



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, June 15 (1-3 pm)

Topic: Coping with Post-Exertional Malaise

Saturday, July 20 (1-3 pm)

Topic: Open Discussion

Saturday, September 21 (1-3 pm)

Topic: To be announced

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FOR EDUCATIONAL PURPOSES ONLY

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Please submit articles or feedback for the newsletter to newsletter@mesocietyedmonton.org or contact our office.

Annual General Meeting



1:00 PM, Saturday, June 22

Central Lion's Senior Centre
11113 - 113 Street, Edmonton, AB
(Wheelchair accessible)
Refreshments will be served



URGENT NOTICE

Please mark your calendar to attend this important meeting. Joining the Board is not required, but your attendance and casting a vote for executive positions is extremely important to the ongoing survival of the Society.

A small, dedicated group of members with ME/CFS have been serving as the Board for the M.E. Society of Edmonton. We have been working hard on your behalf, but we have reached a crisis point where we urgently need more volunteers on the Board.

**If we are not able to fill Board positions at the June 22 meeting,
we will begin the process of dissolving the Society.**

It is a regrettable situation, but a few sick volunteers cannot continue to shoulder the burden. More information regarding the meeting, Board positions available, and proxy voting will be sent separately by mail.



News From Your Board

Edmonton ME/CFS Awareness:

The City of Edmonton lit the High Level Bridge in blue for ME/CFS Awareness Month on May 2, 2019.

Resources page on website updated

Please have a look at our new and improved resources section on our website at <http://www.mesocietyedmonton.org/resources.html>. Handy resources have been compiled there for you to access any time, anywhere. Let us know if you would like to see anything else included; feedback is always welcome and encouraged.



Casino

Our only fundraising activity is a casino every 2 years. Our next one is scheduled for Monday Nov 11, and Tuesday Nov 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.schuler@mesocietyedmonton.org or 780-944-0809.

ME information session

Our first ME information session in Edmonton took place on May 9, 2019. Ten people attended - six patients, three supporters, and one healthcare provider. It was very well received and there are plans for a second course to be held in September, as well as the creation of a six-week information session to focus on suggestions from the session, including pacing, charting, and meditation.



Joyce George March 14, 1930 - March 12, 2019

It is with great sadness that we announce that Joyce Darlene George (nee Has) passed away with family at her side on Tuesday, March 12, 2019 at Battlefords District Care Centre just 2 days shy of her 89th birthday.

Joyce gave back to her community by volunteering for numerous organizations. After she was diagnosed with Fibromyalgia, she became an ardent advocate. I had the pleasure of knowing Joyce from the start.

In 1994 she offered her home for the first of many FM meetings and to anyone with CFS. They would be later moved to the Don Ross Centre. By May she had the ribbons and pamphlets ready for FM Awareness. She started the newsletter (she was often the main contributor). In June 1994, she took on the role of the provincial president of Fibromyalgia Association of Saskatchewan and registered it as a non-profit organization. Joyce reached out to many across Canada, and traveled to BC to meet with the group there. Joyce George was a very kind, compassionate person, and had a great sense of humor.

For those wishing to leave a condolence, you may do so at <https://www.eternalmemoriesfuneral.ca/notices/Joyce-George>

Florence Ferron – Member – ME Society of Edmonton

The Florence Nightingale Award

Annually, the M.E. Society of Edmonton recognizes individuals or groups with the Florence Nightingale Award for their contribution in the fields of education, awareness, research or volunteerism regarding Myalgic Encephalomyelitis/Chronic Fatigue Syndrome.

Florence Nightingale suffered severe symptoms of ME/CFS and was bed bound for several years. She continued her work advancing the nursing profession and improving hospital conditions. Disability does not mean the end to a useful life. Many sufferers of ME/CFS typify the courage and dedication of Florence Nightingale and continue to live their lives under enormous disabilities. Nightingale's birthday, May 12th, was chosen as International Awareness Day for Chronic Immunological and Neurological Diseases.

We are pleased to announce JOHN WODAK as our 2018 winner of the Florence Nightingale Award for dedication and volunteerism.

Happy Retirement John!!

