



Fall 2019 Newsletter

Update from the Board Chairs

We have a large newsletter this fall filled with descriptions of pain related activities from the past several months across Saskatchewan, throughout Canada, and around the world.

The International Association for the Study of Pain (IASP) proposed a **new definition of pain** in August. Read more about the current and proposed definitions of pain on page 2.

The Canadian Pain Task Force, which convened in March 2019 released their **first report** in June outlining the current state of pain management in Canada and their plan for ongoing stakeholder engagement and action over the next 30 months. A link to this report can be found on page 6.

SaskPain board members were involved in two pain conferences in October. The Pain & Therapeutics annual conference was held in Saskatoon on October 5th. SaskPain board members Karen Juckes and Susan Tupper were involved on the planning committee. Board members were involved in three presentations; Ross McCreery shared his story in a patient panel, Krista Baerg presented on pediatric pain management, and Glen-mary Christopher and Susan Tupper presented on resources for pain management in Saskatchewan. A summary of the resources presentation and links to handouts are shared on page 6. The Pain Society of Alberta hosted the four western provinces in Lake Louise from October 18-20th in a conjoint conference that included PainBC, the Pain Society of Alberta, SaskPain, and representatives from Manitoba. Board members Karen Juckes, Krista Baerg, and Susan Tupper attended stakeholder engagement meetings hosted by the Health Canada Pain Task Force. During a plenary

address, Susan Tupper presented an update on provincial pain strategies alongside Maria Hudspith, Executive Director of PainBC, Tracy Wasylak, Chief Program Officer Strategic Clinical Networks with Alberta Health Services, Kerstin Gerhold, Section Head of Pediatric Rheumatology from Manitoba, and Fiona Campbell, President of the Canadian Pain Society and co-chair of the Canadian Pain Task Force.

Two **research networking meetings** led by SaskPain board members in September brought together people living with pain, researchers, healthcare providers and decision makers to identify new research collaborations and partnerships. More information on these meetings and opportunities for engagement in research are described on page 7-9.

With all of these activities, it's exciting to envision a future where **pain is understood, treatments are accessible, and people living with pain partner effectively with healthcare providers**, researchers, and decision makers to create sustainable, community-based solutions for pain. However, there is still a long way to go to make this vision a reality.

Our feature article for this issue is on chronic pelvic pain. On page 3-5, read about the perspectives of a person living with pain, a physical therapist who specializes in management of chronic pelvic pain, a psychologist, and a resident physician specializing in Obstetrics and Gynecology who has developed a training program on chronic pelvic pain. We hope you enjoy reading, sharing, and discussing this issue of the SaskPain newsletter.

Susan Tupper and Glen-mary Christopher,
SaskPain Board Chairs



What do you mean by “Pain”?

By Glen-mary Christopher and Susan Tupper

The International Association for the Study of Pain (IASP) has just completed a public consultation phase to update their pain definition based on the most current evidence and understanding. Given that pain is a nearly universal experience you would think it would be easy to agree on a common definition, but that is not the case. Throughout history there have been many proposed explanations for pain, ranging from an emotion, or "passion of the soul" (Aristotle, ~350 BCE) to "whatever the experiencing person says it is" (Margot McCaffery, 1968). As we learn more about how the pain experience is produced, our definitions will also change. For example, one of the amendments to the 1979 definition stated that if pain persists in the absence of tissue healing it was likely due to psychological reasons - we now know that that's not true; nervous system sensitivity from changes in the structure and function of the brain and spinal cord are the culprits.

The **current definition**: *An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage.*

Some of the issues that have been raised with this definition are:

- The term "unpleasant" trivializes the experience which for some is consuming and debilitating.
- Pain is not always perceived as unpleasant.
- Pain is not just sensory and emotional; it has cognitive and evaluative components such as the perception of threat.
- Description of pain is not always possible. Amendments to the 1979 definition recognized that verbal description was not necessary for the experience of pain.
- The definition suggests that observer validation of tissue damage or description are essential.

