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To Christian Dubé, Minister of Health and Social Services, Québec ministre@msss.gouv.qc.ca

Re: INSPQ report on MCS misrepresents ME and FM

The National ME/FM Action Network has been working on behalf of Canadians with Myalgic Encephalomyelitis (ME) and Fibromyalgia (FM) since 1993. ME has been referred to as chronic fatigue syndrome. ME and FM frequently overlap with each other and with Multiple Chemical Sensitivity (MCS).

ME and FM are complex, chronic, disabling conditions that involve reduced activity levels, cognitive difficulties, sleep dysfunction, fatigue, pain and the need to manage exertion. They are often triggered by infections or other assaults to the immune system. There is a major wave of cases coming as a result of Covid.

A report entitled "Multiple chemical sensitivity syndrome; an integrative approach to identifying the pathophysiological mechanisms" has been posted on the Quebec National Institute for Public Health (INSPQ) website.

While the title focuses on MCS, the report discusses ME and FM as well. It somehow links ME and FM with depression, somatization disorder, phobias, panic disorder, chronic anxiety, alterations in mood, loss of motivation and the inability to feel pleasure. This portrays ME and FM as psychiatric conditions rather than biomedical illnesses.

Even though the World Health Organization has classified ME as a disease of the nervous system since 1969, the psychiatric explanation of ME has influenced public policy in Canada and internationally for decades, denying patients biomedical support and suppressing research. This explanation is finally being examined and is being rejected. A 2015 report by the prestigious US National Academy of Medicine, a 2018 report by an Ontario government task force, a 2021 consensus report by the European ME Network and a 2021 report by the UK National Institute of Clinical Excellence have all rejected the psychiatric explanation of ME and come down squarely on the side of ME being a biomedical illness.

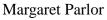
The rejection of the psychiatric explanation of ME necessitates a review of medical services and research programs and calls into question much of the existing ME literature. Very importantly, ME provides a sobering message about how easy and harmful it is to portray an illness as psychiatric when it is not.

We ask that the INSPQ report on MCS be removed from the Quebec government website because of its outdated and harmful approach to ME.

We ask that the Quebec approach to ME be reviewed and revised in light of recent reports confirming ME as a biomedical condition. This has added importance because of the coming wave of long-Covid cases.

We ask that the Quebec approach to FM be reviewed to ensure that psychiatric explanations are not used for biomedical issues.

We urge Quebec to work the Environmental Health Association of Quebec on issues relating to MCS.



Malor

President

Links:

INSPQ report summary (English) https://www.inspq.qc.ca/en/publications/2730

INSPQ report (French) https://www.inspq.qc.ca/publications/2729

Canadian Community Health Survey Statistics on ME, FM and MCS, 2014 English:

https://mefmaction.com/docs/CCHS Stats 2014.pdf

French:

https://mefmaction.com/docs/CCHS_Stats_2014_Fr.pdf

http://mefmaction.com/images/stories/quest_newsletters/Quest112.pdf

US National Academy of Medicine report on ME (English only)

 $\underline{https://www.nap.edu/catalog/19012/beyond-myalgic-encephalomyelitischronic-fatigue-syndrome-redefining-an-illness}$

Ontario government task force report on ME, FM and MCS

English:

https://www.health.gov.on.ca/en/common/ministry/publications/reports/environmental_health_2018/task_force_on_environmental_health_report_2018.pdf

French:

 $\frac{https://www.health.gov.on.ca/fr/common/ministry/publications/reports/environmental_health_2018/tas}{k_force_on_environmental_health_report_2018.pdf}$

European ME Network Consensus report (English Only) https://www.mdpi.com/1648-9144/57/5/510

The lead author is a member of the Canadian ME Research Network directed by Dr Alain Moreau of the University of Montreal.

UK NICE guidelines for ME (English only) https://www.nice.org.uk/guidance/ng206

cc

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