Just
THE FAC'S

"It is better to light a candle than curse the darkness."

- Eleanor Roosevelt

WINTER 2024 | Issue 11

FIBROMYALGIA ASSOCIATION CANADA

FAC Celebrates:

Black History Month is February 2024. Fibromyalgia Association of Canada would like to take a moment to acknowledge the disparity in health care treatment offered to people of colour.

International Women's Day is on March 8, 2024.
International Women's Day is a great time to spotlight health conditions that disproportionately affect women, like fibromyalgia.

Membership

We will accomplish more together, the larger our membership the greater our power.

Membership is free.

If you are not a member of FAC already please join us here https://fibrocanada.ca/en/login/

FAC Celebrates Black History Month

Black History Month is a time to celebrate the achievements and contributions of African Americans throughout history. It is essential to acknowledge the resilience and triumphs of black individuals who have overcome systemic challenges. Simultaneously, it's crucial to recognize health issues that disproportionately affect the black community, such as fibromyalgia. This chronic condition often goes undiagnosed or overlooked. Addressing healthcare disparities within the context of Black History Month is an opportunity to promote awareness, understanding, and support for those facing both historical injustices and health challenges. Together, we can strive for a more inclusive and equitable future.

FAC Celebrates International Women's Day

International Women's Day serves as a poignant reminder of the remarkable achievements and challenges faced by women worldwide. Amidst these stories of resilience, it's crucial to acknowledge the silent struggles, such as those experienced by women battling fibromyalgia. This often misunderstood condition disproportionately affects women. International Women's Day prompts reflection on women's experiences, recognizing that conditions such as fibromyalgia compound the hurdles faced by many. As we celebrate women's accomplishments, it's imperative to foster awareness and support for those grappling with unseen battles, exemplifying the true spirit of solidarity and empowerment.

Volunteer Update

TRANSLATORS NEEDED

Together we are Stronger.

FAC is currently seeking bilingual persons to help translate English to French. This person must be a member of FAC. Membership is free. If you are not a member of FAC already please join us here https://fibrocanada.ca/en/login/

Translators play a crucial role in helping FAC maintain it's bilingual status.

The role can be completed by on-line and doesn't require attending meetings.

If you are interested please go to https://fibrocanada.ca/en/members/volunteer/?sheet_id=14 and sign up.

Navigating the Winter Blues with Fibromyalgia: A Delicate Balance

As the winter season blankets the world in a serene layer of snow, for individuals grappling with fibromyalgia, the colder months can bring about a unique set of challenges.

For those of us living with fibromyalgia, the drop in temperature can exacerbate symptoms, leading to increased pain and stiffness. Additionally, the lack of sunlight in winter can impact mood and aggravate the already-present fatigue associated with fibromyalgia.

Managing fibromyalgia during the winter months requires a delicate balance of self-care strategies. Regular exercise, though challenging in colder weather, remains a crucial component in managing fibromyalgia symptoms. Indoor activities like swimming or gentle yoga can provide relief without exposing individuals to harsh weather conditions. Adequate rest and quality sleep are essential, as fibromyalgia symptoms often intensify with sleep deprivation.

Nutrition plays a pivotal role in supporting the body's resilience. A balanced diet rich in anti-inflammatory foods can help alleviate some symptoms. Moreover, staying socially connected and seeking emotional support are integral aspects of managing the emotional toll that the winter blues can take on individuals with fibromyalgia.

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Navigating the Winter Blues with Fibromyalgia: A Delicate Balance

Navigating the winter blues with fibromyalgia necessitates a holistic approach. By incorporating physical activity, prioritizing rest, maintaining a nourishing diet, and fostering social connections, individuals with fibromyalgia can enhance their well-being and minimize the impact of the colder months on their symptoms.