The **proposed definition**: *An aversive sensory and emotional experience typically caused by, or resembling that caused by, actual or potential tissue injury.*

The accompanying notes to the new definition state:

- Pain is always a subjective experience that is influenced to varying degrees by biological, psychological, and social factors.
- Pain and nociception are different phenomena: the experience of pain cannot be reduced to activity in sensory pathways.
- Through their life experiences, individuals learn the concept of pain and its applications.
- A person's report of an experience as pain should be accepted as such and respected.
- Although pain usually serves an adaptive role, it may have adverse effects on function and social and psychological well-being.
- Verbal description is only one of several behaviors to express pain; inability to communicate does not negate the possibility that a human or a non-human animal experiences pain.

When the finalized definition is released we will highlight it in a subsequent SaskPain newsletter. For more information go to:

<https://www.iasp-pain.org/PublicationsNews/NewsDetail.aspx?ItemNumber=9218>

FEATURE ARTICLE

Chronic pelvic pain from different perspectives

Pain like hot knives stabbing.
A million little needles, deep throbbing.
A cannonball to the belly.
Pain that feeds other pain.
The wildfire that spreads everywhere.

My name is Laura, but you can call me Warrior. I have severe pelvic disease, dysfunction, and pain. For too many years I was brushed off or given band-aid treatments, resulting in debilitating pain and dysfunction that now stretches beyond the pelvis. I have had to retrain my body how to eat, eliminate waste, have sex and orgasm, how to sit, stand, sleep, and so much more. It has been a long journey filled with endless tests, appointments, and more setbacks than I care to remember. Too many times I wasn't sure I had the fortitude to make it through, and my mental health is still a fragile thing. But I'm here, and with hard work have been able to claw my way out of the worst of my pain and heal, albeit step by teensy step. Some of the things I found helped best:

- Finding a Pelvic Floor Physiotherapist specializing in pain
- My TENS machine
- Pelvic Floor Botox injections
- Heating pads and all the pillows
- Visceral massage
- Valium and Baclofen suppositories
- Cannabis and the right medications
- Yoga
- Physiotherapy
- Hot baths with Epson salts
- Online support groups
- Mental Health Counseling

My advice to others: try everything. What doesn't work for one can for another. Living with and treating your pelvic pain must become a job, and you are the boss. Find yourself the right healthcare team, but don't expect them to have all the answers. You must be willing to work harder than anyone else on the team. I'm here to tell you, if you're suffering, you aren't alone. If you're treating patients, yes the pain IS that bad. We are not drug seekers, hypochondriacs, or seeking attention. Our pain may be invisible, but we aren't, and we aren't going away, so please learn how to best treat us. Believing in our struggle is the first step.

Laura Millions is the co-founder of Saskatchewan Pelvic Pain & Endometriosis Warriors, a Facebook support page that just celebrated its 5th year and has over 500 members across the province. It is a page for patients and their loved ones to find support, guidance, and information from other Warriors. Each year they participate in the National Endometriosis and Pelvic Pain awareness walk, and have helped with three patient conferences, knowing the importance of support, awareness and education. When able they have in person support meetings in Saskatoon or Regina.

Private support page: www.facebook.com/groups/SaskEndoWarriorsSupport/

Public group: www.facebook.com/groups/SaskEndoWarriors/

Email: saskendowarriors@gmail.com

National non-profits: Endometriosis Network of Canada (TENc) and Endometriosis Connection of Canada

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FEATURE ARTICLE (continued from page 3)

