Just
THE FAC'S

SPRING 2023 | Issue 08

FIBROMYALGIA ASSOCIATION CANADA

FAC Celebrates Fibromyalgia Awareness Month

In May we recognize fibromyalgia and all who experience this illness.

FAC recognizes that May 12th, 2023 is the 31st anniversary of Fibromyalgia Awareness Day to raise awareness and end the stigma and discrimination that accompany this chronic, invisible illness.

Membership

We will accomplish more together, the larger our membership the greater our power.

If you are not a member of FAC already please join us here https://fibrocanada.ca/application-form/

History of May 12

This year 2023, marks the 31st year for International Fibromyalgia Awareness Day.

[excerpt] …Despite the efforts of a number of dedicated groups and individuals, there are still vast pockets of ignorance and misunderstanding about fibromyalgia. To this day, many patients are faced with medical establishments, governments, family and friends that knows very little about this condition and are threats to human health. It is therefore crucial that all those who are affected by this illness, including family, friends, caregivers, etc., make their voices heard all year round, but especially on May 12th of each year. – Thomas M. Hennessy, Jr. (1954-2013), RESCIND, Inc

The idea of having an International Fibromyalgia Awareness Day originated with Tom Hennessy, the founder of RECIND, Inc (Repeal Existing Stereotypes about Chronic Immunological and Neurological Diseases). Mr. Hennessy was based in the US but understood that this awareness day needed to be an International event.

May 12 was chosen as it coincided with the birth date of Florence Nightingale, the English army nurse who inspired the founding of the International Red Cross. Nightingale became chronically ill in her mid-thirties with a fibromyalgia-like illness. She was often bedridden for the last 50 years of her life. Despite suffering from a debilitating illness, she managed to found the world's first School of Nursing.

FACes of Fibromyalgia Campaign

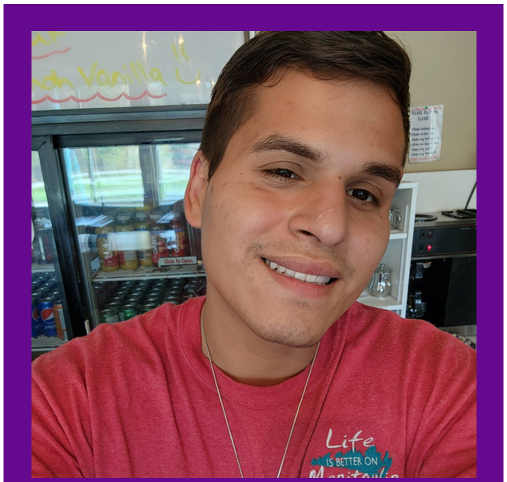
One responsibility of FAC's Awareness Committee is to launch national campaigns to raise awareness of fibromyalgia being a life-altering chronic illness. The FACes of Fibromyalgia Campaign is one such campaign. There are millions of us worldwide with fibromyalgia, so with your help we can keep this campaign going for years.

Note: This campaign is open to anyone, anywhere in the world, with fibromyalgia.

All you have to do is take a "selfie" and send it to admin@fibrocanada.ca

Help FAC "MAKE FIBROMYALGIA VISIBLE"

Emailing your photo is considered consent/authorization for use of your image and likeness by Fibromyalgia Association Canada for the "FACes of Fibromyalgia" campaign



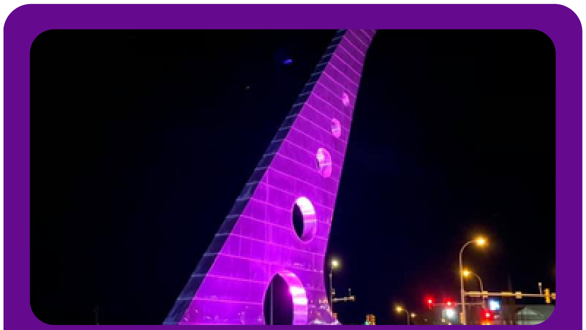
2023 Illumination Campaign

Fibromyalgia Awareness Month and Fibromyalgia Awareness Day are focused on raising awareness for our chronic and debilitating condition. FAC will be promoting Awareness throughout the month but our highlight campaign will be the "2023 Illumination Campaign" on May 12th.

