May 3, 2018
Feedback from Patients and Patient-Caregivers across Canada
Ontario Task Force on Environmental Health - Phase 1 Report

Feedback Number	Feedback	Location Providing the Feedback
1	The Task Force has much value. It also has some shortcomings as is common with "broad-front" (something for everybody style compilation) efforts such as this... especially the repeated emphasis on environmental health issues, as if these were fundamentally common to all the conditions under discussion. Despite the real and progressive value of the task force initial report, there is one fundamental issue, which has no mention: money. This might well form the core building block under the section entitled: "Case For Action". This could be the turning key for rapid and sustained government action. This is the true business case for solving these diseases. This business case has two main components: Testing/referrals and the cost of a huge number of people who are chronically sick unnecessarily. The report talks briefly about long wait times for useless referrals and inconclusive tests. This is so common in the case of ME/CFS that the process even has its own name: "the carousel". A clear understanding of these diseases, appropriately discriminating billing codes and widespread physician improved expertise could remove most of these; save money and reduce wait times making them available for other diseases which benefit from a developed understanding. However, by far the most compelling business case for quickly initiated and sustained government action is both the money (now being spent uselessly) to be saved, and the	**British Columbia**

	money (which would become available) to be gained. The cost to Ontarians of half a million sick people whom the system cannot cure but who are drawing down the medical and the social security systems in the long term and often permanently (decades), is staggering. Add to this, the fact that, the large proportion of these people have been very productive (many highly educated), in society, and therefore paying taxes (and likely could again), is a large opportunity being missed. The ME/FM Society of BC is in conjunction with KPMG preparing the convincing money based business case to explain how compelling is this call to Government and Medical system action.	
2	ME/CFS/FM brings a disease burden that has the ability to seriously affect Patients, as seriously as other more well-known disabling diseases such as MS Lyme Disease, and Autonomic diseases. The NIH estimates that fair annual funding in the US should be more than 25 times more that what it currently receives at $188 Million. In turn Canada would have to calculate its own (DALY) Disability Adjusted Life Years, as a recognized measure of disease burden for funding, considering most patients are so affected, they cut short their ordinary working years. I have read Dr. Copes First Report, in his work on the Ontario Task Force on Environmental Health; and it contains excellent information that I concur with. Many current priorities remain the same, long term! These unresolved issues have been ongoing for decades, which if solutions could be obtained, would make a huge difference in patient care, support, legitimacy of this very real illness, and end up actually streamlining the dysfunctional medical system in which Patients so often find them selves in. The added social impact of having a chronic illness is further compounding situations that can no longer be brushed aside. The government and the public need to find ways to contribute to a growing problem in health care that is enduring many losses, and help find answers to help Patients live with dignity and respect.	**British Columbia**

As noted, the Ministry of Health and Long-Term Care (MOHLTC) has already established a Task Force on Environmental Health to provide recommendations and advice to:

- inform possible guidelines and policies to support patients with conditions triggered by environmental factors;
- increase public and health care providers' knowledge of health conditions triggered by environmental factors;
- identify gaps in evidence, knowledge transfer and care for those affected by these conditions;
- identify patient-focused actions to improve health outcomes of affected patients.

That said, it is a very good start…..but there are more in-depth specifics to be considered!

In brief; there are additional important messages of "Unmet Health Needs" that urgently need to be addressed, and high quality improvements for a needy population which is vastly underserved, and desperate patients are required in the following areas:

- Create Academic Chairs focused on ME/FM/ES/MCS;
- Fund knowledgeable, well trained Medical Support as front line defenses;
- Fund Research for a Biomarker and Root Cause;
- Resolve ways provide Patients Access to Timely Assessments, Diagnosis;
- Reduce lengthily Wait Lists;
- Create Consistent Patient Diagnosis Criteria in Every Province;
- Implementation of an 'Official' Fee Code in Provinces for ME;
- Name Recognition – Decide on one Name ME, SEID, EBV, or ?;
- Resolve Acceptable Definition on 'Official Guidelines' CCC or ICC?;
- Recognize the full extend of a total brain body affected patient, ie: ME, FM, ES, MCS;
- Implement Evidenced based Center of Excellence Patient Care Programs;
- Implement Local Community Support via Public Health Programs for Support and

	Information; • Create more Awareness and Treatment regarding Pain Control/Elimination; • Create more Awareness and Treatment of Mitochondrial Support, Quality Sleep Hygiene, Olfactory management, Pain Control Management, Sleep Apnea etc., • Reduce the Stigma, Isolation, Stress, Lack of Support to Patients; • Improved Information to Hospitals, Educational sources, Employers, Insurance Companies, Family Members, Care Givers; • Improve Access to Treatments; • Improve Education and Training to Medical Students, Physicians, Specialists, Nurses; Nurse Practitioners, Dentists, Physiotherapists, Massage Therapists; Teachers, Lawyers, Employers; Holistic providers, Meditation, Stress Reduction, Relaxation; • Improve Support to Patients in Need of Work place Insurance Benefits, D-CPP, Pensions, Unions; • Improve Access to Healthy Nutrition, Supplements, Prolotherapy, Acupuncture, Social Service Counselling, Grief Counselling, Safe Housing, Home Supports; Orthopaedics, IV Therapy, Canes, Wheel Chairs, Upright Walkers; • Access to Compassionate Assisted Living and Home Care; • Access to Affordable Transportation; • Improve Basic Living Income Support; • Improve Affordability for needed Medications; • Reduce Stigma! • Provide Support for Filling Out Forms; • Implement HOPE for Patients; • Support System for Patients Fighting for Short, or Long Term Disability Benefits • Recognize Treatment Management must be individualized depending on Patients limitations; • Provide Patients with Centers of Excellence regionally, with public access links for in-depth information, and also suitable for Medical Professionals such as GP's, Specialists, Endocrinologists, Rheumatologist's, Cardio Specialists; and Family	

	Members Education; • Recognize that Power (Government) Never Gives Up Power, with out a FIGHT! • Implement Treatments appropriate (generally) to other medical treatments…. • Implements Steps that Make the Health Minister….Appear as a “Winner” in all jurisdictions for support, and to eliminate waste, fraud, challenges for taxpayer solutions to become solved; • Accurate Mycoplasma Testing & Treatment; • Accurate Lyme Testing; • Provide pre-printed information materials, rather than have Patients take notes; • Provide “Quiet” Resting Rooms; • Create Better Work Place ES/MCS Awareness; • Provide Information for Lawyers with respect to ‘Legal Definitions’ involving Disabled ME/FM/ES/MCS Patients; • Create and “After Discharge Care” Program, for Follow Up’s; to allow for “Rapid Access” for Patients in Urgent Need; • Provide Additional Education in Areas of Epigenetics, Post Exertional Malaise, Migraines, MCS, Paediatrics, Infectious Disease, Chiropractic, Osteopathy, Psychoneuropathy, Neurology, Multiple System Atrophy,; • Specific Social Services Counselling for: Hardships, Spousal Abuse, Divorce, Children Neglect, Family Separation, Garnishments, Foreclosure, Bankruptcy, Suicide, and Death; • Improved online Support via the Internet for special groups, Youth, Homebound, Caregivers, Medical Professionals, Rural Residents; • Provide easily attainable access; • Provide Tele-Medicine Appointments; • Implement Home Care Assessments via Public Health Nurses in Patients Home Community; • Allow Patients to have an Family, Friend or Advocate with them at Appointments, to relay symptoms and problems, and to intervene on behalf of the Patients Cognitive	

	difficulties; • Increase Disability Benefits to a proper living wage!!!; • Create Information Packages for ALL Emergency Departments; • STOP referring to ME Patients as having Psychological Problems; • Realize that often SHAME…..Looks Like Trauma!; PTSD; - Its Very Real! • Create Information Training for Home Care Personnel; • Appreciate that Emotional Pain may not just be Psychological, it is a result of mis-treatment and frustration over lack of quality care; • Review Community Support for Home Food Delivery, Foot Care, Diabetic Meds; • Provide Experts to create Video Links to help train Medical Personnel; • Do Not Dismiss Patient Complaints; • Patients Require Affordable Residency; • Patients Require Access to Treatments; • NO GET! Rename CBT; • Possible Sharing of Services with other Similar Medical Providers if Shortages continue; • Creation of Provincial Task Forces to be held Accountable in a Time Frame; • Set strong Targets to stop the decline in Patients, Health, Life Styles; • Poverty Reduction; • Re-instate the National Council of Provincial Chapters of Health & Welfare, to Ensure Representation, Access to Services and Accountability; • Establish and meet measurable Time & Guide Lines – with some flexibility; • Set Directives with in the Legal System to strengthen the Accountability and Transparency in Government, so shifting political terms in Office won't affect budgets , that will then affect the long term plans; • Preserve! People Deserve basic human rights!; • Create Patient access support in the areas of Mitochondrial, Adrenal, Metabolic, Cardiac, Aging, Vision, Hearing, Dental, Respiratory, Arthritis, Neurological, quality Mental Health care areas;	

- Create Biobanks with well clarified proper/current Criteria; Share Research Findings;
- Increased Public Commutations;
- More Provincially Accurate LYME, HHV6, C. pneumonia Testing; DNA – PCR, or Co-Infection Testing;
- Tilt-Table and Antibody Testing;
- Annual Tele-Video Conferences to Update on Research information; with Access to watch any time;
- Large Trial Studies for Research;
- Researchers should 'network' with other Researchers in Specialty areas like MSA and overlapping Neuro-Immune Dis-eases;
- RESPECT for Patients, who know their own Bodies!
- Clinical Trials
- Increased Funding for Research, Treatment and Medical / Home Care Services;
- Long term care for those with out family or home care support;
- An official consultations with Top HIV/AIDS Medical Professionals, to research how they organized/funded an
- Serious sit-downs with every Provincial Health Minister, to EDUCATE them.

Well known Stanford Researcher Ron Davis (and Parent of an adult Son with severe ME/CFS) has stated that one of the most urgent issues is "It is clear that what is missing…..is FUNDING. **He described ME/CFS as "A Horribly Underfunded Disease!" Progress has been impressive, despite the limited resources, but it is clear that more funding is urgently needed to unravel this mystery, and find both treatments and a cure FAST!!!"**

In recent years, we have research information that ME/CFS itself is a Molecular Disease. Experts in Metabolism, Immunology, Genomics, Neurophysiology, Electrical Engineering and Bioinformatics have presented data. We have learned about innovative ways in research of new supports for Pain, Stimulators, Acupuncture, Energy Medicine, Meditation, FODMAP, Energy Conservation, Allergy testing, Sleep Management, and once considered "alternative therapies" which can also be included in a plan to help benefit patients. I believe an offer of multi-disciplinary approach will additionally help in care management. They will not be a cure; however as Nobel Laureate Mario Capecchi has noted, how important patient participation is in studying any disease, and how impressed he was to work together it can help facilitate and accelerate progress to help live more comfortably. Patients want to contribute!

Pilot Programs under (in BC one of the Medical Authority's) could be accessed, to help address the needs of the patients immediately, and be integrated to become an "After Care Treatment and Support" solution. This might eliminate the burden on Hospitals, and allow a patient a much quicker opportunity to see a medical professional, than having to go back on a several year wait list as the CCDP has. A model of care could be worked, under the added advice of CCDP staff.

With regard to Research, Canada Needs To:

- BE ESTABLISHED - Canada needs to establish its own Research Institute, and also tap in to a blend of federal/provincial Grants and private funding. Once established, it could apply to participate in larger CDC, NIH studies, as per Dr. David Patrick's input and research qualifications.

- BE TARGETED – Research about ME/CFS should be based on a well defined cohort (the recommendation is to use the Canadian Consensus Criteria, or International Consensus Criteria which has a shorter criteria for diagnosing the exhausting fatigue. It must clearly state that ME/CFS has a biological Basis, and in not to be considered a problem of deconditioning or lazy attitudes.

- BE HOLISTIC – Research should cover a range of issues including cause and biomarkers, clinical trials, health management techniques, health and home care, and disability confirming policy services for Employers, Schools and Insurance Companies.

- BE AGGRESSIVE – Estimates of fair funding run in to the multi-hundreds of millions of dollars a year, but a compromise must be found so as to start…or join an existing research study to find answers.

- BE STRATEGIC – With no time to loose, collected data and research should be well coordinated, and Start Soon! Due to the extent that illness, neglect and disability costs affect patient care currently. We need to help eliminate the suffering, and bring Hope to patients. BE EDUCATED!

I would say, from a patient's perspective that "**UNMET HEALTH NEEDS"** are an issue almost of "collaborative damage" to people "lucky" enough to have received a diagnosis. Those that haven't received a diagnosis and are still wandering around the wastelands, having often seen several dozen Doctors; for someone to help them understand why they can't work or be involved with their family, friends. Their Lives as they once knew it….is OVER! .

ME/CFS/FM/Lyme/ES and MCS, all take a huge toll I both human suffering and economic costs. Add to that those living with the added burden of mental/financial/daily living stress, and it can bring a person to death….literally!

Living with ME and FM requires Strength, Courage and Bravery!

I have attended far too many funerals of those who faced great despair, and could not continue the difficult and frustrating medical search for health care and treatment.

