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.

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Support Group Meetings

Everyone is welcome to our Support Group Meetings: Patients, family, friends, and supporters.

The M.E. Society of Edmonton Support Group Meetings are now held over the Internet! Everyone is welcome, Registration is not required and there is no fee to join. These groups are a safe place to share your life, receive support and learn more about ME/CFS. Talking with people who have similar struggles to you is often comforting. We hope you can join us!

You are invited to join us for our next Support Group on **September 18th, 1:00 - 3:00 PM**. Check our website or Facebook page for more details and login information later in the summer. You can also give us a call in September if you have any questions or comments.

Annual General Meeting

Mark your calenders! All members of the ME Society of Edmonton are invited to join us for our Annual General meeting on September 11, 2021 from 1:00 to 3:00 PM. Attendance at this event will support our volunteer Board Members and keep ME Society Edmonton viable for another year. You will be sent more information about this event in August.

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.

M.E. Board Meetings

Our Meetings are open to the public, and you are welcome to join us without becoming a Board Member. We are always in need of Board Members, so please consider helping the M.E. Society of Edmonton by joining our volunteer Board. If you wish to attend a Board Meeting, send us an email to receive login information at general.info@mesocietyedmonton.org

The M.E. Society of Edmonton Board Meetings are now held online! We meet from 1-3 PM, usually on the first Saturday of each month. Dates for our meetings are listed on our website, or contact us for further information.

LIVING WITH ME/CFS

Education. Recognition. Hope.

What Is It

- Education session for M.E. (Myalgic Encephalomyelitis/Chronic Fatigue Syndrome.
- Developed and presented by *Patients Helping Patients*, a group of ME Patients with direction from Medical Advisor Dr. Eleanor Stein.
- Topics include signs & symptoms of M.E. (ME/CFS), strategies for symptom management, keeping hope alive and excellent resources.

Who Can Attend

- Patients, Caregivers, Friends, Family and Healthcare Providers – All are welcome!

Where & When

Online Presentations

2 Hours starting at: 11:00 am PT, 12:00 pm MT, 1:00 pm CT, 2:00 pm ET, 3:00 AT9 Tue

September 28, 2021
Register at:
https://us02web.zoom.us/webinar/register/WN_ZQK-lI3tSdOp1twvbAwrMA

Tues, November 9, 2021
Register at:
https://us02web.zoom.us/webinar/register/WN_hghNigEZSoq4oQSztDpw1w

Florence Nightingale Award – 2020

We are proud to announce that Kristine Miles is our recipient of our 2020 Florence Nightingale Award! We want to express our sincere appreciation for the outstanding work Kristine has done for the ME Society of Edmonton.

In 2008, we were very fortunate to get a recommendation to hire Kristine as our Resources Centre Administrator. She has been a godsend ever since she started. Over the years, we added more tasks and responsibilities to her job description. She mastered all of them quickly. It is extremely comforting to have complete confidence that Kristine will work efficiently and accurately to keep the ME Society on track. We also appreciate that she has learned a lot about ME and had a lot of compassion for those who are struggling with ME. In December 2018, we were very sad to extend our best wishes to Kristine when she left the ME Society of Edmonton to move onto other things.

In Kristine's absence, we were completely lost without her exceptional organization and competence. In October 2020, after truly struggling for almost two years in her absence, I asked her if she would consider returning to work at ME Society. We are tremendously grateful and relieved that she decided to come back to work for us! Once again, the Board can relax knowing that Kristine is taking care of all our office work and ensuring that the ME Society is running smoothly and proficiently! It is a great joy to work with Kristine.

Pathways to Improvements

by ... Eleanor Stein MD FRCP (C)

Pathways to Improvement is a ten-session online education program designed specifically for people with ME/CFS, FM and ES. Each of the eight pathways includes a preparatory lesson including video, audio and web resources. You can do as much or as little as you are able from home on your own. There are 10 live webinars in which you will meet others and have a chance to ask questions of Dr. Stein. Dr Stein has over 30 years of personal experience with ME/CFS, FM and ES and 21 years clinical experience. For more information or to register please check Dr Stein's webpage at http://www.eleanorsteinmd.ca/pathways

In Pathways to Improvement, you will experience the validation that what you experience is real, that millions of others have similar challenges and that even after decades of illness, improvements is possible. You will learn strategies to control of your own health so that you can spend your time, energy and money on what you really enjoy

control of your own health so that you can spend your time, energy and money on what you really enjoy instead of on medical care.

