

# Just THE FAC'S

**Sinéad O'Connor**  
1966 - 2023



*"Fibromyalgia is not curable, but it's manageable. I have a high pain threshold, so that helps—it's the tiredness part that I have difficulty with. You get to know your patterns and limits, though, so you can work and plan around it. It is made worse, obviously, by stress. So you have to try to keep life quiet and peaceful."*  
- Sinéad O'Connor

SUMMER 2023 | Issue 09



## FAC Celebrates Fibromyalgia Awareness Week

During the week of September 5th to 12th, we recognize fibromyalgia and all who experience this illness.

Fibromyalgia Awareness Week is an important time to educate and raise awareness about this chronic condition. It aims to shed light on the challenges faced by Canadians who suffer from fibromyalgia.

### 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/>**





# Fibromyalgia Awareness Week

Throughout Fibromyalgia Awareness Week FAC will have live speakers and some recorded presentations. So far, we will have Disability Lawyer David Brannen presenting live at 12 pm ET on September 5th, 2023 and Dr. Alia Norman from the Cannabinoid Medical Clinic in Newfoundland presenting live at 2 pm ET on Friday September 8th 2023. The complete schedule will be provided in a future email to FAC members and advertised on the FAC website and Social Media.



September 5th to 12th, 2023



## FAC AGM NOTICE

NOTICE is hereby given that the 2nd Annual General Meeting of Fibromyalgia Association Canada will be held on Monday, September 11th, 2023 at 2:30 pm ET on Zoom. Please mark the date on your calendar and a formal notice will be sent out by email, not less than 21 days prior to the meeting. Once you accept the invitation to attend the AGM you will be sent the Zoom link and Agenda. The Agenda will also be on our website and Social Media.





## Meet the Board

Hello my name is Natasha Flynn. I am one of the FAC Board members, the Chair of the Awareness Committee and the Chair of the Social Media Committee.

I was diagnosed with fibromyalgia and ME when I was 8 years old. Now that I am older, my ME is mild and is controllable most of the time. My primary illness is my fibromyalgia. It affects most things that I do.

I find exercise helps me control my fibromyalgia. What has worked best for me is gentle interval running (alternating between walking for a set time and running for a set time). My flare ups are challenging because while the exercise helps, my worst symptom is often fatigue, which makes it hard to push myself to exercise.

I am an Electrical Engineer and I work full time. There are times that I have a fibro flare and I need time off to recover, but fortunately my employer has been understanding and accommodating.

My interests are volunteering, reading, making crafts, swimming, exercising and my pets.





# International Pain Awareness Month

## September 2023

International Pain Awareness Month brings pain professionals and advocates together to raise awareness about chronic pain.

The International Association for the Study of Pain's (IASP) focus this year is the importance of individualized, multidisciplinary and multimodal approach to pain care.

### How to participate

- **Educate yourself about your condition.** People living with fibromyalgia live with a spectrum of symptoms with the predominant symptom being pain. The more you learn about the condition the better equipped you are to live well with fibromyalgia.
- **Spread the word.** Awareness about fibromyalgia can lead to more support, education and research about the cause(s) and management of fibromyalgia. Support and share social media posts to raise awareness and help create a better future for the management of fibromyalgia.
- **Talk to your doctor/nurse practitioner and other health care providers about fibromyalgia.** You can help them to help you. Medical and nursing students receive very little formal education about fibromyalgia.
- **Support a cause.** Donate your time or money to a pain organization like Fibromyalgia Association Canada (FAC) [www.fibrocanada.ca](http://www.fibrocanada.ca). You can make a difference. Contact the association to see how you can help. Every bit counts. Together we can make a difference.





# FIBROMYALGIA ASSOCIATION CANADA

## FACes of Fibromyalgia Campaign

It is through awareness campaigns like FACes of Fibromyalgia that we, as people with fibromyalgia, can challenge stereotypes, break down barriers, and promote understanding of how devastating life with fibromyalgia can be. Ultimately, raising awareness is essential for building a better future for those of us with fibromyalgia, but FAC needs your help to raise this awareness and break down those barriers that we experience. FAC needs your selfie to keep the FACes of Fibromyalgia Campaign going. Don't be afraid to share your face for fibromyalgia.