We must learn from some of the successes of British Columbia's Complex Chronic Disease Program, and others who see and work with ME/CFS/FM/LYME DISEASE and MCS Patients!

I hope my input will be of interest to help Dr. Copes create new solutions, which I strongly believe will help streamline heath car and delivery, to bring about a much better, safer, more

	timely access to diagnosis and treatment in the Future! Canada has every opportunity to be a "Front Runner" in this area. As both a Patient and a Friend of the late Dr. Bruce Carruthers who co-Authored the Canadian Consensus and International Consensus, he would be honoured to know that it was his Country who came forward to show real Leadership to make a very real difference in the care and treatment of Patients; not only in Canada, but around the World with its recognition!	
3	<u>Issues that should be added to the Task Force Report:</u> 1) Promotion of "real" illness by MD's. specialists, discarding psychosomatic or neurotic labels 2) Education MD's (doubtful ones) and public that these are serious illnesses affecting all aspects of person's life.	**British Columbia**
4	<u>Do you agree or disagree with what is written, and why?</u> The report does a very good job at laying out some of the basic issues to do with medical care for patients. Given that the Task Force "was established by the Ontario Ministry of Health and Long-Term Care to provide advice on how to overcome the gaps in knowledge, care and attitudes" for ME, FM and MCS, the expectations are that they would identify issues pertaining to this mandate, which I believe they have. • They prioritised creating a 1st report which would provide concrete actions for the government which could be quickly achieved. This is great as it reflects the urgency of the situation for these patients, and gives governments something to do quickly which can have a positive impact on patient's lives. • Their first recommendation was to address stigma via a statement from the Minister of Health. This is a good start, but needs to go MUCH further to really change the conversation. As Margaret says in her slides there is a huge un-learning and re-learning curve needed to truly address the issue of stigma in the health care system.	**British Columbia**

	In BC anti-stigma campaigns have been developed around mental health (https://news.gov.bc.ca/releases/2018MMHA0001-000113), drug addiction (http://towardtheheart.com/reducing-stigma), and of course hiv/aids • Addressing issue of education is important. Having an academic chair who focuses on ME and illnesses that fall into the same category is good. The question is, how to categorise. Neuroimmunological might be good. • Recommendation about billing codes important for BC. We don't have any. We also need diagnostic codes. And having them reflect the complexity of the illness, allowing for more time with patients, is particularly important. These codes are very complicated to implement in BC, so we definitely need Ministry of Health leadership. • Case Definitions and clinical practice guidelines: the most respected ME definitions and guidelines are based on the Canadian Consensus Criteria. I would strongly suggest adopting these until a new set are created. The evaluation of the guidelines - Appendix 3 - seems very odd. None of the most respected guidelines are recommended or reviewed, with the IOM not even mentioned. • Clinical care pathway to develop a patient-centred system of care is good. Need to look at barriers to appropriate testing and care. Here in BC there are tests available to CCDP and not used (e.g. SPECT scan and infectious disease testing), and anti-virals/anti-biotics also averted, despite evidence of infection. Need to ask why. • Making hospitals safe is critical, so this recommendation is great. As is making hospitals accessible and accommodating for patients. Policy will need to go hand-in-hand with education. • The long-term care home recommendations are valuable. • Primary care provider education is critical. While the report does try to address the lack of knowledgeable health care providers and educators, it does not present a plan which could generate anywhere near the number of properly trained health care providers required to help the hundreds of thousands of patients with the diseases. The enhanced skills program is a start, but current practitioners also need educating - un-educating & re-educating. How will we create enough educators to then go on to educate the current and next generation of practitioners? And this has to apply to	

non-medical health care professionals as well. Need to learn from other disease examples which have faced the same issue.

- Introducing an Enhance Skills Program for residents is an excellent idea for other jurisdictions as well.

Did the authors miss anything important?

- While the issues of the lack of a formal medical specialty was addressed, there doesn't seem to be a recommendation that this is where we need to head. A good recommendation would be to create a new specialty which deals with neuro-immunological diseases.
- Home care - eligibility rules need to be expanded to included disabilities which compromise energy and pain
- Persons with disability definitions - need to include pain and energy limitations
- Accessibility and accommodation of patients in all health care and support settings
- Poverty - this impacts health and safety of patients
- Housing - also impacts health and safety of patients
- Isolation - also impacts health and safety of patients
- Research - of the patient population as well as clinical research. Both are fundamental to helping this patients in any significant manner. We know nothing about the ME or FM cohorts in British Columbia.

Do you have questions for Dr .Copes?

- What are the benefits and weaknesses of having a report that focuses on three illnesses rather than a report for each?

Dr. Copes would also like to receive information that could inform the next phase of the task force's work (see page 31 in English, page 39 in French). In particular, he would like to learn about experiences in other jurisdictions that could help the task force.

Do you have suggestions for the next phase?
Are there experiences in other jurisdictions that could help the Ontario Task Force more forward?

Yes, the BC and Complex Chronic Diseases Program:

- Set up to be a Center of Excellence for Lyme, ME and FM, but has failed because of lack of front line expertise and leadership. Patients are diagnosed and managed by a team of health care providers, however, testing and treatment is extremely limited, as is clinical research. This is far from a center of excellence, although patients do feel validated when they go through this program
- Originally was a response to the Schmidt Report to deal with Lyme, in particular to provide testing and treatments that were available to patients outside of the country. From day one the CCDP failed in this task, and this weakness - testing and treatment - is relevant to ME and FM as well.
- ME patients fought for the first 2-3 years to have the Canadian Consensus Criteria implemented, and GET /CBT were only removed from their Doctor's Resources pages after much struggle late last year. In other words, patients had to educate the doctors/educators.
- Currently is a diagnosis and management referral center which patients can only access for up to 18 months, with a two year wait list. Before and after that patients are left to their own devices struggling to find help in a health care system which does not know about the illnesses. FM patients are able still to go to Rheumatologists, but ME patients have no-one. The CCDP is now trying to educate referring GPs about the illness to help their clients, but many patients complain that their GPs don't have time or interest.
- There are no new ME knowledgeable doctors in BC as a result of this program. Only recently taking on interns (maybe 2). With such a severe shortage of knowledgeable doctors, educating GPs and students is a painfully slow process.
- GPs only practice at the clinic 1 day/week. Dr. Arseneau may practice 2 days.

	• Due to severe lack of knowledgeable health care providers, patients have had to become much more educated about their diseases than is normal or just. The BC Women's Hospital sees evidence of this in the fact that patients at the CCDP are far more engaged in medical and research issues to do with their diseases than patients in any other program at the hospital. • The CCDP has slowly become more receptive to patient input. It would seem that the provincial requirement that patients be meaningfully involved at all levels of the health care system has influenced them. A community survey and outreach initiative they did in partnership with our Patient Organisations has led to some changes in focus and priorities, e.g. piloting remote access program, focus on education of referring GPs and medical community in general. • Patient representation is currently limited to the Community Advisory Board. We strongly feel that patients should be represented on ALL committees: clinical, research and hiring related. • At the core of the issues on the clinical side of the program is the lack of a knowledgeable medical director, who is aware of frontline research and clinical practices, and who knows how to work with this patient community. The hospital finally took this on board and made a strong effort to look for a high calibre Medical Director, searching nationally and internationally. This was very difficult, as there are very few potential candidate world-wide. Patients were involved in the interview process. A strong candidate has been found, but immigration and medical licensing has slowed down the process incredibly. It is almost 1 1/2 years since the initial interview. It seems we could be waiting another year, or more, for the new Medical Director to step in.	
5	<u>On the recommendations in the report:</u> Step #1 - a public statement of acknowledgement of the diseases. This is an important first step. When the BC government established the Complex Chronic Diseases Clinic and allocated funds (albeit a small amount), this paved the way for patients, families, advocacy	**British Columbia**

groups, and supportive physicians to speak openly, get involved, present data and provide input. The media also initially became interested in the area, although this seems to have has faded with time. For patients, this provides acceptance of their illness, their suffering and hope for the future. It also creates a spirit of accountability and acknowledges responsibility of those who have agreed to forge ahead and make things right.

Step #2.1 - Create new diagnostic criteria for each of the three conditions. I agree that clear and accepted diagnostic criteria are essential for physician acceptance and appropriate patient care. I have some words of caution. The Task Force report cites an array of diagnostic criteria from around the world that have been developed by various groups, yet seems to discard each one for a variety of reasons. While I am not familiar with the exact protocols followed to come to this conclusion, I suspect they are derived from the need for evidence-based standards of research and care. Herein we find our catch 22. As we know, there has been a shameful dearth of research and hence much ongoing scepticism of the biological basis for these conditions. How can evidence-based research and care protocols be developed if no one can agree who has the illness in the first place or if the illness exists at all? Establishing yet more new diagnostic criteria could take years and may still not be successful or acceptable for all interested groups. Just look at the recent attempts in the US to establish criteria for ME/CFS. My view is, that, along with Step #1, Ontario must consider moving forward with what we have and then commit to improve the existing standards with research and clinical practice. This will take courage. Perhaps, then, Health Canada can be compelled to review the Canadian Criteria (for ME and FM) and re-establish a national standard with an expert panel from across Canada, incorporating new research, current care standards and best practices. As patient representatives on the board of the Complex Chronic Diseases Clinic in BC, we fought long and hard for the program to accept the Canadian Criteria for ME and FM, and establish them as the baseline for moving forward. We were only partially successful, but it helped establish a baseline for discussion, move the conversation forward and keep patients engaged. The MEFM Society of BC made copies of these criteria available to all who looked for them (patients, families, physicians and medical students) and encouraged they be shared with treating physicians. It was a

	good partnership of action. <u>What I think is missing:</u> Patient/Advocacy Engagement: I believe, the involvement of patients will be key to success of any program that is developed. It is nice to see several patients on the Task Force itself, and I am sure there is willingness to involve patients as the initiative moves forward. Patient involvement is perhaps already embedded as a guiding principle, but could be embedded as a key recommendation. Patients, advocacy groups and other patient representatives are able to assist in a myriad of ways, only a few of which could be: * Input to diagnostic criteria and clinical experience * Communication throughout the patient community via support groups and advocacy efforts which helps build awareness, acceptance and support for the program * Participation in physician education initiatives, like the UBC patient mentorship programs, health fairs and input into curriculum design Economic Impacts: My impression is that attempts to establish a business case for investment in this patient community have somehow been inconclusive. The economic impact from the less than full productive status of this patient group must be staggering given the demographics and levels of disability. As you know, Vic and I are willing to try and create such an economic impact assessment for BC and perhaps this could be used to frame the discussion elsewhere. Overall, it's good to see Ontario moving forward to try to address the serious shortfalls in helping people with ME, FM and MCS.	
6	<u>Do you agree or disagree with what is written in the Task Force Report, and why?</u> I appreciate the tone of this report, the urgency of what is needed.	**British Columbia**

The big elephant in the room from my point of view is that you are lumping 3 diseases as one concept of environmental illness. From the definition of environmental illness being disease resulting from exposure to the environment, I have a hard time understanding that my disease presentation fits this mold. (confirmed EBV triggered ME) It does not. Then there is a mention of 'environmentally-linked' conditions. Unless you are addressing to the Green Party, there is no need to lump all 3 diseases, without even considering Lyme disease, and wrap it up as environmental illness. Here in British Columbia, there seems to be a different kind of rebranding going on. All unexplained diseases especially those relating to women most goes under Central Sensitization Syndrome. All of the diseases that are unexplained and left behind by the health care system deserve research finding using the technologies and the talent that we have in 2018. One good example of this is the work of Dr. Ron Davis with metabolomics for patients with ME. Patients deserve sharp research on each disease, not rebranding and generic treatment with patient education and vitamin water.

And if environmental illness needed to be the right term for my disease, then other diseases such as Parkinson's disease, Rheumatoid arthritis, lupus, cancer, HIV and Alzheimer's also need to be considered into environmental illness. But they don't. Each one of them belong to a medical specialty and receive actual research funding.

'Environmental illness' is a case of misrepresentation and further stigmatizing of patients into a label that is neither appropriate nor is helpful in mainstreaming these conditions into the health care system.

I disagree that this is a burden that needs to be put on patients when the burden we are facing is already enormous.

The reports also makes little mention of the amount of research and clinical trials that needs to be performed in order to find cause and treatments of these diseases. These diseases need

	and deserve a spot in mainstream medicine. Not in a shady corner of a Woman’s hospital. In terms of experiences in other jurisdiction, I am from British Columbia and we have a provincial program here. The program is based on multi-disciplinary team and they have as mentioned earlier, seemed to rebrand all of the conditions as Central sensitization syndrome and their program is simply based on education of what CSS is and how to ‘calm the brain’. This is ridiculous. This is indeed a CBT program aimed at preventing further expenses into health care. The rebranding is unhelpful and is not based on science. It is simply based on a theory that cannot be proven scientifically. You will also note that our patient population is quite diverse and while some are attempting to heal themselves through food and nutritional supplements, there is no evidence supporting anybody ever recovered from diets or supplements. Some want holistic, and others like me want a medical approach and a more aggressive approach than wait and see or accept to live the rest of my life like this. I was thankful to try treatments not offered here in Canada and I feel that Canadian patients need to be offered this option, according to their level of comfort in taking risks. The field of HIV moved forward because patients demanded more aggressive treatments. Canadian physicians and researchers need to interact with the international community in that regard and must prepare for multi-center clinical trials. The British Columbia model of care assume that patients are well enough to attend weekly group sessions to learn about their illness and about self-management. In fact this is the core of the program. They also assume family doctors are willing participants in learning and managing their patients’ illness. They don’t. Nothing happens at the family doctor level. Sadly the British Columbia model rebrands patients as ‘Central Sensitization Syndrome’ simply a label based on a theory, and the basis of explaining medically unexplained syndrome, and a myriad of useless self-management techniques to ‘calm the brain’. This is a dead end for patients. It does not lead to research, does not lead to treatments, and it does not lead to biomarkers for individual diseases.	

