

ANNUAL REPORT 2018/2019



Changing the way pain is managed in Canada

MISSION

To innovate and improve the quality and delivery of pain prevention, assessment, management and research for all Canadians.

Officially launched in 2016, the Chronic Pain Network is a pan-Canadian collaboration of patients, researchers, healthcare professionals, educators, industry and government policy advisors to direct new research in chronic pain, train researchers and clinicians, and translate findings into knowledge and policy. The Network also provides direct funding to twenty research projects, covering population studies, behavioural studies, basic science and clinical trials. Patients are engaged as partners, working with professionals to identify priorities to improve health outcomes, identify new treatments and deliver a more effective healthcare system to fellow Canadians. The ultimate goal of the Network is 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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Dr. Norm Buckley Scientific Director

A MESSAGE FROM THE SCIENTIFIC DIRECTOR

"Life is pain, Highness. Anyone who says differently is selling something," or at least that is what the Dread Pirate Roberts proclaims to Buttercup in both the book and movie versions of The Princess Bride. This has also, unfortunately, been the prevailing attitude of many for so long in terms of chronic pain – it is simply a part of life that those experiencing must learn to deal with.

In recent years, however, this attitude has begun to shift, thanks, at least in part, to the hard work of people like Mary Lynch, Dwight Moulin, Jim Henry, Barry Sessle, Manon Choinière and Christine Chambers. This last year especially has seen major leaps in the attention given to chronic pain with the establishment of the Network Centre of Excellence Solutions for Kids in Pain and the announcement of the National Pain Task Force.

Bridges are being built across chronic illnesses such as hemophilia, to work together to both better understand and treat the pain experienced by those living with these diseases. Perhaps most importantly, people living with chronic pain are being given a voice and incorporated more and more into the discussion. They are helping to better inform and shape future generations of researchers and medical professionals.

While it is true that some parts of life may be painful, with each year we are learning. We are learning better ways to treat chronic pain, we are learning better ways to manage chronic pain, and we are learning better ways to support those living with chronic pain.

NETWORK IN NUMBERS (TO DATE)



One in five Canadians lives with Chronic Pain



2,164 Twitter followers and 1,265 tweets







projects awarded funding



Provinces represented within the Network through Patient Perspective Partners, Principal Applicants, Clinical Research Network sites, Projects or Partnering Institutions



\$344,725 Spent on Training & Mentoring initiatives such as the North American Pain School and the Connaught Summer School

Committees within the governance structure

124 Members on Network committees that meet on a regular basis

Network governance committee meetings







b Partnering

Patient Partners have provided expertise through governance since 2016

> **Principal Investigators** and Co-Principal Investigators

publications on pain published by Network Principal Investigators







HIGHLIGHTS

Though one in five Canadians lives with chronic pain, it is only in recent years that the topic has started to gain attention in the media. At the 2019 Canadian Pain Society Annual Scientific Meeting, the Federal Minister of Health, the Honourable Ginette Petitpas Taylor, announced the formation of the Canadian Pain Task Force. The Task Force consists of eight members, several of whom are members of the Chronic Pain Network's governance structure.

Bringing a mix of both professional and lived experience, the Task Force has a three year mandate to assess how chronic pain is currently addressed in Canada; identify best and leading practices as well as potential areas for improvement in the prevention and management of chronic pain in Canada; and to collaborate with key stakeholders to disseminate information related to best practices for the prevention and management of chronic pain.

Recognizing the importance of patient engagement and inclusion in these

processes is still a relatively new concept but one that is steadily gaining momentum and is also a key mandate of the SPOR initiative.

This year, the CPN's *Patient Engagement committee* formed the Patient Advisory Group with the purpose of holding bimonthly meetings to allow researchers and trainees the opportunity engage in conversations with Patient Perspective Partners. The committee also created additional resources to aid in these efforts, including a "Tips for Research Conversations with Patient Partners" document which can be found on the Network's website.

Shaping future generations of pain researchers and medical professionals is key to achieving the ultimate goal of the Network: changing the way pain is managed in Canada. The Network's *Training & Mentoring committee* continues to further this mission by supporting five educational opportunities for pain researchers and other healthcare professionals, ensuring the inclusion of a patient perspective in these initiatives.

