



FIBROMYALGIA ASSOCIATION CANADA

Annual General Report 2023-2024



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Trudy Flynn

Dear Members,

As Chair of Fibromyalgia Association Canada (FAC), it is my privilege to welcome you to FAC's third Annual General Meeting.

With the generosity and support of our members, we are progressing toward FAC's vision of becoming a recognized nationwide association, with a respected voice and reliable resources for Canadians living with fibromyalgia.

The number of people being diagnosed with fibromyalgia is increasing along with the need for more awareness, research, education, and advocacy. FAC is here to meet these growing demands, provide support and resources for those affected, and drive progress in understanding and managing our condition.

I would like to extend my heartfelt thanks to our dedicated volunteers, and board members. Your hard work and commitment are the backbone of our

organization. Additionally, I want to express my gratitude to our members and donors. Your support enables us to continue our vital work and make a difference in the lives of so many.

Following this Annual General Meeting, I encourage each member of FAC to become engaged and active within the FAC community. Your participation is crucial. Whether through volunteering, attending events, or simply spreading awareness by liking and sharing our posts on social media, every effort counts. Together, we can continue to drive change and offer hope to those living with fibromyalgia.

Thank you for being a part of Fibromyalgia Association Canada. I look forward to an inspiring and productive year ahead.

Sincerely,

Trudy Flynn

Chair

Fibromyalgia Association Canada

Chair Report

Throughout this past year, FAC has continued its unwavering commitment to improving the lives of those affected by fibromyalgia.

The foundation of Fibromyalgia Association Canada (FAC) was laid during a phone call between two individuals amid the COVID-19 pandemic. They discussed the lack of a national association dedicated solely to fibromyalgia, as it was often overshadowed by other conditions and received minimal attention as an add on condition. This conversation sparked action, and in February 2021, 15 like-minded individuals gathered for the first FAC meeting. Since that initial meeting, FAC has made significant progress and has now emerged as a well-recognized national association for fibromyalgia.

FAC is entirely run by volunteers who have fibromyalgia. FAC has no paid staff; all the work is carried out by individuals who intimately understand the daily challenges of living with fibromyalgia because they face those challenges themselves or are partners of someone with the illness who face those challenges.

Awareness, Research, Education and Advocacy remain

Chair Report

the pillars of the Association.

Building an awareness of fibromyalgia is an important aspect of FAC. The Awareness Committee has worked diligently on Awareness Campaigns throughout the year. The Illumination campaign was the most ambitious effort to date and FAC was able to increase the number of landmarks/ buildings illuminating in purple to raise awareness and shine a light on the challenges faced by those living with fibromyalgia.

Researchers continue to reach out to FAC for assistance in recruiting participants for their studies. This ongoing connection with the research community will be crucial in the future, particularly when FAC secures the funding needed to drive its own research initiatives.

Our educational campaigns are making an impact and gaining FAC a reputation for factual information. We have collaborated with healthcare professionals to provide presentations and informational sessions for both members and the public. These efforts have helped educate not only the fibromyalgia community, but also the broader public about the challenges associated with living with fibromyalgia.

Chair Report

Advocacy efforts have been diligently focused on Bill C-22, also known as the Canada Disability Benefit Act, engaging policymakers to secure increased funding and improved healthcare policies for individuals reliant on disability benefits. Through this advocacy, FAC has effectively amplified the voices of those FAC represents. Despite successful advocacy efforts, including recommendations made by FAC and other groups, Bill C-22 was enacted into law with monthly income allocations for disability benefits falling below the threshold advocated for by FAC. This shortfall underscores the ongoing need for advocacy to address the financial challenges faced by individuals living with disabilities such as fibromyalgia. FAC remains committed to advocating for an increase in this benefit, aligning it with the necessary amount for individuals to live above the poverty line in Canada.

As we move forward, our mission remains clear: to improve the quality of life for all those affected by fibromyalgia.

FAC's strength is our community. As Chair of Fibromyalgia Association Canada (FAC), I am reaching out to you with a heartfelt appeal to join us in our

Chair Report

mission to support individuals living with fibromyalgia. FAC is a community-driven organization, entirely run by volunteers who understand the challenges of fibromyalgia firsthand. We rely on the dedication and support of individuals like you to make a difference in the lives of those affected by this condition.

Whether you can spare a few hours to volunteer and work at one of the monthly committees, spare some time to work on our campaigns, share your story to raise awareness, or contribute financially to support our initiatives, every action counts. Your involvement, no matter how big or small, helps us provide essential resources, advocate for better care, and advance research efforts.

Together, we can make a meaningful impact and ensure that individuals living with fibromyalgia feel supported, understood, and empowered. I encourage you to reach out to us and get involved in whatever way you can. Your support is invaluable and deeply appreciated.

Thank you for standing with us in our commitment to make a difference, because 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



Board Member

Janice Sumpton
London, Ontario

Board of Directors



Board Member

Natasha Flynn
Halifax, Nova Scotia



Board Member

Lina DeMattia
Chatham, Ontario



Board Member

Mary Delaney
Kingston, Ontario



Board Member

Sherry Wasdal
Calgary, Alberta

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

\$247.14

Bank Monthly Fee

\$59.40

Domain Name

donated until February 2029

**Ontario Non-Profit
Network (ONN)**

\$113.00

Total

\$2173.46

Financial Update

August 31, 2023 to April 30, 2024

Bank Account	\$837.72
Total Revenue	\$837.02
Total Donations	\$ 837.02
Total Expenses	\$1487.38
Bank Fees	\$62.40
Insurance	\$1885.32
Zoom	\$230.00
Balance	\$187.36

Governance

Motions

AGM24-01

Confirm a Board Member

I would like to make a motion to confirm the appointment of Mary Delaney as a member of the Board of Directors.