7	<u>Issues that should be added to the Task Force Report:</u> 1) Research - look at historical cases such as mine which have information about efficacy of treatments because we have "tried them all" over 30 years of illness. 2) Training - overcome the medical reluctance to accept information. 3) Exercise - teach "exercise can kill you" for those with CFS 4) Home care - greater funding of basic care such as meals, house cleaning, rides, etc. + accepting the diagnosis 5) Disability - appearance doesn't always show what the reality is e.g. I don't use a cane because my hands hurt too much + my arms are too weak to carry it so my walking ability is compromised. To see me standing at the bus stop I "look okay" 6) Media - please put information out in the media a LOT. We hear all about cancer every day, many times. 7) Support groups - I cannot attend groups (physical, mental, sensory problems) I cannot use social media or computers (sensory, visual, financial). Phone calls must be short and I must lie down while talking. I like written info or short letters so I can read + re-read at my leisure. I am alone about 98% of the time - but too much social contact is also problematic. I don't know what the answer is, but I hope the community doesn't forget we are out here.	**Alberta**
8	Dear Dr. Copes Overall, I think this report provides a good overview of the challenges faced by people living with these illnesses. The clearly defined steps to mitigate these challenges are comprehensive. I do, however, strongly disagree with one area of the report.	**Alberta**

	Recommendation #2.1 Developing clinical case definitions and clinical practice guidelines to support standardized, high quality, patient-centred care. As was pointed out in your report; there is already a multitude of guidelines. While healthcare delivery is a provincial jurisdiction, if we are ever to clear the path to be understood, we must make it simpler, not more convoluted. If the International community cannot agree on one set of standards, I believe we must at least have one set for across Canada. In the absence of clear national guidelines, we will end up with 13 more and patients will forever fall into the cracks. I urge Ontario not to go it alone in this regard but that a task force is used to establish national guidelines. Thank you or the opportunity to review the report and provide my thoughts	
9	Most healthcare providers (HCPs) require education on POTS, and the potential for / management of crashes severe enough to necessitate care in acute/sub-acute settings. Clinic / hospital waiting rooms should provide opportunities for patients to lay down while waiting. This could be achieved by providing reclining wheelchairs or benches. Transfer assistance / equipment should also be available as needed. Dim, quiet waiting areas are necessary. Some patients are unable to leave their homes / beds for medical appointments. This could be addressed through telephone / telehealth "house calls". Many doctors are hesitant to pick up a telephone. The reasons for this (e.g. billing concerns) should be reviewed and addressed. Patients may also need testing available in their homes. Ensure that educational / work requirements (esp. mandatory gym class) do not compromise patients' right to refuse treatment (particularly CBT/GET). Patients / families should be provided with self-declaration opportunities for disability programs such as HomeCare and educational needs. Self-reporting of GET/CBT harms should be made available in a manner similar to what is currently available for drug therapies.	**Manitoba**

	Also, steps should be taken to warn patients of the potential harm from GET/CBT just as would be done for any other concerning treatment in use.	
10	<u>Are there issues that should be added to the Ontario Task Force list?</u> Yes: o Dealing with social isolation, especially in homebound patients with low income. o Building emotional supports for patients because the disbelief process is draining emotionally. o Patient reporting of harmful treatments like PACE, GET etc. o Ensuring diagnosis and treatment protocols are set-up with room for an inclusive approach rather than exclusive isolating even more patients. o Ensure options for doctors to try different treatments, off the shelf medications and alternative treatments. o Recognize the spectrum of the illness, at the moment most the patients who suddenly get very severely ill get diagnosed more often than those at the more functional end of the spectrum. o Recognizing subgroups of patients with pronounced fatigue with different sub-symptoms. o Provide options for patients to appeal doctor diagnosis, testing, treatment, or appeal refusal of any of these and also the right to challenge incorrect medical history information in specialist letters. o Develop a feedback system for patients to ensure no one falls through the cracks. o Ability to report to a central ombudsman when treated poorly or refused diagnosis, testing, treatment. o Press release by the Minster of Health recognizing this illness as real and needing resources and support. Same with the College of Physicians and Surgeons. o Assemble a Pan-Canadian Ministers of Health Task Force on these illnesses. o Make set actions to ensure the recommendations don’t just sit on a shelf but are implemented	**Manitoba**

11	Do you agree or disagree with what is written in the Ontario Task Force -Year 1 Report, and why? • I think the year-1 report is very good. The task force members have done an excellent job & it appears the issues people with these diseases face have been conveyed, understood & reflected in the report. However, it looks like **Recommendation 1.1**, while already done, did not meet is stated goal. While the year-1 report clearly & boldly addresses the stigma problem head-on, the actual Health Bulletin published on Sep 29/17 completely fails to reflect this. No-one reading the bulletin would understand the tremendous problem patients with these diseases have re: stigma. Re: diagnosis, I can't recall exact stats, but isn't it in the neighbourhood of 90% of cases go undiagnosed? It looks like the statement may have been diluted to the point where it doesn't say much at all, unfortunately. Did the authors miss anything important? • I believe **Recommendation 2.1**, without a recognition that we already have case definitions that are in use internationally, may be reinventing the wheel. The issue of case definitions with these diseases is long & fraught. However, at least with ME/CFS, we already have case definitions, both clinical & research. (If this is mentioned in the year-1 report & I missed it, I apologize). There is what is known as the "Canadian Consensus Definition", [www.ahmf.org/me_cfs_overview.pdf] published in 2003, I believe still widely used internationally. There is the U.S. Institute of Medicine Report, published in 2015, [http://nationalacademies.org/hmd/Reports/2015/ME-CFS.aspx] with updated case definitions. In between, there is also the "International Case Criteria", published in 2011. So, while the work should continue to further revise these case definitions, this work should be done collaboratively with U.S. and other researchers and definitely not in isolation -- probably best through the IACFS/ME (International Association for Chronic Fatigue Syndrome/Myalgic Encephalomyelitis). Dr. Leonard Jason is the international expert on case definitions in ME/CFS. • **Recommendation 4.1** is very important and I am so pleased to see it there (& I believe it has been approved?) However, it doesn't go anywhere near far enough. Again, in the	**Toronto, Ontario**

interests of not re-inventing the wheel, we already have a specialist centre in the EHC, as the report rightly recognizes. This centre should be built upon in *every way*. It is my understanding the EHC is funded for 0.8 FTE's. I think the funding for physicians there needs to be expanded to several FTE's, as well as administrative support. ME/CFS alone is a very common condition. In addition, it is critical that the EHC be funded to see patients with these diseases for more than the current limit (I believe) of 2 visits! I am not aware of any other medical specialty where the patient is limited to 2 visits. This is nowhere near enough. ME/CFS is typically a life-long condition, like many other chronic diseases. This is, in my opinion, a blatant inequity.

- **Section 4 – Primary Care Provider Education** - until there is proper access to specialist physicians at the EHC, a very easy "quick hit" would be to disseminate the "Chronic Fatigue Syndrome/Myalgic Encephalomyelitis Primer for Clinical Practitioners, 2014 Edition", published by the IACFS/ME. http://iacfsme.org/ME-CFS-Primer-Education/News/News-Related-Docs/2014/ME-CFS-Primer-for-Clinical-Practitioners-(2014-rev.aspx. In 2015, the IOM also published a physician's guide (available at the website listed above – IOM is now renamed "National Academies".

Do you have questions for Dr. Copes?

- I would like to understand what is meant, in practical terms, by "patient-centred system of care" and also "clinical care pathways". I would also very much appreciate, when this system is developed, to see the current system compared alongside it, so patients can understand what would change ("as is" vs "to be").

Dr. Copes would also like to receive information that could inform the next phase of the task force's work (see page 31 in English, page 39 in French). In particular, he would like to learn about experiences in other jurisdictions that could help the task force. Do you have suggestions for the next phase? Are there experiences in other jurisdictions that could help the Onario Task Force more forward?

- I think Dr. Copes should definitely have the task force review the work of the U.S.

	federal committee CFSAC “Chronic Fatigue Advisory Committee” [https://www.hhs.gov/ash/advisory-committees/cfsac/index.html]. There is so much work that has been done there over the past decade & more – on these exact areas of care, research & education - that I’m certain that collaborating with current & past CFSAC members would save reinventing the wheel. *[edited to add: In my opinion, the #1 most important thing for ME patients is to be able to see an ME-literate physician – an ME specialist like those at EHC – on an ongoing basis. All the task force’s recommendations are worthy, but if only ****one***** thing could be accomplished, this is that one thing I’d like to see. Patients’ health – both physical AND financial (via LTD reports) depend upon it.]*	
12	ME/CFS Collaborative Pre-Conference – Workshop Request Number 1 It is important to a broad spectrum of patients and families that Ontario’s Task Force on Environmental Health’s (TFEH) report build a good foundation for action in improving health care and related services. It is important to attracting and equipping health care providers to work effectively in this severely underserved area and to be able to address and deflect criticism in a sometimes controversial emerging area with an extreme shortage of resources. It is important that the Task Force’s report reflect well on the Ministry of Health and Long Term Care, enabling it to address or deflect criticism of at least two kinds much of which can be anticipated from lessons learned: including that the task force is half-hearted about real change, and the Ministry is being unscientific, catering to noisy patients about imaginary or inconsequential illnesses. Strategic utilization of the expertise of the expert panel selected to comment on or develop new clinical case definitions in Recommendation 2.1 will be crucial to the credibility of the Task Force Report – but it is unclear and troubling what they are being asked to do (discussed below)	**Toronto, Ontario**

Composition of Task Force Makes Expertise and Role of Expert Panel Crucial

The area of Environmental Health including care of patients with ME/CFS, FM and ES/MCS, is marginalized, treated inequitably and stigmatized, but it differs substantially from most other marginalized areas. It is not primarily on the basis of a social determinant of health such as limited income, language, ethnicity etc. Persons with ME/CFS, FM and ES/MCS are marginalized on the basis of lack of extensive medical evidence in emerging fields of medicine. Many in the medical community feel justified in marginalizing these areas of medicine until that knowledge base is more established and are quick to criticize and discount what they see as poor quality scientific work. There is a basis of well-established primary care practice, research and education from many sources for most marginalized groups that needs to be adapted or "customized" for their particular circumstances. However, strategically building the knowledge base for care, making headway in research and education, developing a range of knowledgeable health care professionals is central to making progress for those with ME/CFS, FM and ES/MCS.

It appears that when the process to create the TFEH was initiated the need for relevant front line expertise was not adequately factored in – there is only one front line Ontario physician currently working with patients with these conditions on the task force – an inequitable situation. There is no physician with a large ME/CFS, or FM practice. For developing strategies for Diabetes, Primary Healthcare Planning, Ophthalmology, Ehlers-Danlos and Home and Community Care Ontario task force membership has been heavily front-line provider/experts familiar with needs, resources, logistics, promising practices, pitfalls and lessons learned.

Using the limited resources of the expert panel to maximum benefit is therefore very important.

TFEH Recommendation 1 – The need for Minister statement/commitment

TFEH Recommendation 2 – Develop a common understanding of ME/CFS, FM and ES/MCS

Questions for Dr. Copes:

- What has the expert panel been asked to do and why?
  -Is it to reach consensus on recommending existing case criteria?
  -Is it to create new (and unvalidated) case criteria? (possibly be used as "illustrations"?
- Have the Task Force and MOHLTC considered the inevitable criticism?
- Is there funding for the panel to consider guidelines/guidance material
- If not, could funding from "case criteria" be redirected?
- The terminology "clinical practice guidelines" and "standardized" patient care, in the medical world can be a technically very demanding standard – Please clarify what is mean here.

In Task Force Recommendation 2, it is not clear what the Expert Panel is being asked to do.

2.1 Clinicians and researchers in these areas will not be able to develop "gold standard" case definitions until the underlying mechanisms are better understood as a result of research. It would be helpful if the expert panel is being asked to reach consensus (with possible commentary) on the use of existing ME/CFS/SEID, FM and ES/MCS case criteria, such as the USA's IOM and the Canadian Clinical Case definition on ME/CFS.

However, creating new case criteria would not make these conditions (TF p. 19-20) easier to diagnose and treat but would create new problems. (Only significant research based understanding of causality will make significant improvement of case criteria possible.)

Creating new case criteria is a very complex process and requires validation research studies using large numbers of subjects and thus extensive funding to earn acceptance. Creating new case criteria also means that research done using the 'old' case criteria are of decreased relevance since the subject population is now different – and new research must be done to confirm the old findings.