Physical Therapist's Perspective

Pelvic pain has become a condition that is growing in need of awareness and treatment. The source of the pain can be difficult to diagnose, and appropriate treatment can be even more challenging to determine. Sometimes we can link pain to a specific trauma or injury – for example, an injury to the pelvic floor during labor and delivery, low back, hip or pelvic girdle pain, or an abdominal component of endometriosis, bladder infections or bowel conditions. Other times, there may be no definitive cause of the pain, which can be very frustrating for those trying to determine the reason for this change in their life. Some people may have pain constantly, while others have discomfort only with a specific activity, or with intercourse. There are often several pieces to the puzzle, including bowel and bladder habits, hormone levels, and activity in daily life, as all of these require action from the pelvis and the core muscles of the body. First, muscles need to learn how to contract properly and what a release is. The goal then is to re-train the muscles in the way they respond to movement, pressure and pain. The corresponding muscles of the hips, abdomen and low back are also partners in movement, and need to work as a team without one group overtaking the others. Physical Therapy (PT) is an important component in the management of people with chronic pelvic pain. We provide comprehensive assessment and treatment of the musculoskeletal, visceral, and neurological factors that influence pain as well as education about the pelvic floor and other anatomy and the pain system. PTs require advanced training to practice in this area.

Bree Rutten is a Saskatoon-based healthcare provider with degrees in Physical Education and Physical Therapy practicing at Crave SPORT Services (306-934-2011). She has taken more than 20 post graduate courses focusing on pelvic floor assessment and treatment, including pelvic pain, visceral manipulation and exercise approaches.

For information on physical therapists who treat pelvic floor conditions in Saskatchewan:

<http://www.sasksurgery.ca/pdf/pelvic-floor-phys-therapists.pdf>

General information on pelvic pain:

<https://pelvichealthsolutions.ca/for-the-patient/>; <http://pelvicpainrehab.com/blog/>

Psychologist's Perspective

Chronic pain of any kind can interfere with all aspects of life, including doing the things we want to do, having the relationships we want to have, and even being the person we want to be. These broad effects of chronic pain can increase the suffering attributable to the pain itself and complicate our efforts to cope with it. The challenges of coping with chronic pain are different for each individual and depend partly on the nature of the pain they experience. Chronic pelvic pain can be particularly challenging to cope with as it can affect some of the most fundamental and intimate aspects of life, including sexuality. A psychologist, preferably in collaboration with other treatment providers, can work with a person struggling to cope with chronic pelvic pain, to identify and address the particular emotional, thinking, and behavioral patterns that might be contributing to their suffering.

Psychological services for individuals with chronic pelvic pain are somewhat limited at present. A
(continued on page 5)

FEATURE ARTICLE (continued from page 4)

list of private (not publicly funded but often covered by health insurance) registered psychologists with competence in treating health issues such as pain can be found at <http://www.skcp.ca/>. Click: Public Info, then click: List of Registered Psychologists. Click on any psychologist on the list, then click: New search. Enter the search term "health".

Health care providers in Saskatoon and area can refer individuals with emotional difficulties related to coping with chronic pelvic pain to the Department of Clinical Health Psychology (306) 655-2341. Contact local health authority mental health services for regional information.

Dr. Bruce McMurtry is a Registered Doctoral Psychologist. He has provided psychological assessment and treatment for individuals with chronic pain and/or other physical health issues in several settings for over 20 years, in addition to providing consultation, conducting research and public speaking on psychological aspects of pain. He is currently working in the Department of Clinical Health Psychology with the LiveWell Chronic Disease Management program at Royal University Hospital in Saskatoon.

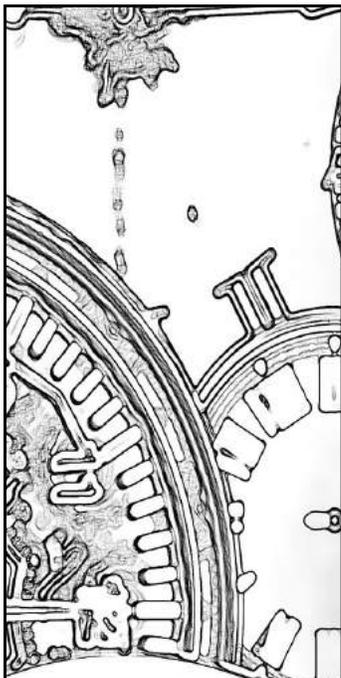
Physician's Perspective

Chronic pelvic pain is a complex multi-faceted problem that places a substantial burden on people living with the condition and on healthcare resources. It is common and affects people of all ages. 15-20% of women have chronic pelvic pain lasting for more than 1 year.

