# FIBROMYALGIA ASSOCIATION CANADA

# Annual General Report 2022-2023

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# Letter From The Chair

*Trudy Flynn*

Dear Members,

Welcome to Fibromyalgia Association Canada's Annual General meeting. It is so nice to have you here with us today.

The seeds of Fibromyalgia Association Canada (FAC) were formed when two individuals had a phone call during Covid and discussed the fact that fibromyalgia, as an illness, did not have its own national association. Fibromyalgia was an add-on to other conditions and very little attention was paid to people with fibromyalgia. From that phone call, 15 like minded individuals came together for the very first meeting of FAC in February 2021. FAC has come a long way since that meeting and today we are becoming a well recognized National Association for fibromyalgia.

Researchers are reaching out to FAC from around the world asking FAC to share their research and to help them recruit participants for their research studies.

**FAC advocated for Bill C-22 and many of our recommendations were incorporated into the Final Bill.**

**On May 12, 2023, 133 buildings and landmarks lit in purple to help FAC raise awareness of fibromyalgia and Fibromyalgia Awareness Day. Proclamations were given in many towns and cities across Canada declaring May 12th as Fibromyalgia Awareness Day.**

**Well known organizations recognized Fibromyalgia Awareness week 2023, even though it is only the 2nd year it has been held in Canada.**

**FAC has come a long way and I would like to thank the Board of Directors and all our Committee members who have helped us achieve so much in just 2 ½ years. The success of FAC could not have happened without your hard work.**

**Thank you again for attending our AGM.**

***Sincerely,***
***Trudy Flynn***
***Chair***
***Fibromyalgia Association Canada***

# Chair Report

**One of the joys of preparing an annual report is that it gives me the opportunity to look back and appreciate all that Fibromyalgia Association Canada (FAC) has accomplished in the past year.**

**FAC is an organization that is entirely run by volunteers with fibromyalgia. We do not have paid staff, so all the work accomplished is done by people who know the challenges that people with fibromyalgia face on a daily basis because they face those challenges themselves.**

**FAC is a national association and represents all of the fibromyalgia community across Canada. We are committed to being a national association for all Canadians, regardless of where they live, what language they speak, and their accessibility needs. With the help of volunteer translators, we are able to provide a bilingual (English and French) website.**

# Chair Report

This AGM covers the time period of September 1, 2022 to August 31, 2023. Next year FAC will be holding the AGM on May 27, 2024 to move it closer to the end of FAC's fiscal year, March 31st. The FAC AGM will continue every year after to be on the last Monday in May.

FAC has accomplished a lot this past year, which will be covered in the Committee reports, and hopes to accomplish even more in the year ahead. FAC now has a strong Strategic Plan which will guide us in the best direction for the fibromyalgia community.

FAC is always looking for help. I would ask everyone to get involved by joining one of FAC's committees or simply following us on our Social Media (X which was formerly Twitter, Facebook, Instagram and LinkedIn) and sharing our posts. That in itself is a valuable contribution. The more our posts are shared the more people we reach.

Thank you everyone and remember together we are stronger.

# Board of Directors

**Chair**
Trudy Flynn
Halifax, Nova Scotia

**Vice Chair**
Mario Domingue
Northbay, Ontario

**Treasurer**
Maggie O'Brien
LaSalle, Ontario

**Executive**
Angela McAlduff
Waterford, Prince Edward Island

**Research Co-Chair**
Janice Sumpton
London, Ontario

**Awareness Chair**
Natasha Flynn
Halifax, Nova Scotia

# How It All Began

Fifteen like-minded people came together in February 2021 with a shared vision to bring attention and positive change to the needs of those with fibromyalgia.

We realized there was a lack of treatment, support, knowledge and no national voice for fibromyalgia.

Subsequently, Fibromyalgia Association Canada (FAC) was created.