It would seem unwise for the MOHLTC to choose to compete with the USA Institute of Medicine, its prestige and resources, or to discard the Canadian Clinical Case definition that got the centrality of post exertional malaise correct in 2003, has been the basis for research and is relatively well accepted by those treating ME/CFS.

There are two FM criteria (ACR – American College of Rheumatology, 1990 and modified 2010 ACR) broadly accepted for qualifying for disability compensation. A new definition, particularly if not validated, could have difficulty gaining acceptance – causing confusion and difficulty for patients. There is currently a debate in the Rheumatology community (Ref noted below) about the relative merits of those two case criteria. It would seem unwise for the Task Force and MOHLTC to get involved in that professional debate.

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<u>Attitudes Toward and Management of Fibromyalgia: A National Survey of Canadian Rheumatologists and Critical Appraisal of Guidelines</u>

Agarwal, Arnav; Oparin, Yvgeniy; Glick, Lauren; Fitzcharles, Mary-Ann; Adachi, Jonathan D.; Cooper, Matthew D.; Gallow, Lucas; Wong, Laura; Busse, Jason W.
JCR: Journal of Clinical Rheumatology. 24 (5): 243-249, August 2018.

Background
Canadian rheumatologists' attitudes toward and management of fibromyalgia remain uncertain.
Objective
The aim of this study was to explore management strategies and attitudes of Canadian rheumatologists toward fibromyalgia and concordance with guideline recommendations.
Methods
We administered a 17-item cross-sectional survey to Canadian rheumatologists and explored the concordance between respondents' management practices with the 2012 Canadian Guidelines for the diagnosis and management of fibromyalgia.
Results
Among 331 Canadian rheumatologists who were approached, 140 returned the survey for a 42% response rate. The majority felt that fibromyalgia was a useful clinical diagnosis (110/138 [80%]) but was divided as to whether fibromyalgia was objectively defined (75/138 [54%]) or a psychosocial condition (42/138 [30%])

or could result in an inability to work (37/138 [27%]). Contrary to guideline recommendations, most (82/134 [61%]) endorsed that tender points were useful for diagnosis. Half endorsed potentially refusing consultations with fibromyalgia patients, and only 42% (59/139) agreed that there were effective therapies for this syndrome. Consistent with the guideline, most respondents managed fibromyalgia with education, exercise therapy, antidepressants, and nonnarcotic analgesics (≥89% for all); however, fewer than half agreed that any of these modalities were effective (endorsement ranged from 9% to 47%). Assessment of the 2012 guideline revealed a number of important limitations.

Conclusions

Canadian rheumatologists largely do not provide primary care for fibromyalgia. Most adhere to guideline recommendations for management of fibromyalgia, but few endorse these interventions as effective. Further research, including updating of the 2012 Canadian Guidelines for the diagnosis and management of fibromyalgia, is required to inform this disconnect.

Underlining added -- Debate in Rheumatology community – Tender points dropped in ACR 2010.

Critics would be quite justified in question the merits of new case criteria until costly validation is done and questioning the logic of funding new case criteria at this time – just not good science!!

It would be preferable to use some of that limited expertise time and funding for recommendations on guidance materials (which would unlike new “case criteria” improve care) and for recommendations about system design, care, education and research strategies. Is funding available for guideline/guidance review and development?

Leveraging suitable existing materials, and creating overviews such as Centre for Effective Practice Tools would be helpful.

The USA Center for Disease Control lists as Resources the IACFS/ME Primer (which uses the Canadian Clinical Case Definition) and the International Writing Group for Pediatric ME/CFS Primer.

Physicians and the MOHLTC could comfortably deflect criticism citing the recognition of and status of the IOM and CDC.

What is meant here by the terminology “clinical practice guidelines” and “standardized …. Care” needs to be clarified. Evidence-informed guidance materials and approaches to patient care are possible for emerging areas of medicine and for conditions with multi symptoms in multi systems, but in the medical world the terminology evidence-based clinical practice guidelines and standardized care can mean a technical precision and evidence-based level that would be difficult if not impossible for these conditions to meet without extensive further research. The challenge is made more difficult by commonly overlapping multi-morbidity in these patients. Many things in primary care are not based on solid research-based evidence. Patients need assistance now, even if good clear research-based answers don’t yet exist. And for the patients particular needs the physician may need to choose care that differs from guidelines.

TFEH Recommendation 3 - Lay the groundwork for a patient-centred system of care (TF23-26)

Questions for Dr. Copes:

- How much “detail” is expected in clinical care pathway?
- Was funding provided as requested by the Task Force?
- Could Centre for Effective Practice Tools be developed for each condition?
- Will the Task Force promote updated Hospital Guidelines?

3.1 It is not clear what the degree of detail in a clinical care pathway is expected for these conditions. Given the multi-system, multi-symptom nature of these conditions, the limited understanding of causality, the limited tools for assessment and treatment it is not possible to have a care pathway similar to those by Cancer Care Ontario for a specific type of cancer that has been extensively researched. More generalized care paths would be possible. Currently diagnostic testing and other resources are limited for ME/CFS and ES/MCS.

	Pattern recognition and ruling out other conditions are central aspects of providing care. Thus education of physicians, nurses and other healthcare providers is very important. Much of the material in pages 103-112 of the Academic and Clinical Perspectives Compendium of the Business Case proposal is still relevant to laying the groundwork. These recommendations were developed by physicians on the front-line with very extensive experience with these conditions and the challenges of educating healthcare providers to work in this area. There are ranges of presentations of symptoms and levels of severity within each condition and as mentioned above, multi-morbidity is common – therefore "one size" pathways will not fit all. The range of other services required will also vary significantly from patient to patient. Funding and developing, with the Centre for Effective Practice, tools for each of the three conditions, in conjunction with front line physicians, nurses and other care providers would be useful. Given the high prevalence and seriousness of these conditions, what patients need is equity with the range of services that patients with other common chronic conditions have. The question is how to strengthen the foundation and build expeditiously towards that goal, utilizing lessons learned and in a climate of financial restraint. Patients with chronic conditions such as diabetes have a choice of pathways – family doctor, specialist, Centre of Excellence, education through any of these, CHC, health links, public health, support services It is unfortunate that educational groundwork outlined in the Academic and Clinical Compendium mentioned above did not happen after the Business Case was submitted in 2013. It will be slow scaling up without more health care providers knowledgeable in this field.	

Recommendation 3.2 Making Hospitals safe and 3.3 Making long term care homes safe … (TF p 25-27)
Work needs to be done in these areas including further efforts to establish scent-free policies.

An important starting point would be updating of the Hospital Guidelines mentioned on page 106 of the Academic and Clinical Compendium and pg 26 of the TF report. This would make care safer for patients, easier and more efficient for health care personnel and facilitate explaining the need for 3.2 and 3.3.

TFEH Recommendation 4 – Increase the number of knowledgeable providers (TF 27-29)

It is very important the enhanced skills program continue. Both knowledgeable family physicians and physicians who concentrate in this special area are needed. Eventually it needs to become a specialty when research has advanced the field.

Did the Authors Miss Anything Important?

- The report should include statistics on multi-morbidity similar to those in Appendix A of the Academic and Clinical Perspectives Compendium. These statistics show higher rates of approximately twenty chronic illnesses. This is an important characteristic of these illnesses and it would be helpful if specialists in those other areas would take an interest in ME/CFS, FM and ES/MCS, look for them in their patients, and possibly bring new insight to the understanding of ME/CFS, FM and ES/MCS. (National ME/FM Action Network will soon be updating the statistics).

- The report should have mentioned that the Ministry of Health-funded research at Uof T pointed to genetic differences in detoxification pathways in MCS.

- The report mentioned shortage of funding for research and stigma being barriers. It should also have mentioned that the application process to compete for limited funding is very demanding, requiring high skill in proposal writing and much time (which interested clinicians may not have). Assistance in the application process could help make a difference.

- The process sometimes missed equity issues: eg. composition of the Task Force needed more front-line expertise for the purpose; stage of development of fields re case criteria, guidelines/guidance materials – needs reasonable expectations.

- The report should have looked at barriers to equity and progress at the Environmental Health Clinic and reduction of services
  - governance/and position in the **provincial** healthcare system vs local hospital priorities
  - needs for security of types of funding (not just health service provider) and workable channels to the Ministry or LHIN re funding and the need for expansion of services (care, education, research, policy etc)
  - performance measures for family practice – how many patients seen, how promptly – not suitable for very complex patients with ME/CFS, FM and ES/MCS – long waiting list, long assessment appointments

- It is surprising that the Task Force did not make at least some reference to the Academic and Clinical Perspectives Compendium (pp 77-83) about the projected “Hub” or central clinic in a Academic Health Science Centre and pages 103-112 about preparation of training programs etc.

Observations for the next phase (TF p. 31)

As noted on pages 1 and 2 (above) the Task Force makeup has limited front line expertise to be designing a system of care, education, research, support services and strategy for ME/CFS, FM and ES/MCS. What other resources will they draw on? Eg. for research, could ideas from experts at the Montreal CIHR conference be drawn on? This will be important in leveraging lessons learned both in Ontario and in other jurisdictions to develop systems of care, education and research, health promotion that are effective and efficient, avoiding pitfalls, and in deflecting criticism re lack of credibility.

Basically what is needed is access to a broad range of services comparable to those for patients with other debilitating chronic conditions and the necessary research and education to support them.

The questions are: how detailed are the recommendations to be? What resources are available to design this? What resources will be available to take action and scale up after the Task Force report is submitted?

It would be wise to build on the material on the Hub/central clinic and preparation of training programs from the Academic and Clinical Perspectives noted on the previous page.

Community health centres have expressed interest in providing services and refer to their experience in providing a range of services such as for diabetes and heart disease. However, these are well-established areas with strong case criteria, clear care guidelines, extensive research and a wide range of readily available personnel with suitable training.

A questionnaire done by CHC physicians and nurse practitioners showed a clear lack of comfort with diagnosing and treating ME/CFS, FM and ES/MCS. It appears that CHC personnel may be significantly underestimating the training necessary before providing service in this area. (Clinical & Academic Perspectives, pp 55)

For some patients the range of services currently offered in CHC's or FHTs for other illnesses will be attractive, but others just want a knowledgeable family physician.

TFEH Recommendation 1 Making a statement … Making a Commitment to Improve …

1.1 If the Minister/Ministry is to address the equity issue for these conditions the actions need to include addressing hidden bottlenecks:
- Funding research, helping to locate funding for research, providing skilled personnel to assist in competitions for funding
- Ensuring that the Environmental Health Clinic or Hub is located in an Academic Health Science Centre and has streams of funding that in addition to patient care, support educational program development, health promotion, policy development etc. These streams of funding must be directly from the Ministry or LHIN and the clinic must be able to communicate directly with the Ministry or LHIN about need for increased services and funding. (Currently the hospital wants and needs to focus on its own local priorities and EHC services have no effective way to get urgently needed funding to address financial needs.)
- Performance measures for family practice – how promptly patients are seen and how many are seen -- are not appropriate for detailed assessments of these complex patients who have usually been to multiple physicians with little benefit.

1.2 Establish 3 Academic chairs …. Across the province
It would be preferable to concentrate the funding and expertise in one central clinic/Hub in an academic health science centre to begin

ME/CFS Collaborative Pre-Conference – Workshop Request Number 2

- I think we should have both family doctors and Specialists not either or

- I think we should have both a Centre of Excellence and a Network of Specialists.

13	<u>Questions and Suggestions for Dr. Copes and the Task Force:</u> This work should be shared with other provinces. There was a business case put forward by a working group, which led to this task force. Is that business case publicly available? If not, could it be made available? Likewise, some reports have been prepared for the Task Force. Could these be shared? What might be done to increase the uptake of this document? What are provincial strategies to reduce stigma? Social isolation is becoming a very recognized public health issue. What can Ontario do to reduce social isolation among people with ME/FM/MCS? Who are other stakeholders and how do they fit in? (Examples, RCPSC, CIHR, Deans of Medicine) The ME area is just emerging from a protracted battle over biomedical versus psychosocial. Is the Ontario government comfortable entering the field so soon after the battle? With ME having taken the wrong road, the evidence base needs to be sorted out. The choice is to make recommendations now or to wait until matters are more settled (which would leave people without service longer). How is this issue being addressed	**Ottawa, Ontario**
14	Overall I think the Ontario Task Force Report is presented with clear goals and good recommendations reflecting a clear understanding of the challenges faced by patients and the shortcomings in our health system to deal with them.	**Southern Ontario**

I was glad to read consideration will be given to confusing terminology such as environmental health and environmentally linked conditions.

I am confused over the CPG reviews. I read the Australian CFS Clinical Practice Guidelines as best I could with my limited concentration and they appeared to be so out-dated that I am surprised they were even on the list for consideration. Has the report by the Institute of Medicine (2015), which provides an in-depth objective review of all clinical studies and their conclusions leaving no doubt that ME/CFS is a pathological disease with severe exertion intolerance been taken into consideration? Guidelines I have found helpful, parts of which have been used as reference by my doctors and their students when bought to their attention are:

Both the CFS Guidelines and the ME/CFS: A Clinical Case Definition and Guidelines for Medical Practitioners by Carruthers et al. More and more researchers are using the Canadian Consensus Document for research criteria, which may have been overlooked by the contributors.

