

I am not **FAKING**  
**BEING ILL,**  
I am **FAKING**  
**BEING WELL!**

Just  
**THE FAC'S**

FALL 2022 | Issue 06



## FAC Recognizes Invisible Disability Week

Invisible Disability Week is October  
16th to 22nd, 2022.

Fibromyalgia is an invisible disability.

**Just because you can't see it,  
doesn't mean it's not real!**

### 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/](https://fibrocanada.ca/application-form/)



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# FAC Recognizes Invisible Disability Week October 16 -22, 2022



**An invisible disability is a disease or illness that others can't see. It brings an extra layer of stress to a health-challenged life.**

**Invisible conditions can be just as disabling as visible conditions – oftentimes more so – but they don't get the empathy or credibility that visible conditions get. When people can't see the disability, they tend to diminish the severity of the disability. That can be really difficult for somebody who's actually going through it because research suggests that those who have a strong support network actually have better outcomes.**

**Fibromyalgia is an invisible medical condition. People with fibromyalgia put on a smile and try to push through the pain when we are around people. We want to live & be ourselves ... but then everyone thinks we're fine!**

**People need to learn not to make assumptions. Just like FAC's "FACes of Fibromyalgia", we may not look like we have a disability but we certainly do. Something the general public needs to know is when you see someone in the mall, on the bus, in the store, even if they are young, they may still be dealing with a disability.**





# FIBROMYALGIA ASSOCIATION CANADA

## FACes of Fibromyalgia Campaign 2022

The "FACes of Fibromyalgia" Campaign is continuing.

Open to anyone with fibromyalgia:

- Take a headshot photo of yourself
- Include name or initials & city/town & province
- Submit your photo & information via email to [admin@fibrocanada.ca](mailto:admin@fibrocanada.ca)
- FAC will add your photo to a photo montage "FACes of Fibromyalgia" on social media & FAC website
- Emailing your photo is considered consent/authorization for use of your image and likeness by Fibromyalgia Association Canada for the "FACes of Fibromyalgia" campaign





## Meet The Board

**Hi Everyone,**

**I'm Suzy and welcome to our fall newsletter. Thank you for being here!**

**I hope your summer went well and your flare kit was well stocked. I know the extreme heat brings on challenges for many of us. I live in Fort McMurray, Alberta, which has a hot and dry summer climate, so I am grateful to be in a place where the summer weather is manageable.**



**Suzy Groenewegen**

**I moved to Fort McMurray from Ottawa in 2018 for work, but shortly after I moved out west I became ill. I had to take a medical leave in 2019 and it remained permanent. My background is in social work and developmental services. I started my career working with at risk children and youth who were wards of the Children's Aid Society. I then transitioned into helping people of all ages who either had a serious medical condition, a developmental delay, autism, and/or a psychiatric condition.**

**It is in my nature to help, so I knew once I became ill I needed to find a way that I could still fill my purpose. When I learned about Fibromyalgia Association Canada in 2021 I was eager to join. I knew I wanted to be part of a community that helps others access the necessary resources they need to manage their life with fibromyalgia as best as possible. In late spring of 2021, I took on the role of the Regional Representative for Alberta and became a board member. I also co-lead the Advocacy/Awareness meetings.**

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## Meet The Board

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Besides volunteering for FAC, I also volunteer with the senior's society. I love dogs, so I dog sit or dog walk as often as I am able to. I practice yoga and I love to paint, so when time and energy allows, these are the activities I find myself drawn to.

I hope you have an activity you enjoy to help you get through these extreme Canadian temperatures. Feel free to reach out and let us know what your coping strategies are. Your suggestion could save someone's day!

*Suzy Groenewegen*



## FIBRO FAC's

If you have fibromyalgia, a well-run support group can provide an important network for talking to others living with the condition.

The support groups that provide the most benefit are those with an educational component.



