2018 Jackson Mooney Patient Grant Recipient Announced:

Meet Sarah Anderson

DMRF Canada, in partnership with Jackson Mooney and his brother Jeff, are thrilled to announce that DMRF Canada selected the 2018 Jackson Mooney Patient Grant recipient. Meet Sarah Anderson, a high school graduate interested in pursuing her teaching degree at the University of Winnipeg. Sarah suffers from generalized dystonia because of oxygen deprivation at birth. When describing her educational goals, Sarah says; "*despite the inevitable challenges living with dystonia presents, I was always that typical child who looked to the future with goals such as eventually having a career. For this reason, academic success has been a major focus for me.*"

A dedicated student, Sarah has been on the Honour Roll for three consecutive years. This year she was named her High School's Valedictorian. Sarah will be entering University in September 2018, with a goal to become an educator. "Growing up, I was fortunate to have many teachers who not only passed on valuable academic lessons but inspired me through their knowledge and dedication. It is both my goal and my dream to educate and be that role model for the children of tomorrow."

Jackson's vision when he established the grant, was to make life easier for dystonia patients who were trying to further their education. "I wanted to give someone a real chance to do something exceptional – something that they might not have had an opportunity to do. This grant is aimed at helping in a small way".

This year's grant valued at $4,500 will be directed to Sarah's tuition costs. "I have always been a 'glass is half full' type of person, but tuition is one challenge that a positive attitude alone can't overcome. I'm truly grateful to receive this grant as it takes me another step closer to reaching my career goal of becoming a teacher."

Catching Up with Last Year's Jackson Mooney Patient Grant Winner

Neil Merovitch was the Jackson Mooney Patient Grant Recipient in 2017. We had a chance to catch up with Neil last month and we're pleased to confirm that Neil is entering the third year of his PhD in Physiology at the University of Toronto. Neil continues to be focused on understanding the mechanisms underlying social memory deficits associated with neurodevelopmental disorders.

This past year Neil also won the first-place poster award at the 3rd Zebrafish for Personalized/Precision Medicine Conference. **Best of luck, Neil!**

One of the key learnings from the survey was that dystonia patients continue to suffer from pain. In attempting to help patients determine how to best deal with their pain, DMRF Canada asked Dr. Gordon Ko to provide his theories on how he treats his Cervical Dystonia patients' pain. Below you will find details on the 4 Component Approach.

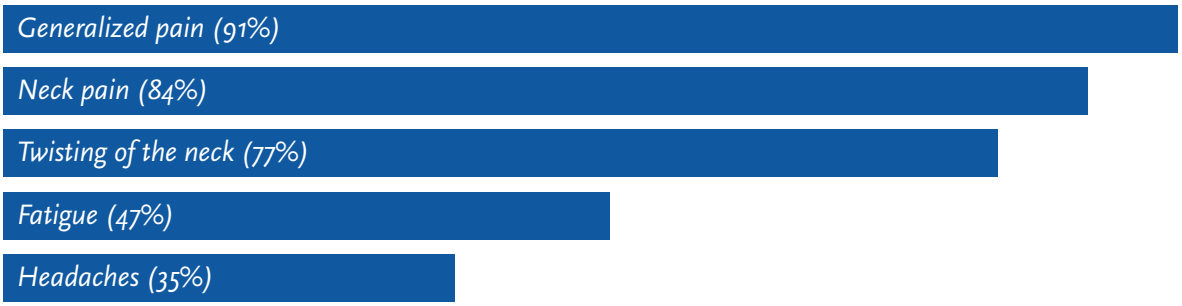
A reminder that every dystonia patient experience is different. The four-component approach takes into account that there are many different reasons for physical pain. It is DMRF Canada's policy to provide a variety of ideas and news regarding all types of dystonia, but not to endorse any of the drugs, treatments or methods discussed. DMRF Canada encourages you to consult with your physician about procedures mentioned herein. therapy and treatments included herein.

Treating painful cervical dystonia: The 4 Component Approach

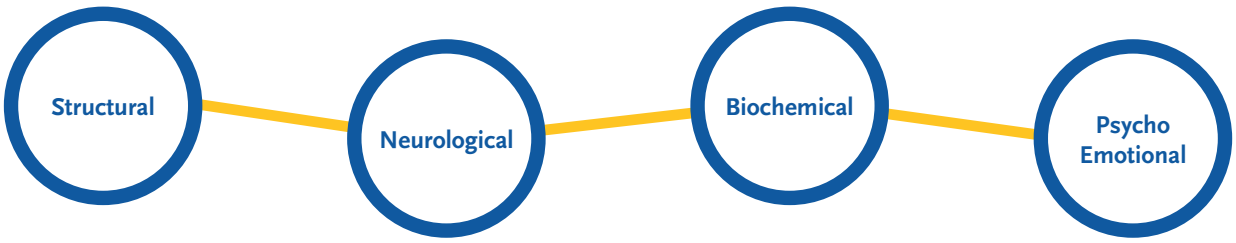
By Jasmine B. Ko, Department of Kinesiology, McMaster University

Pain in cervical dystonia (CD) was first described years ago* and again in 2017, when the DMRF Canada Survey and subsequent report; Real Patients, Real Responses found in 397 patients across Canada, that the most important aspects of CD were: generalized pain (91%), neck pain (84%), twisting of the neck (77%), fatigue (47%) and headaches (35%).