Review of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: an evidence-based approach to diagnosis and management by clinicians by Alison C. Bested / Lynn M. Marshall, **Published Online**: 2015-11-27 | **DOI:** https://doi.org/10.1515/reveh-2015-0026

A personal favourite are the International Guidelines, which are based on the Canadian ones, as I relate to the emphasis on post-exertion malaise. It is by far my worst symptom, exacerbating all others of which just one is fatigue and that is not my worst symptom by far.

I also hope that Dr. Byron Hyde's expertise and his own definitions will be taken into consideration as I agree with his definition that ME and CFS are not one and the same and by grouping them together simply muddies the waters further.

	I am also uncertain as to whether clear definitions and guidelines can be developed without identifying sub-sets or cohorts, which could bring more clarity to research, results, possible treatments etc. Some have proven genetic links (multiple members in families), some have autoimmune issues, some start with a new infection of unknown origin bringing sudden onset of the disease, to name just a few. The severity of the disease needs to be taken into consideration as well as what works for those with mild vs moderate vs severe can be very different. This could perhaps be something for consideration in the next phase of the task force's work. I am fully supportive of Centres of Excellence for those strong enough to able to travel to them. For those of us unable to travel any distance, or talk and interact with others for any more than an hour at a time, I believe there is a great need to recruit specialists who are willing to do consultations via Telemedicine with patient's family physicians present. The technology is there. The specialists are there. However no consideration is given to the limitations of the patients who could be missing testing and possible treatments that could improve their health and quality of life. There is not a single immunologist willing to consult via Telemedicine. I am able to travel the 10 minute round trip to my local clinic that is setup with Telemedicine. I am unable to travel the 3-hr round trip to see specialists in Kingston without having such bad post-exertion neuro-immune exhaustion that I do not fully recover from the experience. Hence a gradual decline in my condition and becoming housebound after 2 years. This too could perhaps be something for the next phase of the task force's work. I think this also means family physicians would need to play a greater role for those affected more severely. It would also be very helpful if our health system allowed for in-patient testing. If that was available the above scenario for myself could at least have been reduced, possibly avoided, and I would have a better quality of life than I have now. As education progresses, I believe it needs to extend to all those working health care, including nurses, technicians, physiotherapists, etc.	

	There is more I would like to contribute but this is the best I can manage today! The ideas on Care Pathways are very interesting. I think the Task Force is doing brilliant work and I am very grateful to them all for the work being done on our behalf. I would like to extend that to those that have made the upcoming Montreal Conference possible as well. Thank you again for the opportunity to provide some feedback. I was diagnosed with Post-Viral Recovery (by an understanding Rheumatologist) after 4 months and Myalgic Encephalomyeltis (by Dr. Byron Hyde) after a sudden infectious onset of unknown origin soon after a flu vaccination when I was in my early 50's. I am fortunate I have an understanding family physician. After becoming ill, within four weeks my mother in her eighties could function much better than myself, with a better quality of life, and that continued until last Thanksgiving, when in her 90's she succumbed to infection and passed away in February. I am now in my 10th year of this debilitating disease.	
15	<u>Did the authors miss anything important?</u> On page 9 under "Our Mandate" you state, "Increase public and health care providers' knowledge of these health conditions and reduce stigma." Further into the report you have suggestions for increasing awareness and information for medical students, physicians and nurse practitioners. However I have found many other professionals have been important to the management of my symptoms. These include, for example, pharmacists, physiotherapists, legal/insurance assistants and mental health therapists. Physiotherapists can help in adapting to new ADL and managing our energy levels. Mental health professionals, especially therapists, can help with the grief, anxiety, depression, isolation, reaction to stigmatization and changing self-image that so often result from suffering from these conditions. Another area I would respectfully suggest looking into is the use of online services. You	**Hamilton, Ontario**

	mentioned Telemedicine and this is so important especially in smaller communities. Some of the auxiliary services I mentioned above can also be adapted to online consulting. I have found that dealing with professionals from my iPad while lying in bed a great improvement over having to go for appointments while still helping to counteract isolation. Do you have questions for Dr. Copes? Page 22 Recommendation #2.1 Develop clinical case definitions and clinical practice guidelines to support standardized, high-quality, patient-centred care. Would you recommend these be developed for Ontario alone or as part of a national definition and national guidelines? Do you have any plans to recommend services for caregivers?	
16	Do you have suggestions for the next phase (of the task force)? I would like to recommend that the Task Force include the issue of Disability, e.g. Disability Accommodation with Invisible Disabilities, and thus, have representation from someone currently or formerly of the Ontario Human Rights and an MD familiar with the issue of disability accommodation in a practical sense, and possible a consumer/survivor who has worked/is working with one or more of the disabilities. In terms of employment. Many us were employed before, if we are of adult age. Of those, many, if not most, would have had issues of workplace accommodation. Some of those persons may have not known what they were ill/disabled with, and thus could not seek accommodation for a disability not yet identified and thus their health got worse. Others sought disability accommodations and they were not consistently granted. Others, such as myself, HAD disability accommodations, only to have them not upheld when a new Executive Director/Supervisor arrived, and/or Board of Directors.	**Toronto, Ontario**

	I believe persons can work with MCS for example, and even milder CFS/ME, but we must have consistent accommodations that are upheld, otherwise the withdrawal of the accommodations leads to deterioration, in one's health, that for many is not reversible. For myself, I have had to file two Human Rights Complaints as I went from excellent accommodation to non-compliance. I have never been well enough to return to work after the 2nd workplace/complaint as my health was too compromised. Likewise, attending school or post-secondary education with the disabilities is an ongoing challenge. Thus, I recommend that the Task Force include persons knowledgeable about Human Rights, a rep from the OHR, or at least someone who was previously on the OHR. When Barbara Hall was the Commissioner on the OHR, three of us, lead my Audrey McKenzie, of MEAO, met with Barbara Hall on such matters. She seemed to have an understanding of our disabilities. We also did some presentations at the OHR, but I am not aware of any progress on this front currently, but I am aware of persons struggling to work with MCS, CFS/ME and Fibro and these people need much more accommodation, support, and encouragement than they receive as they battle to work with this primarily invisible disability. I also would like the task force to consider that while there is no prescribed treatments for the conditions, supportive treatments can support the persons with MCS, CFS, and fibro such as osteopathic, RMT, acupuncture, and physiotherapy--but only physio that is geared to persons with the disabilities and does not push people beyond their energy envelop. These supportive treatments can enable persons not to deteriorate further. However, most of us are on declined income and many of no longer even have health benefits from our former workplaces. In addition, many of us are on LTD and at age 65 will have not income except for CCP and OAS. I don't think the issues of employment and income have been addressed by the initial work of the task force and I hope the next phase can. I look forward to the next phase of the task force and some action that can actually help those	

	of us with the illness and our family and friends who may try to support us.	
17	FEB.19th, 2018 Dear Dr. Eric Hoskins, MPP St. Paul’s While I agree with many of the recommendations, I believe even though the recommendations are a first step, that we need some more concrete inclusions and I urge the Ministry of Health to more fully expand and integrate existing services, including hospitals, long term care, and home support services; all these services need to include MCS, CFS/ME, and Fibromyalgia in intake, assessments, and treatments. In addition, I am strongly of the opinion there must be an increase in MD’s who Also, we need (more) specialists in other areas, such as cardiology, respirology, ophthalmologists, Gastroenterology, etc. who have a working knowledge of MCS, CFS/ME, and Fibromyalgia and thus can more fully address our health care accommodations. While I very much thank the Minister and the Task Force for their work, I feel the recommendations need some specific implementations and active actions to bring about medical change to address our health care needs and following are my amendments to the specific recommendations of the Task Force Report: Recommendation #1.1: Making a formal public statement recognizing ME/CFS, FM and ES/MCS As a person with MCS and CFS/ME, while I would appreciate the Minister of Health and Long-Term Care further acknowledging ME/CFS, FM and ES/MCS, my preference would be for the Minister’s formal statement of recognition to include an active action, e.g. modifying the current Ministry of Health and Long Term Care forms and assessments to include ME/CFS, FM, and ES/MCS. For example, if someone receives an assessment for home care, e.g. PSW,	**Toronto, Ontario**

the LHIN's assessment form does not take into account the disabilities of ME/CFS, FM, and MCS. Nor if an intake for nursing, the LHIN does not appear to have these disabilities as illnesses that can be checked off as occurs with other illness, such as asthma, diabetes, cancer, etc. This can result in inappropriate services for MCS, CFS/ME, and Fibro.

Recommendation #1.3: Modernize the K037 fee code to include all three conditions
While I fully concur that the task force the ministry should re-initiate the process to modernize the Ontario Health Insurance Program (OHIP) fee code K037 – in collaboration with physician and patient experts – to ensure it recognizes all three conditions, again, we need action on all levels such as intake, assessment, and treatment, in addition to the billing codes for all three conditions.

Recommendation #3.2: Make hospitals safe for people with ME/CFS, FM and ES/MCS
Recommendation #3.3: Make long-term care homes safe for people with ME/CFS, FM and ES/MCS.

In addition, the hospital system and Long Term Care services also needs to fully incorporate the accessibility medically such as acknowledging the disabilities on all admitting forms for pre-existing conditions and treatment plans. Without medically acknowledging the conditions medically, the hospitals cannot be 'safe' for persons with the conditions.

Likewise, most health conditions and disabilities have provision for acute care within a hospital setting for critical illnesses, but I am not aware of any such services in Ontario. This, while the task force is recommending that hospital be make 'safe' for persons with MCS, CFS/ME, and Fibromyalgia, it would seem befitting that part of that should incorporate the option for increasing hospital services, e.g. Expanding the services of the Women's College Hospital, Environmental unit, up to and including short term hospital stays for those that are severally ill with the conditions. Currently there is no acute care for such persons.

Simultaneously, the Home support services also must become fully accessible and safe for

	persons with MCS and CFS/ME such as all Meals on Wheel having a range of dietary options for persons with the disabilities such as no dairy and gluten free meals; PSW’s with no scent. Currently, the LHIN’s Case coordinators complete an assessment including a mini-cog dementia test. As highlighted on the Side bar, page 11, for the Task Force Report, the disabilities of ME/CFS, FM and ES/MCS, although distinct conditions, they share some common symptoms – particularly fatigue and memory and concentration problems. However, it does not appear that the LHIN’s assessment by the coordinators take into account the disabilities of ME/CFS, Fibro and MCS which can give symptoms of memory challenges and concentration and thus there is the risk of persons with the conditions being assessed as having dementia rather than acknowledging their MCS, CFS/ME and this is yet another stigmatization of those of us with the disabilities. A substantial proportion of people have two or all three of the conditions. While I thank the Minister and the Task force for all of their work, my family has struggled with MCS since the 1980’ and myself with CFS/ME since 1998 after contracting mononucleosis; it is such a long time to address these issues. In fact, I recall when the 1985 Report of the Ad Hoc Committee on Environmental Hypersensitivity Disorder was released and those recommendations were never fully implemented, but did lead the way for the initial phase of the WCH Environmental Unit, but we need expansion of services including at the WCH. While I thank the Minister and the Task force for all of their work, my family has struggled with MCS since the 1980’ and myself with CFS/ME since 1998, and my mother is now approaching 88 and it is quite distressing to realize there is an inadequate level of home care for persons with MCS, and the related disabilities. The Ontario Human Rights recognizes the disabilities, but we have a long way to go to make the lives of persons with MCS, CFS/ME and Fibromyalgia on par with other illnesses in terms of medical and social services in compliance with the Ontario Human Rights Code. Could I please request that the Minister (or an official of the Minister) respond to the matters	

	I have raised and also address them to the Task Force on Environmental Health? Thank you for your assistance and I look forward to a reply to my letter.	
18	I was talking to someone today. She has just gone through a horrible experience not being believed. She will submit to you if she can recover in time, but her basic messages are: • Task force report is good • It needs more urgency • Hospital staff need to understand ME • Housing is a very important issue - if you housing is bad, you can't take care of yourself.	**Toronto, Ontario (source of the verbal input)**
19	The most important thing is to do right now is train more doctors. The fellowship program at the EHC needs to be re-introduced and properly advertised. The program needs to be expanded. There needs to be a center in a well-respected teaching hospital such as Women's College Hospital, Mount Sinai, St. Michaels etc. It's the only way to attract the best doctors, to do biomedical research, and counter the stigma associated with ME, FM and MCS. The EHC needs proper funding. It needs full-time staff and full-time healthcare professional positions. There also needs to be the funding in place so that the newly trained physicians can work there when they have completed their fellowships. (Why train in a new area if there are no jobs available in the field?). I do not believe that Community Health Centers should be given a lead role in treating ME, FM and MCS. We don’t have a network of CHC catering to multiple sclerosis or other complex, chronic diseases. Furthermore, unless the CHC’s reputation changes (and they become well respected), sending people with ME, FM and MCS to CHC will reinforce the idea that some people have that these are not serious disabling diseases.	**Toronto, Ontario**