The Network's Indigenous Health Research Advisory committee surveyed CPN participants earlier this year in order to gain insight into the knowledge and understanding that researchers and healthcare professionals currently have about working with Indigenous Peoples and how to conduct research with Indigenous populations. Survey results are being used to guide the creation of support materials and determine content for future webinars to better guide researchers looking to work with Indigenous Peoples and communities.

Patient perspective partners continue to be engaged in all aspects of the Network's governance structure, playing an active role on each committee. The *Patient Oriented Research committee* reviewed and provided feedback on 16 projects, ensuring they are on schedule in achieving the milestones outlined in their proposals and continue to align with Network priorities.

As Network projects move further towards completion, ensuring results can be

shared widely and in language that is easily understood by the general public becomes increasingly important. One way in which the Network's *Knowledge Translation committee* is helping to ensure that research output is both accessible and easily understood is by increasing the output of plain language journal article summaries using the PainPLUS CPN platform. The committee is also working on a series of webinars to provide researchers with tips and examples of how to better incorporate patient perspective partners in the research process from hypothesis to publication.

Network Patient Perspective Partners have provided critical input to the *Registry Working Group* through their participation. The Adult Registry Working Group was able to reach a final consensus on the domains, sub-domains and measurement tools to be included in the Canadian Adult Patient Pain Registry. A pilot study is underway to test the feasibility and acceptability of implementation in multidisciplinary pain treatment clinics. The Pediatric Registry Working Group pilot tested the Canadian Pediatric Patient Pain Registry at the Hospital for Sick Children. Patients answer a series of patient-reported outcomes prior to clinic visits. Across Canada, two pediatric pain clinics are using paper versions to administer the questionnaire, while four sites are using the electronic version.

Four Network-affiliated projects are currently underway within the *Clinical Research Network* (CRN), utilizing both adult and pediatric sites. The CRN is currently accepting additional proposals for multi-site studies and continues to seek out new and innovative ways to foster collaboration.

NETWORK FINANCIALS



Project Funds Distributed to Date (56%)



MATCH TO DATE

One of the requirements for the successful application of the Strategy for Patient Oriented Research (SPOR) Grant, such as the Chronic Pain Network, was securing a minimum of I:I match funding from non-federal government partners. Through both cash and in-kind matches, the CPN was able to secure \$20,767,855 over five years in designated funds from partnering institutions. Of this, the CPN has received 57% (\$8,841,527) of the cash match and 65% (\$3,336.969) of the inkind match to date.

PROJECT FUNDING

The bulk of the Chronic Pain Network's budget each year is allocated to research in Chronic Pain. This year, \$1.2 million was awarded, through Network funding to research projects across Canada.

To date, more than \$3.4 million has been spent directly on research. This accounts for 56% of total Network funds dedicated to research. Remaining funds allocated to pain research will be distributed in the final two years of the Network.

EXPENSES

Year Three of the Chronic Pain Network saw 39% of its budget spent directly on pain research through the funding of Networkaffiliated research projects. Delays saw the Clinical Research Network receiving Year Two and Three funding in just one year, causing it to account for 40% of Year Three spending. Committee activities, annual meetings, Patient Perspective Partner payments and new initiatives made up II% of expenses, with the Network's coordinating centre accounting for just I0% of spending.

GROWING PARTNERSHIPS & BUILDING CONNECTIONS

One of the main benefits of a network is the opportunity to grow partnerships and build connections. Sometimes this involves cultivating new partnerships between people or institutions who had not previously had the opportunity to meet. Other times it may simply be connecting the dots between ideas, resulting in new ways for collaboration to occur. This past year saw both of these kinds of connections form as a result of the Chronic Pain Network.

The Pain Management in Hemophilia (PMiH) partnership established in 2017 continues to grow. As a result of a situational assessment survey administered to key stakeholder in 2018, the PMiH group was able to determine needs, resources, knowledge and trends amongst healthcare professionals in hemophilia. These results are being used to help shape content for an interdisciplinary workshop to be led by the DeGroote Pain Centre. The workshops will train hemophilia teams in interdisciplinary pain care.



Laura Stone discusses the Epigenetic Signature of Human Chronic Pain at the Canadian Consensus Conference on Biomarkers in Pain Research.