For more information or to register go to http://www.eleanorsteinmd.ca

International Association for

IACFS/ME

Chronic Fatigue Syndrome/ Myalgic Encephalomyelitis

2021 Virtual Clinical/ Scientific Conference
August 19-21, 2021

Check their website to register: https://www.iacfsme.org/2021-iacfsme-virtual-conferenceearch presentations

The program will include:

- Research presentations
- Clinical workshops
- Virtual poster sessions
- Patient and advocates lecture series

"The conference will focus on the biomedical, public health, and behavioral aspects of ME/CFS and associated comorbidities. A portion of the meeting will also be devoted to COVID-19 and its relevance to ME/CFS research and clinical care."

"The meeting will be recorded so that people unable to attend may watch the proceedings at their convenience."

Scientist, Ronald W. Davis PhD of Stanford University and Tracie White

have recently published a new book called

"The Problem Solver"

Dr Ronald Davis - Professor of Biochemistry & Genetics Director
of Stanford Genome Technical Centre
Open Medicine Foundation ME/CFS Scientific Advisory Board

"At the height of his career of 30 years in genetics, Ron Davis (79) switched to a "Researcher" of a disease many of his colleagues have never heard of. Ron's quest changed as a result of his 37 year old son Whitney, developed a extreme severe case of Myalgic Encephalomyelitis being totally bedridden for years.

Whitney has been in the state of incapacity to eat without a feeding tube, move or speak which leaves many victims in crippling fatigue and exhaustion. At one time, Whitney traveled the world as a professional photographer through remote locations like Nepal, India and Central America. In 2012, Whitney finally was diagnosed with ME/CFS after months of testing and numerous specialists. Sounds and visual stimulation became too much to handle causing a lot of stress to Whitney.

Ron, whose gene-mapping techniques revolutionized the field of modern Biology and were used in the "Human Genome Project". Ron acknowledges why so many Covid 19 long haulers have stayed sick since, the pandemic (parasites, Viral and Bacterial infections) and find a usable diagnostic tool. It is interesting to note immune cells from ME/CFS patients conduct electricity differently than healthy individuals. Ron totally believes this puzzling situation is solvable. There needs to be many more scientists and a lot more money to determine what exactly triggers ME/CFS.

I'm happy to report that Whitney has started to show slight signs of improvement since, trying a drug that balances natural chemicals in the brain by elevating dopamine."

Further information is available with pictures in
People Magazine, April 12, 2021

ME Awareness Day / Week / Month

Saturday May 1st, the Open Medicine Foundation hosted an Open House featuring 6 funded research teams presenting their latest research. Thanks to Dr. Stein she summarized these presentations:

- Dr Ron Davis from Stanford team talked about the ongoing research for evidence of past or current infection in people with ME/CFS. He updated the ongoing research to validate the metabolic trap theory. Each time he explains it, it becomes clearer. Until this is clarified it is best not to add tryptophan.
- Dr Ron Tompkins from Harvard discussed how his team is applying the lessons of studying the physiology of trauma to ME/CFS - trying to ask the question "Why doesn't ME/CFS resolve?They are adding people with unresolved COVID infection to their study sample.
- Dr Wenzhong Xaio from Harvard is the computational wizard analyzing the OMF big data study and Dr David Systrom's invasive cardiopulmonary exercise test data. They are finding a big peak of pro-imflammatory cytokines after exercise in CFS/ME & POTS patients
- Dr Jonas Bergquist from Uppsala University in Sweden has a study underway comparing people with ME/CFS, people recovering from COVID with herpes simplex encephalopathy. Their study is unique as they are gathering proteomic and metabolomic date from cerebrospinal fluid. They too are looking for markers of people who don't recover.
- Dr Alain Moreau from the University of Montreal presented his work on microRNA epigenetics in ME/CFS and gave a nice summary of how epigenetics works. He is combining the microRNA data with patient symptoms and physiological measure from the Hexoskin wearable. His studies are in the severely ill.
- Dr Chris Armstrong has returned to Melbourne after spending time at Stanford. His team will be studying the Nitrogen hypothesis. People with ME/CFS burn protein for energy more than healthy controls. This means there is more nitrogen to excrete and this nitrogen in the form of ammonia may slow energy production causing a trap of sorts. He explains that people may be able to manage this challange for some time but, then when the body is stressed for some reason they run into trouble and energy production decreases. -Dr Eleanor Stein

http:/www.youtube.com/watch?v=CzQ5wWkuJug&t=1739s&ab_channel=OpenMedicineFoundation-OMF

"ACTION CIND provided several ZOOM information sessions during the month of May 2021, that were very helpful and informative"

"Webinar on Friday May 6, 2021 - Dr. Norman Buckley, Scientific Director of Michael G DeGroote Institute for Pain Research and Care presented "Improving How We Understand and Manage Chronic Pain in Canada".