	I am fortunate to have Dr. Nancy Klimas, a specialist in the USA treat me for ME and FM. The following tests have been helpful - they have informed my treatment plan and led to improvements in my health: natural killer cell test, cytokine panel, EBV and HHV6 tests, blood volume test, and cardiopulmonary exercise test.	
20	Je vous laisse, au nom de l'AQEM, mes commentaires sur le rapport du Task Force. Les représentants de l'AQEM vous enverront les démarches faites auprès des gouvernements. Premièrement, je voulais féliciter le groupe de travail sur la santé environnementale pour ce travail incroyable. Il est clair que ce travail pourra servir de référence pour toutes les autres provinces à faire reconnaître ces trois maladies stigmatisées auprès de la population et du personnel médical. Je suis en accord avec toutes les recommandations du rapport mais j'ajouterais quelques petites nuances. **Lignes directrices**: bien sûr qu'il nous faut des lignes directrices pour les maladies, ne serait-ce que pour établir le diagnostic. Évidemment le groupe se penche également sur la rigueur de ces lignes pour approbation et c'est un point très important également. Je recommanderais, lors du processus de sélection de candidats pour émettre ces lignes directrices, des experts renommés dans le domaine quitte à aller chercher des experts de l'extérieur du Canada. Je pense, entre autre pour l'EM/SFC, à Leonard Jason épidémiologiste à De Paul University à Chicago. Un très bon collaborateur qui pourrait donner un excellent point vu et un travail rigoureux sur ces futurs lignes directrices. Le problème avec les lignes directrices est qu'il y en a trop et il y en aura encore plus avec les années à venir au fur et à mesure que la recherche découvrira de nouvelles pathophysiologies et classera les patients en sous-groupe car on commence à comprendre, pour l'EM/SFC, qu'il y a probablement différents sous-groupes de patients. Est-ce bon de faire de nouvelles lignes directrices? Dans le contexte d'un programme de santé à implanter dans une province pour le personnel soignant et pour avoir une méthodologie rigoureuse je crois que oui. Mais ces lignes devront être adaptées sans faute comme mentionné, aux 5 ans. Mais il commence en y avoir beaucoup de lignes directrices. Y aurait-il un autre moyen d'émettre	**L'AQEM - Quebec**

le diagnostic sans passer par le refonte de lignes directrices???? Question pour Dr Copes…….

Concernant le code d'honoraire aux médecins: évidemment de reconnaître ces trois maladies mais aussi de payer les médecins plus cher étant donné la complexité de la maladie. Au Québec, les médecins sont payés plus lors de maladies chroniques étant donné le temps passé en consultation auprès des patients. Il serait, à mon avis, important de payer les médecins plus cher. Ce pourrait également inciter les médecins à prendre en charge les patients. Je ne sais pas les normes au niveau de l'Ontario et si c'est possible

Petite question concernant le financement du programme de perfectionnement des compétences des résidents de 3e année en santé clinique environnementale.

Qu'est-ce que ces résidents apprennent? Sont-ils en contactent avec des médecins spécialistes des trois maladies environnementales.....j'imagine que oui

Recommandation pour la prochaine phase et son modèle de soins:

Comme il est demandé d'octroyer des chairs de recherches dans trois centres universitaires de la province, je pense que pour débuter le suivi des patients, ces centres devraient être priorisés. Il faut reconnaître qu'au début du processus, il sera difficile d'éduquer tous les médecins (généralistes, spécialistes). À mon avis, développer des centres de traitements associés aux chairs de recherche feraient en sorte qu'il n'y ait pas de faux diagnostics ou d'erreurs de traitements. De plus, les services d'ergothérapeutes, travailleurs sociaux, psychologues etc. sont souvent accessibles dans ces centres ce qui donnerait plusieurs niveaux de traitement au même endroit. L'éducation serait plus facile au début en ciblant ces centres étant donné la proximité des spécialités médicales.
Évidemment les patients auraient à se déplacer beaucoup plus pour avoir accès aux services mais je vois très mal au début comment les médecins généralistes pourraient faire un suivi adéquat avec les meilleures recommandations lorsque l'on voit comment ces 3 maladies sont stigmatisées
Lorsque les maladies se feront connaître, et que la formation continue sera au rendez-vous chez les

	médecins généralistes, ceux-ci pourront à ce moment prendre le relais par moment. Un peu comme on voit présentement dans bon nombre de maladies. Les généralistes sont capables de prendre en charge des maladies qui autrefois ne l'étaient pas. Encore une fois, bravo pour ce travail et en espérant que le gouvernement sera au rendez-vous pour mettre en place les recommandations et celles à venir.	
21	Input to Dr. Copes and the Task Force Report: Do not understand why the Canadian consensus document was not reviewed and not considered a guideline. It seems like it is being dismissed and a lot of work and money will be spent in redoing what has already been done. Do not like the name of the task force although I read why it is called that. It seems we are simply moving away from the psychological stigma by grouping them under an environmental banner. I never agreed with grouping CFS and FM together as they are very different illnesses and it makes it very difficult and much more onerous to do info awareness session and other promotional work. Other illness especially share similar symptoms yet are not grouped together. The work of the Integrated Chronic Care facility (formerly the NS Environmental Health Clinic should be recognized and partnered with to learn from their experience and expertise. Education and training should also be directed to Schools of Nursing and Physicians Ongoing training courses. Provide for a centre of excellence where Physicians can go for a one-week skills course or better still a one year residency like the one in Dallas Texas. Not sure what was meant by the fee-code issue? I think a fee-code should allow for at least	**PEI**

	30- 60 minute consults for family Physicians and specialists. What is missing is the lack of discussion on a holistic approach to treatment and the need to have a coordinated approach and access to physiotherapists, dieticians, OTs , workplace counsellors, etc. If not in one centre then at least through one contact point like the concierge approach in the states where one doctor coordinates the services required. What is missing is discussion on the range of severity in cases and the resulting impact at all levels.	
22	I agree with the recommendations reached by the Ontario Task Force, however, from my experience since falling ill with CFS in Sept 1991, little will change until the Minister of Health makes a formal statement recognizing ME/CRS, FM and ES/MSC. The statement should emphasize the serious debilitating nature of these conditions and the fact that they are organic conditions, i.e., not psychological. Following such a statement, there should be a massive education campaign for all citizens of the country including medical, healthcare, home-care, first-responders, police and legal personnel. Only when recognition and education are supported from the top-level of the government, can the other recommendations of the Task Force possibly be attained. One exception to my first sentence above is Consensus and Definition guidelines. A couple of decades ago, The National ME/FM Action Network convened two expert panels of medical professionals to produce separately Consensus and Definition guidelines for ME/CFS and FM. There still remains the need to produce one for ES/MSC.	**New Brunswick**
23	I have received the Task Force Phase 1 Report and have reached page 17; I am too tired to continue for a while. I will pass my frustrations on as I read through the information. Example. When preventative investigations are "required". When you explain to your physician your concerns re the symptoms of ME/FM/MCI, which most doctors do not take seriously anyway. eg. (routine.. …no serious GI symptoms) Lower e.g.GI examination, due to	**New Brunswick**

	positive family history of colon cancer. I have concerns of being tilted up and down, blood pressure dropping, risk of heart attack, or cardiac arrest, being treated medically with stents, etc. as would happen without any thought of the pre-existing condition of ME/FM/MCI. I may not survive the test and another medical death occurs; and I am one more of the millions missing. I have experienced this sudden drop of BP and the symptoms of feeling quite unwell, perspiring profusely etc. etc. when having a barium enema, as the colonoscopy that was performed could not be completed past the right flexure. (Possibly due to adhesions from laser surgery for endometriosis twenty five years ago). I am seventy two years old now and I am due for another one again after 5 years... still no pathologic bowel symptoms and have postponed it twice as I do not feel well enough to put my body through such a physical assault of cathartics, fasting and then the exam itself, which is changed to a CT colonoscopy, which will include other dyes and chemicals that I may be allergic to. Until there is a medic alert on my chart and physicians take ME/FM/MCI seriously, I am not going to subject myself to routine testing for routine patients. I do not feel safe in their hands-period! Trying to stay alive in Fredericton.	

24	**Living with Fibromyalgia as a Child**	New Brunswick
	I will try to tell you what it was like living with fibromyalgia for most of my life and not knowing what was wrong and not diagnosed properly until I was fifty-two years old in 1997. At the age of two years I was tipped over in a wooden highchair and landed on the back of my head. This may have been the beginning of fibromyalgia for me. (a scar about the size of a quarter, was detected on my cerebellum during brain imaging in 1997.) Mother told me laughingly that I was the only child she knew who asked to go to bed as I would get so tired. I had bouts of losing my strength. Once the doctor thought I had polio, but I recovered without any deformity or paralysis. Many times I would find a spot, inside or outside our family home and fall asleep during the day. I was a sensitive child and remember feeling so hurt while I was laughed at because I could be so sick and tired one day and by the afternoon of the next day fully recovered. I remember my mother saying "I was so worried about Judi when I left for a buying trip to St. John's. By the time I got home the next day, she was fine. I believe the new coat I bought her made her better." Very early in my life, I learned not to complain about the way I felt, because I was not taken seriously anyway. I suffered in silence. Despite my bouts of tiredness, and "growing pains" as it was called, I was considered a very pleasant, lovable and happy child who received from, and gave a great deal of affection to my family and friends. I suffered terribly from nasal stuffiness, when I would lie down, especially during the summer. I constantly carried a Vick's inhaler. I remember the doctor telling my mother I had the sniffles. My nose was always runny or else blocked up . I also suffered from severe headaches, over my right eye and through the right side of my head, especially on hot sunny days. I can cry now thinking about how much I suffered with these headaches. I would lie in a dark room for hours, become nauseated and vomit. Then I	

would feel better. When I felt well enough to eat again I would ask for mashed potato with mustard on it.

I got motion sick. It helped if I looked directly in one spot or lie down with my eyes closed. I thought, and I would say that my eyes made me sick. It wasn't the motion, it was my eyes, as watching a movie or television would make me sick also. Sometimes looking at bold prints or plaids, or checks would make me nauseated as well.

I remember having blurred vision, which would come and go; and abnormal blinking. I was taken to St. John's to see Dr. Lynch. By the time I was examined, I could see properly and I did not need glasses. He told my mother that I had some sort of inflammation behind my eyes, which he treated with drops.

There are many times that images appeared brighter than other times. It is almost like when you turn on an extra light.

I had many sties on my eyelids. As soon as one got better another one would start. They were very painful and made me tired.

Colds and flu were a big part of my young life. I also had a bout of pleurisy. I can still feel the pain when I breathed. I was in bed a long time getting over that episode.

I would get terrible cramps in my stomach and without much warning I would have diarrhea.

Every cut or scrape meant infection. I can still remember my mother cleansing my sores with boiling salt water.

When I would run and play, if I did not twist my ankles, I would get "stitches" in my sides and would have to stop because I would get completely out of breath.

I remember while walking through a park one day, there was a loud noise behind me. I completely lost control of my legs and fell to the ground. My legs felt like rubber.

When I swam I would get leg cramps that would come on suddenly especially if I extended my leg too far or pointed my toes. I remember once I was far out in the pond. Thank God there was a shallow reef under me, when I had to stop, If not, I would have drowned, even though I was a good swimmer.

During the winters, I would easily get cold hands and feet. Once I had to go to the doctor because my toes were swollen and red. He told my mother that I had chill blains. My hands and feet would get cold, go numb, and then they would feel like they were burning.

The headaches started to be less severe, but with menarche came fainting spells, rashes on my armpits, no acne though, but mouth ulcers and cold sores galore. My hair became very oily. I had to wash it daily.

As a teenager, I still required a lot of rest and I went to bed very early at night. I could not stay up late and function the next day. Rarely did I over-tire myself, because that meant headaches. I remember once after a high school dance, I was in bed all weekend because I was exhausted and my legs were so weak and sore.

When I participated in sports, I would have pains in my legs and could not understand why nobody else playing the sport felt like I did. The soreness would go away, if I got past the first few minutes of exercise. I learned to live with muscle pain as just being normal. Very early in my life I learned that pain could be "worked off or exercised away." I tried not to complain too much as my mother was not well herself and I felt I was adding too much to her worries. She kept taking me to the doctor, but was told that nothing seriously was wrong with me.

Looking back over my life, I believe that I would have had a much better quality of life if only I had known that something physically was wrong with me. I would become so frustrated many times because of how sick and tired I felt and not knowing why.

I thank God that I did not lose my spirit or zest for life and despite Fibromyalgia I have become the person who I am today.

Living with Fibromyalgia as an Adult

When I entered nursing at age 18, I was diagnosed with walking pneumonia during my routine physical exam. I had neither temperature nor symptoms except fatigue and a headache, which was very common for me to have. I was placed on bed rest for a week with antibiotics. It took me about a month to get over that bout and regain my strength and energy.

After that setback, I had one attack of tonsillitis after another, mouth ulcers and cold sores. Sometimes I would stay off work because my lips were swollen so much, I looked deformed.

I started having mucous in my stools shortly after that and a barium enema showing no evidence of anything. By now I had learned the term "hypochondria" I felt now that I am turning into a hypochondriac and I had to stop complaining about things because nothing is really wrong and my nursing career could be in jeopardy..

