FIBROMYALGIA ASSOCIATION CANADA

Annual General Report

2021-2022

fibrocanada.ca

@FAC2022

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Letter From The Chair

Trudy Flynn

Trudy Flynn stands in front of Halifax City Hall in Nova Scotia May 12, 2022, celebrating the success of "Illuminate Fibromyalgia".

This campaign was made with the intention of celebrating thirty years of Fibromyalgia Awareness.

Welcome to Fibromyalgia Association Canada's first Annual General Meeting.

FAC is a non-partisan, bilingual, national organization representing people with fibromyalgia and committed to making fibromyalgia visible to all Canadians. On June 15th 2021, FAC became a federally incorporated non-profit.

Something that is important for you as to know is that Fibromyalgia Association Canada or FAC is an organization that is entirely run by volunteers.
How often have you heard or even said yourself, it is "just fibromyalgia"?

Our illness is not "just fibromyalgia". Fibromyalgia is painful. Fibromyalgia is extremely fatiguing, fibromyalgia makes it extremely difficult to concentrate and fibromyalgia affects memory and cognitive function. Fibromyalgia is devastating and life-altering to over 2 million Canadians. Our illness is not "just fibromyalgia".

Fibromyalgia Association Canada is here to change the attitude, that it is "just fibromyalgia". We are here to raise one unified national voice to advocate for increased awareness of our illness, to promote and push for more research into our illness and to find a cause and cure. We are here to educate not just those with fibromyalgia, but also our caregivers, the health care community and our governments. Most importantly we are here to raise the quality of life for all Canadians living with fibromyalgia.

Thank you for joining Fibromyalgia Association Canada and being part of FAC's attempt to raise awareness of our illness and fight for our rights.

Sincerely,
Trudy Flynn
Chair of Fibromyalgia Association Canada

Chair Report

Fibromyalgia Association Canada (FAC) is an organization that is in its infancy, run by a small number of volunteers. We are a community-based organization founded by people with Fibromyalgia, for people with Fibromyalgia. I look back over the past year and a half with satisfaction and pride for what we have achieved.

As a national association, we believe it is fundamental that our organization represent diversity, geography and marginalized communities in 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.

FAC became a federally incorporated not-for-profit on June 15, 2021. We are presently in the process of finalizing our Fibromyalgia Association Canada trademark.

Chair Report

FAC has shown many times that we are excellent at being able to pivot and change directions. When an election was called we wrote a letter to all the Leaders of the major political parties and had it signed by as many people with fibromyalgia as possible during the 5 weeks of campaigning. The letter was not just to educate our Federal Leaders but to ask questions trying to keep the Political Parties accountable to the 2 million people across Canada with fibromyalgia.

When the Federal Election was over, we wrote letters and sent them to every newly elected MP across Canada. The letters made sure the MP's were not just aware of fibromyalgia, they were also aware of the newly formed national association called Fibromyalgia Association Canada.

When our members complained about how they were being treated by the health care system, FAC wrote a Fibromyalgia Patient's Bill of Rights, which many of our members took to their doctors and successfully lobbied to be more fairly treated and listened to.

Chair Report

When one member decided to see if they could get a few buildings to light up in purple for May 12th, Fibromyalgia Awareness Day, it turned into an “Illumination Campaign” with the support of most of our volunteers. The Illumination Campaign ended up with 90 buildings lighting up and many towns and cities requesting proclamations to declare May 12th as Fibromyalgia Awareness Day in their communities and their provinces.

When our members asked us how to treat a fibro flare, we developed a downloadable Fibro Flare Kit. When we decided to start a Newsletter “Just the FACs” to educate and reach out to our members, our volunteers stepped up to write articles, interview support groups and spend countless hours designing and formatting this newsletter.

When we were looking for some way to raise awareness, a volunteer suggested a ”FACes of Fibromyalgia Campaign” and our members came through, sending us over a hundred faces for the campaign.