**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](mailto: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*





## Advocacy: Bill C-22

The ground-breaking *Canada Disability Benefit Act* received Royal Assent on Thursday, June 22, 2023. Bill C-22 will come into force no later than one year after this date.

This time period will help to ensure that the government establishes the necessary regulatory framework to administer the benefit and that eligible recipients receive the benefit as soon as possible.

While it is far from perfect, this is a huge moment to celebrate after years of advocacy by the disability community. FAC was happy to see that many of our community's concerns were addressed in the new bill. Much of the work remains in setting regulations that will finalize the details of this much needed benefit.

In the spirit of “Nothing Without Us” and as required by the Act, collaboration with and feedback from persons with disabilities will be essential in the development of the Canada Disability Benefit Regulations.

There will be two phases of engagement. During the regulatory design phase, there will be a series of engagement opportunities to inform the design details and implementation of the new benefit, as well as the drafting of the Regulations.

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## Advocacy: Bill C-22

These include:

- **August 2023:** An information session will be held with disability stakeholders to establish a common understanding of the regulatory process.
- **September 2023:** Technical roundtables and bilateral meetings will be held to bring together the views of experts, stakeholders, and persons with disabilities on key areas under the regulations.
- **Fall 2023–Winter 2023:** There will be an online survey and portal for open submissions to gather input from all Canadians.

The second, more formal, phase will begin with the publishing of proposed Regulations in Part I of the *Canada Gazette*. Canadians will be able to review and provide comments on the proposed Regulations. The Government will then analyze the comments received and may make changes to the Regulations in response to the feedback received before finalizing them. The final Regulations will then be published in Part II of the *Canada Gazette*, at which time they will become official.

In parallel to the regulatory process, there will be engagement and discussions with provincial and territorial governments, who are critical partners in developing the Canada Disability Benefit. The focus of this work will be on optimizing benefit interaction to ensure persons with disabilities have more money in their pockets at the end of each month.





# Patient Engagement

Patient engagement or the involvement of patients in research refers to the active involvement of patients, their families, and caregivers in the design, implementation, and evaluation of research studies. Patient Engagement recognizes the valuable insights and perspectives that patients bring to the research process, as we are experts in living with our conditions and our experiences with the health care system. This collaborative team approach aims to ensure that research is patient-centered, addressing the needs and priorities of patients thus creating stronger research.

Patient engagement can take various forms, such as involving patients in research planning committees or advisory boards, conducting patient interviews or focus groups to gather input on study design and outcomes, or having patients participate as co-researchers.

What patient engagement is not is patients participating in the research study. For example a patient partner would help develop survey questions they would not answer the survey questions. A research participant would answer the survey.

There are many benefits to patient engagement. It enhances the quality and relevance of research by ensuring that it aligns with patients' needs and preferences. Patients can provide valuable insights on what outcomes matter most to them and their communities or suggest improvements in study procedures based on their experiences. It promotes inclusivity by giving a voice to those who are directly affected by the condition being studied.

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# Patient Engagement

Patient Engagement empowers patients as partners rather than passive recipients of healthcare. Moreover, patient engagement fosters transparency and trust between researchers and participants. By involving patients in decision-making processes related to research protocols or informed consent materials, researchers demonstrate respect for patient autonomy and build stronger relationships with participants and their communities.

The PxP Conference advertised in the next article is an opportunity to learn more about patient engagement and available patient resources.

Sign up at <https://pxphub.org/>





# PxP September 2023: For Patients, By Patients

## *Partnering to make research stronger*

You are invited to join the very first PxP (For Patients, By Patients) conference. This FREE, virtual event aims to bring you all kinds of knowledge, skills and resources on Patient Engagement in any kind of health research. The conference has been designed specifically for patients and other people with lived experience, no matter their experiences as a patient partner, and is entirely led by patients too. Every topic and speaker on the program were chosen by our experienced international committee of patient partners.

