



THE MYALGIC ENCEPHALOMYELITIS ASSOCIATION OF ONTARIO (MEAO)

DIRECTORS' REPORT

ANNUAL GENERAL MEETING

June 26, 2019

The Myalgic Encephalomyelitis Association of Ontario (MEAO) last held an Annual General Meeting (AGM) on May 2nd, 2018. This report details the major activities from that meeting to present.

MEAO'S OPERATIONS:

By-Laws and supporting Policies and Procedures

- The membership ratified the new by-laws at the AGM in 2018.
- The MEAO board worked extensively with the new policies and procedures that were produced during 2017-2018.

Membership Renewal Process:

- In 2018, MEAO moved to an annual calendar renewal process with memberships being effective for the calendar year (January to December).
- The renewal process starts in September annually with at least 2 reminders and sometimes more, sent out from September to the end of December
- This has made it easier for your volunteer board to manage the renewal process.

MEAO Objects

- The current objects for MEAO as stated in the Letters Patent were approved in 1992. They are very outdated and need a refresh.
- As a first step, at MEAO's AGM of May 2, 2018, a Resolution was passed that recognizes and officially acknowledges that MEAO is an association that provides voice and support to individuals, their families, caregivers who are living with complex, chronic environmentally-linked medical conditions, focused on by not limited to myalgic encephalomyelitis/chronic fatigue

syndrome (ME/CFS), fibromyalgia (FM) and environmental sensitivities/multiple chemical sensitivity (ES/MCS) in Ontario.

- Since the 2018 AGM, the MEAO board started work in conjunction with our corporate lawyer to send new draft Objects to Canada Revenue Agency (CRA) for their approval and comments.
- We have provided to CRA via our lawyer, MEAO's activities and reasons for changing the Objects of 1992.
- We were advised by our lawyers that this process takes several months as CRA is backlogged.
- Our lawyer has made progress with CRA and received several positive answers and suggestions for finalizing the draft Objects. The board is confident that within the next several months, there will be a conclusion that is satisfactory.
- We have heard from our members that you want to ensure that the charitable status of MEAO will not be in jeopardy with the revised Objects and therefore, the MEAO Board is prudently asking CRA's input prior to presentation to the membership for comment. Once we have received CRA's approval in principle, we will share the proposed changes with our members so that you can comment.
- Any change to the Objects will be voted on by the membership.

FINANCIAL STATEMENTS:

- MEAO's financial statements for the year ending 2018 were distributed to all members and will be further discussed at the AGM.
- Our previous chartered accountants, Cowperthwaite Mehta retired and the MEAO board has engaged the firm of Welch LLP as our chartered accountants. They are proficient in charity and not-for-profit organizations.
- At the AGM the report of Welch LLP concerning the MEAO's financial statements of 2018 will be presented.

CALL FOR NOMINATIONS:

- The Call for Nominations which included attributes that a nominee should ideally have, was sent out mid-April and the membership was given 30 days to reply. The Declaration of Consent and Commitment and the Code of Conduct was also attached to the form.
- See Nomination Report for further details.
- According to the Bylaws, the Board has the authority to appoint vacancies. After the AGM, if any member is interested in joining the board, please contact the MEAO Board of Directors.

UPDATE ON THE FINAL REPORT OF THE TASK FORCE FOR ENVIRONMENTAL HEALTH

- Denise Magi, President of MEAO is your representative on the Task Force for Environmental Health
- During the Ontario election of 2018, the task force, as every task force that was taking place at that time, was put on hold until the new government was elected and decided how to go forward with their various task forces.
- The Task Force on Environmental Health was put on hold for 6 months. After significant advocacy by MEAO, the work started up again in late October, 2018. The task force membership then had to complete 6 months work in 6 weeks – a very daunting and complicated task to get a final report finished and submitted to the Ministry of Health and Long Term Care (MOHLTC) on time.
- The task force did in fact, finish its mandate and submitted the final report to the MOHLTC on December 21, 2018.
- The Final Report was publicly released on May 15, 2018 with an announcement made by the office of Minister Christine Elliott, Minister of Health and Long Term Care.