May Awareness Month

Throughout the month of May, the global community unites to educate, advocate, and support those of us living with fibromyalgia. It's a crucial time to raise awareness about our misunderstood condition, fostering empathy and understanding. By sharing stories, dispelling myths, and promoting research, May Awareness Month empowers individuals to seek help, reduce stigma, and encourage a compassionate approach towards those of us navigating the complexities of fibromyalgia. Together, we can foster a world where empathy triumphs over the ignorance of fibromyalgia.

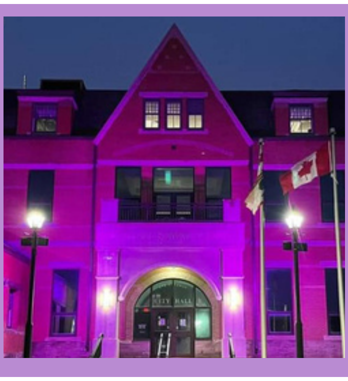
Illumination Campaign Kickoff

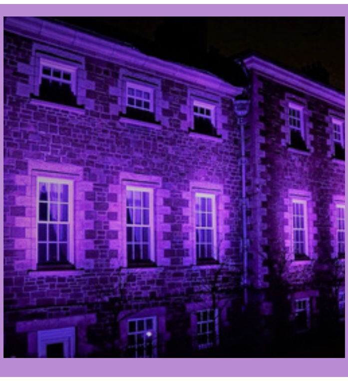
Get ready to be dazzled as FAC kicks off another spectacular Illumination Campaign to raise Awareness of Fibromyalgia in 2024. Starting this week, we're beginning our requests to light up buildings and landmarks across Canada. On May 12th embrace the magic as buildings and landmarks come alive in purple, creating a heartwarming visual experience for all. This campaign aims to raise awareness of fibromyalgia across Canada. Join us as we illuminate the darkness and pave the way for a brighter future for those of us who live with fibromyalgia. Want to know who has illuminated in your town or city?

Go to https://fibrocanada.ca/en/awareness/may12th/illumination-2022/ and https://fibrocanada.ca/en/awareness/may12th/illumination-2023/

If you know of any landmark or building that illuminates in your area that is not on the list please email the name to admin@fibrocanada.ca so we can contact them and bring them into our campaign.

Let the illumination begin!





Meet the Board

Hello friends,

My name is Lina DeMattia, and I am a recent member of the Fibromyalgia Association Canada (FAC), Board of Directors. I have been a volunteer with FAC for the past two years. Serving on the Education and Awareness Committees.

In my work experience, I journeyed with clients who had Alzheimer's disease and their families. I wore many hats at the society, the last being a Regional Education Coordinator. I never felt this was a job but my vocation in life, which I treasured.

My Fibromyalgia journey started in my Twenties. I was formally diagnosed in 2018. Through this journey I have learned many life lessons. I have learned to pace my activities, do what I can when I can, and I have accepted that life has changed for me, but it is still a good life.

I enjoy the outdoors, spending time at our trailer near Lake Erie and loving up my grandchildren.

Networking with Support Groups

FAC has begun to actively connect with fibromyalgia support groups with the purpose of bringing together persons with fibromyalgia from across Canada.

This is a positive step, as it will foster a sense of community, provide support, and facilitate the exchange of information and experiences among those of us dealing with fibromyalgia.

Connecting with support groups is a valuable strategy to raise awareness, share resources, and offer a platform for individuals to discuss their challenges and successes. It can also help in organizing events, campaigns, or initiatives to promote awareness and understanding of fibromyalgia within the broader community.

If you know of a support group in your area or if you would like more information on this campaign please contact education@fibrocanada.ca. If you are the administrator of a support group please register your group here https://fibrocanada.ca/en/register-your-fibromyalgia-support-group/

FACes of Fibromyalgia Campaign

Help FAC "MAKE FIBROMYALGIA VISIBLE"

The "FACes of Fibromyalgia" campaign humanizes the often misunderstood condition of fibromyalgia. By featuring real faces, the campaign dispels misconceptions, advocates for increased awareness, and encourages a more inclusive dialogue surrounding fibromyalgia. The campaign fosters compassion and solidarity among those affected by this complex and invisible health issue.