Conference dates: September 12-14.

Learn more and register here: <https://bit.ly/PxP-Register>

Day 1, Boost your skills: the what, why and how of patient engagement in health research.

Day 2, Trailblaze new approaches: advancing health research innovation with patient partners or as a patient partner.

Day 3, Strengthen patient partnerships: raising the benchmarks for best practice.

Follow PxP on Twitter,  
Instagram and LinkedIn.  
Email: [contact@pxphub.org](mailto:contact@pxphub.org)  
Event hashtags:

**#PxPHub #PxP23**



**For Patients, By Patients**



# David Brannen and Resolute Legal

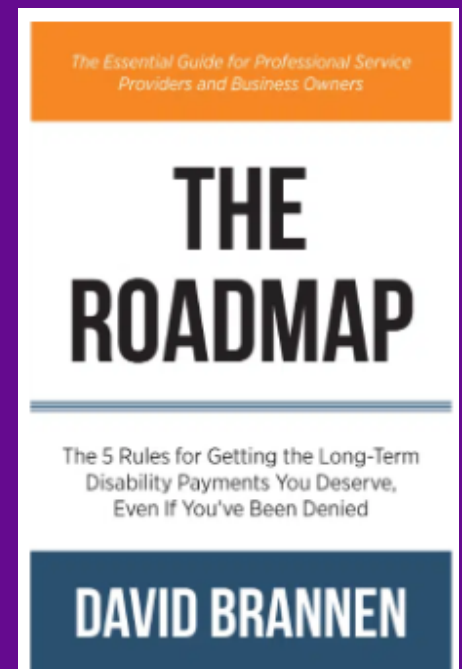
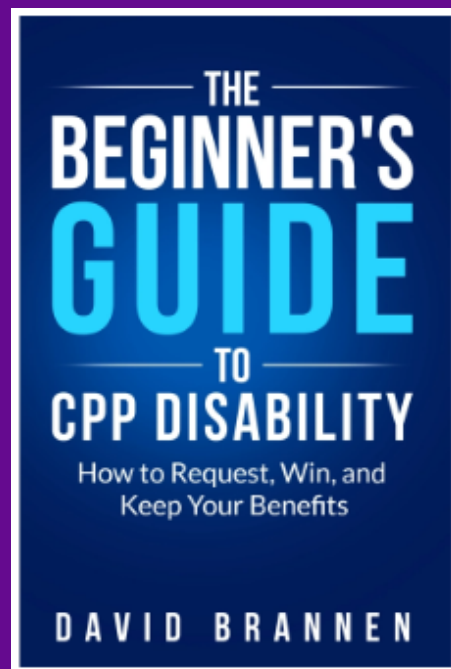
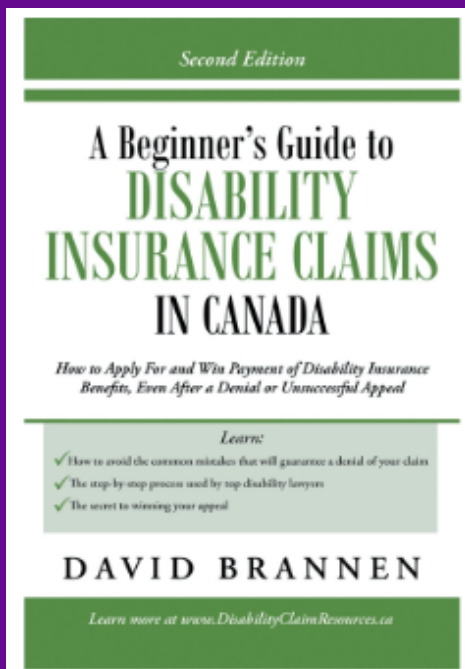
FAC is collaborating with Resolute Legal Disability Lawyers, to provide educational information regarding disability benefits for all members of FAC.

David Brannen, will be doing a Fibromyalgia Awareness Week presentation for FAC.

