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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

May, 2020

Dear Members and Friends of MEAO:

We hope that anyone who is receiving this newsletter has not had a case of COVID-19. It's been a huge shock to all of us but a global pandemic of the Corona Virus COVID-19 has hit us all no matter where we are in Canada. It affects each and everyone of us in some way and we all need to do our part in fighting the pandemic. See Page 5 for some guidelines to follow to keep yourselves safe and healthy in the midst of this crisis.

FINAL REPORT OF THE TASK FORCE ON ENVIRONMENTAL HEALTH – NEXT STEPS

You'll recall in MEAO's January newsletter, we attached MEAO's letter to Minister Christine Elliott in which we asked for immediate action regarding implementation of the recommendations. Many of you also made a copy of that letter and sent it to the Ministry of Health. It appears to have worked.

Health Minister Christine Elliott, sent a letter to the President of Public Health Ontario (PHO), Dr. Peter Donnelly, asking for PHO's assistance in leading a review of the final report and recommendations of the Task Force on Environmental Health: 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). The objective of this work is to assess the recommendations of the Task Force and identify real solutions that will directly benefit Ontarians. PHO was given a six month time period to conduct this review.

Dr. Donnelly appointed Dr. Brian Schwartz to lead this initiative. Dr. Schwartz is the Vice-President of Public Health Ontario (PHO). He is also associate professor at the Dalla Lana School of Public Health, University of Toronto. Among his areas of expertise are public health, emergency preparedness and response, emergency medical services many areas of research within public health.

Just prior to COVID-19 restrictions, MEAO was advised of this development and we were invited to meet with Dr. Schwartz to begin to discuss next steps. We were very heartened by Dr. Schwartz's commitment to proceed quickly and in a collaborative manner. However, as the COVID-19 situation has continued to evolve, there has been an exponential escalation of PHO's activities to support the provincial response. As a result, in consultation with the Ministry of Health, PHO has placed a temporary pause on the review of the Task Force's final report and recommendations.

We have followed up with Dr. Schwartz and he immediately assured us that the work will continue as soon as possible but he has asked us to be patient as they put all their energies towards COVID-19 at this time. We are assuming that he will be given a new deadline for the review once COVID-19 allows for other work to resume.

As always, as soon as we hear of this work going forward, we will advise you and keep you up to date.

Meanwhile, we'd like to thank all the doctors, nurses, all medical professionals and all frontline workers in all sectors for their tireless work in keeping Ontarians safe during COVID-19.

May 12th Awareness Day for May 12th International Awareness Day for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), Fibromyalgia (FM) and Environmental Sensitivities/ Multiple Chemical Sensitivity (ES/MCS)

MEAO was scheduled to have its awareness day event on May 12th at Queen's Park but as you can all guess, it's been cancelled due to COVID-19. All events and all gatherings are cancelled.

City of Toronto Proclamation: Even the yearly proclamation is affected and the City of Toronto has cancelled all proclamations no matter the topic.

THE REPORTS OF THE TASK FORCE ON ENVIRONMENTAL HEALTH:

We are again giving you pertinent links for your information:

1. 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

A **summary** of the recommendations of this final report are attached to this newsletter – 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

2. 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

For quick and easy reference, attached to this e-newsletter please find:

- a) Links to important COVID-19 Information and Resources
- b) Statement delivered on behalf of Minister Christine Elliott, in Legislature on May 15, 2019 (a year ago) by MPP Natalia Kusendova. We're providing this once again as a reminder and in view of this year's awareness event at Queen's Park being cancelled.
- c) Summary of the Recommendations of the Final Report of the Task Force on Environmental Health

JOIN MEAO AND MAKE A DIFFERENCE

If you're not yet a registered member of MEAO, now is the time when we need you the most. Turning the Task Force's recommendations into reality requires that we take action together, speaking with a unified voice for people living with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), Fibromyalgia (FM) and Environmental Sensitivities/Multiple Chemical Sensitivity (ES/MCS).

We encourage you to become a full member of MEAO. Your \$25 membership fee ensures:

- You will be part of the official voice for people living with ME/CFS, FM and ES/MCS, and your voice will be heard in official forums.
- You will have voting rights at our annual general meeting
- You will have the latest information on our projects, including the Task Force on Environmental Health, including all news and information relating to the implementation of the recommendations of the Interim Report and the Final Report of the Task Force on Environmental Health
- You will receive all of MEAO's regular e-newsletters and e-newsflashes via email. MEAO is using the services of Canada Helps for memberships, renewals and donations.

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

To start or renew a MEAO membership 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
 2. General Donations
 3. Membership and Combined Donation

- 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

VERY IMPORTANT: Read each drop down menu carefully and ensure that [if you want to be a full voting member of MEAO, under "NAME" you must give your full name and address and email address](#). Do not click on anonymous unless it's for an anonymous donation.

Canada Helps will issue you a tax receipt directly on behalf of MEAO.

NOTE FOR THOSE WHO ENROL A SECOND MEMBER PER HOUSEHOLD:

There are several members who enrol a second member. To make it easier for those who have two memberships per household, you can register two members per household on the same Canada Helps form. [Just remember to click the correct amount for two memberships and to note in the message column on the Canada Helps form, the full names of those you are registering as members.](#)

As always, MEAO will keep you updated on any news and developments that we receive.

Stay safe and stay well.

Best wishes from the MEAO Board of Directors.

