



## M.E. - Myalgic Encephalomyelitis

(CFS – Chronic Fatigue Syndrome)

Our mission is to offer moral support, to provide relevant information, and to encourage research regarding M.E.

### Support Group Meetings

Everyone is welcome to our Support Group Meetings: patients, family, friends, and supporters. These meetings are offered free of charge, and you do not need to sign up or register, just drop in and join us for the afternoon.

There will be time to discuss any issue at every meeting.

*Please refrain from wearing scented products.*

Support Group Meetings are held on Saturdays at the **Central Lions Senior Recreation Centre**. This facility at 11113 - 113 Street is handicapped accessible and has plenty of free parking. In severe weather, please call the office at 780-944-0809 and listen to the message to check for cancellations.

Saturday, July 20 (1-3 pm)

Open Discussion

Saturday, September 21 (1-3 pm)

Symptoms and Diagnosis of ME/CFS

Saturday, October 19 (1-3 pm)

Coping with Losses Associated with ME/CFS

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### FOR EDUCATIONAL PURPOSES ONLY

**Disclaimer:** Our newsletter is published by the M.E. Society of Edmonton. It is a cooperative effort of volunteers. The Society's executive, board of directors, and newsletter editors do not accept responsibility, legal or otherwise, for the opinions and content of articles printed in their newsletter. We do not endorse any healthcare professionals, products, or medical treatments that may be mentioned in any of the articles and personal stories in our newsletters or at our meetings. They are provided to demonstrate the wide range of treatments that individuals have tried. Every individual has unique health concerns. It is recommended that anyone wishing to start/stop treatments mentioned in our newsletters do so under the close supervision of a healthcare professional

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Please submit articles or feedback for the newsletter to [newsletter@mesocietyedmonton.org](mailto:newsletter@mesocietyedmonton.org) or contact our office.

## Report from the Annual General Meeting

By Diane Ching, President

Thank you to the members who were able to attend our AGM on June 22; your involvement is greatly appreciated.

A small group has volunteered to serve as the Board of the M.E. Society for the 2019 -2020 term. Our thanks and congratulations go out to the new Board:

President: Lynn

Past President: Diane

We are still in need of a Vice President!

Secretary: Karen

Treasurer: Gabe

Board Members: Heather, Tracy, Tara, and Oriana.

The willingness of these individuals to take on the additional physical and mental challenges to manage the Board and keep the M.E. Society in business means the important projects the Society has started can continue. Support Group meetings, newsletter, website, and Social events will continue, and the Board can move forward with the search for an Advocate to replace John Wodak.

On behalf of the Board, we would like to extend our thanks to our volunteer accountant Anita Gonzalez for the excellent work she does with our finances and John Wodak as he concludes his service as our volunteer advocate.

Having a Board in place means we can carry on with these important programs and keep the momentum going. We finally have the ear of the people who need to hear us, we can't stop now!

Personally, I would like to express my thanks to everyone who has served on the Board with me since 2007. It has been an honour and a privilege to share in the struggles of the ME/CFS journey with everyone, and though progress is slow, I am hopeful for a better future. Good things are happening!!

### Casino

**Our only fundraising activity is a casino every two years. Our next one is scheduled for Monday, November 11 and Tuesday, November 12, 2019. It will be at the Century Casino, 13103 Fort Rd, Edmonton. We need to fill approximately 40 volunteer spots. If you, or anyone you know is able to help, please contact Michele at 780-944-0809 or [michele.schuler@mesocietyedmonton.org](mailto:michele.schuler@mesocietyedmonton.org)**

**If we don't fill all our volunteer spots we can lose our casino funding!!!**

### Education and Awareness

The ME Society of Edmonton has been making great strides forward over the last couple of years, and projects begun by the Board now require a part-time employee to continue with implementation. See page 3 for details.

The following projects are moving forward under the direction of the new Board and the new Awareness and Education Coordinator, Judy-Anne Wilson.

1. "Patients Helping Patients", a group of patients from across Canada, under the guidance of Dr. Stein, have been supported by the ME Society of Edmonton since they came together. They have created an Information Session and got it up and running in Calgary.