He is a former occupational therapist and is the author of several consumer books on winning disability claims in Canada. His firm focuses exclusively on representing people in disability claims, including long-term disability, CPP disability, workers' compensation, disability tax credit, and disability-related employment wrongful termination.

<https://www.resolutelegal.ca/>

<https://www.resolutelegal.ca/learning-centre/>





## James Lind Alliance

Research objectives should be focused toward advancing knowledge that has a meaningful impact on health. However, research agendas are mostly driven by the health care community, with limited input from patients.

The James Lind Alliance (JLA) is a non-profit making initiative which brings patients, caregivers and clinicians together in Priority Setting Partnerships (PSPs) to first identify and then prioritize unanswered questions about an illness and / or the effects of treatments that this group of people agrees are the most important. This information helps ensure that those who are funding health research are aware of what matters to patients, their caregivers and clinicians since they are the end users of any funded research.

In 2014, the Canadian Institute of Health Research (CIHR)'s Institute of Musculoskeletal Health and Arthritis (IMHA) and the James Lind Alliance (JLA) set up a PSP to identify the unanswered questions about the management of adult fibromyalgia from patient / caregiver and clinician's perspective and then prioritize into the top ten that patient/ caregivers and clinicians agreed were the most important. This PSP was completed in 2016.

To see the top 10 Priorities go to https:

[//www.jla.nihr.ac.uk/priority-setting-partnerships/fibromyalgia-canada/top-10-priorities.htm](https://www.jla.nihr.ac.uk/priority-setting-partnerships/fibromyalgia-canada/top-10-priorities.htm)

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## James Lind Alliance

**Fibromyalgia Association Canada has reviewed each of the top Fibromyalgia Top 10 Priorities and wondered how many of these have actually been researched. We will be posting one question with the appropriate research in every Just the FAC's newsletter.**

### Priority Question # 1

Can early targeted/personalised treatment plans based on sub-grouping and/or staging of severity improve outcome for people living with fibromyalgia?

**If you want to see the research on this question, go to <https://fibrocanada.ca/en/research/top-research-priorities/james-lind-alliance/>**

**Scroll to the bottom of the page and click on Priority# 1 to find the research associated with this question.**





# 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](mailto: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](mailto:education@fibrocanada.ca)

Stay tuned for more updates on this next Campaign.





# Featured Canadian Support Group

**Featured Support Group: *Fibromyalgia Canada***

**Admin: *Dawn Drouin***

## ***What made you decide to start a support group?***

Around 2011, I started dealing with debilitating widespread pain, brain fog, fatigue, and depression. My doc at the time ran a gamut of tests but they all were coming back normal so he diagnosed Fibromyalgia. I scoured the internet trying to find information on this disease and at that time, there wasn't much. I decided to create Fibromyalgia Canada so I could share my experiences with others dealing with the same thing. I needed more information! I wanted to help others going through the same thing I was. And boy, was I surprised and grateful for the responses.

## ***Is it rewarding?***

Absolutely! I felt vindicated! I didn't feel alone any longer. And the new members were piling in and they were so grateful for the connection with others suffering.

## ***What are your challenges?***

We have TWO major rules. You **MUST** be Canadian and you cannot profit within the group. At the beginning we had multilevel marketers trying to sell their cures and they got sneaky but by private messaging our members, I put a stop to that and now it's a major question when joining. I also created a group just for sales called Easing Fibro:

<https://www.facebook.com/groups/fibrocanbiz/>

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## Featured Canadian Support Group

### *How did you get members?*

I don't quite remember. I think I advertised in some other fibro groups.

### *How did you make people aware that you exist?*

To be honest, once members started coming, it didn't stop. Today we still get about 10 new members per day. We have over 6400 members.

### *What services do you offer?*

Mostly information. For example, government programs and how to access them. We also accept organizations that are doing studies to participate in the group to better research this disease and finding a cure.