Pelvic floor myalgia is a common cause or contributor to chronic pelvic pain. It is defined as pain originating from the pelvic floor musculature. 63% of patients with self-reported chronic pelvic pain examined by a physician and 73.7% of patients examined by a physiotherapist were found to have pelvic floor myalgia. This condition is frequently unrecognized and under-treated and can result in persistent symptoms, progression into central sensitization, patient visits to numerous health care providers, unnecessary laparoscopic surgery, psychological distress, and impaired quality of life. It is important for physicians to assess the pelvic floor musculature and provide early referral for appropriate treatment.

Our team designed a new effective multidisciplinary training program for teaching physicians the assessment of the pelvic floor musculature to identify a possible muscular cause or contribution to chronic pelvic pain. In our research study, we found both video and hands-on versions of the training program to be effective and useful for clinical practice. For both versions, we designed a guide with step-by-step instructions of how to perform the assessment. Our training program has been presented provincially, nationally, and internationally.

Dr. Maria Giroux is a 4th year resident physician specializing in Obstetrics and Gynecology with a special interest in chronic pelvic pain completing her training at the University of Saskatchewan. She has a Bachelor of Science degree in biomedical biology from Laurentian University and completed her medical school training at the Northern Ontario School of Medicine. Maria currently practices in Regina. She is Founder and Chief Executive Officer of the OBGYN Academy, a not-for-profit educational resource. For more information on their training program, see their website: <https://obgynacademy.com/chronic-pelvic-pain/>. If you would like more information on their training program or to schedule a hands-on workshop, please email mag640@mail.usask.ca.



Canadian Pain Task Force—Update

In March, 2019 Health Canada convened a task force to examine management of pain in Canada. The Task Force consists of a small group of clinician, researcher, and patient advocate representatives from across Canada. Their work is supported by a larger External Advisory Panel, and additional stakeholder engagement taking place over the next 3 years. The first report describing the current status of pain management in Canada is available at:

<https://www.canada.ca/en/health-canada/corporate/about-health-canada/public-engagement/external-advisory-bodies/canadian-pain-task-force/report-2019.html#intro>

The report is a comprehensive and compassionate summary of the primary issues and impact of pain. Throughout the report are quotes from twelve Canadians who share their experiences of living with and managing pain. One quote reads,

“It was during the intake interview and history taking that the doctor stopped writing, put his pen down, and looked at me and said these words that will forever resonate with me: “it’s okay, we believe you”. Those words, that act of validation was a turning point for me.”

The task force is engaging diverse stakeholders across Canada in a series of regional workshops, the first of which was held at the Pain Society of Alberta conference in Lake Louise on October 18th, 2019. SaskPain board members Karen Jukes, Krista Baerg, and Susan Tupper attended this meeting, sharing their perspectives on the Saskatchewan situation. There were excellent discussions about opportunities to share information and resources between provinces in order to better disseminate and scale-up initiatives. We will follow the work of the Canadian Pain Task Force in future editions of the SaskPain newsletter.

Resources for Pain Management in Saskatchewan

Presentation at the Pain & Therapeutics Conference, Saskatoon, October 5, 2019



Glen-mary Christopher and Susan Tupper presented two break-out sessions at this year’s annual interdisciplinary conference hosted by the [Continuing Medical Education](#) department of the University of Saskatchewan. [A list of resources](#) for pain management and education was shared, contributed to by patients and healthcare providers from across Saskatchewan. Not all of these services are specific to pain management, but they are possible resources that people living with pain can use. The list and our [presentation handouts](#) are available in the Resources tab of the SaskPain website. We will continue to add to this list as new information is shared. If you are aware of other great programs, please let us know at info@saskpain.ca.