Presently, Judy-Anne, a founding member and one of the Information Session Facilitators, and the other group members are piloting and scheduling on-line presentations of the Information Session. These are meant to accommodate bed-ridden patients or those unable to attend classroom presentations. They will be facilitated by Judy-Anne and others throughout the fall and winter seasons. Look for confirmation dates and contact information in our next newsletter.

2. The Awareness and Education Coordinator is also working with Primary Care to facilitate a second running of the classroom presentation of the ME/CFS Information Session in Edmonton. See page 4 for details.

3. The Board and the Awareness and Education Coordinator will also be reconnecting with the Health Science Council at the U of A in the fall to assess the progress made since their last meeting. Diane Ching, John Wodak and Judy-Anne Wilson gave an informative presentation to the Council last fall.

4. A Canadian Collaboration of Scientists, Healthcare Providers and Patients started to form after the last IACFS Conference, and since then they have gathered in Montreal and have been preparing research and collaboration grant applications. A network of ME/CFS, Fibromyalgia, and Sensitive Disorder Organizations are beginning to connect across the country, putting together work groups and arranging monthly meetings on-line.

5. Judy-Anne's work with Primary Care also includes looking for both a specialist (probably an Internist) and a G.P. to champion ME/CFS in the Edmonton-area medical community. If you have a doctor that has been helpful, diagnosed your ME/CFS, or has shown some interest in obtaining further information about ME/CFS, please let Judy-Anne know. A message can be left for her on the office phone or she can be emailed at:

[JudyAnne.Wilson@mesocietyedmonton.org](mailto:JudyAnne.Wilson@mesocietyedmonton.org)

## ME/CFS Information Session Facilitators Needed

The ME Society of Edmonton and 'Patients Helping Patients', an across Canada patients group have developed a two-hour introductory information session on ME/CFS basics for patients, families, caregivers and other interested parties. The program is based on accepted ME/CFS management practices. We will be offering the session in a classroom format throughout the Alberta Health Services' Edmonton Zone (Z4). We are seeking experienced educators and workshop facilitators who are ME/CFS patients to co-facilitate classroom sessions.

### As the ideal candidate, you:

- Have been diagnosed with ME/CFS for a minimum of five years and have experienced enough symptom improvement to inspire others.
- Are healthy enough to reliably follow through on facilitation commitments.
- Have proven experience in education, facilitation, counselling or healthcare.
- Have strong communication, interpersonal and group management skills.
- Demonstrate empathy, compassion and optimism.
- Actively utilize the ME/CFS management principles and practices outlined in the program and can speak to their validity in symptom improvement. (i.e., Energy management and lifestyle adaptations that assist health.)
- Are willing to follow the program as it is designed.
- Are willing to facilitate as a team.
- Are able to meet with your co-presenter in person or online prior to sessions to agree on content responsibilities.
- Have a laptop computer you can take to classroom sessions for displaying PowerPoint slides and videos (this is flexible).

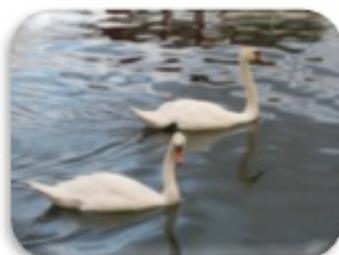
### Compensation

An hourly wage and transportation costs.

### To Apply

Please share with us in a short cover letter why you are interested in this position and how your personal experience with **ME/CFS symptom improvement** might be an inspiration to others. Please do not share your entire ME/CFS history. Please send your resume and cover letter to:

[JudyAnne.Wilson@mesocietyedmonton.org](mailto:JudyAnne.Wilson@mesocietyedmonton.org)



## Alberta Healthy Living Program

### ME/CFS Information Session

Thursday, October 24, 2019  
2:30 – 4:30 pm

Conference Room 1, East Edmonton Health Centre  
7910-112 Avenue NW, Edmonton, AB

Registration will begin in late August or early September, using the Central Access Number 780-401-2665.

Come and see the new ME/CFS Information Session as created by a team of ME patients from across Canada. The ME Society of Edmonton has been supporting the creation of this program for the last two years. We are proud to be able to welcome you all to this informative session, which is available to patients, their support workers, health care professionals, and the general public, through our local Primary Care Network. Please bring layers of clothing to facilitate comfort, and a water bottle for easy access. A fruit snack will be provided.

