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Mr. Amarjot Sandhu, MPP, Chair
Ms. Julia Douglas, Clerk

23 January, 2020

Recommendations to the Standing Committee on Finance and Economic Affairs
2020 Pre-budget Consultation- for Immediate Assistance to People with ME/CFS, FM, and ES/MCS

Dear Mr. Sandhu MPP and Ms. Douglas:

Care Now- An Action Plan to Improve Care for People with ME/CFS, FM, and ES/MCS was submitted to the Ministry of Health and Long Term Care (MOHLTC) by the Task Force on Environmental Health in Dec., 2018, and released to the public in mid-May, 2019, but it appears there has been no government action on their recommendations since that time.

There is a long-standing and urgent need for a broad range of services in this poorly understood,, under-served, and hard-to-serve area of complex, chronic conditions, such as myalgic encephalomyelitis/chronic fatigues syndrome (ME/CFS), fibromyalgia (FM), and environmental sensitivities/multiple chemical sensitivity (ES/MCS).

Building a good foundation for such a program will take time- but patients need help now. Patients are concerned that in the current fiscal climate with many competing priorities the Government may want to postpone any substantial action.

We are writing to recommend some modest steps the Government should also be taking now while a broader plan is being developed and further initiated.

The Environmental Health Clinic (EHC) at Women's College Hospital, Toronto is a valuable provincial resource to leverage in any expansion of services in this area. The EHC was created and funded by the MOH in 1996, in addition to a Research Unit at University of Toronto, as the only government-funded clinic in Ontario dealing with complex, chronic, environmentally-linked conditions, and one of only 3 in Canada. The EHC has had decreased funding over the last number of years, and operates with part-time staff in a small facility. The wait list for assessment of patients is 17 months- very upsetting to patients and staff alike. Patients have usually been seen by many other physicians in a search for assistance before being diagnosed at the EHC and the contributors to their illnesses identified.

The following suggestions relate to recommendations in the Task Force on Environmental Health's two reports:

1. **Increase the number of knowledgeable providers-Continue to fund the Clinical Environmental Health Post Graduate Year 3 Fellowship Program**. It is crucial to have

more physicians knowledgeable in these areas to expand quality care and teach other health professionals. Some of the current very small number of physicians are on the verge of retirement.

The MOHLTC asked for a proposal to continue the funding for **2 more academic years to train 2 Fellows**, which was submitted by Dr. Michael Kidd, Director of Post-graduate Medical Education, Department of Family and Community Medicine in Oct. 2019. The cost per annum would be **$116, 533.07**, and the funding is going through the approval process.

Recently, the EHC had interest expressed by a physician with research training, Dr. Rahul Shetty, who joined the Research Network for ES/CFS and FM, chaired by Dr. Alain Moreau in Montreal, funded by the Canadian Institutes of Health Research. He plans to work with the EHC's Research Director, Dr. Kathleen Kerr, and is very interested in learning more about patients with those conditions, which are often overlapping with ES/MCS. The EHC Education Coordinator wrote to the MOHLTC with a copy to the Enhanced Skills Director of the DFCM, hoping for the Ministry's commitment to funding the Program for the next 2 academic years, and hopefully beyond, and received a reply that it is in the Minister's approval process.

As stated by Dr. Kidd, "The Clinical Environmental Health program underwent an Internal Review with all our PGY3 Enhanced Skills programs and was deemed to have met the accreditation standards of the College of Family Physicians of Canada which includes a review of program goals, objectives, competencies and curriculum structure". We hope that graduates of the CEH PGY3 Program may soon be acknowledged with a Certificate of Added Competence (CAC) designation, which would encourage health professionals to study Clinical Environmental Health and to broaden their interest in planetary health. In turn, accredited education would hopefully reduce the stigma that patients experience with complex, chronic, environmentally-linked conditions.

2. **Lay the groundwork for a patient-centred system of care- Establish detailed clinical care pathways to support the development of an evidence-based system of care.** The EHC has developed individualized, evidence-based system of care for each patient, which is inherently complex, given the multi-morbidity of their illnesses and the multiple contributors.
   The clinical staff are all part-time, and so increasing the availability of physician, nursing, and administrative staff could lower the wait list, which is currently 17 months.

   Is there a way that additional funding can be designated to the EHC to increase staff at least until the wait list is cleared?