We identified five key areas of focus:

- Awareness
- Research
- Education
- Advocacy
- Finance

# What Is FAC?

## Our Purpose Is To Make Fibromyalgia Visible By:

- Bringing together persons with Fibromyalgia from across Canada;
- Strengthening our presence and influence with government decision-makers;
- Using our experiences with fibromyalgia symptoms to increase medical interests and investments in Fibromyalgia-focused research; and
- Offering patient-led educational opportunities to those interested in learning more about the impact of fibromyalgia on one’s quality of life and daily living

## Mission:

**To build one unified national voice to advocate for fibromyalgia for increased awareness, research, education, funding and improve the quality of life for Canadians with fibromyalgia.**

# Financial Update

## Basic Operating Budget per Annum

| Name of Expense | Amount of Expense |
|---|---|
| **Insurance** | **$1753.92** |
| **Web Hosting Canada Website** | **Paid until May 15, 2026** |
| **Zoom** | **$230.00** |
| **Bank Monthly Fee** | **$59.40** |
| **Domain Name** | **$11.87** |
| **Ontario Non-Profit Network (ONN)** | **$113.00** |
| Total | $2168.19 |

# Financial Update

## September 1, 2022 to August 31, 2023

| Total Revenue | $1175.00 |
|---|---|
| **Total Donations** | **$ 1175.00** |
| Total Expenses | $2977.55 |
| **Web Platform Web Hosting Canada** | **$45.50 (Paid until May 15 2026) (with HostPapa refund)** |
| **Domain Name** | **$11.87 (Donated)** |
| **Zoom** | **$230.00** |
| **Legal** | **$641.33** |
| **Bank Fees** | **$62.40** |
| **ONN** | **$113.00** |
| **Insurance** | **$1885.32** |
| Balance | $562.22 |

# Governance

## Motions

### AGM23-01

### Confirm a Board Member

**I would like to make a motion to confirm the appointment of Natasha Flynn as a member of the Board of Directors.**

### AGM23-02

### Confirm a Board Member

**I would like to make a motion to confirm the appointment of Lina DeMattia as a member of the Board of Directors?**

### AGM23-03

### Accept the Financial Report

**I would like to make a motion to accept the financial report as presented.**

# Awareness Report

**The Awareness Committee meets the third Tuesday of every month at 2:30 p.m. (Eastern Time) to promote awareness on behalf of people living with fibromyalgia.**

## Purpose

- To raise awareness that fibromyalgia is a life-altering chronic illness
- To address and reduce stigmas and stereotypes and to influence changes in attitudes, behaviours, and beliefs toward fibromyalgia
- To raise awareness of fibromyalgia through national campaigns
- To develop social media campaigns in collaboration with the other committees
- To work with other fibromyalgia related groups to raise awareness

## Accomplishments

- Illumination Campaign 2023
- FACes of Fibromyalgia 2023
- Just the FAC's newsletter (quarterly)
- Terms of Reference
- Social Media Campaigns
- May 12th Fibromyalgia Awareness Day
- Fibromyalgia Awareness Week September 5 - 12th 2023

## Goals

### Long Term

- Illumination Campaign to reach 500 buildings and landmarks

### Short Term

- Complete Awareness Calendar
- Patient Stories in Video

**If you would like to get involved, or know more about the Awareness Committee, feel free to contact us at awareness@fibrocanada.ca**

# Research Report

**The Research Committee meets the 4th Tuesday of every month at 2:30 p.m. (Eastern Time) to discover what research is currently being done on fibromyalgia.**

## Purpose

- **To promote and develop fibromyalgia research**
- **To explore past and present studies on fibromyalgia worldwide**
- **To reach out and build relations with:**
  - **Health researchers and clinical trial organizations in Canada**
  - **Professionals and organizations worldwide who are interested in fibromyalgia research**
- **To maintain a list of current Canadian and international fibromyalgia research**
- **To determine where the gaps in fibromyalgia research are**
- **To support efforts to attract financial investments for fibromyalgia research; and**
- **To encourage patient-oriented fibromyalgia research in Canada**

## Accomplishments

- **Worked with the Awareness Committee on the Illumination Campaign 2023**
- **Terms of Reference**
- **Lay Summary of Research study**
- **Research Documents Development**
- **James Lind Alliance Priority # 1**

# Research Report

## Accomplishments

- Promoted Patient Engagement in Just the FAC's Summer Newsletter

## Goals

### Long Term

- Develop a research repository
- Network with international researchers

### Short Term

- Continue to promote fibromyalgia research
- Complete James Lind Alliance project and post results
- Promote clinical trials
- Research blog
- Develop a layman's summary of individual research publications.
- Educate the fibromyalgia community about research results
- Develop a research study score card
- Interview researcher video series for YouTube

**If you would like to get involved, or know more about the Research Committee, feel free to contact us at research@fibrocanada.ca**

# Education Report

**The Education Committee meets the 2th Tuesday of every month at 2:30 p.m. (Eastern Time) to work on educational materials for the fibromyalgia community.**

## Purpose

- To provide patient-led education on fibromyalgia to people with fibromyalgia, their families and caregivers, the medical/healthcare sector, the Insurance companies, legal professionals, businesses and employers, government agencies, community agencies, educational institutions and the general public.
- To educate our target audience on the life altering symptoms of fibromyalgia which often lead to debilitation, disablement, and impoverishment;
- To debunk the myths and misconceptions of fibromyalgia;
- To de-stigmatize fibromyalgia; and
- To emphasize the importance of early diagnosis in order to successfully manage and improve patient outcomes.