Chair Report

When Health Canada turned down FAC's requests to recognize Fibromyalgia Awareness Month and Fibromyalgia Awareness Day, we lobbied harder until finally they recognized the first Sunday in September to the second Sunday in September as National Fibromyalgia Awareness Week.

When we were deciding how to raise awareness on May 12th, we held a very successful Facebook Live Event featuring Dr. Andrea Furlan. So yes, we do know how to pivot and how to make the best use of our resources. We are proud of FAC and all we have achieved and we hope that you are as well.

Sincerely,
Trudy Flynn
Chair of Fibromyalgia Association Canada

Board of Directors

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Trudy Flynn
Halifax, Nova Scotia

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Awareness Chair
Susy Groenewegen
Fort McMurray,
Alberta

Member at Large
Nina Dikih
London, Ontario

How It All Began

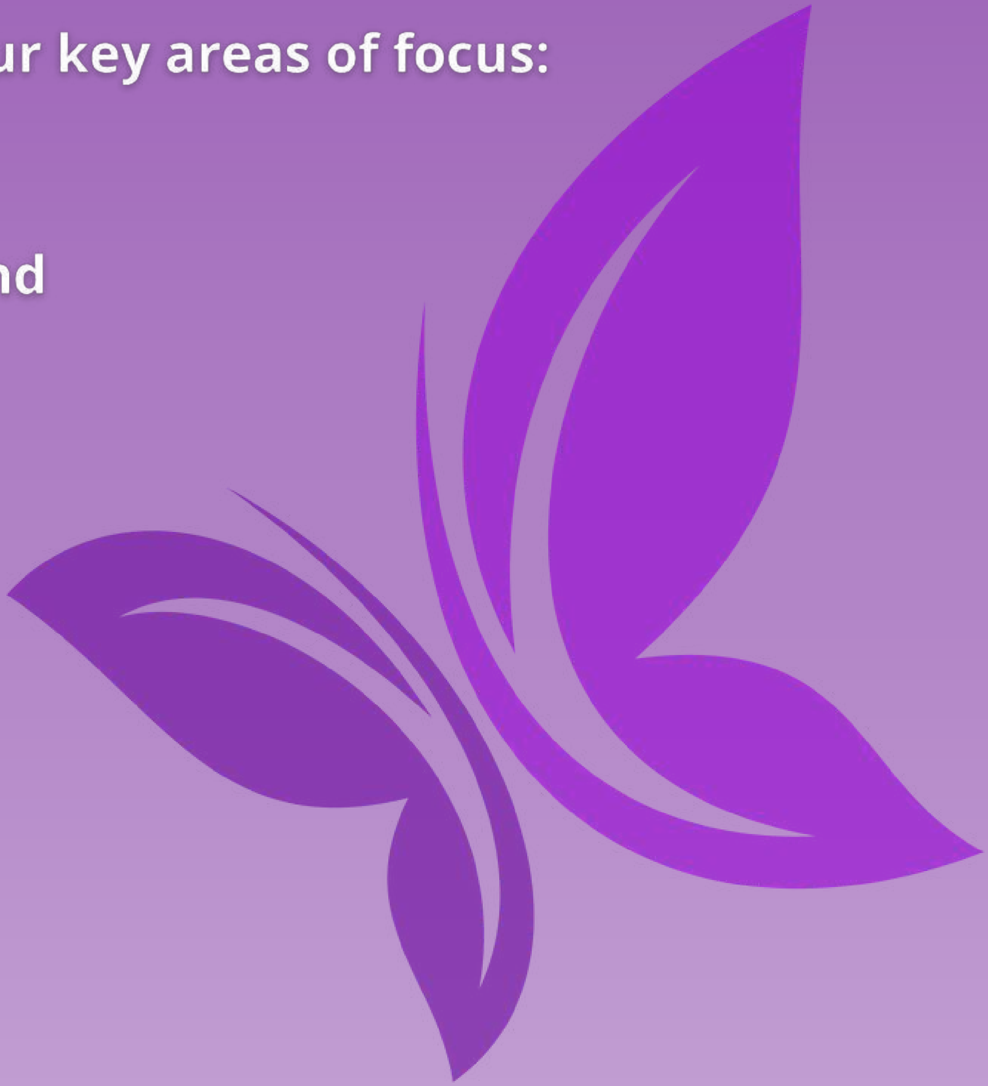
Fifteen like-minded people came together in February 2021 with a shared vision to bring attention and positive change to the needs of those with fibromyalgia.