Research Engagement and Networking Meetings



Patient Oriented Research Planning Meeting—September 14, 2019

With funding from a Patient Engagement and Application Development Award (PEADA) from the Saskatchewan Centre for Patient Oriented Research (SCPOR.ca), SaskPain board members invited other researchers, people who live with pain, healthcare providers and decision-makers to a full day working meeting to plan a grant application to support pain management. We heard from

people who live with pain and their family members about the “marathon of misery” and their priorities for addressing this complex health issue. A research team was developed and we are busy writing a grant to fund this project, led by SaskPain board members, Susan Tupper and Karen Jukes.

Pediatric Pain STOP-PAIN Think Tank—Sept 26, 2019

SaskPain board member, Dr. Krista Baerg organized a pediatric pain research networking meeting. This event brought together approximately 25 patients, multidisciplinary healthcare providers, and researchers. The Think Tank participants were provided the top 10 priorities for pediatric pain research generated by the Partnering for Pain project as a basis for discussion regarding future collaborations. For more information on the Partnering for Pain project, see <http://www.irsc.gc.ca/e/51558.html>. Several excellent research ideas for potential collaborative engagement were proposed. Dr. Baerg and team will be pursuing research grant applications with participants, based on these discussions. This meeting was possible due to support from the Chronic Pain Network, the Division of Pediatric Research and Saskatchewan Health Research Foundation. For more information, contact stoppain@usask.ca.

Upcoming FREE Education Events in SK

ECHO © for Chronic Pain for Healthcare Providers

A series of 10 case-based learning modules for healthcare providers will be offered in January to May, 2020. CME credits available for each class. Contact Cathy Jeffery at cathy.jeffery@usask.ca to register. All healthcare disciplines are welcome.

Education for People Living with Pain

November 19th—Low Back Pain and Sciatica, Mackie Physiotherapy, Saskatoon, Register at: (306) 955-7888.

November 25th—Headaches and Migraines: Causes, Diagnosis and Available Treatments, Donald Physiotherapy, Saskatoon, 7pm. Scan code or phone 306-933-3372 to register.

December 17th—Journey of Strength, Mackie Physiotherapy, Saskatoon, Register at: (306) 955-7888.



Upcoming Pain Conferences

Canadian Pain Society (CPS) 41st Annual Scientific Meeting

Calgary, AB will host the next CPS meeting, a chance for researchers, healthcare providers, and people who live with pain to come together to learn from international experts on pain management. Keynote speakers include Dr. David Bennett, Head of the Division of Clinical Neurology from Nuffield Department of Clinical Neurosciences, University of Oxford, Dr. Sarah Ross, Associate Professor of Neurobiology from the University of Pittsburgh, and Dr. Sean Mackey, Chief of the Division of Pain Medicine and Director of the Systems Neuroscience and Pain Laboratory from Stanford University. [Poster abstracts can be submitted](#) until November 20th, 2019.

Help us Mobilize Knowledge about Pain in Dementia: The #SeePainMoreClearly Social Media Campaign

- Pain is frequently underassessed/undertreated in older adults with dementia. As a result, many vulnerable seniors miss out on effective evidence-based approaches and continue to suffer from untreated or undertreated pain.
- With the support of organizations such as the AGE-WELL NCE and stakeholders, we launched a large-scale social media campaign #SeePainMoreClearly on October 1, 2019, the International Day of Older Persons.
- You will be helping our knowledge mobilization effort by viewing our 2-minute informational video (search “#seepainmoreclearly” on YouTube or use this link: https://youtu.be/9ONjQ7_ZvZA). Resources can be accessed through www.seepainmoreclearly.org.
- Please join our conversation on Twitter using the hashtag #SeePainMoreClearly! We also encourage you to fill out our brief video evaluation questionnaire (link on YouTube video).

Thomas Hadjistavropoulos & Louise Castillo
University of Regina, Canada



Participate in Research

Parents And Teens Needed to Understand Pain Interactions

The Family Health Lab at the University of Saskatchewan is conducting a study on parent-teen interactions and painful experiences. We are seeking teens (13-18) who do not have chronic pain AND teens who have experienced pain at least once a week for 3 months.