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## United States and International News

Chronic Fatigue Syndrome (ME/CFS) Article Rocks Top Medical Journal, by Cort Johnson, July 11, 2019.  
[https://www.healthrising.org/blog/2019/07/11/jama-chronic-fatigue-syndrome-article-tony-komaroff-unifying-model/?fbclid=IwAR2wylJcwK9QCLY-k-hbV\\_RkMc5YEwl8SqNPA-Xri3TXRUKTdoa7gT2ZHv8](https://www.healthrising.org/blog/2019/07/11/jama-chronic-fatigue-syndrome-article-tony-komaroff-unifying-model/?fbclid=IwAR2wylJcwK9QCLY-k-hbV_RkMc5YEwl8SqNPA-Xri3TXRUKTdoa7gT2ZHv8)

The ME/CFS and Fibromyalgia “What Would You Have Done Differently” Survey is available at:  
<https://www.healthrising.org/blog/2019/06/23/chronic-fatigue-fibromyalgia-doctor-treatment-coping-done-differently-survey/>

Sexual Assault Investigation Results in Dr. Jose Montoya’s Termination From Stanford University, by Cort Johnson, June 4, 2019: <https://www.healthrising.org/blog/2019/06/04/sexual-assault-jose-montoya-terminated-stanford-university/>

Presentations at the Harvard ME/CFS Collaboration Symposium 2019 can now be seen on the OMF YouTube channel. The playlist as of July 2 includes seven videos (10-39 min long) at:  
[https://www.youtube.com/playlist?list=PLI4AflZNZEQPNU0GYk3cmEnbQu\\_cYvO5](https://www.youtube.com/playlist?list=PLI4AflZNZEQPNU0GYk3cmEnbQu_cYvO5)

#ME Action released their 2019 research summary on June 12, reviewing the most current and important research into myalgic encephalomyelitis (ME) and ME/CFS of the past 10 years.  
[https://www.meaction.net/2019/06/12/meaction-releases-an-updated-me-research-summary/?fbclid=IwAR0\\_vv3qo0GaRSu5ta1kkU6jLcUMowyYVSi8emSoS0dk-gb2p3BRZAOGgM](https://www.meaction.net/2019/06/12/meaction-releases-an-updated-me-research-summary/?fbclid=IwAR0_vv3qo0GaRSu5ta1kkU6jLcUMowyYVSi8emSoS0dk-gb2p3BRZAOGgM)



## Canadian News



### CIHR Website Update

From Action CIND, June 25, 2019. The Canadian Institutes of Health Research (CIHR) have updated their site with info about ME and FM. This is a great step forward. This is a website address with information that has credibility, that patients can take to their doctors.

<http://www.cihr-irsc.gc.ca/e/51506.html?fbclid=IwAR3KmU5KFCVCMYNA0Cn9r8EeEciUF-YD8xNEa-jKL25QIvoUEYgeD-x2Bfc>

### Less Paperwork For Seniors With Disabilities

Friday, June 28, 2019. AISH recipients will be automatically enrolled in Alberta's seniors financial assistance programs once they turn 65, ensuring uninterrupted benefits.

[https://www.alberta.ca/release.cfm?xID=641383BBC4A75-C8CF-87E3-6F03AA44E7BD9E64&fbclid=IwAR0oATqQY9cSOua\\_BtVs2\\_BPh1jMz9qDH8E4o-JRliDAjP\\_miV0\\_Lh6WsvY](https://www.alberta.ca/release.cfm?xID=641383BBC4A75-C8CF-87E3-6F03AA44E7BD9E64&fbclid=IwAR0oATqQY9cSOua_BtVs2_BPh1jMz9qDH8E4o-JRliDAjP_miV0_Lh6WsvY)

### In the News Media:

White Rock woman shares her struggle with 'horrendous' fatigue, by Aaron Hinks, April 25, 2019, Peace Arch News.