A casual conversation amongst researchers at the Network's 2018 Annual Meeting identified

common themes and opportunities for collaboration, resulting in the Canadian Consensus Conference on Biomarkers in Pain Research. Held in February 2019, the conference provided an overview of the use of biomarkers in pain research, the logistics of biobanking and current research examining biomarkers. Discussion focused on making the most of existing registries, databases and biobanks while developing a strategy for establishing Canadian Pain Research-focused biobank.

LOOKING FORWARD

This past year has seen continued momentum forward in the area of patient oriented research, both in projects and initiatives directly related to the Network, as well as through the independent efforts of those affiliated with the Network. In their work outside of the CPN, Governance member Dawn Richards and past Network Patient Perspective Partner Isabel Jordan were two of four contributing authors of the paper *Patient Partner Compensation in Research and Health Care: The Patient Perspective on Why and How.* The paper looks at the value of lived experience and the need to properly recognize and support the contributions of Patient Perspective Partners. The paper outlines how to put principles into practice in a way that values and honours the patient/caregiver voice. With papers like this, and continued emphasis on the value of the patient perspective in education and training opportunities for health care professionals, we hope to influence future generations of pain researchers to help change how pain is treated and managed in Canada.

Chronic Pain Network projects are reviewed annually by the Network's Patient Oriented Research committee. Network funded projects include clinical trials, basic science, population surveys and behavioural science. Project funding for the Network began to flow in early 2017. With some projects having already been completed, and others are beginning to wind down, the emphasis on Knowledge Translation activities and next steps begins to increase.



The Network currently supports projects across seven provinces. The figure on the left represents the average amount of funding per project that each province will have received over the five-year life of the Network.



Biobank Of Biological Samples From Chronic Pain Patients From Canadian Registries And Screening For Molecular Markers

Leader(s): Luda Diatchenko Institution(s): McGill University

Creation of a biobank of biological samples, including DNA, RNA and plasma proteins, obtained from patients in the registries of SPOR Network grant partners. Samples will be used to identify molecular markers of the chronicity of pain conditions and their response to specific treatments. Recruitment started in April 2018 and is still ongoing; up to now we collected biological samples and clinical data from more than 1.000 participants with Chronic Low Back Pain or Neuropathic Pain from Quebec Pain Registry. We are also targeting acute low back pain participants that will be followed up for I2 months (biological samples and data will be collected at baseline, 3 and 12 months).



Aboriginal Children's Hurt & Healing Initiative National

Leader(s): Margot Latimer and John R. Sylliboy Institution(s): IWK Health Centre, Centre for Pediatric Pain Research, Eskasoni Health Centre, Dalhousie University

Since 2017 we have been reaching out to Indigenous communities in an effort to seek out community and health centre partners. Effective engagement allows us to establish region specific priorities for the study focus as well as research methods based on individual needs and resources. Expansion of the Aboriginal Children's Hurt & Healing initiative to engage additional communities for interest and relationship building, including First Nations, Metis and Inuit across Canada and into Maine. Community connections have now been established and confirmed with a Hamilton site and a site in Winnipeg. Two additional sites, at varying stages of engagement, have confirmed interest in participating. Our success to date has relied on strong community champions and collaborations The ACHH 'Kids Hurt' app is also currently being updated to improve functionality, include 3D imagery and Mi'kmaw language option.



Development Of A Web Application To Help Teens With Juvenile Arthritis And Their Caregivers Make Informed And Personalized Decisions About Pain Management Options

Leader(s): Karine Toupin-April Institution(s): Children's Hospital of Eastern Ontario Research Institute, University of Ottawa

Interviews and consensus meetings were done with teens with Juvenile Idiopathic Arthritis, parents of teens and health care providers to find out their needs in terms of decision-making for pain management and to help develop the intervention. A review of the literature was also conducted to identify evidence-based information on pain management options to present in the intervention. A patient decision aid (which seeks to help people become involved in decision-making by providing information on treatment options and helping to clarify their values and preferences) was then developed in the form of a web application, which is now being tested by users to see if it is easy to use and if it helps teens and parents make decisions to manage Juvenile Idiopathic Arthritis pain.



