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*MEAO - an organization representing and supporting the medical conditions of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), Fibromyalgia (FM) and Environmental Sensitivities/Multiple Chemical Sensitivity (ES/MCS)*

## MEAO'S E-NEWSLETTER

January, 2021

Dear Members and Friends of MEAO:

We hope that everyone receiving this newsletter is well and staying safe during this very difficult pandemic of Covid-19.

MEAO held its annual general meeting (AGM) on September 23<sup>rd</sup>, 2020 and the board of directors would like to bring you up to date with the latest developments.

### REFRESHING OUR ORGANIZATION:

As most of those receiving this newsletter will know, MEAO's key priority for over a decade has been to develop a system of care for Ontarians living with complex, chronic, environmentally linked medical conditions, including myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), fibromyalgia (FM), and environmental sensitivities/multiple chemical sensitivity (ES/MCS).

### NEW OBJECTS

Over a period of six months, we consulted with our registered members and our lawyer and are very pleased to announce that at the 2020 AGM, the members almost unanimously approved the new objects which are as follows:

To advance education and improve care, treatment and support of individuals in Ontario who are living with complex, chronic, environmentally-linked medical conditions, focused on, but not limited to, myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), fibromyalgia (FM), and environmental sensitivities/multiple chemical sensitivity (ES/MCS), by:

- (i) Providing support to individuals, their families and caregivers, such as, publishing newsletters and maintaining website(s) with current information about the relevant conditions; and
- (ii) Working with relevant government and public agencies, health and social services agencies and other professionals, the media and the public.

The application for “Supplementary Letters Patent” has been submitted. We have just been advised by our lawyer that the Supplementary Letters Patent have been approved as of November 13, 2020, and they are now official!

### **A NEW NAME**

The next step is to come up with a new name for MEAO – one that better reflects the three medical conditions that are now officially in our Letters Patent. If you have any ideas, let us know.

### **QUESTIONS RELATED TO GOVERNANCE OF MEAO**

We have answered certain issues over and over in the past few years but we will take this opportunity to respond once again to a few questions that keep cropping up during the year or at the AGM:

1. Is MEAO's charitable status at risk especially by doing advocacy work and with the manner in which the new Objects is worded? Is MEAO acting as a lobby organization and is this a problem?

#### **MEAO's response:**

- MEAO always follows the advice of its corporate lawyers, its chartered accountants and CRA Charities Branch before any decision is made. MEAO would never make a decision that would put MEAO's charitable status at risk.
- Alan Belaiche, legal counsel to MEAO confirmed that the activities of MEAO and the wording of the proposed Objects do not put MEAO at risk of losing their charitable status.
- Finally, legal counsel confirmed that the work that MEAO is doing to advocate for a system of care is appropriate charitable work. This is allowed under the Charities Act and in no way, is considered lobbying
- MEAO is not a lobby organization

2. Is it appropriate for MEAO to provide tax receipts for membership dues?

#### **MEAO's Response:**

- The Board previously and recently, investigated the issue with CRA and Canada Helps.
- Both confirmed the practice of MEAO to provide charitable tax receipts for membership dues is consistent with the rules and regulations.

3. Why is MEAO no longer operating a help-line?

#### **MEAO's response:**

- For several years, MEAO operated a help line supported by a few volunteers. The callers were often people seeking advice on how to find physicians; how to find specialists for ME/CFS, FM and ES/MCS; how to find therapists of

different modalities; how to get financial assistance and some wanted help to fill out forms etc.

- The help line has not been operating for a few years.
- MEAO currently does not have the volunteers or resources to manage this help line at this time. *But more importantly, we believe that using volunteers to respond to these very complex questions opens up MEAO to liability and risk.* Therefore, for these reasons, MEAO will not be operating the help line at this time.
- However, we believe that as part of the system of care, we also need a system of support for caregivers, families and people living with these conditions. We are strongly advocating for a help line supported by professionals as well as many other much needed supports.

#### **4. Environmental Health Clinic:**

One of the issues that some members continue to raise is MEAO's position on the Environmental Health Clinic, especially the financial support for the Clinic.

##### **MEAO's Response**

MEAO has always and will always act in the best interest of the people who are living with all three conditions. We recognize that the Environmental Health Clinic provides a valuable service for the people that they serve.

Over the years, MEAO has always worked collaboratively with the physicians at EHC, including on the Business Case Steering Committee and on the Task Force on Environmental Health.

MEAO's priority is to build a sustainable, system of care for the over 600,000 Ontarians living with these conditions. This means we need to develop a network of care across the province with a Centre of Excellence that supports this network. This has been the MEAO's dogged focus over the past few years – including in the development of the Business Case and on the task force.

MEAO has always supported that the EHC be part of this system of care. We believe that the EHC should remain open and receive the funding that they need to operate.

##### **Advocating for a System of Care**

Since 2012 with the preparation of the Business Case Proposal, MEAO has focused on advocating for a system of care for people living with complex, chronic, environmentally linked medical conditions, including *myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), fibromyalgia (FM), and environmental sensitivities/multiple chemical sensitivity (ES/MCS)*. This has been our laser focus.

Around the same time, the Alliance for Healthier Communities (formerly Association of Ontario Health Centres (AOHC) received a grant from the Ministry of Health and Long Term Care to develop a business case proposal for the Ontario Centre of

Excellence in Environmental Health. MEAO and AOHC formed a partnership for the purposes of aligning the two projects – to complete the study and the business case proposal. The business case proposal was called “Recognition, Inclusion and Equity – The Time Is Now” which is also the title of the aforementioned study.