## Accomplishments

- Developed the "Federal Government and Community Benefits Programs and Service Resource" for the Website
- Wrote "Fact Sheet for Patient and Families"
- Set up questions for "Networking with Fibromyalgia Support Group Campaign"

# Education Report

## Goals

### Long Term

- Education for patients, new and with lived experience
- Education for healthcare professionals
- Education for healthcare students – University, Medical and Nursing schools
- Education for employers
- Reaching out to family physicians through the Colleges of Physicians and Surgeons

### Short Term

- Provide reliable educational material to the fibromyalgia community, allies and medical sector
- Create Fact Sheets for Employers, Medications, Alternative Treatments, Anxiety, Fibromyalgia in Men, Exercise with Fibromyalgia, Fibromyalgia and Vitamins and Minerals, Fibromyalgia and Depression – how having fibromyalgia can lead to depression, Working with Fibromyalgia, How to Tell Children and Family you have Fibromyalgia, Juvenile Fibromyalgia, Fibromyalgia and Medical Cannabis, Fibromyalgia and Service Dogs
- Networking with Support Groups Campaign to create
    - A completed directory of local support groups including in-person, virtual or hybrid throughtout Canada
    - A directory of areas that don't have groups and assist members to start one.

# Education Report

## Goals

**Short Term:**

- **Support Group Awareness Week Campaign to recognise, celebrate and raise awareness of Canadian Support Groups and the invaluable support they provide. The 2023 Campaign theme is Supported, Included, Connected and will be held October 23rd to 29th.**

**If you would like to get involved, or know more about the Education Committee, feel free to contact us at education@fibrocanada.ca**

# Advocacy Report

**The Advocacy Committee meets the third Thursday of every month at 2:30 p.m. (Eastern Time) to advocate on behalf of people living with fibromyalgia.**

## Purpose

- **To unite people living with fibromyalgia**
- **To improve their quality of life**
- **To promote and safeguard their rights**
- **To network and influence decisions regarding fibromyalgia with government, medical, healthcare, and the insurance sectors**
- **To focus on addressing needs and identify gaps in services for people with fibromyalgia**
- **To collaborate with fibromyalgia-related organizations, associations, foundations, and support groups, so we strengthen our united voice to address the needs of those affected by fibromyalgia**

## Accomplishments

- **Campaigned for changes to Bill C-22 (Canada Disability Benefit Act). This was accomplished by sending emails to MP’s, Senators, and promoting on social media to encourage others with fibromyalgia to use FAC’s template and send their own email.**
- **Worked with the Awareness Committee on the 2023 Illumination Campaign.**

# Advocacy Report

**Accomplishments**

- **Developed an Advocacy Training Guide**
- **Completed the Committee's Terms of Reference**

**Goals:**

**Long Term:**

- **List of OT, PT and Massage Therapists who are fibro friendly**
- **Membership drive**
- **Advocate with Federal and Provincial Health Ministers**
- **Develop a Canadian conference**
- **Advocate with College of Physicians re-educating doctors on fibromyalgia**
- **Advocate for project ECHO**

**Short Term:**

- **Advocate for provincial pain clinics and ketamine injections**
- **Gather information on natural supplements that the Federal Government wants to regulate so FAC can advocate**
- **Look at provincial medical plans and any gaps in those plans (Example Ontario not providing medical care for people in the province of Ontario who don't have an OHIP number).**
- **Fibro Flare Kit**
- **Fibro Journal**
- **Newly Diagnosed Booklet**
- **Bill C-22 Updates**

# Advocacy Report

**Short Term:**

- **Posters for Pain Clinics**
- **Develop an ‘How To’ series: How to talk to your doctor, insurance company, lawyer, etc.**
- **Fibromyalgia Community Conference.**
- **Patient Bill of Rights**
- **Social Determinants of Health**