Do you want to help FAC raise awareness of fibromyalgia and help educate people that you don't have to look sick to be sick? If so, visit https://fibrocanada.ca/en/awareness/faces-of-fibro/ to submit your selfie and see the current faces.

Note: This campaign is open to anyone, anywhere in the world, with fibromyalgia. Emailing your photo is considered consent/ authorization for use of your image and likeness by Fibromyalgia Association Canada for the "FACes of Fibromyalgia" campaign

Bill C-22 Update

The framework legislation for the Canada Disability Benefit, the Canada Disability Benefit Act, received Royal Assent on June 22, 2023, after being passed unanimously by the House of Commons and being passed by the Senate. The goal of the benefit is to reduce poverty and support the financial security of working-age persons with disabilities. More information on the Act, including translation into American Sign Language, is available at: https://www.canada.ca/en/employment-social-development/programs/disabilities-benefits.html

The intention now the Bill has received Royal Assent is to move forward with the regulatory development process. To that end, the 2023 federal budget committed $21.5 million in 2023/2024 to continue work on the future delivery of the benefit, including engagement with the disability community and provinces and territories on the regulatory process. More information on the regulatory engagement process, and how to get involved, is available at the above link.

On November 15, 2023, the Government launched the Canada Disability Benefit Regulations Online Engagement Tool to collect insight and feedback from Canadians to help inform the design of the regulations for the new benefit. The tool was available until January 4, 2024. FAC advertised this Online Engagement Tool extensively through our social media platforms.

The Canada Disability Benefit is a key component of Canada's first-ever Disability Inclusion Action Plan. The Action Plan is a blueprint for change to make Canada more inclusive of persons with disabilities based on the principles of equality, anti-discrimination,

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Bill C-22 Update

participation and inclusion in the development of our programs and policies. The Action Plan will evolve over time to respond to ongoing engagement with persons with disabilities. It will continue to reflect the realities of persons with disabilities in an ever-changing world. In addition to the Benefit, it also includes a robust employment strategy for Canadians with disabilities, as well as ongoing work to develop a better process to determine eligibility for federal disability programs and benefits. More information on the Action Plan is available at www.canada.ca/en/employment-social-development/programs/disability-inclusion-action-plan-2.html.

FAC will stay up to date on Bill C-22 so we can update the fibromyalgia community on the latest developments and ensure you have the opportunity to express your views during this process.

YouTube Channel

Fibromyalgia Association of Canada has established another online presence, through its dedicated YouTube channel. This platform serves as a valuable resource for individuals grappling with fibromyalgia. The channel offers a diverse range of content, including informative videos, expert interviews, and personal stories shared by those living with fibromyalgia.

Viewers can access a wealth of information on symptom management, treatment options, and lifestyle adjustments to cope with the challenges posed by fibromyalgia.

https://www.youtube.com/channel/UCicTSl-NJNt1BvhWjwpNBww

Patient Story

My Pain Story by Trisha Jamieson

My name is Trisha Jamieson, I'm 33 years old and this is my pain story. On October 5th, 2022 my doctor sent me to see a rheumatologist to get my fibromyalgia diagnosis. After this I got to work doing my own research. On the up side my life was about to get a whole lot more interesting.

Just after Covid started I got a job at a cannabis store. Shortly after starting I shocked my back and couldn't move my shoulders for 2 months. This amount of pain gave me a significant amount of brain fog and I ended up losing my job. This made me realize that something wasn't right.

After that I found another job, shortly after I found out I had sciatica. The job didn't last long. Time off gave me more time to focus on my mental health. I did all the things that helped like reading more books, studying Buddhism, meditating and spending time with my dogs.

