



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, October 19 (1-3 pm)

Coping with Losses Associated with ME/CFS

Saturday, November 16 (1-3 pm)

Remaining Hopeful While Living With ME/CFS

Saturday, December 14 (1-3 pm)

Making the Most of Your Doctor Appointments

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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 or contact our office.

News From Your Board



Casino

Monday, November 11

Tuesday, November 12

Century Casino

13103 Fort Rd.



Our only fundraising activity is a casino every two years.

We need to fill approximately 40 volunteer spots.

If you, or anyone you know is able to help, please contact
michele.schuler@mesocietyedmonton.org 780-944-0809.



ME/CFS Information Session

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

Thursday October 24, 2018

From 12:30 – 2:30-pm

@

Conference Room 1, East Edmonton Health Centre, Cromdale Bldg
7910 – 112 Avenue. Free parking available



Patients Helping Patients, a group of ME patients from across Canada created this program to support ME patients. It includes diagnostic information and some understanding of the symptoms, as well as suggested skills for improving well-being. This is a basic introductory course which may be helpful to Health Care providers, family and friends of ME patients, the general public, as well as ME patients.

Please bring water and wear comfortable layers of clothing. A mat and/or sleeping bag may also be brought if you would like to have the option of laying down. Food will be allowed in the room and a fruit snack will be provided.

To register call: Central Access 780 401 – 2665

ON-LINE

On-Line presentations of the Session will be held on the dates and times given below. This is a live-streamed presentation with two facilitators. If you wish to sign up for the program, please click on the link and register through Zoom. Please take special note of the time zone.

Wednesday Nov 27, 2019 12 pm – 2 pm MST

https://zoom.us/webinar/register/WN_J5mJd5HfROKvUnXzX20Lgw



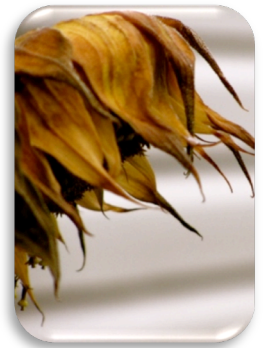
Information Session Co-Facilitators Needed

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.

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.

For more information, and to send your resume and cover letter, please contact:

JudyAnne.Wilson@mesocietyedmonton.org



Canadian News

Identical twins needed for a study. Dr. Alain Moreau is researching identical twins who are either concordant for ME/CFS (both twins have the disease) or discordant (only one twin has the disease). If you live anywhere in Canada and are or have an identical twin with ME/CFS please contact Dr. Moreau to learn more about the study. <mailto:alain.moreau@recherche-ste-justine.qc.ca>

Dr. Byron Hyde admits professional misconduct and resigns from the College of Physicians and Surgeons of Ontario

"On August 14, 2019, on the basis of an Agreed Statement of Facts and Admission (Liability), the Discipline Committee found that Dr. Hyde committed an act of professional misconduct, in that he has failed to maintain the standard of practice of the profession, and has engaged in an act or omission relevant to the practice of medicine that, having regard to all circumstances, would reasonably be regarded by members as disgraceful, dishonourable or unprofessional.

Dr. Hyde is 82 years old. Until July 9, 2019, he was a general practitioner in Ottawa, Ontario. He held a certificate of independent practice with the College of Physicians and Surgeons of Ontario since 1968."

Read more here: <https://t.co/LPnEPvSNiz>



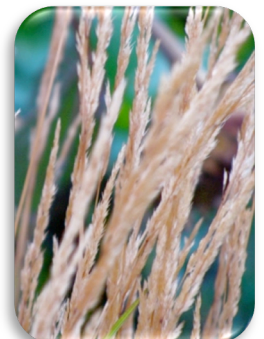
There is now an OMF Canada! <https://www.omfcanada.ngo/>

The Open Medicine Foundation is a non-profit group in the US founded in 2012. Under the leadership of Linda Tannenbaum, the OMF has fundraised over \$20 million for ME/CFS research. They are now supporting 3 ME/CFS research groups in Stanford, Boston, and Sweden.

OMF Canada just received non-profit status and is listed on the Canada Helps website. <https://www.canadahelps.org/en/charities/open-medicine-foundation-canada/>

Dr. Eleanor Stein emailed Marilyn at OMF Canada and asked whether funds donated in Canada would go to Canadian research. Here is her reply:

"The funds raised in Canada will be directed by our Scientific Advisory Board and approved by the OMF CA Board of Directors. The plan is to support the Harvard and Stanford Centers as well as research in Canada. We just added Dr. Moreau (who has been a long-time partner) to our scientific advisory board. In addition, donors have the option to designate their donations if they have a specific interest."