### *What is the best way for people to contact you?*

[fibrocan@gmail.com](mailto:fibrocan@gmail.com)

<https://www.facebook.com/groups/288281227967863>

### *How do members help out with your group?*

I have admins that have been with me for over 10 years. The members are the most important aspect of the group! They bring their experiences, stories, solutions, and most of all support to the new members.





## SYMPTOM

People with fibromyalgia who are heat sensitive can be adversely affected by high temperatures and the barometric pressure.

Hot weather and humidity can cause a person with fibromyalgia to experience increased pain and a flare of other symptoms. Changes in temperature and the barometric pressure can increase fibromyalgia symptoms. It is important that people who live with fibromyalgia are not exposed to prolonged heat.

People with fibromyalgia can experience these symptoms with hot weather:

- swollen hands and feet
- nausea and dizziness
- heat sensitivity
- excessive sweating
- headaches
- dry mouth
- fatigue
- increased pain
- rashes



Ensure you always carry ice water in a refillable insulated tumbler. Wear comfortable breathable light clothing, have a personal fan, and ice packs on hand if necessary.





## Featured Research

**Institute: Lancaster University UK**

**Principal Investigator: Oliver Baldwin**

*Please note  
that this study  
is English only*

**For more information go to**

**<https://fibrocanada.ca/research/participants-wanted/current/>**

**Are you a male living with a diagnosis of fibromyalgia and would like an opportunity to be involved in research?**



### Experience of fibromyalgia in young men.

My name is Oliver and I am conducting research as a student in the Clinical Psychology Doctorate programme at Lancaster University, Lancaster, England.

#### What is the study about?

The purpose of this study is to explore the experiences of young men who have a fibromyalgia diagnosis. There is little to no research that set out to specifically explore the broader lived experiences of young men with fibromyalgia.

This study will therefore look to address this gap and provide an opportunity for young men with fibromyalgia to talk openly about their experiences.

#### Who can take part?

- You must be male
- You must be between 18-34 years of age
- You must have received a diagnosis of fibromyalgia from a healthcare practitioner



## Summer Reads

Summer is often a time to rest and relax with a book. Take some time to check out FAC's website for books suggested by FAC members. Click the the following link:

<https://fibrocanada.ca/en/resources/books-community-picks/>

If you want more details about a book then click on the book. Many of the books are available in various formats on Amazon.ca. If you are interested in purchasing a book please consider ordering directly from the link since FAC may receive a small commission at no extra cost to you.

If there are any books you would like to recommend that are not listed, please click the "Have a book suggestion? Let us know" button on the bottom of the page (see link above).

Happy reading!

### FIBRO FAC's

**People with fibromyalgia may have trouble regulating their body temperature and be unable to adapt to temperature changes. This can cause a lower pain threshold related to both hot and cold temperature exposures. Hot and cold temperature changes can also lead to a flare of other fibromyalgia symptoms.**





## Featured Research

**Institute:** *Queen's University, Kingston Ontario*

Please note  
that this study  
is English only

For more information go to

<https://fibrocanada.ca/research/participants-wanted/current/>

- Do you have chronic pain?
- The Stroman Lab at Queen's University in Kingston, Ontario is currently recruiting participants for an fMRI study of chronic pain and fibromyalgia.





# Chronic Pain?

**We are looking for volunteers to participate in a research Study:**  
*Investigating the neurobiological basis of heightened pain and dysfunction in fibromyalgia, by means of functional magnetic resonance imaging*



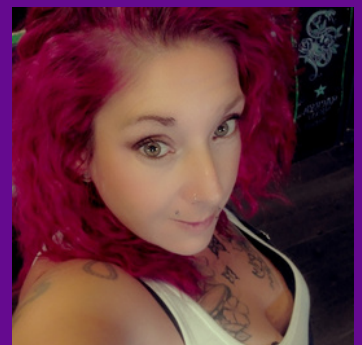
We are looking for males and females (19 to 65 years old) to participate in a research study using magnetic resonance imaging (MRI) to investigate chronic pain. We need people with chronic pain, and people without chronic pain for comparison.

