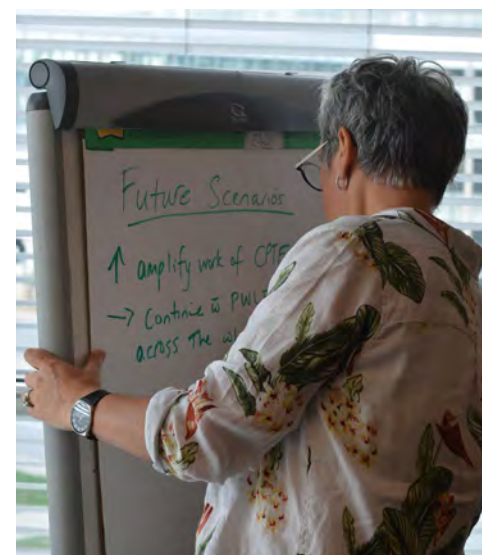
After the welcome to the planning session, Dr. Norm Buckley, the Network's Scientific Director, introduced Dr. Ramesh Zacharias, Chief Executive Officer of the newly announced Centre of Excellence for Chronic Pain funded by Veterans' Affairs' Canada. Dr. Zacharias spoke briefly about the Centre and the work ahead to establish it. The

infrastructure created for the CPN may have a valuable role to play in getting this network off the ground, and there may also be an opportunity for the CPN to integrate with the Centre of Excellence going forward.

Participants were then asked to work in small groups to help develop vision and mission statements that would serve to guide the Network going forward, prior to discussing and developing work plans for four areas of focus: engagement of people living with pain, biomarkers in pain research, the Canadian Pain Registry and the Clinical Research Network.

Leads for each area of focus gave a brief introduction and took questions as part of a plenary discussion. The goal was to discuss and develop a shared understanding, among planning participants, of ongoing and potential future aspects of the Chronic Pain Network.

Dr. Buckley, wrapped up the planning session by thanking participants for their time. The next steps in planning will include clear action steps for the CPN, based on recommendations and comments from participants.



The Network's Patient Engagement committee also held an in-person meeting, on September 24, 2019, where they discussed the committee's aspirations for the Network going forward.

National Pain Awareness Week: Highlighting the Scope of Pain in Chronic Illness

NPAW2019



The first National Pain Awareness Week took place in 2004, after the Honourable Yves Morin made the proposal to Senate on November 4, 2004 on behalf of the Canadian Pain Coalition.

Since its inception, in 2004, National Pain Awareness Week (NPAW) in Canada has taken place the first full week of November each year. It was a request put forth to the Senate, at the request of the Canadian Pain Coalition, to recognize the millions of Canadians who suffer from chronic pain and the tremendous toll it takes on them and on society as a whole.

Though pain was only recently recognized by the World Health Organization (WHO) as a disease in its own right, it has long been a symptom of many other chronic diseases with a daily impact on those living with chronic illness.

This year, for National Pain Awareness Week, the Chronic Pain Network decided to create a social media

campaign highlighting several of those chronic conditions in order to show just how large the scope of chronic pain actually is.

In its seven day awareness campaign, the Network looked at Arthritis, Complex Regional Pain Syndrome, Strokes and Central Post-Stroke Pain, Chronic Post Surgical Pain, Depression, Diabetes and Diabetic Neuropathy and Multiple Sclerosis. Upwards of seven posts each day provided facts about each condition, as well as their connection to chronic pain.

The campaign was very well received, with the Network acquiring nearly 100 new Twitter followers over the course of NPAW and earning 60, 500 tweet impressions.

Coming Events

Who: Ontario SPOR SUPPORT Unit
What: Virtual Masterclass
When: 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.

Who: PainBC
What: Chronic Pain Management Workshop for Occupational Therapists

When: January 31 - February 1, 2020
Where: Vancouver, British Columbia

For Occupational Therapists interested in developing or enhancing sound clinical skills in the assessment and treatment of clients living with complex, acute, and chronic pain.

Visit www.painbc.ca for additional details

Who: Chronic Pain Network
What: 2020 Annual Meeting
When: April 16, 2020
Where: Hamilton, Ontario

Additional details to come.

Who: Canadian Pain Society
What: 2020 Annual Scientific Meeting
When: May 19 - 22, 2020
Where: Calgary, Alberta

Visit canadianpainsociety.ca for additional details.

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