CADENCE: Combination Analgesic Development For Enhanced Clinical Efficacy

Leader(s): Ian Gilron, Luda Diatchenko, Nader Ghasemlou, Elizabeth Vandenkerkhof and Scott Duggan

Institution(s): Queen's University, McGill University, University of Manitoba

This study is a double-blind, double-dummy, randomized, controlled, 3 period crossover clinical trial comparing a combination of the anticonvulsant, pregabalin (PGB), with the non-sedating antioxidant, alpha-lipoic acid (ALA) to each monotherapy in chronic pain. Project outputs will advance knowledge about rational combination. Following the finalization of trial registration, funding, ethics approval, administration and participant screening, the first trial participant was enrolled and began treatment. Once the final participant completes the trial, the database will be locked and analyses of data will begin.



Canadian Surveillance Study Of Complex Regional Pain Syndrome In Children And Youth

Leader(s): Krista Baerg, Susan Tupper and Allen Finley

Institution(s): University of Saskatchewan/ Saskatchewan Health Authority and Dalhousie University

A population study exploring Complex Regional Pain Syndrome (CRPS) cases, in children and youth, presenting to paediatricians and pediatric chronic pain centres across Canada. Having received local REB approval, monthly CRPS surveillance of Canadian Paediatric Surveillance Program participants and pediatric clinic patients is in progress and will soon near completion.

This research will provide important incidence data and describe pediatric case characteristics. This foundational data will promote early recognition and treatment of CRPS in childhood and adolescence, as well as inform the education of pain health professionals both nationally and internationally.



Chronic Pain In The Emergency Department: Understanding Contributing Factors To Improve Health Care Outcomes, Health Care Utilization And Prescription Opioid Abuse

Leader(s): Patricia Poulin and Catherine Smyth Institution(s): The Ottawa Hospital Research Institute, St. Joseph's Care Group and Northern Ontario School of Medicine

A study examining how chronic pain is handled in the Emergency Department (ED); the proportion of patients with chronic pain who are frequent users of the ED, who have had access to self-management, inter-disciplinary interventions or to a pain specialist; ascertain stakeholders' expectations of how chronic pain should be managed in the ED; and explore the different reasons for presentation, care provided, care expectations and access to self-management, interdisciplinary program or pain specialists.



Circadian Control Of Chronic Pain

Leader(s): Nader Ghasemlou and Ian Gilron Institution(s): Queen's University

The study seeks to identify novel mechanisms underlying chronic pain that are affected by circadian rhythms by describing fluctuations in the intensity of pain reported by chronic pain sufferers, and identifying the molecular cues responsible for the generation of central pain in spinal cord injury patients.

This year, a switch to electronic pain diaries was made, utilizing a free online software available through Queen's University using Qualtrics. The diaries were trialled by members of the Ghasemlou Lab over seven days. Data was collected and analyzed to assess quality of data gathered and ease of use. Following IRB approved by Queen's for two sites, collection of patient data has also begun.



Epidemiological Investigations Of Chronic Pain Conditions And Psychiatric Disorders

Leader(s): Renée El-Gabalawy Institution(s): University of Manitoba

A series of epidemiological investigations aimed to understand the complex relationship between chronic pain conditions and psychiatric disorders. In both population-based Canadian and US samples, co-morbidity trends, mechanisms to elucidate co-occurrence, and health and disability-related implications of comorbidities were established. Several papers resulting from this research have now been published, as well as posters presented at scientific conferences.



iCanCope: Randomized Controlled Trial Of A Smartphone And Web-Based Application To Manage Pain In Adolescents And Young Adults (Aya) With Chronic Pain

Leader(s): Jennifer Stinson and Chirtra Lalloo

Institution(s): The Hospital for Sick Children (site lead), Centre for Global eHealth Innovation (University Health Network), IWK Health Centre, Stollery Children's Hospital, Alberta Children's Hospital, University of Saskatchewan, Nova Scotia Health Authority, University of Alberta, Women's College Hospital, Hamilton Health Sciences and Ottawa Health Research Institute

The project seeks to develop and evaluate iCanCope with Pain, the first integrated smartphone and web-based pain management program for AYA with chronic pain. The program aims to empower AYA in pain self-management through improved knowledge, self-efficacy, and coping skills.

This project has benefited from successful multi-site collaboration, with II participating institutions across Canada. To date, the project has recruited I35 out of 300 AYA with chronic pain and continues to onboard interested institutions.