Sincerely,

*Denise Magi
President,
The Myalgic Encephalomyelitis Association of Ontario (MEAO)
and – Former Member of the Task Force on Environmental Health*

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

RE: COVID-19 IMPORTANT AND VERY HELPFUL INFORMATION AND RESOURCES FOR EVERYONE

GO TO the following Public Health Ontario link for several Fact Sheets and Resources they have developed to help you during COVID-19

<https://www.publichealthontario.ca/en/diseases-and-conditions/infectious-diseases/respiratory-diseases/novel-coronavirus/public-resources>

Fact Sheet on How to Protect Yourself from COVID-19; Older Adults and People with Chronic Medical Conditions or Weakened Immune Systems – THIS IS FOR A LOT OF YOU RECEIVING THIS NEWSLETTER

<https://www.publichealthontario.ca/-/media/documents/ncov/factsheet/2020/05/factsheet-COVID-19immunocompromised.pdf?la=en>

Fact Sheet on Take Care of Yourself and Each Other – COVID-19

<https://www.publichealthontario.ca/-/media/documents/ncov/factsheet/factsheet-COVID-19-19-guide-take-care-yourself-others.pdf?la=en>

Fact Sheet on Physical Distancing – COVID-19

<https://www.publichealthontario.ca/-/media/documents/ncov/factsheet/factsheet-COVID-19-19-guide-physical-distancing.pdf?la=en>

Fact Sheet on How to Self-Isolate – COVID-19

<https://www.publichealthontario.ca/-/media/documents/ncov/factsheet-COVID-19-19-how-to-self-isolate.pdf?la=en>

GO ALSO to the following Ontario Ministry of Health COVID-19 website for all the latest information and updates on the pandemic.

http://www.health.gov.on.ca/en/pro/programs/publichealth/coronavirus/2019_guidance.aspx

From Hansard Debates

May 15, 2019

Myalgic Encephalomyelitis Association of Ontario

Ms. Natalia Kusendova: It is my pleasure today to welcome the Myalgic Encephalomyelitis Association of Ontario, or MEAO, to Queen's Park for their advocacy day.

For 28 years, MEAO has been at the forefront of educating Ontarians and front-line care providers, advocating on behalf of and supporting Ontarians living with chronic fatigue syndrome, fibromyalgia and environmental sensitivities.

As a nurse and as an MPP, I have come to appreciate and value the important role of patient advocacy organizations such as MEAO in improving the health and well-being of Ontarians. Today I want to reiterate our government's commitment to work with MEAO to ensure no Ontarians feel like their government isn't taking their medical issues seriously.

To that end, our government today released the final report of the Task Force on Environmental Health. 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.

Summary of Recommendations of the Final Report of the Task Force on Environmental Health

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)

Recommendation 1

Develop a one-to-three year awareness campaign that targets the general public, health care facilities and providers and primary care settings.

Recommendation 1.1 – Develop awareness materials that target the general public and specifically engage priority groups, starting with employers and landlords.

Recommendation 1.2 – Create materials and tools designed to promote awareness of ME/CFS, FM and ES/MCS and explain how to accommodate patients with these chronic conditions in priority health care settings, starting with hospitals, long-term care homes and key home care providers.

Recommendation 1.3 – Increase awareness of ME/CFS, FM and ES/MCS, clinical tools and information, and the need for accommodation, in all primary care settings in Ontario.

Recommendation 2

Develop and disseminate clinical tools and information that support evidence-informed treatment and management.

Recommendation 3

Establish a system to develop and support a cadre of primary health care and specialized providers skilled in managing ME/CFS, FM and ES/MCS.

Recommendation 3.1 – Establish a community of practice to provide training and support the network of primary care clinics that will provide chronic disease management for people with ME/CFS, FM and ES/MCS across the province.

Recommendation 3.2 – Fund a comprehensive strategy to increase the pool of skilled, specialized providers to reflect the high demand for interdisciplinary care.

Recommendation 4

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

Recommendation 5

Develop a shared care planning tool.

Recommendation 6

Modernize the OHIP K037 fee code to include all three conditions and use it to help gather data on their prevalence.

Recommendation 7

Support research to fill critical gaps in knowledge about the pathogenesis, prevention and treatment of ME/CFS, FM and ES/MCS.

Recommendation 7.1 – Leverage the Health System Research Fund (HSRF) to fund priority research into patients’ experience with the health system and improve care and efficiency.

Recommendation 7.2 – Work with funding organizations such as the Canadian Institutes of Health Research (CIHR) and the US National Institutes of Health (NIH) to support funding research projects that explore questions related to the pathogenesis and prevention of ME/CFS, FM and ES/MCS.

Recommendation 8

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

Recommendation 9

Establish a transitional implementation committee to provide the leadership in the initial phases of putting this plan into action.

Recommendation 10

Provide regular updates and progress reports on the implementation of the proposed action plan.

Task force members all agreed with and support these recommendations. The task force also discussed in detail another recommendation on additional funding for the Environmental Health Clinic at the Women’s College Hospital, but did not reach agreement. Some members wanted to see an immediate increase in funding for the Environmental Health Clinic as a way to reduce wait times and improve access to specialized care while the action plan is initiated. Other members were concerned that approach would simply maintain the status quo and potentially delay the much needed investment in developing a centre of excellence and for the enhanced system of primary care proposed in the report. This underscores the challenge ahead to provide immediate and sustainable health care for people with ME/CFS, FM and ES/MCS.