The final report of the task force is entitled -

Care Now: An Action Plan to Improve Care for People with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), Fibromyalgia (FM) and Environmental Sensitivities/Multiple Chemical Sensitivity (ES/MCS)

To access and download the final report go to:

http://www.health.gov.on.ca/en/common/ministry/publications/reports/environmental_health_2018/default.aspx

You will see all ten recommendations when reading the final report - BUT – of special note and importance:

Recommendation 8

Create a centre of excellence in ME/CFS, FM and ES/MCS care, education and research in Ontario

Recommendation 4

Create and support a network of enhanced primary care programs throughout Ontario

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

To access further information on the Task Force on Environmental Health, please go to:

<http://www.health.gov.on.ca/en/public/programs/environmentalhealth/>

VERY IMPORTANT INFORMATION ABOUT THE INTERIM AND THE FINAL REPORTS OF THE TASK FORCE ON ENVIRONMENTAL HEALTH

Since the public release of the Final Report of the Task Force on Environmental Health, MEAO has received questions and comments which we will address as follows:

- Why was the final report or the interim report not more like the recommendations of the Business Case Proposal for an Ontario Centre of Excellence in Environmental Health as submitted to the Ontario government in November, 2013?
- Why was the science of the medical conditions or how care and the types of care are to be established and undertaken, similar to the way that was set out in the business case proposal?
- **Please understand that the Ontario Governments of the day – both Liberal and Conservatives stated that the task force was not set up to implement the recommendations of the business case proposal.** We wish it were that way, but the governments of the day made it very clear that the mandate of the task force was to come up with recommendations on a patient-centred approach to improving supports for the patients living with ME/CFS, FM and ES/MCS- and not to get into any specifics of the business case proposal.
- MEAO board remains committed to the recommendations in the Business Case Proposal and will advocate for the strongest recommendations in both reports.

Report on MEAO's Awareness Day Event at Queen's Park on May 15th:

The Myalgic Encephalomyelitis Association of Ontario (MEAO) had its event to mark May 12th International Awareness Day for **Myalgic Encephalomyelitis/Chronic Fatigue Syndrome**, **Fibromyalgia** and **Environmental Sensitivities/ Multiple Chemical Sensitivity** on Wednesday, May 15th at Queen's Park Legislature Building.

On the morning of May 15th, the final report of the task force was made public – see all links above.

On the afternoon of May 15th, MPP Natalia Kusendova, read a statement on behalf of the Ministry of Health and Long Term Care in which she welcomed MEAO to Queen's Park for their awareness day event. She went on to announce that the final report of the Task Force on Environmental Health had been publicly released that very day and *"We will work to shine a light on these challenges and advance real, meaningful solutions as part of our work to build a health care system that truly works for the people of Ontario and is centred around the patient."*

Thank you again to everyone involved in MEAO for your tireless advocacy on behalf of Ontarians living with chronic fatigue syndrome, fibromyalgia and environmental sensitivities. I hope you will continue this important work."

At MEAO's reception MPP Kusendova, delivered a further announcement that the Minister of Health and Long Term Care, Christine Elliott, will create an implementation committee to see action on the implementation on the recommendations within the final report of the Task Force on Environmental Health. This is of major importance in reaching our goals.

Since that time, MEAO has joined with the co-chairs of the Business Case Proposal and Millions Missing to urge the Minister to fulfil her commitment and announce a chair of this implementation committee immediately.

THANK YOU TO MEAO's Board of Directors

We wish to thank the board of directors of 2018-2019 for all of their hard work, contributions and support to MEAO:

Denise Magi, Adrianna Tetley, Keith Deviney, John Doherty.

MEAO's Website:

<http://www.meao.ca/>

The joint website of MEAO and AOHC being a Campaign for the Ontario Centre of Excellence in Environmental Health:

<http://recognitioninclusionandequity.org/>

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