Improving Personalized Medicine Through Discovery Of Pain Mechanisms Using Patient-Derived Neurons

Leader(s): Steven A. Prescott and Michael W. Salter

Institution(s): The Hospital for Sick Children

A basic research study that uses patientderived sensory neurons to compare cellular changes in leukemia patients who are susceptible or resistant to chemotherapy-induced neuropathy. The long term results are intended to help develop patient-specific treatments against neuropathic pain.



Individual Phenotypes Of Chronic Pain: The Dynamic Pain Connectome Towards Painometer Development And Neuroethics

Leader(s): Karen D. Davis and Cyril Schneider Institution(s): University Health Network; Université Laval & CHU of Quebec

A basic study seeking to identify key indicators of the dynamic pain connectome representing individual pain sensitivities; genotypic characteristics; changes of brain structure and function; changes of sensorimotor control (body manifestations); changes in behaviour (e.g., kinesiophobia); resilience and treatment response. A multidisciplinary approach will link pain perception with brain findings derived from fMRI in patients before and after treatment. Patient recruitment for a study in patients with ankylosing spondylitis is complete. A machine learning model for this patient population has also been developed. A survey of opinions of Canadian stakeholders regarding neuroethics, legal and societal challenges related to brain imaging proxies of pain will be conducted.



Music Program For Chronic Pain

Leader(s): Lee Bartel

Institution(s): Wasser Pain Management Centre, Mount Sinai Hospital, University of Toronto, Faculty of Music, Fred A Litwin and Family Centre in Genetic Medicine

An examination of the effects of a nonmedical and self-administered therapy option for the management of chronic pain, i.e., Rhythmic Sensory Stimulation and Music. Research will also investigate the mechanisms underlying the use of lowfrequency rhythmic sensory stimulation and music as a complementary treatment for chronic pain.

After suffering a delay, the REB was submitted and approved in March 2019. Recruitment for the study began in April 2019 and should be complete by April 2020.



Pain in Older Adults

Leader(s): Thomas Hadjistavropoulos Institution(s): University of Regina

This work has three areas of focus: the cost of pain in long term care; pain cues used by observers to draw conclusions about pain in older persons; and pain self-management interventions for older adults. Health Care Utilization Analysis was completed and initial results were presented at the Canadian Association of Gerontology Conference in October 2018. A paper based on the analysis of utilization was drafted for publication and has been reviewed by coauthors. Data collection was also completed for the decoding of non-verbal pain expressions in older adults with an without dementia. Data analysis was completed in February 2018, and a manuscript has been prepared and will be distributed submitted for publication in the fall of 2019. Finally, data analysis was completed for the evaluation of an online self-management program for older adults. Results will be submitted for publication/presentation in the coming months.



Prediction Of Chronic Pain After Upper Extremity Fracture Or Arthroplasty

Leader(s): Joy MacDermid and David Walton Institution(s): University of Western Ontario and the Hand and Upper Limb Centre

This projects seeks to determine if sex/ gender measurement biases exist in the network pain measures; identify sex/ gender factors that contribute to incident chronic pain after distal radius fracture or worsening pain after upper extremity joint arthroplasty; and examine clinician and patient perspectives of on peri-operative pain management, gender expectations and decision pathways for choices in pain management.

Interviews with patient and physician dyads on gender expectations and pain have begun. Papers have also been published on pain trajectories and the role of depression after distal radius fractures.



Proteomic Analysis Of Chronic Pain To Identify New Therapeutic Targets And Biomarkers

Leader(s): Nader Ghasemlou, Luda Diatchenko and Ian Gilron

Institution(s): Queen's University

The project seeks to identify patients for proteomic characterization who have already undergone genomic screening and to identify patients most closely grouped in terms of age, sex, race and disease progression/pain outcomes.

Pathway analysis of microarrays from spinal cord injury patient-derived peripheral blood cells with and without intractable pain has been completed. A publication regarding the characterization of spinal cord injury pain in the mouse has also been submitted and is under review.



Randomized Control Trials of Neuromodulation to Treat Chronic Low Back Pain, Complex Regional Pain Syndrome, Fibromyalgia and Cancer-Related Pain

Leader(s): Cyril Schneider Institution(s): Université Laval

A randomized control trial of neuromodulation, aiming to collect evidence-based data on noninvasive brain stimulation and noninvasive peripheral stimulation after-effects in chronic lower back pain and complex regional pain syndrome and detecting factors predictive of success (personalized health care). Partnership with patients from all target pain conditions and the deciphering of an imbalanced hemispheric activity in chronic pain (as compared to healthy) have contributed to adapt the protocols to the severity of symptoms.