Getting diagnosed answered a lot of questions as a person who often experiences unexplained bouts of pain – it was validating. Knowing gave me something to focus on researching. I got to work scrolling through the internet, reading books and listening to podcasts.

The journey ahead was going to be rough so I started searching for help. Having a history with depression and anxiety I searched for a therapist and found a free therapist through my doctor. I still see her once a month now and attend Dialectical Behaviour Therapy (DBT) classes every week which have been very helpful.

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Patient Story

Then I came across The Fibromyalgia Podcast hosted by Tami Stacklehouse. I discovered that she has a team of fibro coaches and it was easy enough to sign up so I did. A few weeks later I had my first appointment with Gisele McDiarmid, an absolute gem of a woman. She motivated me to never give up hope and continues to help me today. Talking to her always makes me feel better.

Living with fibromyalgia is hard but as Glennon Doyle says "We can do hard things." If life is easy what do you learn? Not much. When life is hard you learn more. In a weird way I prefer this path because I want to grow. I highly recommend affirmation cards or gratitude practice as these things have helped me stay positive.

Have I had moments of wanting to give up? Yes but that feeling always fades. I know there are people out there in remission and this gives me the motivation to keep going. Isolating for 2 years made me realize the importance of community so I started a fibromyalgia support group and joined the education committee with the Fibromyalgia Association Canada (FAC).

Humans and women are incredibly resilient, millions of people around the world deal with pain every single day. We are not alone and we can help each other. Stay strong warriors! If I can live and find joy in the dark, so can you.

If you would like to submit your story in your journey with fibromyalgia or to read more patient stories go to https://fibrocanada.ca/en/my-pain-story/

SYMPTOM

Fibromyalgia and Raynaud’s Syndrome

Raynaud’s syndrome refers to a condition where your blood vessels constrict more than they should, reducing blood flow to extremities which makes them cold and painful.
Many people with fibromyalgia also have Raynaud’s syndrome. Its impact on blood vessels often aggravates or causes a flare-up of fibromyalgia symptoms, which often involves sensitivity to temperature.

The most common area of the body to be affected by Raynaud’s is the fingers but toes can be affected as well. There are even cases where the nose, ears or lips are affected. The part of the body that is affected will turn white, then blue and can be very painful. As the blood flow returns the area turns red and burns. It can be very painful and may last minutes or hours. Cold and stress are often the triggers.

James Lind Alliance

Research objectives should be focused toward advancing knowledge that has a meaningful impact on health. However, research agendas are mostly driven by the health care community, with limited input from patients.

The James Lind Alliance (JLA) is a non-profit making initiative which brings patients, caregivers and clinicians together in Priority Setting Partnerships (PSPs) to first identify and then prioritize unanswered questions about an illness and / or the effects of treatments that this group of people agrees are the most important. This information helps ensure that those who are funding health research are aware of what matters to patients, their caregivers and clinicians since they are the end users of any funded research.

In 2014, the Canadian Institute of Health Research (CIHR)'s Institute of Musculoskeletal Health and Arthritis (IMHA) and the James Lind Alliance (JLA) set up a PSP to identify the unanswered questions about the management of adult fibromyalgia from patient / caregiver and clinician's perspective and then prioritize into the top ten that patient/ caregivers and clinicians agreed were the most important. This PSP was completed in 2016.

To see the top 10 Priorities go to https: //www.jla.nihr.ac.uk/priority-setting-partnerships/fibromyalgia-canada/top-10-priorities.htm

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James Lind Alliance

Fibromyalgia Association Canada has reviewed each of the top Fibromyalgia Top 10 Priorities and wondered how many of these have actually been researched. Over a period of time FAC will be posting one priority at a time in the Fibromyalgia Association Canada's Just the FAC's Newsletter and the recent research we have found for each priority, the authors of the study and the website where the study can be found.

Question 3:

What are the best ways to manage sleep problems in people living with fibromyalgia?