Last year, 2022, marked FAC's first National Campaign to shine a light on fibromyalgia. We had 90 buildings and landmarks across the country illuminated purple on May 12th in recognition of all Canadians living with fibromyalgia.

As of April 24, 2023, this year's Illumination Campaign has 120 buildings and landmarks supporting "Making Fibromyalgia Visible" by lighting up purple for people with our illness. Many municipalities are issuing proclamations, recognizing May 12th as Fibromyalgia Awareness Day in their province, city, town and village.

The promotion of these buildings and landmarks will have started by the time you receive this Newsletter.



Grand Prairie Sundial, AB

Summerside, PE

Signal Hill, NL

3D Toronto Sign in Nathan Phillips Square, ON

FIBROMYALGIA ASSOCIATION CANADA

FAC Celebrates Mother's Day

May 14, 2023 is Mother’s Day. FAC wishes a Happy Mother’s Day to all mothers. The wish on this Mother’s Day is – happiness. But this is not always the reality, especially for those mothers dealing with fibromyalgia. Having a chronic illness like fibromyalgia can often feel like a full-time job: between doctor appointments, treatments and resting during flare-ups, managing your health can take up a lot of time and energy. Add parenting on top of that and it is easy to feel overwhelmed. The good news for mothers with fibromyalgia is that some psychologists report that the children of women with fibromyalgia feel even more loved and closer to their mother. The reasoning behind this is thought to be because you actually spend more time at home with your children in settings that are warm and close, such as reading a book or watching a movie with them. So leave the guilt behind that you are not a good mother and enjoy your day and keep in mind that if you don't take care of yourself first, you won't have anything left to give your child.

In Memory

Fibromyalgia Association Canada (FAC) would like to extend our appreciation for the Memorial gifts received in memory of the late *Arnold Preston, Laureate Chase and Betty Scott.*

FAC extends condolences to their family and friends. These kind donations will be used to support FAC's mission to improve the lives of persons with fibromyalgia.

SYMPTOM

Migraine is a common and disabling disorder, similar to fibromyalgia. A migraine is a primary headache, meaning not caused by a separate medical problem, characterized by throbbing pain typically on one side of the head. It can bring with it sensitivity to light and sound, nausea, and vomiting.

Some people also experience an aura or warning signs of an impending migraine. Auras can be flashing lights or a funny smell. There can be vision loss or a feeling of pins and needles on one side of their face. They may have trouble speaking or coming up with words, as well.

Studies have shown a definite correlation between fibromyalgia and migraine. More than half of all people with fibromyalgia suffer from migraines. Like fibromyalgia, migraine sufferers face stigma, a lack of resources and may never receive treatment. Like fibromyalgia migraine is not a one size fits all problem. Migraine is different for every sufferer, just as fibromyalgia is different for everyone who suffers from it.

Advocacy: Bill C-22

Living with a disability should not mean living in poverty.

Part of FAC's Advocacy Committee's purpose is to promote and safeguard the right of persons with fibromyalgia and the Bill C-22 advocacy campaign does just that. Bill C-22 is an Act to reduce poverty and to support the financial security of persons with disabilities, like fibromyalgia. If you check out JUST the FAC's winter edition you will see that FAC has been busy promoting for people who have fibromyalgia and are living on any type of disability pension.

Bill C-22 is now at the Senate Standing Committee stage, and should be wrapping up soon.

If you still want your voice heard you can go to **https://fibrocanada.ca/en/advocacy/get-involved/bill-c22/** for a list of the Senators on the Standing Committee and a template of an email you can edit to ensure it says what you wish to say.

In the 2023 budget the Government committed $21.5 million to the groundwork for the development of the Canada Disability Benefit. FAC is encouraged by this commitment, however FAC will be looking for a more substantial commitment to the actual funding of the benefit in the fall economic statement after the Bill receives royal assent. Once Bill C-22 receives royal assent FAC will be advocating to the Minister of Finance to push for this commitment.