The most import aspects of cervical dystonia (CD):



The four components of chronic pain:



Introducing the Four Components of Chronic Pain by tDr. Gordon Ko: Interventional physiatrist Dr Gordon Ko MD FCFP(EM) FRCPC PhD incorporates a "Four Component approach" to find the "why" behind the pain in his CD patients. Coined originally by German physician Dr. Dietrich Klinghardt; MD, PhD, this approach first identifies the root sources of pain (and CD) and resolves them by using a multimodal, interdisciplinary approach.

*Additional research on the relationship between pain and cervical dystonia : Chan J. et.al. Mov Disord. 1991; Jahanshahi M. et.al. Arch Neurol. 1990, Galvez-Jimenez N. et.al. Adv Neurol. 2004.

Structural causes are usually linked to physical trauma (such as "whiplash" after a motor vehicle accident) and overuse mechanisms (e.g. prolonged head forward posture from computer work). Besides imaging studies (x-rays, MRI), further definitive testing may include fluoroscopic-guided facet joint nerve blocks.

Treatment options could include cortisone injections, facet joint radiofrequency denervation, and platelet-rich plasma prolotherapy injections. Likewise, botulinum toxin has been shown to have an effect (beyond relaxing muscle) in reducing nociceptive joint pain. Injections work best when combined with physical therapy to strengthen weak core muscles and restore functional movement patterns. Prior to doing such injections, Dr Ko may seek out other treatments – including having his patients first see a therapist for a trial of acupuncture, and/or Graston therapy to release muscle trigger points.

As president for the Canadian Association of Orthopaedic Medicine (www.caom.ca) which trains MDs on such injections, Dr Ko recommends that such treatment be done by properly trained physicians. DMRF Canada recommends that any investigations into treatment begin with your primary care provider.

Biochemical causes that perpetuate chronic pain could include poor food choices such including highly processed carbohydrates. Other underlying conditions could include gut dysbiosis, toxins, and hidden infections (such as chronic Lyme disease or viral reactivation syndromes, now termed Multisystemic Infectious Disease syndrome, or MIDS). Often the regular testing that a family MD or internist will do is negative, but further tests may provide clues. Based on such testing, the next step would involve seeing a physician trained in Functional Medicine or International Lyme and Associated Disease Syndromes.

Psycho-emotional causes of pain include the stress from physical and/or emotional traumas (including post-traumatic stress disorder - PTSD). Many cases of intractable pain have predisposing factors such as childhood traumas. Evidence-based therapies for PTSD include eye movement desensitization retraining (EMDR), emotional freedom technique (EFT) and hypnosis. Neuro therapy utilizes computer-assisted feedback of brainwave activity combined with visual / auditory input signals to train the brain for improved meditation or concentration. Such approaches work effectively when combined with psychotherapy (e.g. cognitive-behavioral therapy). More information is available with the Association for Applied Psychophysiology and biofeedback.

Neurological causes include actual changes in peripheral (nerves) and central nervous system function that leads to pain perpetuation. This is a phenomenon called "central sensitization" demonstrated on functional MRI (presently used in research). Medical treatment for this includes the use of oral medications such as anti-seizure drugs, antidepressants, muscle relaxants, opioids and cannabinoids. Such oral medications are limited by gut, liver, renal, cardiovascular side-effects.

Perhaps the most exciting approach to reduce both peripheral and central pain sensitization is botulinum toxin – A (BTX-A). This highly purified natural protein is extracted from the "botulism" bacteria. The molecule when injected into muscle, is taken up by the nerve, blocking the nerve from releasing its transmitter. This produces a temporary but prolonged relaxation of muscle typically lasting three months. It has also been shown to inhibit the release of pain neurotransmitters such as Substance P, CGRP and glutamate.

Health Canada has approved Botulinum Toxin-A for first-line treatment of CD, of which there are currently available: OnaBTX-A Botox (since 1995), IncoBTX-A Xeomin (2009) and AboBTX-A Dysport (2016).

For a detailed explanation on how BTX-A works for pain, visit Dr Ko's website (under videos) at **www.DrKoPRP.com**.
For details on how to live well with dystonia, please visit: **dystoniacanada.org/livingwell**. For details on the Dystonia Patient Survey and Report, please visit: **dystonicanada.org/surveyreport**.