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 four key areas of focus:

- Awareness,
- Research,
- Education, and
- Advocacy.



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

Our Mission Is To Build ONE Unified National Voice To:

- Advocate for Fibromyalgia for increased awareness, research, education and funding;
- Improve government disability and extended health benefits; and
- Raise the quality of life of Canadians with Fibromyalgia

FAC Financial Report

FAC has accomplished so much in a short period of time. Despite not having charitable status, we raised approximately $5,000.00 in donations in our first campaign. This allowed us to build the foundation of FAC. We are presently in the process of obtaining FAC's Charitable Status. Once this occurs, FAC will start some fundraising initiatives.

Basic Operating Budget per Annum

Name of Expense	Amount of Expense
Insurance	$1475.00
Host Poppa Website	Paid until Aug 2024
Zoom	$230.00
Bank Monthly Fee	$59.40
Domain Name	$23.72
Post Office Box	$240.80
Ontario Non-Profit Network (ONN)	$113.00
Total	$2141.92

FAC Financial Report

From February 8, 2021 – December 31, 2021

Total Revenue	$5228.09
Total Donations	**$ 5213.09**
Total Expenses	$3748.67
Web Platform Host Papa	**$421.44 unil August 2024**
Domain Name	**Free for one year**
Zoom	**Donated for 1 year**
Legal	**$2763.00**
Summit	**$61.85**
Incorporation	**$213.80**
Thank You Stationary	**$132.58**
Gift Cards for Logo Work	**$100.00**
Cheques	**$6.00**
Libro Bank Membership Share	**$50.00**
Balance	$1479.42

FAC Financial Report

From January 1, 2022 - August 31, 2022

Opening Balance	$1479.42
Total Revenue Year to Date	$1137.94
Donations	**$550.00**
Reimbursement Legal Fees	**$537.94**
Libro Share Reimbursement	**$50.00**
Total Expenses Year To Date	$262.64
Zoom	**$230.00**
Bank Fees	**$32.64**
Bank Balance August 31, 2022	$2354.72

Governance

Motions

AGM22-01

Confirm the Board

I would like to make a motion to confirm the present Board of Directors.

AGM22-02

Accept the Financial Report

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

AGM22-03

Accept By-law

I would like to make a motion to accept the By-law dated April 25th, 2022, and revised on September 8th, 2022.

Note: All motions were passed on September 12th, 2022 during the AGM.

Awareness Report

The Awareness Committee has been meeting monthly since May 2021 with the main purpose to raise awareness on behalf of people living with fibromyalgia in Canada.

Our goal is to help build a national movement of people actively working together to fight for the rights and needs of Canadian persons living with fibromyalgia and change perceptions towards fibromyalgia.

For the 30th anniversary of May 12th as Fibromyalgia Awareness Day, we successfully launched:

- **Illuminate for Fibromyalgia Campaign**
- **FACes of Fibromyalgia**
- **Dr. Furlan Facebook Live Event**

We established a newsletter called "Just the FACs".

We developed and increased an online social media presence for FAC.

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 has been meeting monthly since May 2021 with the main purpose to promote and develop research on fibromyalgia research worldwide.

Our main focus has been to review the James Lind Alliance top priorities for fibromyalgia research to determine the progress that has been made and published.

A summary of published papers on each priority will be listed on the website once reviewed.

