Five percent of Ontario’s population is affected by the often overlapping, commonly disabling and sometimes life-threatening conditions of ES/MCS (Environmental Sensitivities/Multiple Chemical Sensitivity), ME/CFS (Myalgic Encephalomyelitis/Chronic Fatigue Syndrome) and FM (Fibromyalgia). As of 2010, over 568,000 Ontarians had been diagnosed with one or more of these conditions. This number grew from 439,000 in 2005, as reported in Statistics Canada’s Canadian Community Health Survey. It demonstrates prevalence comparable to diabetes, heart disease, cancer and effects of a stroke. These are very widespread conditions, and the 2010 figures are likely underestimates.

Recognition, diagnosis and treatment of these serious conditions are absent from Ontario’s health care system at present. Even though a commission of enquiry recommended services be put into place for ES/MCS as long ago as 1985, exclusion, discrimination and stigmatization of those living with these conditions have been the rule; and Ontario has lost physicians seeking to help these groups.

Currently, well over $150 million per year in health system costs is spent to service these patients in a fragmented, inappropriate and/or harmful fashion - i.e. is completely wasted. This does not include many high costs to society such as preventable disability costs, lost earnings to patients and families, lost taxes - these additional costs are estimated to range into the billions. Also, this does not take into account the often crippling, uninsured medical costs borne by these patients and their families alone, such as drugs, special nutrient supports, or the provision of safe housing.

In October, 2013, a major, two-year study funded by the Ministry of Health and Long Term Care and the Ontario Trillium Foundation submitted a Business Case and extensive supporting appendices to the MOHLTC outlining a plan of action - ‘solutions’ - for a system of care, provisionally called the Ontario Centre of Excellence In Environmental Health (OCEEH)

The hospital- and university-affiliated OCEEH would:

- develop the continuum of care from prevention and primary care to highly specialized care and long term care for these groups
- address the social determinants of health, including shelter and supportive housing - a critical component
- facilitate a cultural change to acceptance for these conditions as chronic disease and disabilities
- build or redevelop safe health care facilities where those with ES/MCS can receive care
- influence social policy to equitably include and address the needs of these groups
- create and support a leading-edge research and education infrastructure

Costs will be offset by significant savings thanks to timely access to the right care at the right time.

STRUCTURE AND FUNCTIONS THE OCEEH

Two pillars

- **PILLAR ONE** develops a system of care to meet the full range of health and social needs of individuals with these conditions - people-centred care, integrated, coordinated, comprehensive, and provided by interprofessional teams.
- **PILLAR TWO** works to remove systemic barriers to health equity so that patients and their families can lead full and productive lives. The goal is to ensure that these conditions are recognized as chronic diseases and disabilities with normal supports so that are treated in an equitable manner to other major chronic conditions; and to help government and health care understand and improve the impact of many common-use chemicals on human health.
A ‘PYRAMID’ AND A ‘HUB AND SPOKES’ - 3 LEVELS

- A specialized ‘hub,’ hospital- and university-affiliated, providing diagnosis and treatment for the most complex cases with referral to the hub by any and all physicians; leading a research program; developing education for health professionals, public sector staff, the general public and patients; and policy department to work on barrier removal and general policy alignment.
- 6-10 specialized primary care ‘spokes’ linked to regional CHCs, directly providing trained primary care and serving as resources for local primary care physicians
- Linkages with, and education and support for, individual primary health providers throughout the province, eventually supporting all providers for basic diagnostic and care capacity.

OBJECTIVES OF THE OCEEH

RECOGNITION INCLUSION EQUITY = NORMALIZATION OF CARE AND SUPPORT

- People receive appropriate, evidence-based, comprehensive, interprofessional primary health care with appropriate health and social services; and access to trained specialists for complex cases
- Services are available at the right place, at the right time, from the right provider.
- All health professionals receive formal training, integrated into their foundational education, and all primary care providers are trained to assess, diagnose and treat/manage these conditions
- Services are delivered using protocols and guidelines, informed by evidence; where evidence does not yet exist, a major research program will contribute to developing new knowledge
- Management for more complex conditions is available closer to home
- Safe treatment facilities are created for those with ES/MCS
- Efforts to create safe housing, including emergency shelter, supportive housing, long-term care homes and safe hospital reception, are a top policy priority
- A spirit of enquiry, innovation, and evaluation pervades.

RESULTS OF THE OCCEH

- The patient experience will be transformed - patients will have access to effective, appropriate care and will no longer have to encounter multiple layers of stigma and discrimination
- Serious illness and injury among those who are at the greatest risk of declining health can be prevented and/or delayed and/or mitigated, with benefits to patients, families, communities and to the province as a whole
- Recent investments in strengthening the primary health care system will be leveraged - the majority of patients will receive care from their primary care provider, who has acquired the required skills and knowledge
- Effective and available social supports, critical to these groups, will be built on and adapted
- A learning environment that can have positive spin-offs for many chronic conditions will be fostered
- Value and sustainability will be delivered through efficient use of resources, including through prevention and appropriate care for patients with environmentally-linked conditions.

Ontario Centre of Excellence in Environmental Health Interim Steering Committee

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