Government of Canada invests \$1.4M in biomedical research to improve the quality of life of people living with myalgic encephalomyelitis

From: <https://www.canada.ca/en/institutes-health-research.html>

August 22, 2019 – Montréal, Québec – Canadian Institutes of Health Research

It is estimated that more than 580,000 Canadians live with myalgic encephalomyelitis (ME), formerly known as chronic fatigue syndrome, or ME/CFS.

This poorly understood, multi-system disease is debilitating and can strike individuals of all backgrounds and at any age.

Patients experience symptoms including unrelenting exhaustion following mild physical and cognitive activity that is not relieved by rest; muscle and joint pain; headaches; inability to remain standing due to sudden drops in blood pressure; and poor sleep quality. The cause is not fully understood, there are no diagnostic tests available, and there is currently no cure.

People living with ME, and their families and caregivers, can now look forward to a more promising future as a result of a \$1.4M investment in a new national network that will create critically needed scientific knowledge about the causes of, and treatments for, myalgic encephalomyelitis.

The Honourable Ginette Petitpas Taylor, Minister of Health, made the announcement today while visiting the Sainte-Justine University Hospital Research Centre in Montreal, where the network will have its headquarters. This investment comes from the Government of Canada, through the Canadian Institutes of Health Research (CIHR).

Minister Petitpas Taylor made the announcement together with Dr. Alain Moreau, a professor at the University of Montreal. Working with a team of patient partners, clinicians, and more than 20 researchers, Dr. Moreau will lead the network that will fill gaps in biomedical ME research and build capacity for research into the disease here in Canada.

- This \$1.4M, five-year investment aims to improve the quality of life of people living with ME through:
 - investigating the causes of ME, including possible links to viruses and genes;
 - linking cohorts of patients and researchers in Canada and the US, enabling investigators to share research samples, clinical data, and analysis methods;
 - supporting graduate students working on ME to build Canadian capacity to research this condition; and
 - benefiting from the wisdom of people with ME who are active research



Patient Immersion Experience

Sept 30, 2019

By Kathleen Londry,

Over the past two years, I volunteered for the Patient Immersion Experience, which pairs medical students with patient-mentors to help them learn what it's like to live with chronic illness.

I really enjoyed spending time with Andrea and Zofia, two bright young medical students who were intelligent, inquisitive, and compassionate. It was a pleasure to meet them and provide insight into what it's like to be diagnosed and live with ME/CFS. They were very accommodating, and the commitment of time and energy for the program was reasonable and flexible.

I benefited as well, as I came to some new insights and perspectives as I thought about ways to convey the complexities of this illness, and my experiences, to these students. I like to think that I helped them understand at least some aspects of the illness,

At the very least there will be more doctors coming through the program who know what ME/CFS is, and can help teach their colleagues as well. The future of medical care in Edmonton looks bright with students like these in the program.



Many patients suffering from chronic illness go undiagnosed for a long time and struggle with the difficulties of feeling misunderstood and isolated by the healthcare system. Without a diagnosis, these patients are unable to access the health care they need or the social services and supports needed to make their lives easier. In our project, we wanted to provide a visual representation of how these patients must feel. On our canvas is a portrait of a patient – their face is cracked by the hurtful words and feelings that they endure before they are diagnosed – feeling misunderstood, isolated, and alone. These thoughts and feelings build up and “break out” illustrating how overwhelming they can be for the patient. However, we wanted to contrast these difficult feelings with the flowers blooming and radiating from the patient to represent the beauty that these patients offer the world. They are not defined by their illnesses but rather their character blooms out of their resilience and refusal to let negative opinions and stereotypes define them.

Patient Mentors Needed:

“The Faculty of Medicine & Dentistry is looking for patients with chronic illness to volunteer as mentors for an innovative program that connects medical students with members of the community. The Patient Immersion Experience (PIE) aims to educate medical students about the fundamentals of clinical practice and the doctor-patient relationship.”

“We strongly believe that physicians should be advocates for their patients,” said Helly Goez, director, physicianship and longitudinal themes and assistant dean, diversity. “This cannot be done without understanding how health care systems work and understanding the patient's perspective.”

Over the course of two years, the students complete several home visits with their ‘patient-mentor’ and accompany them to one medical appointment.

Tracey Hillier, associate dean, MD Program, is thankful to all of the patient-mentors who have participated over the years. “This wouldn't be possible without the invaluable perspectives of the patient-mentors. They really are helping to shape the next generation of physicians,” said Hillier. “We hope that as students continue in their training and future practice, they will have lasting empathy for all patients they will interact with.”