[https://www.peacearchnews.com/community/white-rock-woman-shares-her-struggle-with-chronic-fatigue-syndrome/?fbclid=IwAR2b-YShXMMJqFtl4aN\\_TAW2hgghnJYZCCXq0VCR-wKDOZBRykdUoj-U52LI](https://www.peacearchnews.com/community/white-rock-woman-shares-her-struggle-with-chronic-fatigue-syndrome/?fbclid=IwAR2b-YShXMMJqFtl4aN_TAW2hgghnJYZCCXq0VCR-wKDOZBRykdUoj-U52LI)

CBC Victoria's Adam van der Zwan did this story on the plight of Jemma Lee, who lives alone with severe M.E. (July 8, 2019)

[https://www.cbc.ca/news/canada/british-columbia/severely-ill-galiano-island-woman-turned-away-from-assisted-living-due-to-unscheduled-care-needs-1.5204759?fbclid=IwAR3fut10RfdqESVtAXCVmeH1HK4IXe0Y\\_pA6tSdUCt5jk-ZKoRFANnX918k](https://www.cbc.ca/news/canada/british-columbia/severely-ill-galiano-island-woman-turned-away-from-assisted-living-due-to-unscheduled-care-needs-1.5204759?fbclid=IwAR3fut10RfdqESVtAXCVmeH1HK4IXe0Y_pA6tSdUCt5jk-ZKoRFANnX918k)



### Chronic Pain Survey

The Chronic Pain Association of Canada has put together a survey on opioid use. It takes only a few minutes to fill out. The results will be very interesting! The Chronic Pain Association of Canada is a registered Canadian charity. It is a grassroots organization that has grown because of a desperate need for relief of chronic pain in Canada.

"Health Canada isn't listening. So, we are collecting important data to share with Health Canada. CPAC wants to hear from every pained Canadian who needs opiate medications. This survey is anonymous. We are not collecting any personal information. Share this email with anyone you know and ask them to forward it on. There are over 1 million Canadians who need opiate medicines to function. Let's GO Canada!" Chronic Pain Patient Survey: <https://secureforms.sis.ngo/28592?lang=en&Use=A1>

### Disability Tax Credit

The Minister of National Revenue appointed a committee in late 2017 to provide advice on the Disability Tax Credit. The committee's first report was released in May <https://www.canada.ca/en/revenue-agency/corporate/about-canada-revenue-agency-cra/disability-advisory-committee.html>

### New Canadian Association Forms in P.E.I.

From Dolores Griffin: I am excited to officially announce the name of our provincial ME/FM chapter, which is "ME/FM Coalition of Prince Edward Island". Formed in 2019, the Coalition is a non-profit organization consisting of volunteers dedicated to promoting awareness of ME/FM issues on P.E.I.



## Jewels in the Edmonton Area

### Elk Island National Park

This expansive area just a half hour east of Edmonton is a peaceful location for a day trip, or camping (if you're able). It is a reserve for bison, which can be seen roaming freely in the park, and over 250 species of birds. There are multiple lakes, a sandy beach, and although swimming is not recommended, there are canoe, kayak, and paddleboard rentals. An extensive trail system (over 80 km) goes around the lakes, and through a variety of forested and open plains areas. There are many picnic areas with fire pits. The park is also a dark sky preserve, and favourite spot for astronomers, (PS there are free phone apps that can identify constellations just by pointing your device at the sky!). Rates, schedules, maps, and more information can be found at: <https://www.pc.gc.ca/en/pn-np/ab/elkiland>.



One day, Canada will take over the world. Then they'll all be sorry.

I'd get a lot more sleep if I didn't insist on reading the entire internet every night.

My face tends to say things my mouth won't.

You know that feeling when you go to the kitchen looking for food, and all you find are ingredients?

Sigh. Another fine day ruined by responsibility.

I keep my metabolism on its toes. What's it gonna be today, utter starvation, or 6000 calories?

I love summer in Edmonton. Best week of the year!

Beware!  
I ran out of spoons and am switching to knives.

I hate when a couple argues in public but I missed the start and don't know whose side I'm on.

If you're sitting in public and a stranger sits next to you when there are plenty of other seats, just stare straight ahead and say "Did you bring the money?"

I wish people wouldn't ring my doorbell. I have to stop whatever I'm doing to be quiet and pretend I'm not home.

When someone asks what I did over the weekend, I squint and ask "Why, what did you hear?"