To see research studies that answer this question go to: https://fibrocanada.ca/en/research/top-research-priorities/james-lind-alliance/priority-3/

Featured Research

Conditioned Pain Modulation in Human Subjects

The Researchers are seeking participants diagnosed with fibromyalgia to determine how a 'conditioned' pain stimulus affects the perception of a 'test' pain stimulus.

Participants will undergo stimulation with a heat thermode, to establish their pain threshold.

For more information go to: https://fibrocanada.ca/en/research/participants-wanted/current/

Volunteer Update:
Recruiting for Awareness Committee

Join Fibromyalgia Association Canada's Awareness Committee and make a meaningful impact.

Are you passionate about raising awareness for fibromyalgia and improving the lives of those affected by this chronic condition? Here's your chance to be part of a dedicated team working towards positive change. Fibromyalgia Association Canada is recruiting members for its dynamic Awareness Committee.

As a committee member, you'll have the opportunity to contribute your skills and ideas to innovative awareness campaigns and initiatives. By joining forces with like-minded individuals, you'll play a crucial role in fostering understanding, compassion, and support for those of us navigating the challenges of fibromyalgia.

Whether you're an experienced volunteer or someone looking to make a difference, we welcome your unique perspectives and talents. Together, we can amplify our voice, challenge misconceptions, and enhance the overall well-being of individuals living with fibromyalgia.

Don't miss this chance to be part of a community dedicated to making a lasting impact. Join Fibromyalgia Association Canada's Awareness Committee today and help us build a brighter future for those affected by fibromyalgia.

To volunteer with FAC you must be a member of FAC. Membership is free. If you are not a member of FAC already please join us here https://fibrocanada.ca/en/login/

Fostering Patient Engagement in Research: A Crucial Partnership

Patient engagement in research has emerged as a pivotal aspect of modern healthcare, transforming the traditional researcher-subject dynamic into a collaborative partnership. This fundamental change recognizes the invaluable insights and perspectives patients bring to the table, emphasizing their active involvement in all stages of the research process.

Gone are the days when patients were mere passive recipients of healthcare interventions. Today, we are increasingly viewed as partners in the research journey, contributing unique experiences and perspectives that enrich study design, implementation, and interpretation of results. Patient engagement enhances the relevance and applicability of research findings, ensuring that studies address real-world concerns and improve the overall quality of healthcare.

Patient engagement promotes transparency, accountability, and trust between researchers and the communities they serve. It establishes a two-way communication channel where researchers provide information to patients, and patients, in turn, offer valuable feedback, ensuring that research aligns with their needs and values.

Patient engagement is a transformative force in research, reshaping the landscape of healthcare investigations. Embracing this collaborative model not only ensures more meaningful and applicable research outcomes but also

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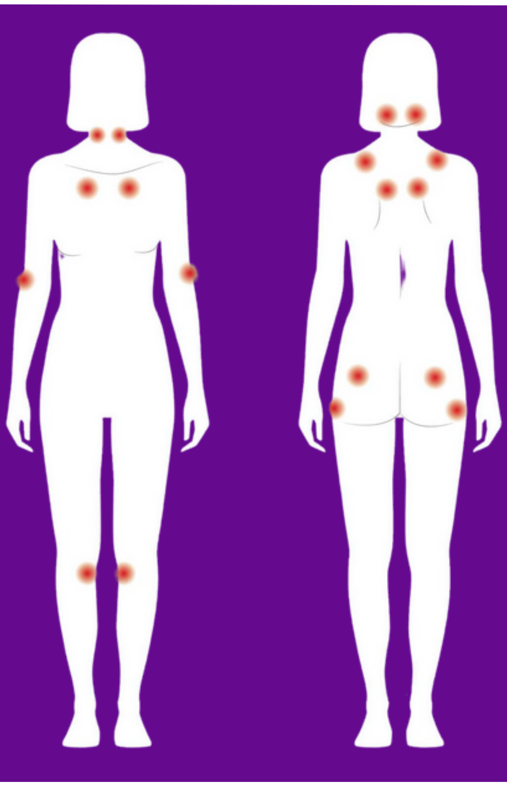
Fostering Patient Engagement in Research: A Crucial Partnership