I kept being involved in sports and swam a lot. When I felt sick or tired I would stay off duty in bed. I felt guilty because my temperature was always "normal." My normal temperature is around 96. I used to think that people thought I was faking.

I managed to complete three years of nursing studies by mostly working in the operating room during my last year of internship, where the environment was more controlled. I only had to look after one patient at a time so I did not have to worry about others who I was responsible for, when they were out of my sight. If I had not found the operating room, I would have had to leave my nursing career because I could not physically keep up. Nursing school was affecting my physical health.

I remember being reprimanded by a supervisor because she caught me standing up, leaning over with an infant propped up in my arms, resting on a change table, because my back was paining so much from sitting on stools while feeding them, and there was no time for a rest period. Again I suffered the pain in silence.

My first job was working In the operating room at Labrador City. We had to work a lot of overtime. I became exhausted and not knowing why, I just told the supervisor one day that I can't work like this anymore and that I would have to quit, if I were not allowed time off to rest. I went home and rested in bed for about three weeks, before I went back to work again. I would have to sneak naps, especially if I were up the night before for emergency surgery. I could not physically keep going five days a week, with overtime. Weekends were not long enough for me to rest up.

My physical problems of muscle pain and fatigue were attributed to the birth control pills I was taking, so I was advised to stop taking them and required minor surgery with general anaesthesia. I was hospitalized for a prolonged period, due to the side effects of the anaesthesia.

I had abnormally long and difficult deliveries for both my children. I was in hospital 10 days after my second child with extreme fatigue. My GI system practically shut down, even though I requested no analgesics or anaesthetic agents because of extreme sensitivities I had experienced to those drugs before. Even my two and one half year old daughter told me that I looked tired. I did not experience any gloom and doom though, or feel depressed or have any negative feelings post partum..

My nursing career was mainly part time jobs in the operating room, as I could not physically keep up with full time work. When I had to work full time, for financial reasons, I always had a live-in homemaker to help me, until my children were grown big enough to share the chores.

Every planned vacation was ruined because I would become sick and tired after the plane ride. I would rather lie on the beach or in bed than go on a tour. I would have to return home at least three days before going back to work so I could rest.

I still had frequent bouts of infections. I had bronchitis five times the year my first child was born. The symptoms would come on suddenly, overnight. The fatigue would last for weeks.

My social life has always been excellent and most of the time I feel very positive and contented.

In 1976, I was involved in a seven car pileup going through a tunnel in Montreal. I cannot say my symptoms got any worse after I recovered from the head and knee injuries resulting from that accident, which kept me off my feet and off work for six weeks.

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During a bout of flu, sinusitis and bronchitis in 1983, I was on decongestants/ antihistamines, antibiotics, Gravol, and Aspirin. I had a toxic drug reaction that caused me to develop psychosis. I always believed that the Gravol I took was the culprit. (Now I know it was the Halcion I was given, when a physician visited me at home because I was too ill to get out of bed. (I had experienced another adverse reaction to Halcion in 1998.)

During that admission in 1983, I do not remember anything that happened for a couple of days. When I was well enough, I was examined thoroughly by psychiatrists and was told I had a toxic drug reaction and to be careful taking drugs, because of my sensitivity to them. After that psychotic episode, I refused to take any over the counter or prescribed medication, except the odd Aspirin for quite a while)

I was still living with fatigue and having upper respiratory symptoms and finally I was prescribed Trinalin, an antihistamine and took them for four years (1991-1995)

In hindsight, I believe now that was wrong because Trinalin gave me false energy that kept me going and getting toxic and more seriously ill..

I had another toxic drug reaction in 1995 when I was physically ill with sinusitis and bronchitis and treated with antibiotics, antihistamines and anti-nauseants. I asked to be taken to the emergency department of the hospital where I was employed, as I knew I was seriously ill. This time I was misdiagnosed as manic depression in the emergency department, and then my nightmare began that lasted until I was officially diagnosed with Fibromyalgia in 1997.

There is documentation on my medical records confirming I have had every symptom of Fibromyalgia that has been researched and recorded. I can honestly say I knew nothing about Fibromyalgia until 1997 when my general practitioner gave me an article to read on Fibromyalgia as he thought that was what was wrong with me. He then referred me to specialists in London, Ontario, and the diagnosis of Fibromyalgia was confirmed with symptoms also suggestive of Chronic Fatigue Syndrome.

Drug sensitivities and adverse reactions are very common with Fibromyalgia. Research shows that doses of one quarter to one tenth of what a normal patient can take are not uncommon. People should be started on the smallest amount possible and increased slowly.

I have had a hard struggle living with Fibromyalgia and I wrote a book, Judging Judi, which helped me deal with that struggle and heal my emotional scars. This book has helped others to relate to what it is like being misunderstood, undiagnosed and then worst of all misdiagnosed with manic depression and treated harshly, unfairly and without respect for over two years, 1995-1997, until I was diagnosed with me/fm in 1997.

Due to ME/FM symptoms, which were exacerbated by drug induced neuro- toxicity from Lithium, which I was forced to take for over a year in 1995-1996, I was unable to work at any job that required any strenuous physical or mental activity for long periods.

My thyroid and heart were also negatively affected with abnormal test results. They are all well documented side effects of Lithium. Psychiatrists did not take seriously my physical symptoms at that time, as they were considered psychogenic, because the Lithium blood levels were normal. The physicians did not realize I was lithium toxic, with normal blood levels as I was suffering from undiagnosed ME/FM

When I could, I volunteered my time to people suffering from Fibromyalgia. I had facilitated a Fibromyalgia Self-help group in NL. from 1998 to 2003, but after I moved to Fredericton, New Brunswick, I have continued to volunteer my time with the National MEFM action Network, working to promote awareness of this serious and debilitating condition.

Living with Fibromyalgia as a Senior

I was fortunate and blessed that I had a secure income with a private long-term disability benefits and Canada Pension Disability from age 52 years, to ensure that I could financially survive, while living with this serious illness.

This disability income did not allow me the ability to save for the time when I reached my senior years, when the insurance payments would cease. Since the age of 65, I have been living well below the poverty level while still dealing with the symptoms of a serious disabling illness.

The therapies that I need to help me cope with this illness are beyond my financial reach, so most of my treatments I do myself in the privacy of my own home, which is creating more isolation for me year after year.

I have difficulty with walking especially on uneven surfaces as my balance is abnormal and that results in sudden falls.

My body movements are slower than normal due to stiffness and pain, including chest pain as the muscles of my heart have become affected and the three valves show pathology according to an echocardiogram that was done in 2016.

Due to fatigue upon any exertion, I spend over half my days resting in bed.

It takes all my waking time looking after myself so that I still may have a half decent quality of life.

Because of hyper mobile joints syndrome that I was diagnosed with a few years ago; now as the muscles around my joints weaken, I have to be careful of dislocating them. Walking upstairs is becoming more and more difficult, but I continue to walk stairs and I will as long as there is a rail there to help me pull myself up over them.

I suffer from multiple chemical sensitivities and due to this my activities are limited to avoid inhalation exposures that cause sudden serious anaphylactic reactions that cause me to become seriously ill that need immediate attention. I carry medic alert information and medication (tri-salts) that help me overcome such reactions.

I have myself set up quite well in my own home. The temperature and humidity can be controlled , so I do not have as many respiratory problems as I would have if I lived in a more toxic environment caused by fumes from carbon monoxide, cigarette smoke and other noxious substances that I am quite sensitive towards.

Because of weakening muscles, I am losing the ability to control my bodily functions of urinating and defecating. At times I need to wear incontinent underwear, which is an added cost to my care. It takes hours looking after this disability and the meticulous care is a necessity to avoid contracting urinary tract infections from cross-contamination of bodily waste.

Because of this chronic illness, it is very important that I have a well-balanced diet and extra vitamins and minerals at all times, which costs extra and should be allowed to be claimed on income tax expenses across Canada.

I have had a severe reaction to a medication (Olanzapine) that I was forced to take sublingually two years ago, which caused a proliferation of blood vessels underneath my tongue, which required oral surgery and then major dental work on my lower teeth, which is not completed yet. The total costs has been almost $10,000.

This setback has interfered with my ability to chew properly because of pain and stiffness in my right temporo-mandibular joint, especially on my right side.
I have had difficulty swallowing for awhile now, and getting worse. I choke easily on dried food that makes me cough and then sneeze, which I have no control over and everything in my mouth comes out all over my napkin.

I mostly eat now standing up, by the kitchen sink, taking warmed soft or soaked dry foods that have to be swallowed by sips of water.

Sometimes when I am eating food that is too dry, it gets stuck in my esophagus and then there is a bigger problem, until I get the food either up or down. The longer it takes the more mucous builds up and the more pain I experience. That is why I mainly eat standing up at the sink.

I try to get my daily food intake in two meals now and drink liquids the rest of the day as the need arises.

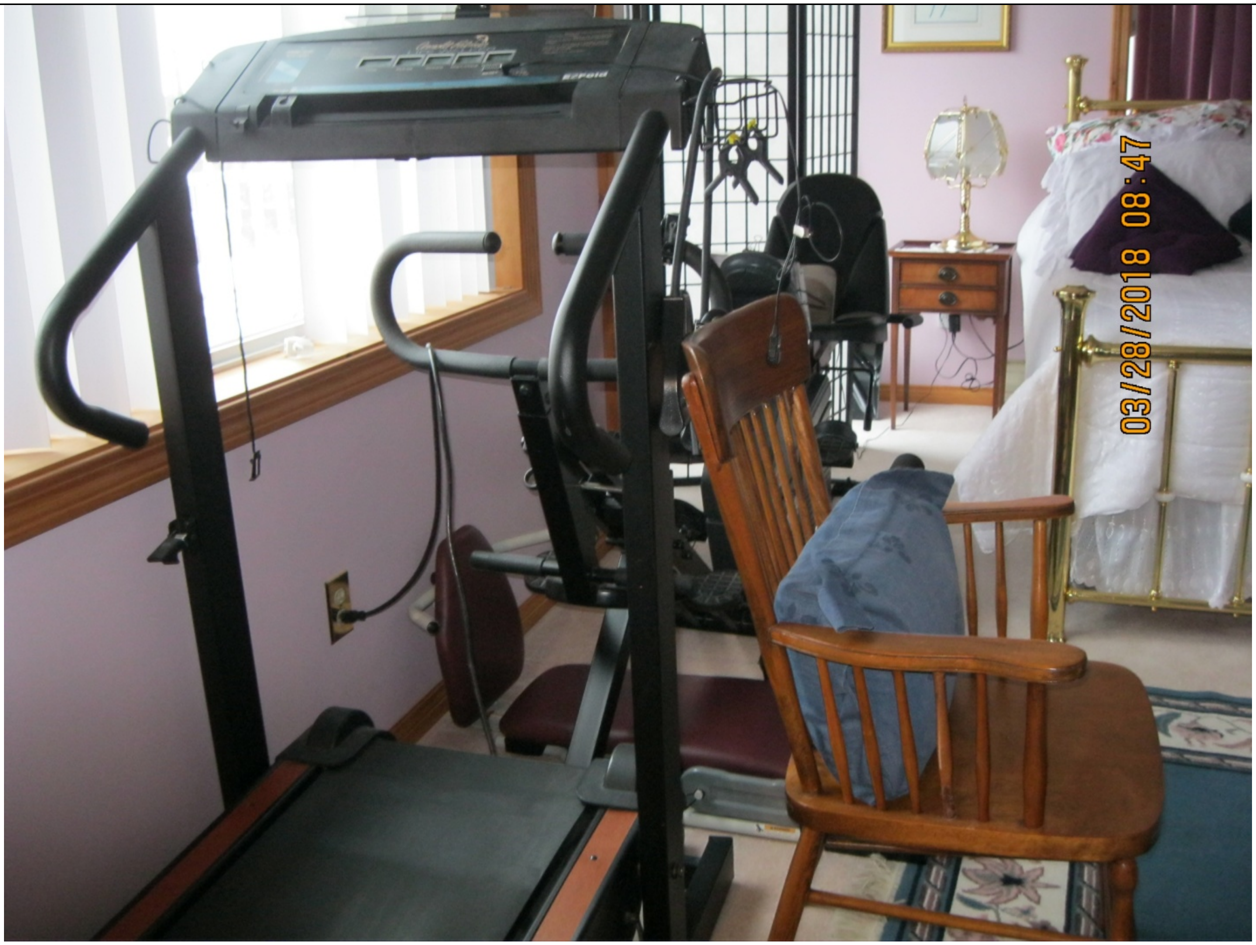
I look forward to the day that the health care teams, social services and other government agencies understand this plague of an illness that has to be given more consideration because more and more people are becoming seriously ill from neurotoxic exposures, causing brain damage that will negatively impact them for the rest of their lives.