## **FAC Celebrates International Men's Day**

**On November 19 International Men's Day celebrates worldwide the positive value men bring to the world, their families and communities.**

**Did you know? Men get fibromyalgia, too. Men with fibromyalgia aren't actually that rare! This is a misconception. However, men with Fibromyalgia often go undiagnosed.**

**Fibromyalgia is a common condition. That means many men are diagnosed as well. Fibromyalgia is much more common in men than previously thought. Men have been thought to represent about 10-20% of fibromyalgia cases. However, newer studies suggest it may be higher, with men making up at least 30% of all fibromyalgia sufferers. It's estimated that as many as 4.8 percent of men worldwide have fibromyalgia – but this may still be a low estimate.**

**As fibromyalgia has been considered, historically, a “women's disease,” physicians erroneously think that men don't get fibromyalgia. They may neglect or may be reluctant to consider this diagnosis when a man presents with chronic widespread pain. Often, men are treated for low back pain – that doesn't account for their other complaints. And/or a man may wish to avoid the stigma of a diagnosis of a predominantly female condition.**

**This can cause problems for men who are living with it – both in getting a diagnosis and in finding support.**

**One high profile patient is actor Morgan Freeman, who has said, “I only get one life, and I will not let fibromyalgia take the joy of living it.”**

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# FAC Celebrates International Men's Day

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Why has there been vast underestimation of how many men have fibromyalgia? It turns out the way people have been diagnosed since 1990 – a tender point exam (an exam developed from studying women) – is not as accurate in men, hence, men are less likely to be diagnosed with fibromyalgia even if they meet the diagnostic criteria. Furthermore, men are less likely to go to the doctor with their complaints.



The stigma associated with having fibromyalgia is real. Men with fibromyalgia feel they have a “women’s disease.” They may also feel stigmatized as “wimpy,” “whiney,” or “lazy,” when they complain of fibromyalgia symptoms, such as tiredness and muscle pains.

Everyone with fibromyalgia faces the misconception that they’re crazy, lazy, or both. When a man has a debilitating pain condition, people may also view him as weak and think especially badly of him if he doesn’t have a job. He may view himself this way as well. (Women are not exempt from these issues.)

Societal expectations and stereotypes of men pose their own problems as well. Our society has certain expectations of men and specific, narrow ideas about what it means to be masculine. Males are socialized from a young age not to reveal or express their feelings and fears. They are told to “just suck it up and keep going.” They are taught by society not to cry, to “stop being babies,” to “man-up.”

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# FAC Celebrates International Men's Day

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**They learned how to hold the sensation of pain on the inside. Men are supposed to be hard-working, tough and oblivious to pain. When the cycle of pain goes on every day, week, month, year, it makes the "If I just ignore it, it will go away" approach seem ridiculous. It is tempting for a man who has fibromyalgia to see himself as inadequate or not manly anymore. Some report feeling like they've failed as a husband, father, and provider. It's a huge blow to the ego to be knocked down with what's considered a "women's condition."**

**This may result in taking longer to get a proper diagnosis. The longer men put off seeing the doctor, the more they put themselves at risk of developing complications that can affect their work, their hobbies, and their relationships. Depression is not uncommon among men who have delayed getting a diagnosis.**

**The well-known fact that men are less likely to seek counseling or attend support groups suggests that men may experience even greater isolation.**

**If you suspect you have fibromyalgia, bring it up to your doctor, as he or she may not consider it because they are accustomed to thinking of it as a woman's illness.**

**If your doctor dismisses the idea based on your gender, you may need to be persistent about it or see another doctor.**

**Also, remember that illness or seeking mental health counselling to deal with these issues is not a weakness. It may help you overcome mental and emotional barriers to getting better.**



## Annual General Meeting

Fibromyalgia Association Canada (FAC) held its first Annual General Meeting on September 12, 2022.

Trudy Flynn, Chair of FAC, introduced the Board of Directors, their position and where they live. Trudy presented the Chair Report to the members, followed by Maggie O'Brien with the Financial Report.

At the FAC AGM the present Board of Directors was confirmed, the Financial Report was accepted, and the By-Laws were accepted. The Annual General report was reviewed and that wrapped up the official portion of the AGM. The Business meeting was adjourned and a Question & Answer period and Meet & Greet followed.

FAC would like to thank all our members who attended the FAC AGM and for all the discussion that was had following the meeting.

FAC has accomplished so much since February 2021 and looks forward to all that will be accomplished in 2023.