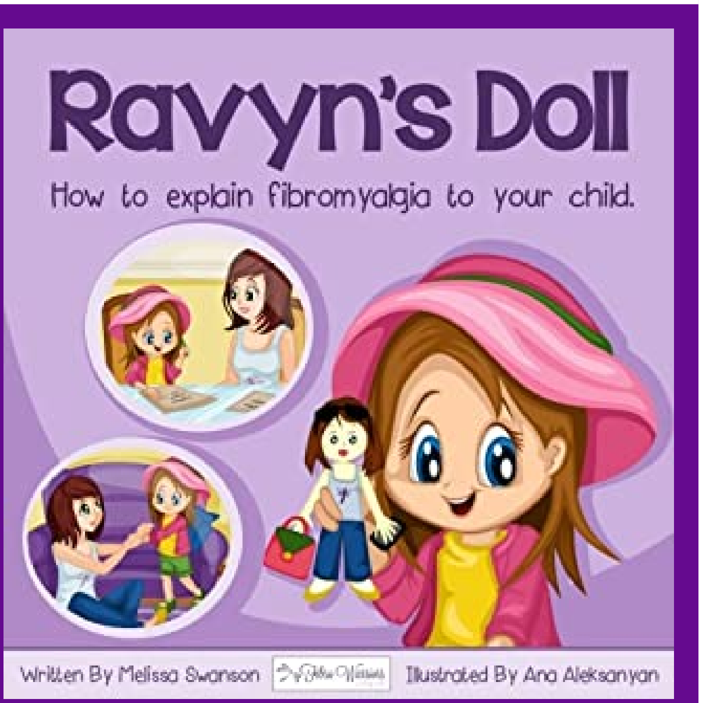
strengthens the foundation of a patient-centered healthcare system. As FAC moves forward, fostering patient engagement must remain a top priority for fibromyalgia research. The FAC Research Committee will encourage researchers, healthcare providers, and policymakers alike to incorporate patient engagement into their work.

FIBRO FAC's

For the past 3 decades, doctors have looked for tender points to diagnose fibromyalgia. These are spots on the body like the jaw, shoulder, upper arm, lower arm, hip, upper leg, etc. that are tender or painful to the touch. More recent research suggests that about 20% of people with fibromyalgia may not have these tender points. Today, doctors will ask you about your pain in each of five regions of your body.



Books on FAC Website



All the kids in Ravyn's class made paper dolls to show someone they love who is hurt or sick. When it's Ravyn's turn to share, she shows a paper doll of her mom — and it looks like there is nothing wrong.

Ravyn teaches the class that even though her mom looks healthy, she's not healthy. Ravyn's mom suffers from fibromyalgia. Ravyn's Doll is a simple and effective way to explain fibromyalgia to your child. It teaches that not all illnesses are visible and explains how living with an invisible illness affects families' daily lives. Ravyn's Doll describes and illustrates why mom or dad can't do the things they used to do — things that other moms, dads or other family members can do.

Other Resources Contained within the book are internet sites and books to read to learn more about Fibromyalgia and other Invisible illnesses, such as Lupus, Lyme Disease, ME, CFS, rheumatoid arthritis, multiple sclerosis, chronic migraine, and others.

A portion of the sale of each book will be donated to the International Support Fibromyalgia Network.

To purchase this book go to https://fibrocanada.ca/en/book/ravyns-doll/ If you purchase this book from Amazon through the FAC website, FAC will receive a small commission at no extra charge to you.