**If you would like to get involved, or know more about the Advocacy Committee, feel free to contact us at advocacy@fibrocanada.ca**

# Finance Report

**Finance meets second Tuesday of the month at 10 am (Eastern Time).**

## Purpose

- **To provide financial analysis, advice, and oversight of the FAC budget**
- **To ensure the organization is operating with the financial resources it needs to provide programs and services to the fibromyalgia community**
- **To ensure that the transactions of FAC are in accordance with the bylaws**
- **To ensure that the financial, human, and physical resources of FAC are managed economically and efficiently, and the operations of the association are carried out effectively.**

## Accomplishments

- **Financal Document**

## Goals

## Long Term

- **Fund Research**
- **Fund ECHO**

# Finance Report

**Goal**

**Short Term**

- **Charity Status**
- **Financial Document**
- **Funding Document**
- **Accounting Policies**
- **Budget planning**
- **Business Plan**
- **Fundraising**
- **Choose an audit**
- **Choose an Accountant**
- **Investigate Fundraising Software**

**If you would like to get involved, or know more about the Finance Committee, feel free to contact us at funding@fibrocanada.ca**

# Our Accomplishments

## 1 Illumination Campaign

The Illumination Campaign began with the aim of having 30 locations "Illuminate for fibromyalgia". A small group of members managed to have 133 buildings and landmarks "Illuminate for Fibromyalgia". We were truly humbled and emotional on May 12th, when we experienced Canada lighting up for fibromyalgia.

## 2 Bill C -22 Canada Disability Benefits Act

FAC spent most of the year advocating for those of us with fibromyalgia who live below the poverty line and try to survive on Disability Benefits.
Many of FAC's suggested amendments were incorporated into the final Act that received Royal Assent on June 22, 2023.

# Our Accomplishments

## 3 Awareness Week

FAC successfully celebrated Awareness Week with 4 live presenters that were well attended. Well known organizations recognized Fibromyalgia Awareness Week 2023, even though it is only the 2nd year it has been held in Canada.

## 4 Research Studies

FAC helped 28 Researchers find participatns for their research studies. Six of these studies were International Studies

# Social Media Highlights

**1,916**
Followers on Facebook

**953**
Followers on Instagram

**2,550**
Followers on Twitter

**403**
Followers on LinkedIn

# FAC Highlights

**505**
**FAC Memberships**

Increase of 200 since 2022

**163**
**FACes of Fibromyalgia**

Increase of 60 since 2022

**133**
**Buildings and Landmarks Illuminated**

Increase of 43 since 2022

# Strategic Plan

**The FAC Strategic Plan (2023-2028) guides our efforts to improve the health and quality of life for people with fibromyalgia.**

## Mission

To build one unified national voice to advocate for fibromyalgia for increased awareness, research, education, funding and improve the quality of life for Canadians with fibromyalgia.

## Vision

To become a valued organization, recognized nationwide, as a respected voice and reliable resource, for Canadians living with fibromyalgia.

## Values

FAC wishes to become a respected association for Canadians living with fibromyalgia. FAC will be compassionate, transparent, ethical, and respectful of all diversities. FAC will develop collaborations and share our learned knowledge. Together we will be resilient and not give up.

## Strategic Areas and Goals

**FAC's work is focused on five strategic areas designed to support our goal of being a valuable resource for those with fibromyalgia.**

## Awareness

- To raise awareness that fibromyalgia is a life-altering chronic illness
- To address and reduce stigmas and stereotypes and to influence changes in attitudes, behaviours, and beliefs toward fibromyalgia
- To raise awareness of fibromyalgia through national campaigns
- To develop social media campaigns in collaboration with the other committees; and
- To work with other fibromyalgia related groups to raise awareness

## Strategic Areas and Goals

### Research

- To promote and develop fibromyalgia research
- To explore past and present studies on fibromyalgia worldwide
- To reach out and build relations with:
  - Health researchers and clinical trial organizations in Canada
  - Professionals and organizations worldwide who are interested in fibromyalgia research
- To maintain a list of current Canadian and international fibromyalgia research;
- To determine where the gaps in fibromyalgia research are
- To support efforts to attract financial investment for fibromyalgia research and
- To encourage patient-oriented fibromyalgia research in Canada