The Honorable Health Minister, Patty Hajdu described the Action Plan for Canada suggesting the 3rd Report is due on the Federal Level to be published by December 2021.

Action CIND Webinar was held on May 7, 2021 presenting "Workwell Foundation" with Stacie Stevens, Chris Snell and Mark VanNess. The Q & A covering Cardio Pulumary Testing (CPAC), Exercise Test Protocol (CPET) that requires a 2 day test primary for Post-Exertional Malaise.

Webinar on May 8, 2021 presenting the ME, FM, CFS, ES/MCS medical expert Dr. Eleanor Stein MD, FRCP(C) with a Q & A session.

Webinar on May 10, 2021 presented Karen Shinn, co-founder of Downsizing Divas - "Downsizing Time for Some Diva Magic". The many advantages of downsizing and great suggestions of where to start & how!"

Cort Johnson - Health Rising Organization

"Cort Johnson is the Founder and Director of Health Rising a website dedicated to covering the latest research and treatment possibilities for chronic fatigue syndrome (ME/CFS) and fibromyalgia (FM). Cort came down with ME/CFS/FM while engaged in an Envirnmental Studies program at University of California at Santa Cruz during 1980's.

Unable to complete the program at UCSC due to ME/CFS/FM, cort received a BA in Philosophy from Cal State Long Beach in the late 1980's, and then a MS in Environmental Studies from San Jose State University in 2000.

Dissatified with the level of content on ME/CFS/FM on the web, Cort decided to take a deep dive into ME/CFS research. The result in 2004 was a basic (Frontpage) content based site focused on explicating ME/CFS/ research and treatment called "Phoenix Rising". Soon afterwards a newsletter was added.

By 2010, with the move to "WordPress", the addition of a blog and a forum package, and hundreds of articles/blogs later, Phoenix Rising had become the most visited ME/CFS website on the internet. In August of 2010 Phoenix Rising became a non-profit corporation.

In December 2012, Cort left Phoenix Rising to form Health Rising and broadened his focus to include fibromyalgia (FM). Over time he has produced over a thousand blogs on ME/CFS and FM that have been hailed for their comprehensiveness and depth. Along with the patients and their supporters Health Rising counts doctors and researchers among its subscribers.

In 2015 Cort was Prohealth Advocate of the year. In 2016 he received a Special Services award from the organization supporting ME/CFS professionals - the International Association of Chronic Fatigure Syndrome/Myalgic Encephalomyelitis (IACFS/ME). Health Rising has also been named one of the best fibromyalgia blogs.

For the past seven years Cort has been travelling the western U.S. with his two dogs in "the big yellow van". His partner - who lives in Toronto - has ME/CFS as well. Besides working he enjoys reading, classical music, botanizing, being present in nature, and participating in the work of Landmark Education." ... by Cort Johnson

Funnies

Hydrating Tip: Drink 4 Liters of Water per day helps you to avoid drama. Because you are too busy peeing. Stay Hydrated!

Health Rising is Remembering Paul Cheney MD, Ph.D.

A Colossus in the field of ME/CFS Passes

"Paul Cheney ME/CFS journey began in the 1984 - 5 "Incline Village Outbreak", which gained national attention - and left him and Dr Peterson ostracized by many in the small Nevada town. Moving on after a couple of years, Cheney at some point established a practice on a island of the North Carolina coast, and later moved to Asheville, NC where he remained for the rest of his life. Except for his work with Dr. Charles Lapp for three year (1992 - 1995), he worked as a solo practitioner."

RESOURCES

Here is a Canadian Government Page for People with Disabilities, providing Information about the various Services you can apply for. Maybe you can pull the information on this site apart under specific titles of each benefit available in a Newsletter sometime.
https://www.canada.ca/en/services/benefits/disability

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

For more helpful resources check out our website:

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

Our office administrator is

Kristine Miles

kristine.miles@mesocietyedmonton.org

Annual Memberships

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

Thank you for your support.

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