# Fibromyalgia Awareness Week

After much lobbying by Fibromyalgia Association Canada (FAC), Health Canada officially recognized September 4th to 11th as National Fibromyalgia Awareness Week. It was posted on Health Canada's Calendar of Health Promotion Days at <https://www.canada.ca/en/health-canada/services/calendar-health-promotion-days.html>.

FAC used Fibromyalgia Awareness week to shine a spotlight on fibromyalgia, some of its symptoms and how difficult it is to live with this condition.

During Fibromyalgia Awareness Week FAC highlighted eight of the most common symptoms of fibromyalgia starting with "Pain" and included "Fatigue", "Fibro Fog", "Migraines and Headaches", "Hypersensitivity to Light, Noise, Touch, & Smell", "Irritable Bowel Disease", "Insomnia" and finished with "Intolerance to Cold and Heat". You can find these symptoms highlighted on our various media platforms.

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# Fibromyalgia Awareness Week

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Another Awareness strategy FAC highlighted was “FACes of Fibromyalgia”. FAC created and released a video highlighting the people who live with Fibromyalgia and sent their photo in for the “FACes of Fibromyalgia” campaign. These people wanted to show their face to raise awareness and garner support for everyone living with fibromyalgia. To continue to raise awareness, FAC has decided to continue this campaign year-round, so please, keep sending in your photo if you haven't already.

Thanks to our membership, FAC continues to grow and will continue to raise awareness of this chronic debilitating condition throughout the year.





## SYMPTOM

A study by the National Institute of Health in the United States determined that a significant number of patients with fibromyalgia reported problems with swallowing. Patients in the study reported suffering from dysphagia, or difficulty swallowing at a rate 40% higher than people without fibromyalgia.

Unfortunately, the reason this sort of symptom is common in people with fibromyalgia remains a mystery.

There's so much that we don't know about how fibromyalgia works, including why it would cause dysphagia.





## Featured Canadian Support Group

The "Fibromyalgia Support Group of Winnipeg, Inc." is a non-profit, charitable organization that was established in 1991 (later becoming incorporated in 1992), by a small group of people who have fibromyalgia. At that time little information was available and it took many years for a diagnosis to be made. The group's mission was, and still is, to educate those with fibromyalgia, their families, health care professionals and the general public as well as to promote research. While fibromyalgia is becoming more recognized and people are being diagnosed sooner it remains a difficult frustrating condition to have and to treat.

The Group is located at 825 Sherbrook Street in Winnipeg, Manitoba. We are an umbrella group of the Manitoba Possible Clearing House.

We meet monthly, excluding January, July and August. At our meetings we have guest speakers who present on any topic that could pertain to fibromyalgia. We also provide a newsletter to our membership 3 times a year and have an extensive lending library consisting of books and videos. We also teach a course, "Taking Charge of Fibromyalgia" which is very informative and helpful especially for those newly diagnosed.

To reach us you can call the office at 204-975-3037 or email us at [info@fmswinnipeg.com](mailto:info@fmswinnipeg.com) All of this information and more, can be found on our website [www.fmswinnipeg.com](http://www.fmswinnipeg.com)

**FIBROMYALGIA**  
The Invisible Disabling Illness

975-3037

The Fibromyalgia Support Group of Winnipeg, Inc.

- ▶ monthly support meetings
- ▶ newsletter
- ▶ information resources

[www.fmswinnipeg.com](http://www.fmswinnipeg.com)



## Featured Research

"Intimacy with Chronic Pain" is designed to understand what intimacy means to those living with chronic pain and how people with chronic pain experience intimacy while dating.

To participate in the study you must be:

- At least 18 years old;
- Have been living with chronic pain for at least three months; and
- Have been actively dating in the past three months.

We know that chronic pain affects people at many different stages of life. We have tried to make the study as inclusive as possible and welcome those who are single and partnered. For us, dating is simply planning an activity that allows you to connect with a partner or date.

If you are interested in participating, please contact [mary.jessome@ubc.ca](mailto:mary.jessome@ubc.ca)

Thank you for your insight. Our research is impossible without you."

Ethics ID: H22-01916



**Dr. Tony Silva**



**Mary Jessome**



## 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; others say they understand but we live it, so we get it!

You can help support yourself and others with Fibromyalgia as you contribute when you can, how you can. 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.