If you're feeling a sudden calm, it's because I just took your voodoo doll out for a picnic on a grassy hill. You're welcome.

Dear Life,  
When I said things couldn't get any worse, that was NOT a challenge.

I'm still waiting for that fairytale scene where the animals clean everything for me.

Sleeping is hard in the summer, because the blankets are too warm, but without them I'm vulnerable to monsters.

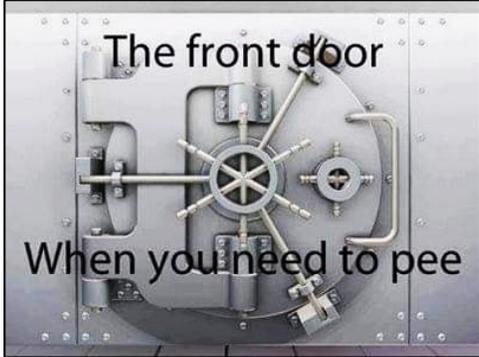
You know that thing in your head that tells you when something is a bad idea? How do I get one of those?

People who say "go big or go home" seriously underestimate my willingness to go home.

At a recent job interview I was asked if I could perform under pressure. I said I wasn't sure, but I could do a decent Bohemian Rhapsody.



**THIS IS WHY I HAVE TRUST ISSUES**



**The front door**  
**When you need to pee**

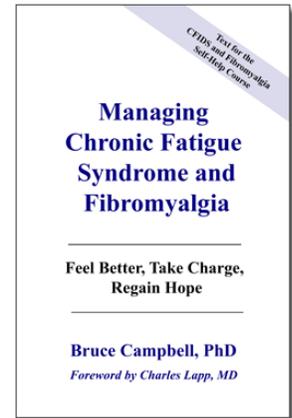


## RESOURCES

### Useful self-help articles

Many useful articles are frequently written or updated on the ME/CFS and Fibromyalgia Self Help website: <http://cfselfhelp.org/library/type/articles>.

“The ME/CFS and Fibromyalgia Self-Help Program is a non-profit organization offering a suite of low-cost and free online self-help courses, plus other resources for people affected by ME/CFS and fibromyalgia. Founded in 1998, it has conducted hundreds of self-help groups teaching thousands of people how to manage their illness. We also provide articles, forms, worksheets and online books in the Library on this website, as well as an online self-study course at <http://www.treatcfsfm.org/> and our founder's story at the <http://recoveryfromcfs.org/>. (Bruce Campbell, PhD).”



### Board Meetings

Board meetings of M.E. Society of Edmonton are open to the public, so everyone is invited and welcome to attend.

Meetings are held in the Conference room in the Adtel Building at 11630 Kingsway Avenue NW, Edmonton, but please note that it is not wheelchair accessible. You can attend meetings at our office or online. Call our office ahead of time to receive the information to join our meetings.

We meet from 1:00-3:00 p.m., usually on the first Saturday of each month, with the next ones on Sep. 14 and Oct. 5.

Please consider attending. If you wish to become a Board Member, please contact our office.

Contact our office at 780-944-0809 or [michele.schuler@mesocietyedmonton.org](mailto:michele.schuler@mesocietyedmonton.org) to be advised of any changes.

### M.E. Society of Edmonton

Phone: (780) 944-0809

#7, 11630 Kingsway Avenue NW,  
Edmonton, AB T5G 0X5

**Hours:** By appointment, only. Please call and leave a message to schedule an appointment

(Closed July, August and holidays)

[general.info@mesocietyedmonton.org](mailto:general.info@mesocietyedmonton.org)

[www.mesocietyedmonton.org](http://www.mesocietyedmonton.org)



### Annual Memberships

Memberships can be purchased at any time, especially for newcomers!

Thank you for your support.

For more helpful resources  
check out our website:

<http://www.mesocietyedmonton.org/resources.html>

Our office administrator is

**Michele Schuler**

[michele.schuler@mesocietyedmonton.org](mailto:michele.schuler@mesocietyedmonton.org)

**Feeling hopeless?  
Thinking about suicide?  
Help is available 24hrs/7d a week**

**Crisis Support Centre**

**Distress Line:**

**(780) 482-4357**

**Crisis Response Team:**

**(780) 342-7777**