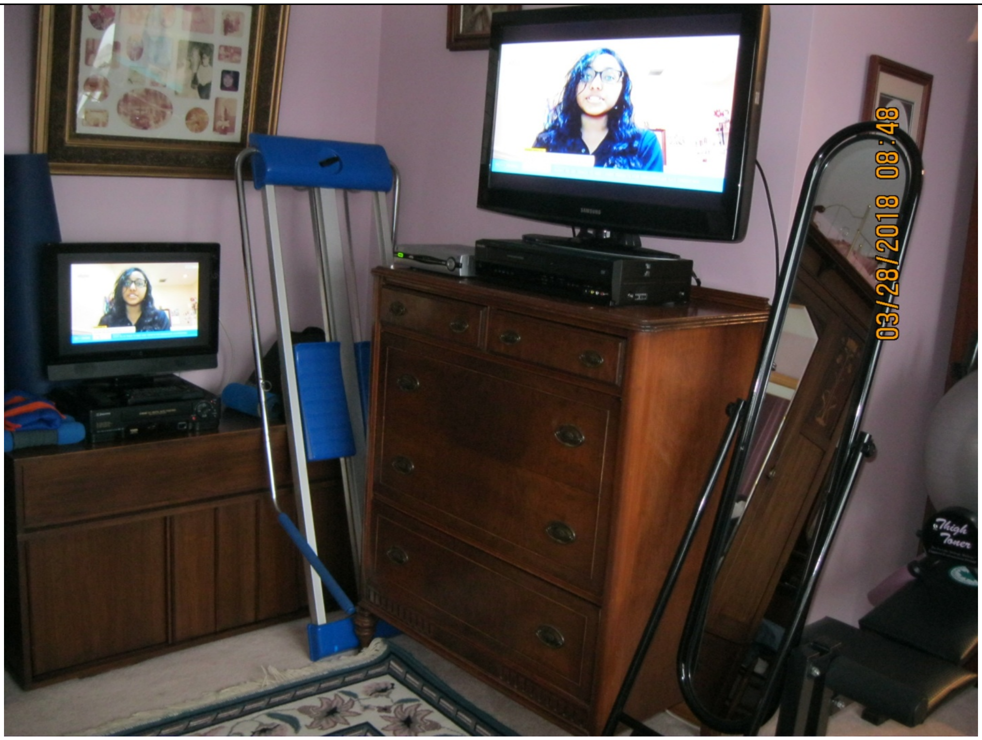
The last example of this “unknown illness” was illustrated when the diplomats and their families were stricken ill in Cuba. Perhaps now is the time for real serious action, financial and otherwise to find out the causes and most importantly prevention or at least prompt and correct treatment.

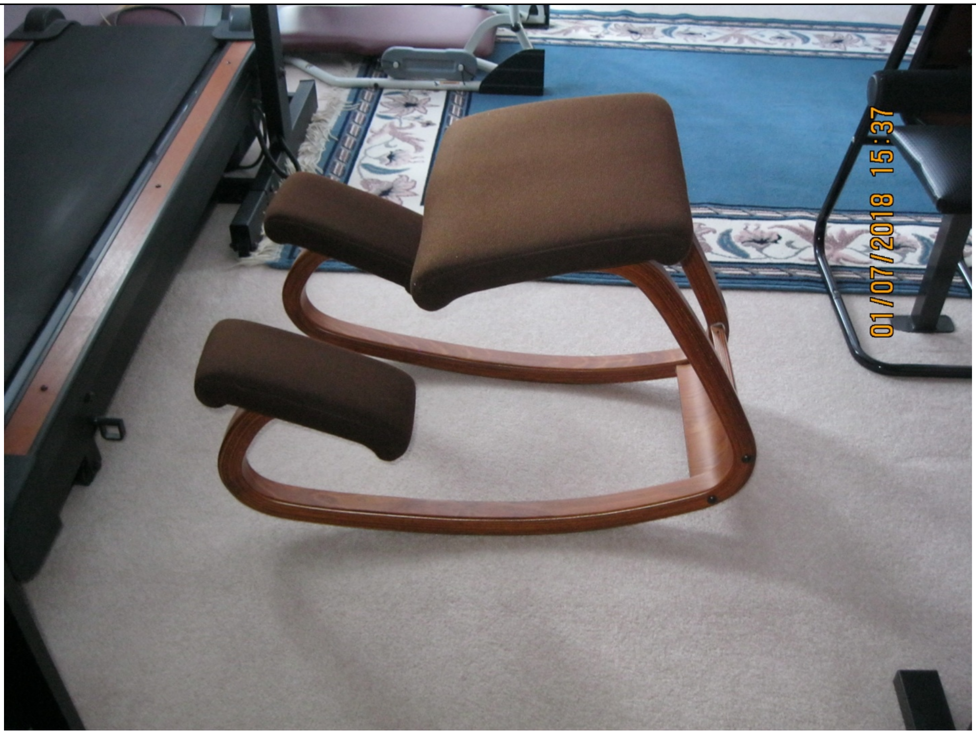
When people become ill and incapacitated because of neurotoxic assaults on their brain, our most misunderstood and important organ we have, it must be taken seriously and treated appropriately in order to help us ensure we live a half decent quality of life that every human being deserves. We must be able to live without the stigma that comes from simply not being understood by the medical community, as right now more harm is being done to us than good.

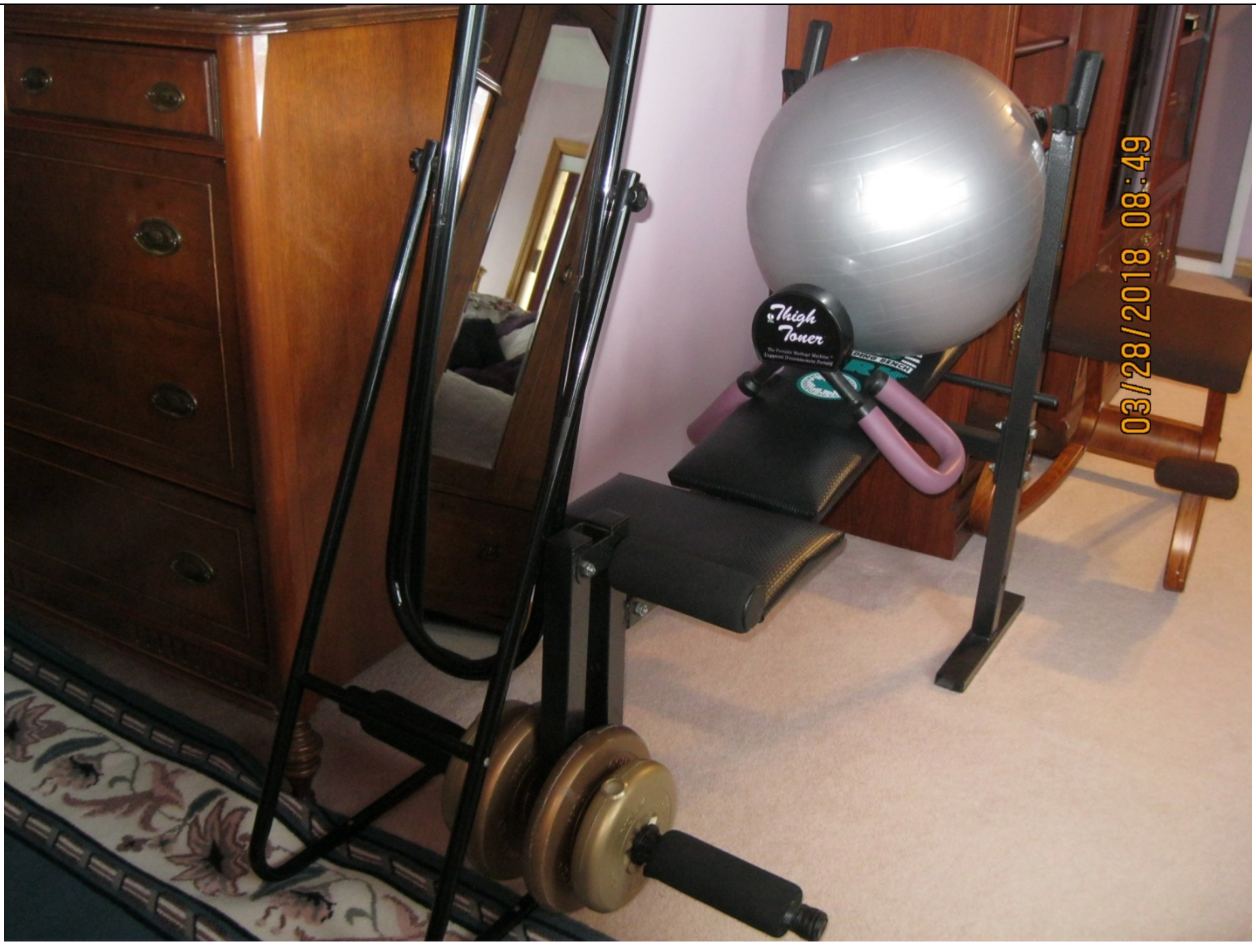
Written and revised, April 18, 2018, by Judith M. L. Day, author of Judging Judi

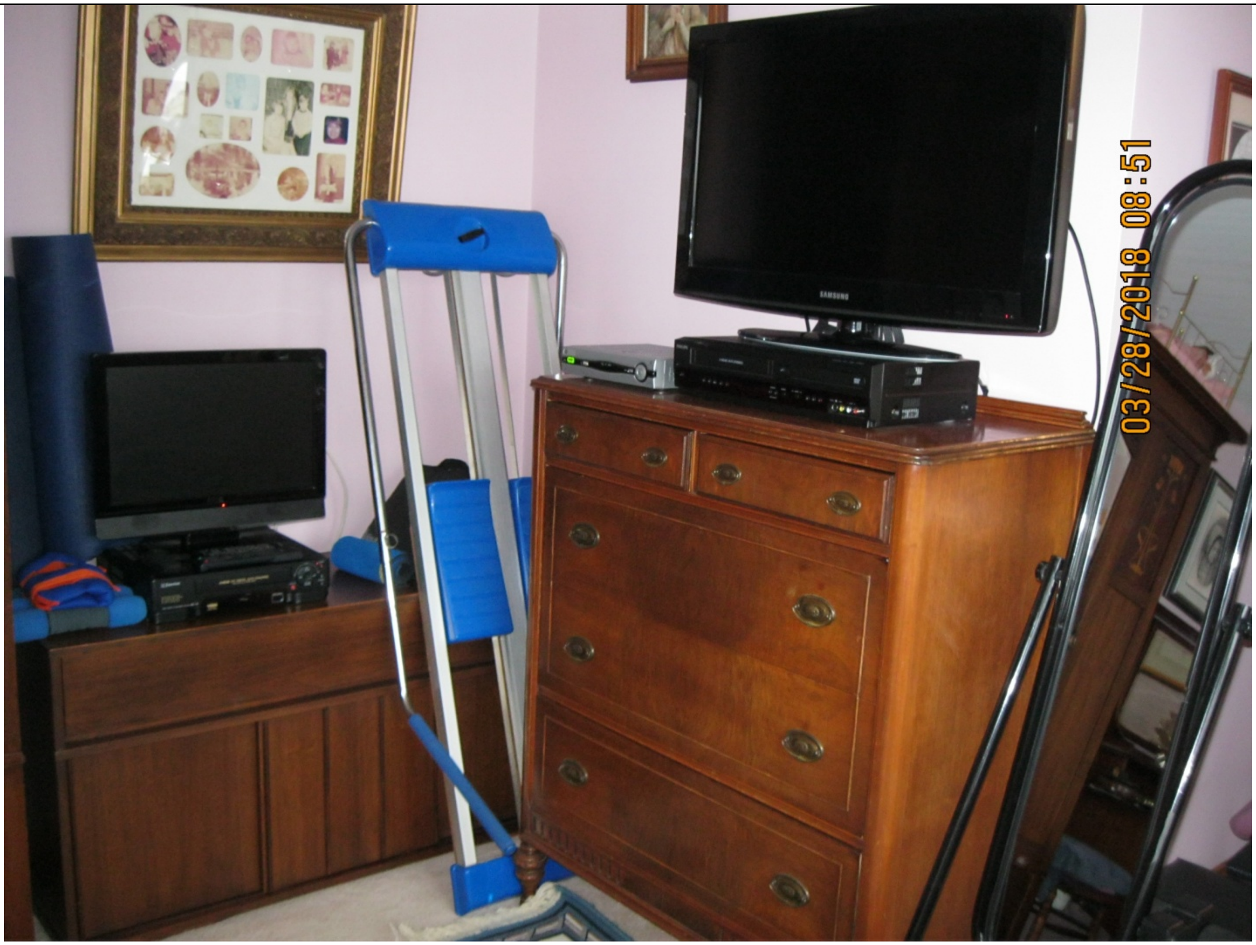
Below are pictures taken of my at-home gym, This is where I begin my day, every day.

	03/28/2018 08:47	

	 03/28/2018 08:48 Thigh Toner		

	 01/07/2018 15:37	

	 03/28/2018 08:49	

		
25	As I get older, the illness is really taking its toll on me: The last straw was the reaction in my mouth that I had experienced when I was given OLANZAPINE sublingually (against my better judgement) that caused major damage to my tongue, gums and molars that were in the way. I had another visit to one of the four oral and dental specialists, who have been working	**New Brunswick**

	on my mouth for the past two years now. My dentist told me today, It may take up to two more years before total recovery may happen. Can you imagine?	