On Saturday May 11, 2019, friends and members of the M.E. Society of Edmonton gathered to thank John Wodak for his commitment to helping others and wish him well on his retirement.

Over the years, John helped many people obtain disability benefits, and this positive outcome impacts not just the individual involved, but their family and generations after.

In addition to his work with the Society in Edmonton, he also worked with the National MEFM Action Network, meeting with representatives from Canada Pension Disability Program and developing a guide for applying for and appealing CPP-Disability benefits. We thank John for his years of volunteering to provide such an essential service to the ME/CFS/FM community.



Diane presenting plaque to John.

"The M.E. Society of Edmonton (CFS) acknowledges John Wodak volunteer advocate since 1996. Helping those in need to obtain the financial support they are entitled to. We appreciate your patience, kindness and generosity of time."



Diane Ching (president) presented John and Carol Wodak with matching engraved travel mugs and gift certificate for dinner out.



A scrapbook was presented to John commemorating his contributions to the M.E. Society and the larger ME/CFS community. Included in the scrapbook are several cards and letters expressing thanks and gratitude from those that John has helped.

Canadian News

Awareness Day in Calgary news:

Global News in Calgary had an interview for M.E. Awareness Day. The video "Calgarians rally at City Hall to raise awareness about neurological disease" (6 min) can be seen at:

<https://globalnews.ca/video/rd/1520911427893/?jwsourc=cl>



Town Hall meeting with Health Minister

On April 14, the Federal Minister of Health participated in a town hall meeting on health care organized by Toronto MP Rob Oliphant. Millions Missing Canada advertised the event. Several ME patients attended and spoke about their experiences with ME. You can see videos of two of the speakers and the Minister's response on the Millions Missing Canada Facebook page. The Minister showed that she is indeed aware of ME and interested in learning more.

Chronic pain task force:

In March, the federal Minister of Health appointed a task force on chronic pain. They have three years to

- look at how chronic pain is currently being addressed in Canada
- look for ideas on how to improve prevention and management (national consultations and evidence reviews)
- work with affected communities to share best practices.

You can read about the task force here: <https://www.canada.ca/en/health-canada/corporate/about-health-canada/public-engagement/external-advisory-bodies/canadian-pain-task-force.html>

BC Women's welcomes new director for Complex Chronic Diseases Program

April 04, 2019 BC Women's is thrilled to welcome Dr. Luis Nacul as the new medical director and research director of the Complex Chronic Diseases Program (CCDP).

Dr. Nacul is an internationally renowned leading clinician and researcher in his field with a broad understanding of complex chronic diseases treated at CCDP from medical, health services and research perspectives.

One of the challenges in treating complex chronic diseases is that their causes are unclear. In his capacity as CCDP research director, Dr. Nacul will leverage an established clinical program to expand research into complex chronic diseases.

This is an important gain for the program, as CCDP patients with myalgic encephalomyelitis /chronic fatigue syndrome (ME/CFS), fibromyalgia syndrome and symptoms attributed to chronic Lyme-like disease will be able to benefit directly from research discoveries.

Dr. Nacul will also have an appointment as a researcher with the Women's Health Research Institute. His research time is funded by the BCCDC Foundation for Public Health through its BCCDC Foundation Research Scholar Award.

<http://www.bcwomens.ca/about/news-stories/stories/bc-women%E2%80%99s-welcomes-new-director-for-complex-chronic-diseases-program?hootPostID=68eabe0de007bfc8dbe222c8e542cb6e>

Newsletters

Dr. Eleanor Stein has uploaded a newsletter for April 2019 at <http://eleanorsteinmd.ca/newsletters/> with a summary of select presentations at the NIH Accelerating Research on ME/CFS symposium April 4-5.

United States News

Dr. Alison Bested will be talking about pacing on the next US CDC ME/CFS stakeholder engagement and communication webinar/conference call on Monday, June 3 from 1 pm to 2 pm mountain time. For more information go to: <https://www.cdc.gov/me-cfs/programs/meetings.html>

Historic Congressional Resolutions for ME! <https://www.meaction.net/2019/05/24/resolutionpassed/> On May 23rd, by unanimous consent, the United States Senate **PASSED** bipartisan Resolution, S. Res. 225 "Supporting the goals of International Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Awareness Day". Also, this week the House introduced an identical, bipartisan resolution, Resolution 399.