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Advocacy: Bill C-22

The list of Amendments FAC would like to see for Bill C-22 are:

1. **Increase the amount of paid and volunteer work allowed for beneficiaries of the Canada Disability Benefit.**
2. **Integrate conversations about National Pharmacare into the debate and deliberation about the Canada Disability Benefit.**
3. **Look at the effect of turning 65 for beneficiaries of the Canada Disability Benefit.**
4. **The text of Bill C-22 currently contains no protections against claw backs of the Canada Disability Benefit by the federal government, provincial or territorial governments, and/or private insurance companies. Claw backs must be addressed in Bill C-22 or the Canada Disability Benefit will not work as intended.**
5. **Appeal rights must be included in the Bill. Dispute resolution should be accessible, timely, and transparent**
6. **The application process should be simplified and people with disabilities who already qualify for pre-existing provincial or territorial disability programs should automatically qualify for the Canada Disability Benefits. It should be easy for those who are not already on other programs to apply directly for the Canada Disability Benefit.**
7. **The benefit amount must be high enough to raise disability income above the poverty line above the poverty line and should include the cost of living with a disability.**

Migraine World Summit

Fibromyalgia and migraine are conditions that often occur together. Fibromyalgia Association of Canada recently partnered with the Migraine World Summit to promote this year's migraine education event, which took place March 8-16, 2023. Migraine and headache diseases are under-diagnosed, under-treated, and poorly managed throughout the world, just like fibromyalgia. The Migraine World Summit works to amplify conversations about education, advocacy, and self-management of this debilitating disease.

The Migraine World Summit empowers attendees to have important conversations with their healthcare provider and apply their new knowledge to make lasting improvements in their health and in their life. Each year, 32 experts in migraine and headache diseases are interviewed about topics selected by the community. This year, areas of interest included research and treatments, practical advice, general migraine information, and the mind-body connection.

Extending the conversation on available treatments, speakers answered questions about medication overuse headache and the safety of dihydroergotamine (DHE), triptans, and certain supplements. Non-drug treatments were discussed, like yoga, green light therapy, digital health apps, and neuromodulation devices.

In addition to tackling research and treatment, interviewees provided practical advice to aid in migraine management. This involved guidance on the best ways to speak with a primary care provider about migraine, recommendations for dietary changes, tips on how to avoid or plan for visits to the emergency room, and real-world data from Migraine Buddy app users. The importance of lifestyle factors like social support, sleep, and routine were also emphasized.

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Migraine World Summit

There were many sessions that answered more general migraine questions. Some speakers responded to questions about migraine symptoms, prevalence, and disability; patterns in disease progression; and how to get back from chronic to episodic migraine. Experts from Europe and Asia spoke about migraine prevalence, regional triggers, and treatment availability. Additionally, topics and conditions related to migraine were covered, including sleep problems, the brain-gut connection, and continuous post-traumatic headache.

Several speakers focused on mental health and its connection to migraine. Experts talked about a variety of behavioral therapies, including mindfulness, and how each can each be used to manage migraine. One interview focused on the science of brain retraining, the role our thoughts and emotions play in our own pain perception, and pain reprocessing therapy. Other sessions addressed the connected issue of stigma. Migraine-related stigma, just like fibromyalgia stigma, is often a problem in healthcare, the workplace, the migraine community, and personal relationships. This was the focus of a talk, as well as the role of self-advocacy in combating this stigma. Another speaker discussed migraine issues in the LGBTQ community.

This year, the Migraine World Summit helped raise more than $20,000 in donations for charities, foundations, and organizations. This brings the total to over $165,000 since its inception. The Summit takes place each March and is available for free in its entirety when it is live. You can find more information and watch eight interviews for free at http://www.migraineworldsummit.com?afmc=j6

If you choose to make a purchase using this link, 50% of your purchase price will be donated to Fibromyalgia Association Canada.