**Do you have constant pain in multiple places in your muscles or joints?  
Do you often have fatigue, sleep problems, trouble concentrating?**

**If you have some or all of these problems, or none at all, and may be interested in participating, to get more information please email [StromanLab@queensu.ca](mailto:StromanLab@queensu.ca)**

**Participants with fibromyalgia or chronic pain will be compensated \$60 for their time/inconvenience and participants without chronic pain will be compensated \$40**

This study has been reviewed for ethical compliance by the Queen's University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board.





# Migraine Canada

Migraine Canada is a young national charity founded in late 2018 to support the migraine community. It is the only national, volunteer-based charity focused on supporting all Canadians impacted by migraine and other headache conditions.



## How are Fibromyalgia and Migraine Related?

Migraine is characterized by severe, often “pounding”, head pain, nausea and/or vomiting and sensory hypersensitivity. It can be a life altering and debilitating condition. Dizziness, vertigo, cognitive difficulties, and neck pain are common with migraine attacks. Migraine often significantly impacts quality of life, mental health, relationships, social interactions, and workplace productivity.

Migraine and fibromyalgia share common symptoms:

- head pain
- sensitivity to light and noise
- nausea

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## Migraine Canada

In some studies, over 30% of people with migraine also had fibromyalgia and almost 56% of people with fibromyalgia had migraine. There are close links between fibromyalgia and headaches, as tension type headaches and migraine are some of the most common fibromyalgia symptoms. Having fibromyalgia can make migraine more severe.

Recognize that features thought to be tension or sinus headache are often migraine. If you have a diagnosis of fibromyalgia and have many of the symptoms associated with migraine but migraine has not been diagnosed, keep a diary (see [Migraine Canada's website](https://migrainecanada.org/)). By tracking the number and intensity of your attacks, you can share with your primary care provider for consideration that you may also have migraine.

It is not “normal” to live with daily head pain.

<https://migrainecanada.org/>





## Featured Research

**Institute:** *Laval University Quebec City*

**Principal Investigator:** *Tania Augière*

Please note  
that this study  
is French only

For more information go to

<https://fibrocanada.ca/research/participants-wanted/current/>

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et de services sociaux  
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LAVAL

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Centre interdisciplinaire  
de recherche en réhabilitation  
et intégration sociale

Fonds de la recherche  
en santé  
Québec

## Vous vivez avec la fibromyalgie?

Dans le cadre d'une étude visant à évaluer l'impact de la douleur sur la perception de l'environnement et du corps durant des tâches de perception visuelle et de stimulation tactile, nous recherchons des participants vivant avec la fibromyalgie.

### Pour participer vous devez:

- Être âgé(e) de 18 ou plus
- Avoir un diagnostic de fibromyalgie
- Avoir une vue normale ou corrigée
- Pouvoir vous déplacer au centre pour deux rencontres

🕒 Première rencontre **1h30** et deuxième rencontre **2h**, séparées d'une semaine  
 📍 Centre de recherche le **CIRRIIS**, 525 boulevard Wilfrid Hamel, Québec (QC), G1M2S8 ou **AFIM**,  
 911 rue Jean-Talon Est, Montréal (QC), QC H2R 1V5  
 🚗 Une compensation financière vous sera offerte pour couvrir les frais de déplacement



- Ne pas avoir subi d'opération chirurgicale dans les 3 derniers mois
- Ne pas être atteint(e) de troubles neurologiques
- Ne pas avoir de blessures sur les membres supérieurs (brûlure, hématome etc.)



## Volunteering

FAC is currently seeking persons with fibromyalgia to fill the role of Regional Representatives for every province and territory in Canada.

Regional Reps will play a very important role in Campaigns such as the Illumination Campaign and the Education Campaign "Networking with Support Groups".

The role is not difficult and does not require a lot of time, with only one meeting per month. Any other work can be completed by email.

If you are interested please go to [https://fibrocanada.ca/en/members/volunteer/?sheet\\_id=14](https://fibrocanada.ca/en/members/volunteer/?sheet_id=14) and sign up.

FAC would love to have you.

Together we are Stronger.