3. **Change the conversation and increase understanding and recognition of these conditions- make a statement reinforcing the debilitating nature of these conditions, dispelling the misperceptions that they are psychological and making a commitment to improve care, education and support for caregivers.** Lack of knowledgeable practitioners and other resources in the community is a major challenge, and thus, without these resources the EHC cannot provide ongoing care currently. It is especially important for patients to self-manage, including anticipating and avoiding triggering exposures, strategically pacing their limited energy, managing pain, as well as coping with the emotional aspects of dealing with and explaining these poorly understood, confusing, and frequently marginalized conditions. The support of their family physicians is essential, and would be encouraged more. This customized assistance would not be covered in a general Coping with Chronic Illness Program in the community.

   To meet the need for increased understanding and care, from 2000-2005, the EHC had a 10-week annual preventive group program developed by a psychologist, Dr. Annette Lorenz, accompanied by an individual "life context support" program by an environmental physician, also trained in physician psychotherapy, Dr. L. Marshall, which was highly successful. The patients did well individually and supported each other and their family physicians, and were still doing better at a one-year follow up group visit. Unfortunately, the EHC could not continue to pay the psychologist, nor to continue the research started on the effectiveness of these strategies. Dr. Marshall started a helpful, but under-funded life context support program in 2017, continuing it until 2019. Patients were most appreciative of supportive letters written to their family physicians, employers or landlords. Dr. Lorenz has continued to evolve her customized group program with police forces.

   If both programs were reinstituted, the program would cost **$18, 895.00**, including recruitment of group members and controls, psychological testing and interpretation, pre-group feedback, running of groups of 20 patients for 2 hours weekly for 10 weeks, post group feedback, individual 'life context support' counselling as needed, offered online via the Ontario Telemedicine Network (improving access for patients), with letters to family physicians, employers etc., research assistance, and preparation of an article for publication.

4. **Develop a common understanding of ME/CFS, FM, and ES/MCS- by expanding the monthly education of EHC Clinical Team Members (doctors and nurses), Fellows, medical students and residents.** Because the clinic is small, and has only 2 private rooms, the doctors and nurse(s) have to rotate. Hence, they do not have sufficient opportunity for communication about patients with complex, multi-morbid conditions, a key learning strategy. This engenders some confusion in the detailed clinical care pathways for these complex, chronically ill patients, in this relatively new field where sharing of clinical observations and insights is especially important.

Once monthly, all the EHC Team members meet for 2 paid hours, commonly extending for an extra unpaid 2-3 hours. Given that it takes 2 unpaid hours of travel time taken from busy schedules to reach the clinic, we estimate that it would cost **$32,000 per year to cover the monthly meetings to pay non-salaried staff for an extra 2 hours to learn to improve their clinical practices, and then to teach students and residents, and provide support to family physicians.** This seems fair because it recognizes the multiple unpaid contributions by the EHC physicians to enhance the care, education and research efforts on behalf of Ontario people with ME/CFS, FM, and ES/MCS,

5. **Make hospitals and long-term care homes safe for people with ME/CFS, FM, and ES/MCS.**
   Patients who often develop a wide range of symptoms, including cognitive problems, from low level exposures to chemicals commonly used in hospitals, such as disinfectants and cleaning materials, may delay or avoid going to hospital because they are frightened of having reactions, and have difficulty explaining their condition and need for accommodation. This can be confusing and time-consuming for hospital staff. Patients report negative experiences with skepticism and disbelief that interfered with obtaining appropriate care.

   The EHC wrote ***Environmental Health in Hospitals*** in 2001, parts of which were subsequently used by the Ontario Hospital Association and, in particular, the Quinte Hospital Region, to develop guidelines for a fragrance-free environment. To update the manual and create related documents, would encourage use as a learning resource in future. It would require literature review, interviewing patients and key hospital and long-term care home employees, including learnings from implementation in Quinte, revising the written guidelines, submitting them to review, and revising them again, for a cost of approximately **$10,000.00.**

We are recommending you take action on these ideas. The total per annum expenditure for a considerable increase in literacy and advances in care (4 recommendations) about ME/CFS, FM, or ES/ MCS, would be $177,428.07, in addition to staff funding to decrease the wait list.

We think these suggestions would be most important to immediately progress, and would in no way interfere with the long-term goals.

Sincerely,

Eleanor Johnston- person with lived experience
Yvon Hemsol- 580 Christie Street, Unit 904, Toronto, Ontario M6G 3E3 *(member of family that <u>all</u> had MCS as a result of living in house with insulation (UFFI) that was later banned.) Had MCS myself since 1980's and CFS/ME since 1998.*