MIGRAINE WORLD SUMMIT

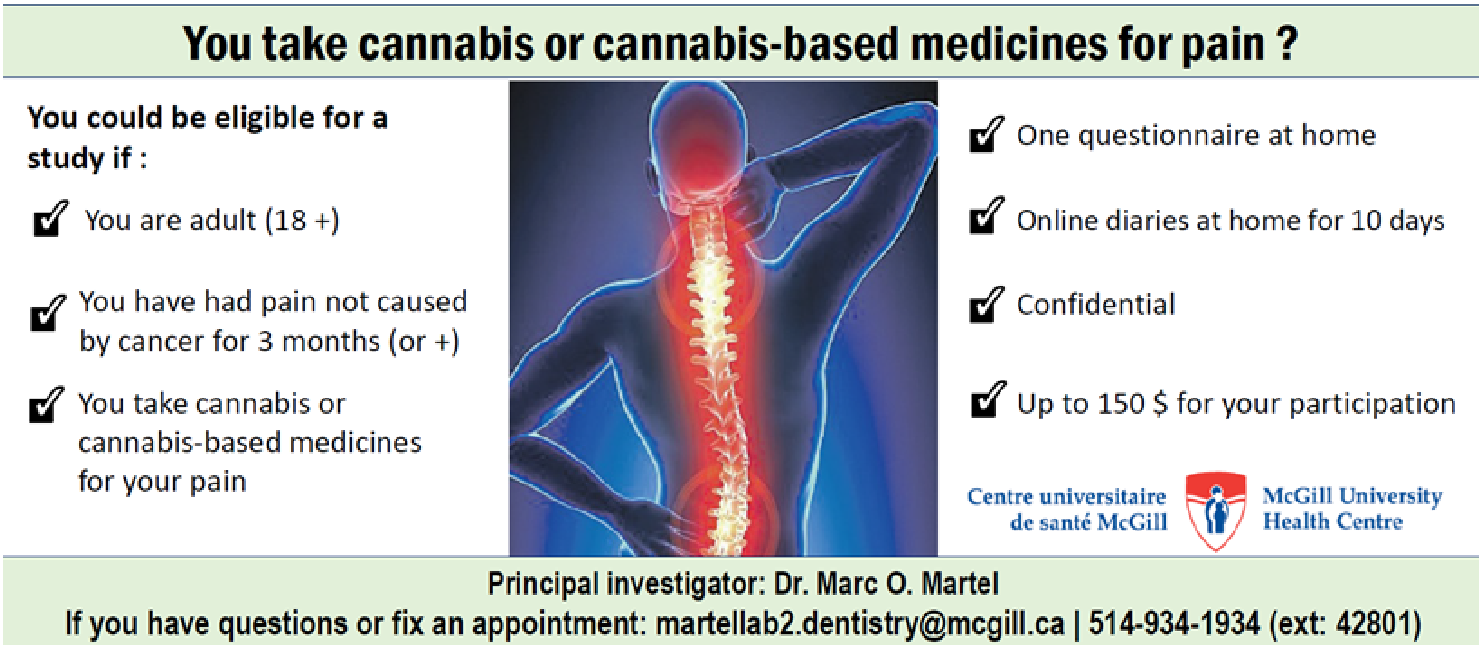
Featured Research

Cannabis and Daily Outcomes in Chronic Pain

Institute: ***McGill University***
Principle Researcher: ***Dr. Marc O Martel and Dr. Mary-Ann Fitzcharles***

This completely remote study aims to look at the effects of taking cannabis daily on chronic pain and related outcomes. The study consists of a phone call to confirm eligibility, a baseline questionnaire done once at the beginning of the study, and 10 days of daily electronic diaries completed using an app on the smartphone.

For more information go to https://fibrocanada.ca/research/participants-wanted/current/



You take cannabis or cannabis-based medicines for pain ?

You could be eligible for a study if :

- ☑ You are adult (18 +)
- ☑ You have had pain not caused by cancer for 3 months (or +)
- ☑ You take cannabis or cannabis-based medicines for your pain

- ☑ One questionnaire at home
- ☑ Online diaries at home for 10 days
- ☑ Confidential
- ☑ Up to 150 $ for your participation

Centre universitaire de santé McGill
McGill University Health Centre

Principal investigator: Dr. Marc O. Martel
If you have questions or fix an appointment: martellab2.dentistry@mcgill.ca | 514-934-1934 (ext: 42801)

BOOK REVIEW on “8 Steps to CONQUER CHRONIC PAIN” by Dr. Andrea Furlan

Dr. Furlan is a Canadian physician who specializes in treating pain. She has just published the book “8 Steps to Conquer Chronic Pain, A Doctor’s Guide to Lifelong Relief”.

