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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 NEWSFLASH

October, 2020

Dear Members and Friends of MEAO:

We hope that everyone receiving this newsletter is well and has not had a case of COVID-19. It's been a difficult seven months and it's going to be a difficult winter much to everyone's dismay, with the cases of COVID rising **everyday**.

UPDATE ON NEXT STEPS REGARDING THE RECOMMENDATIONS OF THE TASK FORCE ON ENVIRONMENTAL HEALTH

You'll recall that we previously advised that in February of this year, Minister of Health Christine Elliott appointed Public Health Ontario (PHO) to lead 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. In February, PHO was given a six month time period to conduct this review.

Dr. Brian Schwartz, the Vice-President of Public Health Ontario was appointed to lead this initiative. Dr. Schwartz and PHO have always been very committed to this project. However, when COVID-19 evolved so quickly in the month of March, the project was put on a temporary hold because all of the efforts of Public Health Ontario were focused on COVID-19.

Then in early October, we received 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.

Dr. Schwartz advised as follows:

“I am very pleased to announce that Bill Manson joined PHO in the role of Strategic Advisor, Environmental Health and will be working directly with me on this initiative. Bill has extensive senior leadership experience in health care, proven expertise in local and system level change management including integrations and transitions, performance and quality, program development and implementation. Throughout his career, he has consistently produced results, using strategic leadership, identifying opportunities, initiating creative ideas and implementing action plans with defined outcomes. Bill has participated on provincial committees including an inter-ministerial committee on environmental health, transgender health and the transition of Ministry programs to Local Health Integration Networks.”

It was also very heartening to us that when we recently wrote to Minister Christine Elliott, she responded to confirm:

“PHO remains fully committed to carrying out this work in a way that meaningfully engages stakeholders and partners and results in a plan that identifies real solutions that will improve care. PHO is currently working on a plan to resume its work on this initiative and hopes to have a concrete plan in place in the next few weeks.”

The MEAO Board wants to thank Minister Christine Elliott, Dr. Brian Schwartz and Bill Manson for their ongoing commitment and we look forward to hearing details of the new plan.

To refresh your memory, we attach the summary of the recommendations of the Final Report of the task force. As soon as we hear what the new plan is, we will of course, let you know.

THE CONNECTION BETWEEN COVID-19 AND MYALGIC ENCEPHALOMYELITIS

It has been in the media for months that there is a real connection between COVID-19 and myalgic encephalomyelitis. Researchers and scientists are working with data regarding the similarities of those who have long term symptoms of COVID-19 that are similar to those of myalgic encephalomyelitis. This is huge news and lends to the long sought after credibility of myalgic encephalomyelitis. Dr. Schwartz and Bill Manson are well aware of this connection and this information should help the plan of the next steps.

We here at MEAO thank Minister Elliott and Dr. Schwartz for their leadership and tireless work during the COVID-19 pandemic and for their ongoing commitment to the review process.

Stay safe and 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/>

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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.