Featured Research

For adolescents with chronic pain **– Two studies about understanding the perspectives and experiences of adolescents ages 14-18 years old coping with chronic pain.**

Study #1

Questionnaire Study: This study consists of an online questionnaire that takes about 20 minutes to complete and involves reading stories depicting common challenges faced by adolescents with chronic pain and responding to questions about how you would cope in these situations. Responses are anonymous and you can withdraw from the survey at any point.

Study #2

Interview Study: The study takes about 60-75 minutes to complete and involves participating in an online questionnaire and interview via Zoom. The online questionnaire will involve demographic questions and questions about your pain condition. The interview will involve questions about your understanding of the word "coping", experiences coping with chronic pain, and perspectives on how sociocultural factors (e.g., gender, culture, socioeconomic status) influence coping and should be considered by healthcare providers.

For more information go to:
https://fibrocanada.ca/en/research/participants-wanted/current/

UNIVERSITY
of GUELPH

Featured Research

Early experiences, psychosocial processes and fibromyalgia symptoms

Study #1

Call for participants with fibromyalgia.

Are you between 18 and 65 years old and suffering from Fibromyalgia? Do you usually experience excruciating pain and tiredness that few understand?
Do you want to play a more active role in helping to understand and raise awareness of your condition?

Study #2

Call for participants without fibromyalgia or any chronic diseases.

We need a group of people WITHOUT FIBROMYALGIA, PTSD OR OTHER CHRONIC DISORDER to serve as a control group. Your help as a "healthy subject" is essential to help us better understand how people with this disease differ from the rest of the population. Are you between 18 and 65 years old? Do you want to play a more active role in understanding and raising awareness of fibromyalgia?

For more information go to:
https://fibrocanada.ca/en/research/participants-wanted/current/

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Featured Canadian Support Group

Featured Support Group: Barrie Fibromyalgia Support Group

What made you decide to start a support group?

I had been taking a DBT course through my therapist and several people in the group had fibro. They had a lot of good insights and I learned a lot from them. Participating in the group made me feel better and inspired me to start the group. I think community is very important for everyone. It gives people hope and helps them feel less alone.

What is the name of your support group?

Our group is called Barrie Fibromyalgia Support Group

Where is your group located?

We are located in Barrie, Ontario but will be accepting members from surrounding areas as well.

How did you advertise to gain new members?

I contacted pain clinics and physiotherapy offices and offered to drop off posters and cards. I also took posters to all the rec centres and posted them on the community board at The McLaren Arts Centre.

How did you make people aware that you exist? In the community, Pain Clinics, Dr. offices, etc

Contacted Pain Clinics, physiotherapists and asked my therapist, family and friends to spread the word.

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Featured Canadian Support Group

How do your members help out with your group?

Our members post in the group and share stories with each other in our chat. Many have offered to help with ideas and offer me assistance with technology as I'm not the most tech savvy person.

How do you maintain group engagement?

I try to post in the group at least twice a week and we communicate in the chat with each other. For future meetings my fibro coach has offered to do a presentation. We plan on having other guests as well.

What services do you offer?

The main service we offer is support. We offer empathy, compassion, understanding and just hear each other out when we need to vent about our struggles.

How often do you meet?

We plan on meeting once a month. I'm definitely open to meeting more often if people want to.

What are some of the challenges you face?

We all face challenges every day. Fibro makes us tired, frustrated and forgetful yet we persevere and come together to help one another.

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Featured Canadian Support Group

What is the most rewarding aspect(s) for you?

Our members post in the group and share stories with each other in our chat. MHelping each other deal with the challenges that come from living with chronic pain and other autoimmune diseases. Many people with fibromyalgia have other conditions too.any have offered to help with ideas and offer me assistance with technology as I'm not the most tech savvy person.

What is the best way for people to contact you or join your group?

The best way to contact us is through Facebook:
www.Facebook.com/groups/barriefibromyalgiasupport/

My email is fibromyalgiabarrie@gmail.com
My phone# is 647-309-9126 feel free to call or text me anytime if you have questions.