This book is written in layman’s terms, simplifying the complexity of medical jargon into easy concepts described in words, pictures and enhanced with patient cases as examples. It is an easy-to-read book that outlines how you must change to change your pain. The overall steps are likened to climbing the mountain to conquer pain which is broken down into eight steps.

Dr. Furlan starts by explaining in easy-to-understand terms what pain is, the different types of chronic pain and the multiple different ways one needs to live better with pain.
Fibromyalgia is an example of “nociplastic pain”, a relatively new classification of pain. In people with fibromyalgia their pain system is malfunctioning.

The analogies used throughout the book help the reader to understand the concepts needed to understand chronic pain and how to manage it. It is an interactive book where she invites the reader to record items in a journal as you read the book. There are QR codes throughout the book which enable easy access to Dr. Furlan’s YouTube videos for further information.

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BOOK REVIEW on “8 Steps to CONQUER CHRONIC PAIN” by Dr. Andrea Furlan

The Key Concepts are highlighted in text boxes for easy reference and the book is fully indexed for finding information quickly. At the end of each chapter there is a Conclusion page that lists the key points in that chapter which gives a nice review. There is also a chapter-by-chapter list of references and resources for additional reading.

Dr. Furlan provides information on how to talk to your doctor about your pain. She tackles the tricky situations around opioids with how to prepare for difficult conversations with your doctor about starting, decreasing or stopping opioids.

Fibromyalgia is described as a type of chronic pain throughout the book. “Conquer Chronic Pain” discusses the importance of body movement and the positive effects movement has on improving your quality of life living with pain. It is important to pace and start low and go slow.

This is an excellent book for people living with chronic pain and their caregivers as well as for anyone wanting to understand what chronic pain is and how to manage it.

Review by Janice Sumpton, (person living with chronic pain, Pharmacist Emeritus)
March 31, 2023

Featured Research

Perceived Origins of Chronic Pain: A Cross-Sectional Survey of Canadians Living with Chronic Pain

Institute: ***McMaster University***
Principle Researcher: ***Dr. Andrew Jin***

The purpose of this study is to better understand the etiology of chronic pain in Canada and to characterize the demographics of Canadians living with chronic pain, including symptomatology, utilization of health services, and perceived treatment responses. Current data we have was collected almost 30 years ago, outside of Canada. We believe this information is very important to prevent and manage chronic pain effectively.

For more information go to
https://fibrocanada.ca/research/participants-wanted/current/

Hi, we are Jin, Sepehr, Navroop & Maurice, from **McMaster University**, conducting research study to learn more about the **Origin of your pain**!

Please copy/click URL Link below or
Take screenshot of QR code and in Gallery,
click ◉ on iphone or 'Go to website' on android.

Calling all **adult Canadians** that live with **pain for more than 3 months**.

Will you give us about **10-25 minutes** of your time to fill out an **Anonymous, Online survey**?

https://surveys.mcmaster.ca/limesurvey/index.php/835666?lang=en

Any questions or issues, please contact: jina7@mcmaster.ca

McMaster University

CRCHUM
CENTRE DE RECHERCHE
Centre hospitalier de l'Université de Montréal

UQAT
UNIVERSITÉ DU QUÉBEC EN ABITIBI-TÉMISCAMINGUE

This study has been reviewed by the Hamilton Integrated Research Ethics Board under Project # 15867. En Ver 3.0 (Modified Date: February 13, 2023)

Education Campaign Networking with Support Groups

Part of FAC's Purpose is to bring together people with fibromyalgia from across Canada and our next Campaign "Networking with Support Groups" will help us achieve this goal. FAC would like to identify all our Canadian Support Groups and create a directory / map so all people living with fibromyalgia will easily be able to find a support group in their area. FAC would also like to identify gaps across the country where no support groups presently exist and assist in creating new groups. As part of the Education Campaign FAC would also like to collaborate with all the Support Groups to find ways we can work together to reach and educate as many people across Canada as possible.

If you are aware of any Support Groups in your province or area that are not listed on the FAC Resource list at https://fibrocanada.ca/resources/fm-support-groups-across-canada/ please contact education@fibrocanada.ca

If you are aware of any Support Groups that are listed on the FAC Resource list that are no longer active please contact education@fibrocanada.ca

Stay tuned for more updates on this next Campaign.