A highlight of the year was the opportunity to virtually attend the 2021 International Congress on Controversies in Fibromyalgia Conference in June. The speakers were international scientists and clinicians specializing in fibromyalgia.

A summary of theories on causes, drug management, and types of pain are on the website.

Information on how research is done and how to read scientific papers and access the accuracy of research seen in the news is available .

Research Report

Canadian fibromyalgia and chronic pain research studies currently looking for participants are reviewed and then listed on the website.

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 has been meeting monthly since May 2021. We have established our Purpose, Scope of Responsibilities, and proposed action plan.
Our main short-term purpose is to provide patient-led education to people with fibromyalgia, their families and caregivers.

Our main focus has been to provide educational material to our website including:

- **Section on Understanding fibromyalgia outlining an overview, symptoms, causes, fact or fiction, coronavirus and fibromyalgia, and the doctor-patient relationship.**
- **Inspirational patient stories about their journey with fibromyalgia.**
- **Section for Professionals containing what they need to know about fibromyalgia.**
- **Resources including lists of Canadian Fibromyalgia Support Groups and Pain Clinics Across Canada, and recommended books for patients about fibromyalgia topics.**

Education Report

- **Supporting the development of a Fibro Flare Kit.**
- **Development of a Fibromyalgia Fact Sheet for Patients and Families to be shared shortly.**
- **We are in the process of creating a document on Government and Community Benefits, Programs and Services for patients**

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 has been meeting monthly since May 2021 to advocate on behalf of people living with fibromyalgia in Canada.

Our purpose is to unite Canadians with fibromyalgia in order to improve our quality of life by raising our collective voice and to serve as a national association capable of promoting activities advantageous to the fibromyalgia community.

Some of our accomplishments are:

- **A Patient's Bill of Rights was published on the FAC website.**
- **A "How to Talk to your Politician" document was developed and published on the FAC website.**
- **Letters to Newly Elected Members of Parliament were sent advocating on behalf of people with fibromyalgia.**
- **Petitions were sent to the leaders of each major political party during the Federal Election campaign.**

Advocacy Report

- **A "Fibro Flare Kit" was created and available for download on the FAC website.**

- **An article about fibromyalgia and FAC was published in the PEI college of physicians and surgeons newsletter.**

If you would like to get involved, or know more about the Advocacy committee, feel free to contact us at advocacy@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 90 buildings and landmarks " Illuminate for Fibromyalgia". We were truly humbled and emotional on May 12th, when we experienced Canada lighting up for fibromyalgia.

2 FACes of Fibromyalgia

We will showcase the "FACes of Fibromyalgia" in a video as we raise awareness during September's "Fibromyalgia Awareness Week!" The video will be on FAC's website.

We are continuing this campaign, so please share your FACe with us!

Our Accomplishments

3 Fibro Flare kit

A "Fibro Flare Kit" was created as a resource to help you manage a flare when you can't think clearly.

The "Fibro Flare Kit" is downloadable from FAC's website at fibrocanada.ca

4 Just the FACs

A newsletter was created for those with fibromyalgia, caregivers, and friends.

"Just the FACs" highlights awareness, research, education, and advocacy campaigns.

Social Media Highlights

14,694 Weekly Views on Facebook

510 Followers on Instagram

415 Monthly Views on Pinterest

1,539 Followers on Twitter

203 Followers on LinkedIn

FAC Highlights

307
FAC Memberships

217
Flare Kit Downloads

103
FACes of Fibromyalgia

2
Grant Submissions

90
Buildings and Landmarks Illuminated

Our 2023 Strategy

FAC Will:

- Concentrate on building our infrastructure
- Build trust with funders, supporters, and beneficiaries
- Cultivate a culture of learning among similar organizations
- Celebrate the achievements of our members

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 initiatives, which assists in building a national fibromyalgia organization.

All FAC members are appreciated, valued and 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"