Strategic Approaches To Personalized Diagnosis And Treatment In Chronic Pain

Leader(s): Serge Marchand and Louis Gendron, with Phillippe Sarret and Nicolas Beaudet

Institution(s): Université de Sherbrooke and Centre de Recherche du CHUS

The evolution of the project is going very well. We have the standardized measurement of over 300 healthy subjects for both sexes in three age groups. For each subject, we have the psychophysics measurements to establish a normalized chart for endogenous pain inhibition and central sensitization (temporal summation). We also have blood samples for biomarkers, autonomic responses and psychometric measurements. We started the same measurements in population of chronic pain patients.



Targeted Pain Therapies For Cancer Patients

Leader(s): Gurmit Singh and Jan Huizinga Institution(s): McMaster University

This study is part retrospective study, using biobank samples to investigate biomarkers focused on breast, prostate and lung cancers that have metastasized to the bone and cause severe chronic pain. With the retrospective study now complete, a prospective study biomarker analysis is being investigated in baseline and cancer patients with and without cancer pain, ultimately resulting in validating biomarkers before and after treatment with novel agents. A paper has been submitted to the Journal of Pain Research.



THE ROLE OF PARENT MENTAL HEALTH IN PEDIATRIC CHRONIC PAIN

Leader(s): Melanie Noel

Institution(s): Alberta Children's Hospital (site lead), University of Calgary; Hospital for Sick Children and the IWK Health Centre

A multi-site, clinical research study seeking to determine the cognitive, behavioural, and biological mechanisms underlying the relationship between parental mental health issues and children's pain outcomes in a sample of youth with chronic pain.

THE SYSTEMATIC MERGING OF BIOLOGY, MENTAL HEALTH AND ENVIRONMENT (SYMBIOME) LONGITUDINAL DATABANKING PROJECT

Leader(s): David Walton, Joy MacDermid, Jim Elliott, Walter Siqueira, Lynn Cooper, Brian Corneil, Eldon Loh, Gordon Good, Siobhan Schabrun and Jordan Miller

Institution(s): University of Western Ontario, McMaster University, McGill University, University of British Columbia, Queen's University, Northwestern University (Chicago), Western Sydney University (New South Wales), University of North Carolina at Chapel Hill, Canadian Pain Coalition and Gordon Good Law Offices

The SYMBIOME databank seeks to establish a robust, rigorously-collected and maintained longitudinal acute-to-recovered or acute-to-chronic databank of biological, psychological and social indicator variables that will allow advanced exploratory and confirmatory analyses of the trajectory and causes of pain and disability following acute musculoskeletal trauma.

PATIENT PERSPECTIVE PARTNERS - 2018/2019

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Department of Anesthesiology & Pain Medicine, University of Alberta

The Arthritis Society

Association Québécoise de la Douleur Chronique

Bayer

Department of Anesthesiology, University of British Columbia

Canadian Anesthesiologists Society

Canadian Pain Society

Centre de recherche du CHUS

Centre de recherché du Centre hospitalier de l'Université de Montreal

Children's Hospital of Eastern Ontario

Children's Hospital Foundation of Saskatchewan

Department of Anesthesia, Dalhousie University

Eli Lilly Canada Inc.

Hamilton Health Sciences

Health Information Research Unit, McMaster University

Hospital for Sick Children (SickKids) Research Institute

Hotel Dieu Chronic Pain Clinic, Queen's University The Improving the Lives of Children with Chronic Pain Charitable Foundation (ILC)

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Multiple Sclerosis Society of Canada

The Ottawa Hospital Research Institute

Pain BC

Pfizer

Purdue Pharma

Quebec Pain Research Network

Queen's University

University of Regina

College of Medicine, University of Saskatchewan

Saskatchewan Health Research Foundation Faculty of Medicine and Health Sciences, Université de Sherbrooke

University of Toronto Centre for the Study of Pain

Faculty of Music, University of Toronto

Department of Physical Therapy, Western University

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