Featured Research

Patient's Perspective and Experiences Regarding Fibromyalgia

Institute: ***University of Coimbra, Portugal***
Principle Researcher: ***Prof. Pereira da Silva***

This study aims to learn more about the clinical manifestations, life events, and disease burden that people with fibromyalgia usually experience.
The Researchers are seriously concerned that many of the symptoms and sources of suffering by patients with fibromyalgia are commonly overlooked and undervalued, both by peers and care physicians. As such, their main goal lies in learning more about the clinical manifestations, life events, and disease burden that people with fibromyalgia usually experience.

For more information go to
https://fibrocanada.ca/research/participants-wanted/current/

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Featured Research

The Chronic Pain Centre of Excellence for Canadian Veterans: Veterans' Coping with Chronic Pain and Related Issues: Cannabis Users and Nonusers (VECTOR)

Institute: ***Hamilton Health Sciences***
Principal Investigator: ***Vikas Parihar, PharmD, RPh***

This study will examine any differences in chronic pain and mental health conditions in Canadian Veterans who are current, past, or never users of medicinal cannabis. The questionnaires will take you approximately 30 to 60 minutes to complete.

For more information go to https://fibrocanada.ca/research/participants-wanted/current/

FIBRO FAC's

Episodic Disabilities are life-long conditions of a relapsing and remitting nature for which there is no cure Fibromyalgia is considered to be an episodic disability because people with fibromyalgia can fluctuate between having days where they can function and days when they can't leave their bed (flare). The duration and severity of a fibromyalgia flare (disability) will vary.

Mississauga Civic Centre Clock, ON

Featured Canadian Support Group

Featured Support Group: ***Fibromyalgia Awareness Network***
Admin: ***Catherine Taylor***

What made you decide to start a support group?

When I was diagnosed with fibromyalgia in 2007, I felt isolated and alone with limited resources to draw on. After a year of struggling through on my own, my doctor told me about a 7-week course on fibromyalgia being sponsored through the Canadian Arthritis Society. I signed up immediately. Through this course I learned valuable information on available treatments at that time and various ways to help manage it. I made a few new friends and their support went a long way to easing the loneliness that surrounds this condition. Fibromyalgia robbed me of many things and I was left with a feeling of powerlessness. I've long believed that knowledge is power and I set out to help others with fibro by providing them with education and support. Above all, I wanted to create a safe, non-judgmental space to share common experiences and feelings.

Is it rewarding?

Yes, very much so. I'm an empathetic, giving person and helping others has always been gratifying for me.

What are your challenges?

Growing membership has been a challenge. We're small at 250+ members. However, sometimes the smaller groups allow for a closer-knit group that come to think of each other as extended family members.

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Featured Canadian Support Group

How did you get members?

Mostly word-of-mouth and a blog that I wrote.

How did you make people aware that you exist?

When I first started the group, I'd been a member of a local fibromyalgia support group that met in person. Many of them joined my group that time. I used to have a fibromyalgia blog and my readers learned of my support group that way.

What services do you offer?

We're pretty old-school, lol. The group's mission statement is to educate those with fibromyalgia and their families. It's focused on promoting awareness of FMS, exchanging information, education, as well as acting as a support group for people living with fibromyalgia. We're a trusted place to come and vent and receive a virtual hug from folks who understand. Recently we held our first Zoom meeting for those interested in deepening their online friendships.

What is the best way for people to contact you?

Facebook, Messenger and my email is provided if asked for.

How do members help out with your group?

One way is by inviting others to join the group. Members often share posts and provide support and friendship. If I don't have an answer to a specific question, I can rely on someone within the group to respond with their own experiences.

FIBROMYALGIA ASSOCIATION CANADA

Volunteering

Want to volunteer somewhere fun, where you can share your talents, your passions, and your interests in a supportive environment?

Fibromyalgia Association Canada (FAC) wants you to participate at your own pace, in a safe space, where we understand one another because of our lived experience.

You can help support yourself and others with Fibromyalgia as you contribute when you can and in whatever way you can. There is absolutely no pressure.

You can be on a committee of your choice, volunteering in a positive space.

Join FAC today.

It is free and you do only what you can when you can.