University of Texas on May 7, 2019: Does insulin resistance cause fibromyalgia? A newly confirmed link with insulin resistance may radically change the way fibromyalgia and related forms of chronic pain are identified and managed. <https://www.sciencedaily.com/releases/2019/05/190507145523.htm>. The report can be accessed at <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0216079%20>.

He pioneered technology that fuelled the Human Genome Project. Now his greatest challenge is curing his own son. By Ryan Prior, May 13, 2019, CNN <https://edition.cnn.com/2019/05/12/health/stanford-geneticist-chronic-fatigue-syndrome-trnd/index.html?no-st=1557647877>

Stanford University press release "Biomarker for chronic fatigue syndrome identified" April 29

<http://med.stanford.edu/news/all-news/2019/04/biomarker-for-chronic-fatigue-syndrome-identified.html?linkId=66719226>

Related articles:

Threading the Needle: Nanoneedle Scores Big in First ME/CFS Test by Cort Johnson | May 7, 2019.

<https://www.healthrising.org/blog/2019/05/07/threading-the-needle-nanoneedle-scores-big-in-first-me-cfs-test/>

Groundbreaking Blood Test to Identify Chronic Fatigue Syndrome - Study shows new blood-based test accurately identified people with ME/CFS. by Karen Lee Richards • ProHealth.com • May 2, 2019.

<https://www.prohealth.com/me-cfs/library/groundbreaking-blood-test-identify-chronic-fatigue-syndrome-90986>

An OMF-Funded Research Publication: A nanoelectronics-blood-based diagnostic biomarker for ME/CFS <https://www.omf.ngo/2019/04/29/omf-funded-research-nanoelectronics-blood-based-diagnostic-biomarker/> (includes links to articles in medical and mainstream media).

International News

The March issue of the ME Global Chronicle is available at

https://let-me.be/e107_plugins/download/download.php?list.1

The Spring 2019 issue of Breakthrough magazine is available online at

<http://www.mereseach.org.uk/information/breakthrough-magazine/>

Simon McGrath's latest articles about research can be found at:

<https://mecfsresearchreview.me/>



A Letter From Jennifer Brea

<https://www.meaction.net/2019/05/21/a-letter-from-jennifer-brea-about-her-me-remission/>

May 21, 2019. Yesterday, I shared the news with our community that all of my symptoms of myalgic encephalomyelitis (ME) are now in remission. This is the outcome of a long journey that began last year with surgery for thyroid cancer; took an unexpected turn for the worse with the sudden onset of a new symptom, central apnea, as a result of that surgery; and culminated in a diagnosis of craniocervical instability and tethered cord syndrome. Since June, beginning with the thyroidectomy, I've had five surgeries. It has been the most challenging year of my life. The remarkable outcome, though, is that all of my symptoms of ME are resolving. This doesn't mean I am 100%—I am still recovering from the surgeries themselves, a process that will take at least twelve months. (You can read more of the story at <https://medium.com/@jenbrea/ci-tethered-cord-series-e1e098b5edf>.



What I will say is that by every objective measurement and subjective expert opinion, my ME diagnosis was accurate. I just never imagined as an acute, viral onset patient, that my symptoms could have a structural, mechanical cause. My hope going into surgery was simply that I might resolve the apnea and other neurological symptoms that developed or worsened after thyroid surgery. Recovery from ME is something I never thought would happen for me personally without many more years, even decades, of research.

I have no idea if this will last. I have no idea what this means for other people with ME. I am just one patient and this is my story. But, my story of remission makes it even more clear to me than ever that we must fight for research to better understand the mechanisms underlying all of our cases.

This has always been a movement of people with ME, all along the spectrum of severity, fighting alongside their caregivers and able-bodied friends, family, clinicians, researchers, policymakers and allies. I will never forget the experiences that I have gone through over the last eight years of illness. There are people in our community who have changed my life forever. With my improved health, I will continue to fight alongside each of you for equality, dignity and better care; to challenge stigma and advocate for research dollars and medical education. I will not give up. I am in this fight until every person living with ME, no matter the cause, has access to diagnosis and care. This is why the work of #MEAction is so important.