AGM24-02

Confirm a Board Member

I would like to make a motion to confirm the appointment of Sherry Wasdal as a member of the Board of Directors

AGM24-03

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. ET 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 2024 – 166 +**
- **Faces of Fibromyalgia promotion**
- **Just the FAC's newsletter (quarterly)**
- **Social Media Campaigns**
- **May 12th Fibromyalgia Awareness Day**
- **Fibromyalgia Awareness Week September 5 – 12th 2023**
- **Symptoms of Fibromyalgia Campaign for social media**

Awareness Report

Goals

Long Term

- **Illumination Campaign to reach 500 buildings and landmarks**
- **Communicate, enhance and underscore FAC's reputation as a trusted source of authoritative, high-quality information about fibromyalgia**

Short Term

- **Maintain Awareness Calendar**
- **Patient Stories in Video**
- **FACes of Fibromyalgia**
- **Set up an Illumination Committee and a project plan**

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 on the 4th Tuesday of every month at 2:30 p.m. ET 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 2024**
- **Worked with the Education Committee on Myths and Facts (supported with links to applicable research)**
- **Lay Summary of Research studies**
- **Intramuscular pressure in Fibromyalgia (2021 Katz)**

Research Report

Accomplishments

- **Passive Transfer of Fibromyalgia symptoms from Patients to Mice (2021 Goebel)**
- **Lay Summary**
- **Assessing Diagnostic Tests – What is Sensitivity and Specificity?**
- **James Lind Alliance Top Research Questions – literature published to answer these questions**
- **Promoted current research on FAC website and on social media to assist in recruiting patients to participate in fibromyalgia-related research**
- **Contributed Research-related information to the FAC Newsletters**

Goals

Short Term

- **Continue to promote fibromyalgia research**
- **Post results for James Lind Alliance project**
- **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**

Research Report

Goals

Long Term

- **Develop a research repository**
- **Network with international researchers**
- **Update 2012 Canadian Fibromyalgia Guidelines**

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



The Education Committee meets the 2nd Tuesday of every month at 2:30 p.m. ET 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

- **Worked on Illumination 2024**
- **Had 1st annual Networking with Fibromyalgia Support Group Campaign**
- **Book List**
- **12 Days of Christmas Social Media campaign**
- **Educational Presentations**
- **Contributed to the newsletter**
- **Fact Sheet on JM Fibromyalgia**

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 your have fibromyalgia, Juvenile Fibromyalgia, Fibromyalgia and Medical Cannabis, Fibromyalgia and Service Dogs, etc**
- **Myths**
- **Networking with Support Groups Campaign to create**
- **A completed directory of local support groups including in-person, virtual or hybrid**

Goals

Short Term

- **A directory of areas that don't have groups and assist members to start one.**
- **Support Group Awareness Week Campaign to recognise, celebrate and raise awareness of Canadian Support Groups and the invaluable support they provide. The 2024 Campaign is being held the last week in October.**

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. ET to advocate on behalf of people living with fibromyalgia.

Purpose

- **Unite people living with fibromyalgia**
- **Improve their quality of life**
- **Promote and safeguard their rights**
- **Network and influence decisions regarding fibromyalgia with government, medical, healthcare, and the insurance sectors**
- **Focus on addressing needs and identify gaps in services for people with fibromyalgia**
- **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 to encourage others with fibromyalgia to use FAC's template and send their own email.**
- **Worked with The Awareness Committee on the 2024 Illumination Campaign.**

Advocacy Report

Accomplishments (con't)

- **Created a self care social media campaign**
- **Fibromyalgia Community Conference**

Goals:

Long Term:

- **List of OT, PT and Massage Therapists who are fibro friendly**
- **Membership Drive**
- **Advocate with Health Ministers Federal and Provincial**
- **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 (research accessibility)**
- **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 OHIP 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 advocate for increased benefits**
- **Posters for membership drive**

Advocacy Report

Short Term: (con't)

- **The How to Series: How to talk to your doctor, insurance company, lawyer, etc.**
- **Patient Bill of Rights**
- **Social Determinants of Health**
- **Pain Chart for Fibromyalgia (non- numerical)**

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 ET

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**
- **The transactions of Fibromyalgia Association Canada are in accordance with the bylaws; and,**

The financial, human, and physical resources of Fibromyalgia Association Canada are managed and operated economically and efficiently.

Accomplishments:

- **Finance Policy**

Goals

Long Term

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



Finance Report

Goals

Short Term

- **Charity Status**
- **Funding Document**
- **Accounting Policies**
- **Budget planning**
- **Business Plan**
- **Fundraising**
- **Choose an auditor**
- **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 166 + buildings and landmarks "illuminate for Fibromyalgia". We were truly humbled and emotional throughout the month of May, when we experienced Canada lighting up for fibromyalgia.

2 Social Media

FAC's social media branding has become highly recognizable and has been praised by other associations as a model for effective brand recognition. It is often said that when you see the FAC branding, you can trust that the information provided is accurate and valuable.

Our Accomplishments

3 Research

The FAC Research Committee completed the James Lind Alliance [Top 10 Priorities for Fibromyalgia Research](#). The Research Committee reviewed all top 10 questions and ensured each one of the questions had been adequately researched both nationally and internationally. These questions along with the Research will be published on the website and in FAC's Newsletters one question at a time until they are all published.



Social Media Highlights

3624

**Followers on
Facebook**



498

**Followers on
LinkedIn**

1076

**Followers on
Instagram**

2967

**Followers on
Twitter**

FAC Highlights

641
FAC
Memberships

Increase of 136 since
September 2023



178
FACes of
Fibromyalgia

Increase of 15 since
September 2023



166
Buildings and
Landmarks
Illuminated

Increase of 33 since
2023

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"