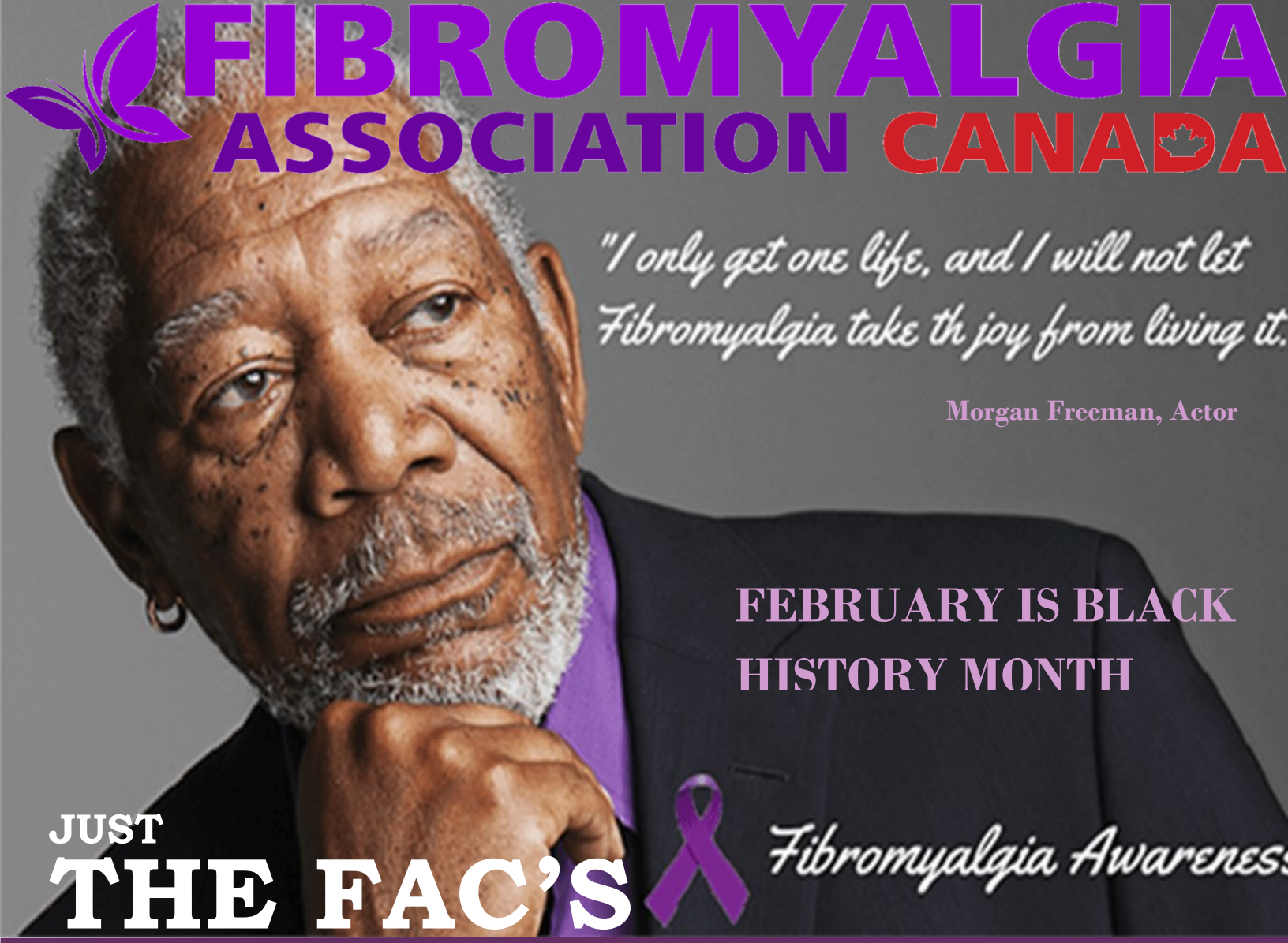
FIBROMYALGIA ASSOCIATION CANADA



JUST THE FAC'S

FEBRUARY 2022 | ISSUE 1 | NEWSLETTER

COLLECTIVE VOICE

Welcome to the first issue of Fibromyalgia Association Canada's Newsletter, *Just the FAC's*. A newsletter is a great way to promote engagement, & communication with our members.

But it comes with a catch: we need a wide readership. Please feel free to share with your family, friends, and caregivers. If you are reading this and are not a member of FAC, please join us: https://fibrocanada.ca/en/membership/application-form

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Participants wanted for CircaPain study. More information on website

DOULEUR CIRCA PAIN

Message from the Chair

Welcome to Fibromyalgia Association Canada's (FAC) premiere newsletter. This month marks one year since a group of like-minded people came together to question why fibromyalgia does not have its own national voice and FAC was formed. FAC wants to represent all people with fibromyalgia across Canada. Every Board Member of FAC has fibromyalgia.

My name is Trudy Flynn, and I am the Chair of FAC. I am a medically retired nurse from Nova Scotia. I was diagnosed with fibromyalgia almost 30 years ago. My road to advocacy began with a Clinical Trial. In 2014 to 2016 I was part of the Steering Committee for the Canadian Institute of Health Research (CIHR) - James Lind Alliance Adult Fibromyalgia Priority Setting Partnership, (more on this in the Research summary). I was a fibromyalgia patient advocate at the Canadian Pain Summit in Toronto in 2016 where I was invited to join the Research Ambassador team at the CIHR's Institute of Musculoskeletal Health and Arthritis (IMHA).