#MEAction's impact is growing. Our movement is stronger and more engaged than ever as reflected in last week's #MillionsMissing, which comprised more than 200 actions in 22 countries on six continents. In the UK, more MP's have become active participants in our movement than ever before. In the US, advocacy week on Capitol Hill brought over 100 meetings with representatives and Senators. Clinicians, nurses, and social workers all over the US are earning Continuing Medical Education credits by watching Unrest. We have big plans to keep this momentum going and to continue to build the capacity and reach of our movement, organizing at the local level and mobilizing the community around even more actions you can take to increase awareness, medical education and advocate for research.

While I know that remission stories can bring hope, they can also be painful. If this news brings up ambivalent or mixed feelings for you, that is valid. They did for me, too, and I am still processing them.

As I continue on my journey of recovery, I am committed to fighting even harder for health equality for all people living with ME. Join us in this fight. In solidarity, now and always,

Jennifer Brea

Related articles:

Could Craniocervical Instability Be Causing ME/CFS, Fibromyalgia & POTS? Pt I – The Spinal Series by Cort Johnson, Health Rising, February 27, 2019. <https://www.healthrising.org/blog/2019/02/27/brainstem-compression-chronic-fatigue-syndrome-me-cfs-fibromyalgia-pots-craniocervical-instability/>

Jennifer Brea's Amazing ME/CFS Recovering Story: the Spinal Series – Pt. II by Cort Johnson, Health Rising, May 21, 2019. <https://www.healthrising.org/blog/2019/05/21/jennifer-brea-chronic-fatigue-mecfs-recovering-story/>

Spinal Stenosis, Chronic Fatigue Syndrome (ME/CFS) and Fibromyalgia: The Spinal Series #3, by Cort Johnson, Health Rising, May 29, 2019. <https://www.healthrising.org/blog/2019/05/29/spinal-stenosis-chronic-fatigue-fibromyalgia/>

The Atypical Thyroid Issues in Chronic Fatigue Syndrome (ME/CFS), Plus a New Thyroid Subset? By Cort Johnson on Health Rising, Mar 4, 2019. <https://www.healthrising.org/blog/2019/03/04/hypothyroid-chronic-fatigue-syndrome-thyroid-ntis/>



Orthostatic Intolerance



There is an Educational Video from Dr. Lucinda Bateman in the ME/CFS and FM Educational Video Series that explains orthostatic intolerance (30 min). OI, Postural Orthostatic Tachycardia Syndrome (POTS), neurally mediated hypotension (NMH), and orthostatic hypotension can all be manifestations of ME/CFS and FM. In this class you will learn to access orthostatic intolerance objectively, how to differentiate between these syndromes and strategies to manage the symptoms they present. <https://youtu.be/HkIYZmZT3Zs>



There were recent articles on ProHealth by Suzan L. Jackson on What Is Orthostatic Intolerance and How to Diagnose It, April 25, 2019 <https://www.prohealth.com/me-cfs/library/orthostatic-intolerance-part-1-diagnosing-oi-82944>, and How to Treat Orthostatic Intolerance (OI) May 3, 2019 <https://www.prohealth.com/me-cfs/library/orthostatic-intolerance-part-2-treating-oi-82949>

Adrienne Dellwo has an article from March 7, 2018 on Orthostatic Intolerance and Low Blood Pressure (with links to related articles at the end) <https://www.verywellhealth.com/orthostatic-intolerance-715915>

Health Rising Articles

Taking a Stand: Fibromyalgia, Orthostatic Intolerance and the Autonomic Nervous System by Cort Johnson | Aug 24, 2018

<https://www.healthrising.org/blog/2018/08/24/fibromyalgia-orthostatic-intolerance-autonomic-nervous-system/>

Dr. Bell on Orthostatic Intolerance in Chronic Fatigue Syndrome and Fibromyalgia by Cort Johnson | Oct 4, 2015