The program culminates in an art project shared with the patient mentors and their families, reflecting what the students have learned over the last two years.

If you are interested in participating in this year's program (starting in October) please contact patient.immersion.experience@ualberta.ca or 780-248-1311.”

Jewels in the Edmonton Area

Kinsmen Recreation Centre

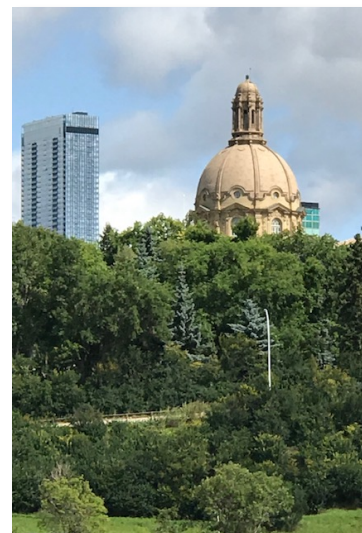
There are so many wonderful places in Edmonton's River Valley! One location that is accessible (bus or free parking) is Kinsmen Park, on the south side of the river just under the High Level Bridge and at the entrance to the new Walterdale Bridge.

There are quiet dirt hiking trails, paved multi-use trails (for wheelchairs or scooters), the free Queen Elizabeth Outdoor Pool, spray park and huge playground for children, and interesting views of nearby bridges and downtown.

For more information on the trails, there are many online information sites like: <https://www.alltrails.com/trail/canada/alberta/kinsmen-park-trail>.

For overall information on the park, check out:

https://www.edmonton.ca/activities_parks_recreation/parks_rivervalley/kinsmen-park.aspx.



Reminder for whoever needs it: Go put your laundry in the dryer.

My GPS has learned to say "Your OTHER left!"

Some days you eat salad and do yoga. Some days you eat cupcakes and don't wear pants. It's called balance.

Does refusing to go to the gym count as resistance training?

Sometimes, finding words is harder than finding Waldo.

My legs go out more than I do.

The only thing I drink from a shot glass now is Pepto Bismol.

I have such fond childhood memories. Like thinking \$100 is a lot of money.

I run like the winded.

Don't bother walking a mile in my shoes; that would be boring. Spend 30 seconds in my head, that'll freak you right out!

I don't remember much from last night, but the fact that I needed sunglasses to open the fridge this morning tells me it was too much.

Always remember to look both ways before crossing a woman.

Never tell someone they're crazy. Unless you want to see crazy.

I have no words to describe this day. I do, however, have a ton of obscene gestures.

Oh dear!!!
Did I forget to give a damn?

Some days, the supply of available swear words is insufficient to meet my demands.

I Googled "understanding myalgic encephalomyelitis" and the computer crashed.

Interviewer: So, tell me about yourself.
Me: I'd rather not, I kinda want this job.

I don't snore. I purr with the force of 1000 kittens.

If by "crunches" you mean the sound chips make when you chew them, then yes, I do crunches.

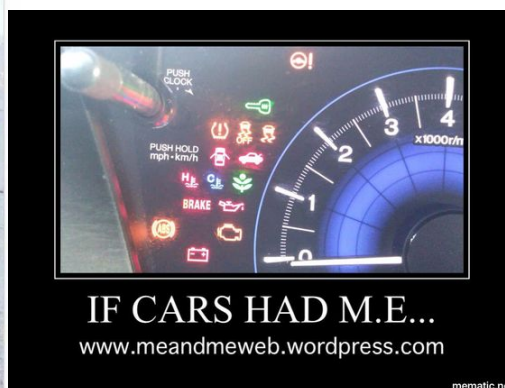
I thought the dryer made my clothes shrink. Turns out, it was my fridge.

Today has been cancelled.
Go back to bed.

The following memes and more can be found at:

<https://themighty.com/2019/05/mecfs-memes-funny-myalgic-encephalomyelitis-chronic-fatigue-syndrome/?sfns=mo>

When you try and enjoy life for a second



RESOURCES

Who you gonna call?

(Instead of Ghostbusters)

Office administrator: Michele Schuler, michele.schuler@mesocietyedmonton.org

President: Lynn Read, lynn.read@mesocietyedmonton.org

Awareness and Education Coordinator: Judy-Anne Wilson,
judyanne.wilson@mesocietyedmonton.org

Newsletter: Ed, newsletter@mesocietyedmonton.org

Support Group Facilitator: Lynn Read, lynn.read@mesocietyedmonton.org



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 November 2 and 30.

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 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

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

**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