Participation involves completing questionnaires and a variety of tasks, including a discussion between the parent and teen and the hand-in-cold-water task. The questionnaires take approximately 30-45 minutes to complete and can be done online. The tasks are completed at the Family Health Lab and take approximately 1 hour to complete. Those who participate can receive up to \$50 for their time (\$100 per parent/teen dyad). For more information: family.health.lab@usask.ca or www.familyhealthlab.com/painstudy

Study on Health of Adolescent Females

The Family Health Lab is conducting an online study to understand more about the health of adolescent females.

To participate the teen needs to:

1. Have a parent provide consent for the teen to participate
2. Have had their first period
3. Be aged 14 to 18 years old and currently in high school
4. Live in Canada or the United States

For more information or to participate please follow this link: <http://familyhealthlab.com/teenhealth>

Participants will be entered to win one of three \$100 CAD Amazon Gift cards.

Pediatric Chronic Pain Registry

- Youth aged 12-18 who live with chronic pain are invited to join a pediatric chronic pain registry
- You would be asked to complete forms every 3 months for the first year and once every year until you turn 18
- This will help us learn more about how chronic pain effects youth and young adults over time
- For more information, email cj.mcmahon@usask.ca

Participate in Research

Dementia, Pain, and Virtual Reality Study

We are recruiting male, rural, or non-European family caregivers of people who live with dementia to take part in a 30-60 minute interview. Share your experiences on pain management and your opinions on virtual reality for pain education. For more information contact Dr. Susan Tupper at 306-655-1041; email: susan.tupper@saskhealthauthority.ca or Kirstie Gibson at kig579@usask.ca.

This study is funded by the Saskatchewan Health Research Foundation (SHRF), the Centre for Aging and Brain Health Innovation (CABHI), and the Eunice Bilokreli Research Fund with the College of Medicine, U of S in collaboration with the Saskatoon Council on Aging (SCOA) and the Alzheimer's Society of Saskatchewan. Education materials developed from this research will be hosted on the SaskPain website.



Pediatric Chronic Pain Research Studies

Looking for youth and young adults aged 12-25 who live with chronic pain and their parents to sign up to learn about future research studies. For more information or to sign up go to: <https://is.gd/permissiontocontact> or email cj.mcmahon@usask.ca

Include your announcements in upcoming newsletters

SaskPain distributes quarterly newsletters to over 250 healthcare providers, healthcare administrators, and people living with pain in the province— and we continue to grow. Share your news or announcements about upcoming pain-related events in the next newsletter. Upcoming deadlines for submission are: September 1, December 1, March 1, June 1. Email your announcement to info@saskpain.ca.

Visit our website: saskpain.ca



Find past issues of newsletters, SaskPain reports, the Saskatchewan Pain Charter, and links to resources at www.saskpain.ca. The website will be undergoing revisions in November and December, 2019. We look forward to unveiling our new site in the new year.



DID YOU KNOW... 1 in 5 Canadians suffer from chronic pain?



Online Therapy Unit

SERVICE, EDUCATION AND RESEARCH

If you experience symptoms of depression and anxiety resulting from **chronic pain** and want help at your fingertips. The Online Therapy Unit for Service, Education, and Research is offering a **FREE eight-week course** to improve coping with chronic pain.

- Our five online modules are based on cognitive behavior therapy, and designed to improve chronic pain management.
- During the course, you will receive weekly support and guidance via secure email.

You may be eligible if you:

- Are over 18 years of age and residing in Saskatchewan
- Have experienced pain for at least three months
- Have access to a computer with Internet
- Are willing to take part in a research study and are willing to provide feedback
- Are not at risk of suicide



Online Therapy Unit

SERVICE, EDUCATION AND RESEARCH



306-337-3331

online.therapy.user@uregina.ca

www.onlinetherapyuser.ca

The Online Therapy Unit is funded by the Canadian Institutes of Health Research, Rx & D Foundation, and the Saskatchewan Health Research foundation and has received ethics approval from the University of Regina Research Ethics Board.