<https://www.healthrising.org/forums/resources/dr-bell-on-understanding-orthostatic-intolerance-in-chronic-fatigue-syndrome-and-fibromyalgia.238/>

Standing Clear: Drug Stops Orthostatic Intolerance in ME/CFS In Lab – Next Steps by Cort Johnson | Feb 3, 2015

<https://www.healthrising.org/blog/2015/02/03/standing-clear-drug-stops-orthostatic-intolerance-mecfs-next-steps/>

Problems Standing? Studies Suggest Autoimmunity Causes Orthostatic Intolerance: Implications For Chronic Fatigue Syndrome by Cort Johnson | Apr 17, 2014

<https://www.healthrising.org/blog/2014/04/17/problems-standing-autoimmunity-causes-orthostatic-intolerance-implications-chronic-fatigue-syndrome/>

Dr. Cheney's Home Brew to Increase Blood Volume <https://www.healthrising.org/forums/resources/dr-cheney-s-home-brew-to-increase-blood-volume.444/>

A cheap and easy blood volume enhancer you can make at home. Dr. Cheney's Home brew contains no sugar and is another viable blood volume enhancer for people with ME/CFS, POTS and/or orthostatic intolerance

- 1 cup filtered water
- 1/8 teaspoon of Sea Salt
- 1/8 teaspoon of "No Salt" salt substitute (potassium).
- Add lime juice or an herbal teabag as well as stevia for taste (or something to give it flavor without altering the electrolyte balance: peppermint, peach, raspberry zinger, etc.)

You can add 1 cup of Seltzer Water in there too, however, if you do, you need to double the amounts of Sea Salt & "No Salt" as has been done in the recipe below.

Cheney recommends four to eight glasses Gookinaid or Home Brew a day.

<https://www.healthrising.org/forums/resources/enhancing-blood-volume-for-chronic-fatigue-syndrome-me-cfs-pots-and-orthostatic-intolerance.44/>

Jewels in the Edmonton Area

University of Alberta Botanical Garden

Formerly known as the Devonian Gardens, this oasis is located on the north side of Devon and just SW of Edmonton. The site is largely accessible, with main paths paved, secondary paths are groomed rock, and some paths within sites and in remote areas are dirt paths. There is a café near the main entrance, and several bathrooms. They have guided tours, and a free hop-on-hop-off trolley that circulates the gardens. The new Aga Khan garden is amazing, along with the Japanese Garden, the Alpine Garden, the Healing Garden, just to name a few of the architectural/groomed areas, as well as quiet trails for peaceful reflection. See the website for dates and times, special programs, and admission prices. Note that they have half



People who ask me what I'm doing tomorrow probably assume that I know what day of the week it is.

Beauty comes in all shapes and sizes: small, medium, large, circle, square, thin crust, thick crust, stuffed crust, extra toppings.

Hello darkness my old friend
I stood up too fast again.

When I'm feeling mean, I make the other half of the Oreo watch.

Why do they bother putting baking instructions on cookie dough packages?

The person before me got \$5 worth of gas. My day doesn't seem so bad now.

If only my teeth were as white as my legs.

I'm glad you're learning to laugh at yourself.

That was kind of getting awkward for the rest of us.

Hey, I found your nose. It was in my business again.

I completed the first item on my bucket list today ...
I got the bucket.

The longer I'm left unattended in the doctor's office the more rubber gloves I can blow up
Just saying.

Why does life keep teaching me lessons I have no desire to learn?

Dear Sneeze, if you're gonna happen, happen. Don't put a strange look on my face then leave.

I'm in a really good place right now. Not emotionally, spiritually, or financially.
Just on the couch with my pet.

I can cope with the voices inside my head, but the voices outside my head drive me crazy.

Back in my day, we didn't have Instagram, Snapchat, or Facebook. We had to bore people in person with photo albums.

I know my limits. I don't pay any attention to them, but I know them.

I'm like a kid in a candy store. I can't afford anything.

I bought some animal crackers the other day, and the box said "Warning: Do Not Eat if Seal is Broken". I opened the box, and sure enough ...