After continued advocacy and following up with the MOHLTC for approximately 2-3 years and many delays, the following was accomplished:

- In May, 2016 at MEAO’s May Awareness Day event at Queen’s Park, the Ministry of Health and Long Term Care announced that an inter-ministerial task force would start soon.
- In June 2016, the Task Force on Environmental Health began a term of two and a half years during which an Interim Report was submitted to the Ministry of Health and Long Term Care.
- In December 2018, the Final Report of the Task Force was submitted to the MOHLTC.
- In May 2019, the announcement by the MOH that the final report was to be made public was at MEAO’s Awareness Day event at Queen’s Park.

MEAO then began to press to get action on the implementation of the recommendations that were made in the final report of the Task Force on Environmental Health.

In early 2020, the Minister announced that she had appointed Dr. Brian Schwartz, Vice President Public Health Ontario to review the recommendations of the final report of the task force and submit a report to the Minister with suggestions of developing an implementation plan. The report to the Minister was to be completed in six months being approximately July, 2020.

In March, 2020 COVID intervened and the work was put on pause. Then in MEAO’s Newsflash of October, 2020 we announced some very welcome and wonderful news from Dr. Schwartz, who advised that the review will now go forward with the help of Bill Manson who has joined Public Health Ontario in the role of Strategic Advisor, Environmental Health to work directly with Dr. Schwartz. Bill has been well known to MEAO for many years and he was a member of the Task Force until he had to resign due to other matters needing his immediate attention.

Bill’s role is to advise and assist Dr. Schwartz with the report that is to go to the Minister and they’ll review the recommendations of the final report of the task force and submit a report to the Minister with suggestions of developing an implementation plan.

We know that Bill has been consulting with many support groups with expertise and lived experience with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), fibromyalgia (FM), and environmental sensitivities/multiple chemical sensitivity (ES/MCS), health care leaders, doctors, researchers and health care providers. Bill is still hoping that he and Dr. Schwartz can submit a report to the Minister by early spring, 2021 but we will have to wait for further news from Bill and Dr. Schwartz as to how the project is proceeding and what the timelines will be.

As soon as we know more, we will advise you.

### **MEAO'S WEBSITE WILL BE REFRESHED**

This is being worked on with a new webmaster and we hope to have more news on this in the coming months. This also has not been an easy job due to lack of funds to construct a major new website.

**PLEASE REMEMBER** - the MEAO board continues to be diligent and determined to move forward on building a system of care. It has been our priority for 10 years.

If you want to join us for this important work, please join, renew or rejoin MEAO because we need your support now as much as ever.

### **Here are the instructions for joining or renewing MEAO membership:**

MEAO uses the online services of Canada Helps for all membership applications and renewals and general donations.

MEAO is now doing all communications including forwarding of newsletters by email. Therefore, please ensure that you provide a valid email address on the Canada Helps forms.

To renew your MEAO membership NOW or to make a donation, please go to this link:

<https://www.canadahelps.org/en/charities/the-myalgic-encephalomyelitis-association-of-ontario/>

- Click the red box "Donate Now"
- Click inside the Box **"Apply your donation to a specific fund set up by this charity"** and the drop down menu appears giving you three options
  1. Memberships (Membership fee is \$25.00)
  2. General Donations
  3. Membership and Combined Donation – to include \$25.00 for membership plus whatever additional amount you'd like to donate
  4. There is also a spot called Dedicate This Donation if you'd like to give in honour or in memory of someone special
- For Membership Renewal to MEAO, click on the box for \$25.00 and click "Memberships" on the drop down menu
- For Membership and Donation, click the amount that you'd like and then click **"Membership and Combined Donation"** on the drop down menu **which should include \$25.00 for membership** plus whatever amount you'd like to donate
- Canada Helps will issue you a tax receipt directly on behalf of MEAO

### **A REMINDER OF IMPORTANT LINKS:**

To access and download the final report of the Task Force on Environmental Health go to:

[http://www.health.gov.on.ca/en/common/ministry/publications/reports/environmental\\_health\\_2018/default.aspx](http://www.health.gov.on.ca/en/common/ministry/publications/reports/environmental_health_2018/default.aspx)

To access and download the Interim Report of the Task Force on Environmental Health go to:

*Time for Leadership: Recognizing and Improving Care for those with ME/CFS, FM and ES/MCS*

[http://www.health.gov.on.ca/en/common/ministry/publications/reports/environmental\\_health\\_2017/task\\_force\\_on\\_environmental\\_health\\_report.pdf](http://www.health.gov.on.ca/en/common/ministry/publications/reports/environmental_health_2017/task_force_on_environmental_health_report.pdf)

MEAO's Website: <http://www.meao.ca/>

The joint website of MEAO and Alliance for Healthier Communities (formerly AOHC) being a Campaign for the Ontario Centre of Excellence in Environmental Health: <http://recognitioninclusionandequity.org/>

Correspondence to MEAO: [info@meao.ca](mailto:info@meao.ca)

The MEAO Board of Directors sends best wishes to all. Please stay safe and stay well.

Sincerely,

Denise Magi

*Denise Magi*

*President,*

*The Myalgic Encephalomyelitis Association of Ontario (MEAO)*

*On behalf of the Board of Directors of MEAO*