## Strategic Areas and Goals

### Education

- To provide patient-led education on fibromyalgia to:
  - Persons with fibromyalgia, their families and caregivers:
  - The medical/healthcare sector
  - Insurance companies
  - Legal professionals
  - Businesses and employers
  - Government agencies
  - Community agencies
  - Educational institutions
  - The general public
- To educate our target audience on the life altering symptoms of fibromyalgia which often lead to debilitation, disablement, and impoverishment
- To debunk the myths and misconceptions of fibromyalgia
- To de-stigmatize fibromyalgia, and
- To emphasize the importance of early diagnosis in order to to successfully manage and improve patient outcomes

## Strategic Areas and Goals

### Advocacy

- To unite people living with fibromyalgia
- To improve their quality of life
- To promote and safeguard their rights
- To influence decisions regarding fibromyalgia with government, medical, healthcare, and the insurance sectors
- To focus on addressing needs and identify gaps in services for people with fibromyalgia
- To collaborate with fibromyalgia-related organizations, associations, foundations, and support groups, to strengthen our united voice to address the needs of those affected by fibromyalgia

## Strategic Areas and Goals

### Finance

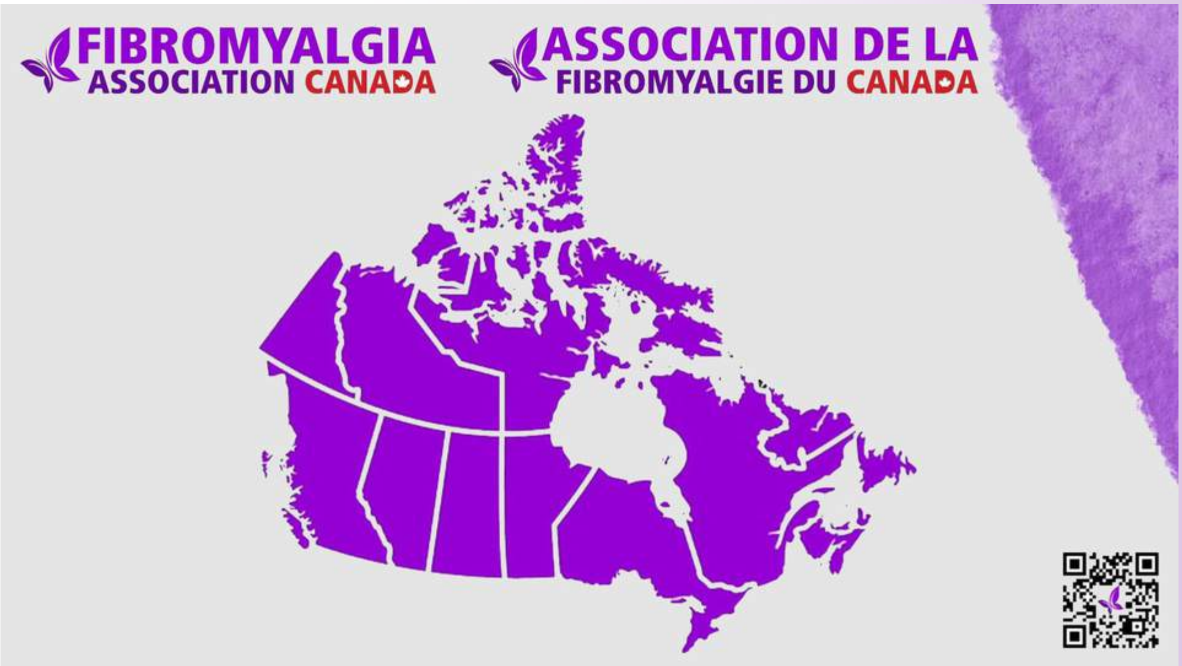
- To provide financial analysis, advice, and oversight of the FAC budget
- To ensure the organization is operating with the financial resources it needs to provide programs and services to the fibromyalgia community
- To ensure that the transactions of Fibromyalgia Association Canada are in accordance with the By-laws and
- To ensure that the financial, human, and physical resources of Fibromyalgia Association Canada are managed economically and efficiently, and the operations of the Association are carried out effectively

# Acknowledgements

**Fibromyalgia Association Canada (FAC)**
**would like to extend its appreciation to those members who have provided support.**

**Thank you to those who have generously contributed by donating to our funding initiative, which assists in building a national fibromyalgia organization.**

**All FAC members are appreciated and valued. We inspire each other.**



**We thank you for your ongoing support of Fibromyalgia Association Canada**

**"We can't do this alone, but we can do it together"**