Me after completing 1 of the 20 things I'm supposed to do



Whatever my spirit animal is, I'm pretty sure it's still hibernating.

My speech isn't slurred, I'm just speaking in cursive.

My brain doesn't work that well, but my sense of humour is still intact.

I wish they would make my daily supplements fit in my Pez dispenser.

I once saw some idiot at the gym put a water bottle in the pringles holder on the treadmill.

Warning:
Going to sleep on Sunday will cause Monday. Staying awake all night does not prevent Monday. There is no cure.

Sometimes my body is like that wheel on the grocery cart. You know the one.

"Hey wanna go party tonight?"
Me:



I need professional help. A chef, a maid, and a butler should do it.

I finally got 8 hours of sleep. Took me 4 days, but whatever ...

If you make something easier for yourself, they call you lazy. If you make something easier for everyone else, they call you a genius.

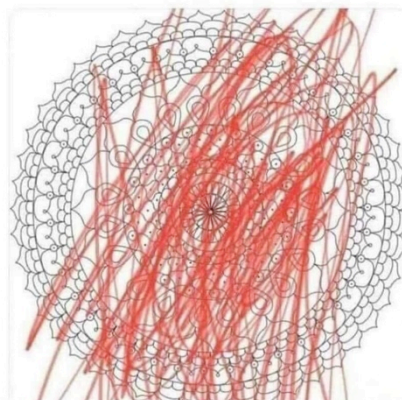
I have neither the time nor the crayons to explain this to you.

My tolerance for idiots is extremely low today. I used to have some immunity built up, but obviously there is a new strain out there.

... That awkward moment when you're wearing Nikes and you can't do it.

Never let the printer know that you're in a hurry.

I have started coloring to manage my stress and anxiety.



Remember when teachers said "You won't have a calculator everywhere you go"? Well, we showed them.

Why does cooking take like 6 hours, eating about 3 minutes, and washing dishes around 7 days and 7 nights?

Today, I was about as useful as the "G" in lasagne.

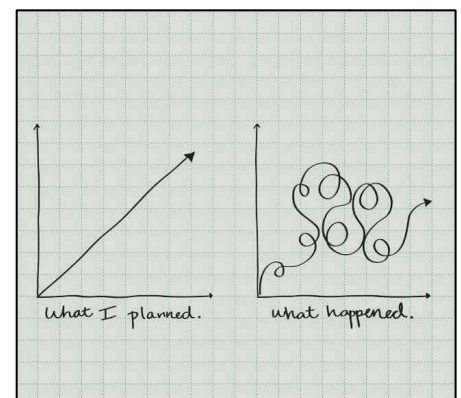
My life can be summed up in one sentence ...
"Well, that didn't go as planned."

How to dress for cold weather:

1. Take your pants off.
2. Go back to bed.

I didn't sleep much, but I got a few solid hours of worrying done.

A telemarketer called and asked to speak to whoever runs the household. So I passed the phone to my dog.



RESOURCES

Yoga

Our last issue included an article about Massage, Yoga, and More. Two of our readers have provided more information about articles and YouTube videos that they found useful:

How 'Yoga Nidra' Works: https://www.huffpost.com/entry/how-yoga-nidraworks_b_58efcea5e4b048372700d692

Yoga Nidra Guided Meditation <https://www.youtube.com/watch?v=KII-HUHbxEI>

YouTube channel **Aroga Yoga** <https://www.youtube.com/channel/UChu7WM-WhIXYBmBbFGx05A>

The Ultimate Cheat Sheet on Yoga for Chronic Illness <http://arogayoga.com/the-ultimate-cheat-sheet-on-yoga-for-chronic-illness/>



Anxiety disorders and reactions secondary to ME/CFS

Many people come across doctors who simply think we are depressed or anxious. If you're looking for a resource that will help explain mental health issues that are secondary to having ME/CFS, then refer to pages 16-17 of the IACFS/ME Primer for Clinical Practitioners 2014 Edition, available at: http://iacfsme.org/portals/0/pdf/Primer_Post_2014_conference.pdf

M.E. Society of Edmonton

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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! Only \$20!

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**