In 2018 I became an IMHA Patient Engagement Research Ambassador working to incorporate patient engagement (PE) in the research process. In 2019 I joined the Maritime SPOR Support Unit (MSSU) set up by CIHR to promote and participate in PE in the Maritime Provinces. I am on the Scientific Leadership Committee and Patient Partner Council at the MSSU as well I participate in various research studies.

I home school my grandson (grade 10) and I am the Vice Chair of Run Nova Scotia. I love to run with my daughter, and it helps keep our fibromyalgia symptoms manageable. Yes, my youngest daughter has fibromyalgia. She was diagnosed at 8 years of age. When we run, we must do interval running, where we run for a period of time, (which changes depending on how we feel). I love to geocache, hike, bike, and kayak. I have a puppy named Walter who helps to get me out for a walk every morning.

We will accomplish more together, the larger our membership the more power we have. If you are not a member of FAC already please consider joining us here https://fibrocanada.ca/en/membership/



Trudv Flvnn with Walter at Pockwock waterfall in Nova Scotia.

Advocacy

The Fibromyalgia Association Canada's (FAC) Advocacy Committee members have collaborated to develop an advocacy plan which will eventually lead to engaging communities to raise awareness, which will in turn advocate for systemic change on behalf of all Canadians living with Fibromyalgia. We are engaging with others to build alliances and coalitions to further our goals. Through understanding our public policies and legal processes we can better navigate the political landscape to succeed.

This advocacy plan involves a process of first educating ourselves and others by producing documents and graphics that are shared to social media and our website we have created knowledge about the basic & latest information on fibromyalgia.

First, knowing your rights as a patient, and how to access health care to obtain a suitable treatment plan are all key factors in your overall health. Our committee has created information on How To Be Your Own Advocate, the FM Patient's Bill of Rights, Health Legislation in Canada, and How To Talk to A Politician. These are the first in a series of how-to articles that will begin to build our advocacy foundation.

Awareness

The Fibromyalgia Association Canada's (FAC) Awareness Committee has made steady progress since forming in 2021.

First, we would like to share some exciting news. We have partnered with the United Kingdom to join them in their annual National Fibromyalgia Week, taking place the second week of September. We hope to create more recognition and understanding about fibromyalgia and its effects by forming relationships with other fibromyalgia associations as more spring up across the globe.

The FAC Awareness Committee prepared letters for the Members of Parliament in all Canadian provinces and territories to bring attention to FAC's purpose and mission. We are incredibly pleased to note that a few members of parliament from various provinces responded to our letters and are interested in supporting our cause.

Last, but not least, the Awareness Committee prepared an informative introduction about FAC for a provincial newsletter distributed to doctors across Prince Edward Island. We hope to to do the same for other provinces and territories. Stay posted for next month's update where we will share more progress.



Purple Awareness Ribbon

The Fibromyalgia Ribbon is purple as it means to show support for fibromyalgia awareness.



Education

Over the last six (6) months, the Education committee has been hard at work collecting and assessing reliable information from credible sources, both from patient and medical perspectives, to understand what fibromyalgia is. We shall continue to pass them on to you via our website in the form of articles and/or videos. The goal of the Education committee is to de-stigmatize fibromyalgia by providing virtual and in-person patient-led workshops for educating physicians, healthcare workers and providers, as well as the fibromyalgia community and support groups across Canada. We will be developing educational materials which could be passed on to your loved ones or medical team to increase theIr understanding of fibromyalgia.

Collectively with other committees, we will create a list of Myths and Facts images, to debunk the myths and misconception of fibromyalgia. We would like to encourage you, your family and/or caregiver to write or record (video) your story to share on our website. A patient story is YOUR experience in your own words. By sharing your story, it will help others understand how living with a difficult and painful condition like fibromyalgia can be. It plays a role in your journey toward physical and psychological healing. It will also make others feel less alone.



Brain Fog

Fibromyalgia goes beyond pain. It can also affect your thinking ability and memory, a symptom called Fibro Fog, and your energy level, leaving you with extreme fatigue. Fibro Fog, also known as Brain Fog, is a common way to describe the brain-related problems that can occur with Fibromyalgia.

FIBRO FAC'S

Currently, it is estimated that over 1,155,000 million people in Canada have been diagnosed with Fibromyalgia.

Research

The Fibromyalgia Association Canada's (FAC) Research Committee has been busy since its inception in the spring of 2021. In June of last year, two Research Committee members attended the Fibromyalgia Congress, sponsored by National ME/FM Action Network. The considerable knowledge gained from the Congress is still forming the direction of the Research Committee's work. The articles on the FAC website on drugs and potential causes of fibromyalgia are summaries from the Congress and there will be more articles from this even in the future.

From 2014 to 2016, the James Lind Alliance and the Canadian Institute of Health Research set up a project that would identify the top ten priorities or unanswered questions concerning fibromyalgia. FAC's Research Committee is examining these ten priorities and will be posting on the FAC Research website examples of how each of these priorities has been researched. We will begin posting this month, so stayed tuned. Another reason to keep your eye on the Research Section of FAC's website is to check on upcoming Research/ Clinical Trials that will be posted. If you hear of any clinical trial or research study that you think should be the Research section of FAC's website, please contact us research@fibrocanada.ca.

VOLUNTEER OPPORTUNITIES

COMMITTEE MEMBERS

REGIONAL REPRESENTATIVES

Bring your skills, strengths, talents, & work at your own capacity