

Dear Panel Members,

First, I wish to say thank you very much for all your hard work on this historic document. It has been a wonderful Christmas present, and after 25 years as a patient in the ME trenches, your document has given me hope that ME paradigms are shifting.

Second, I would like to suggest that we just go with the label Myalgic Encephalomyelitis. Chronic fatigue is prevalent in a lot of diseases; the label CFS has served to add to the confusion about the reality of this very debilitating disease.

Line 4 - of course there is no one single diagnostic test for ME: **there is no one single diagnostic test for MS either**; perhaps ME is another such disease where a group of test results need to be examined to come to a diagnosis; indeed there are many tests that do show abnormalities in ME patients (as per the Canadian Consensus Document, by Dr. Bruce Carruthers et al.); I believe that continually repeating the mantra "there is no diagnostic test for ME" translates in physicians' and the public's mind's to mean there is no indication of any abnormalities whatsoever; doctors unfamiliar with ME are very surprised when more in depth or specifically targeted testing does show abnormalities: e.g. heart rate abnormally increasing or blood pressure dropping while doing an in office simple supine vs. standing test

- as well, this damaging mantra (there is no diagnostic test), seems to mean there is no scientific proof for the existence of this disease; it is not a real/physiological disease, and therefore these people are malingering - are crazy or lazy

- in light of the situation with MS, and that a group of tests must be done to diagnose MS, it is amazing, and very puzzling that the medical system has not caught on to the fact that ME may also be an illness whose assessment must follow a similar pattern

Line 7 - thank you for confirming that this is a major disability - that confirmation is extremely welcome! ME is not a walk in the park! **According to Leonard Jason et. al. : "The three most prevalent causes of death [in ME] were heart failure, suicide, and cancer, which accounted for 59.6% of all deaths. The mean age of those who died from cancer and suicide was 47.8 and 39.3 years, respectively, which is considerably younger than those who died from cancer and suicide in the general population."**

- if ME is just malingering scam artists taking advantage of the system, why are they killing themselves?

Lines 10 and 11 - I thoroughly agree! We have been on our own out here for decades; the lack of medical support makes us vulnerable where financial support systems are concerned, and because our doctors don't believe us, our friends and family may not support us either

Line 32 - there is a clear definition internationally used: The Canadian Consensus Document by Bruce Carruthers et.al. ; the confusion has been that several older, flawed definitions are still in use, which causes problems with studies etc.

Lines 32 to 43 - I would agree there is much confusion in the scientific community regarding what definition to use, what to test etc.: this of course causes researchers clinicians, and funding agencies to avoid this field of study

- again, the mention of the lack of one specific test hampering progress is mentioned - I do not know what the IOM report will cover, but I think the medical community has to move on, and may have to accept that there are a cluster of tests and symptoms that can be used to diagnose ME just as there are in MS; **I believe that tenaciously holding onto the concept that we have to**

search for the one single magic bullet diagnostic test for ME, after decades of research, is in itself holding up progress - let's move on!

Lines 44 to 57 - thank you very much for thoroughly describing the mess that ME research is in; as ME patients we have waited decades for validation, holding onto each new scrap of positive confirming research as if it was a life preserver; our lives are in various states of ruin because the medical and scientific community have let us down; all aspects of our lives and our family's lives have been very negatively effected

- those of us who have been proactive in seeking alternative medical help may have found little of value as regards real improvement, and some have drained their finances to the point of bankruptcy, thus adding to the overwhelming burden of this disease

Lines 65 to 73 - it is ironic that as sick as we are, we have to be very determined and make extraordinary efforts to prove our illness by researching as much as we can about it, and by seeking out the more in depth testing that indicates abnormalities, as well as covering all the related fees ourselves

Line 79 - I think there are many ME patients who understand their disease very well - these patients often find themselves in the role of educating their doctors, not the other way around; I do agree that more education needs to happen, especially with doctors!

Lines 82 to 86 - thank you for summarizing the research that has found abnormalities; it is unfortunate that this is mostly still at the research level, family physicians are not aware of this progress, and patients are not able to easily access this testing if at all

Lines 92 and 93 - thank you for emphasizing that this is not a psychological illness - countless doctors likely still believe we are "crazy"!

Lines 108 to 117 - CBT and GET do not work for ME! MS patients are not subjected to this as their only treatment. I don't believe any other disease has these therapies offered as the ultimate cure. Please note the Overview for the Canadian Consensus Document on page 4, which details ME patients' response to exercise. Scientific references have been included in the Overview re the negative effect of over exertion on ME.

-offering these therapies as a cure or even a valid treatment for ME completely negates the validation given in your report that ME is a real physiological illness - we go back to square one with the erroneous presumption that ME people are crazy or lazy, if we give any credence to these therapies!

- I would accept CBT as of minor assistance to be used as a coping tool for ME, and I would strongly caution that GET not be used by anyone not extremely familiar with ME; again please note the effects of exercise sited on page 4 in the Overview of the Canadian Consensus Document

Line 130- self management: that's pretty much all most of us have had for decades; some practitioners however well meaning have caused irreversible harm; some don't know how to help, but cost us a small fortune; some are hostile; some are ridiculous; some are supportive, but can't be really effective, and the few specialists around are not accessible due to costs, long waiting lists, etc.

- for proactive patients with ME searching for even a modicum of improvement, the hunt can be a minefield full of expensive, useless or harmful treatments; when we do hit something that helps, it may be due to our own research

Line 142 - doctors have to be cautious with their diagnosis of all patients; ME is a garbage can diagnosis; they don't know what we have so we get thrown in the ME BIN; people who do not have ME get thrown in the ME BIN; doctors of all stripes trivialize ME; alternative physicians don't understand or know what ME is; in this respect they have a lot in common with mainstream physicians; many alternative physicians appear to think they can fix ME with herbal and vitamin supplements; ME patients are desperate, and may turn to anyone who has diplomas on the wall and wears a white lab coat; lots of really dumb and costly therapies can sound good to people desperate for some relief from their suffering

Line 181 - yes, I agree, medicine has not implemented what we already know about ME; veteran doctors in various fields have never even heard of ME, and have no idea what it is; those with ME patients do not know what more comprehensive testing to do; health care plans may not allow these more expensive and comprehensive tests for ME - that may be another block to assessment and treatment

Line 191 - I agree that primary care physicians need to be focused on regarding education, however, without an infrastructure complete with specialists to back them up, we will still be lacking in assistance; the abbreviated appointments afforded to patients and their primary medical care givers is inadequate to address ME; **we need ME trained specialists! And lots of them!**

Line 317 - there is money available for ME research, lots of it; it just has to be re-allocated; funds for more benign diseases may receive many, many times the amount of research funding that ME does; we have seen this time and time again! Decision makers have to make more sensible decisions about where the research money should go; as the NIH report has indicated ME is a major disabling disease, it should be a priority for funding, not the ugly red headed step child of the medical and research community

Line 328 - please adequately fund the collaborative centers - we have waited a long time for this help; under funding and tokenism will not help; administrators of these clinics have to realize how sick the patients are, and they need money, lots of it!

Line 334 - very few people recover from ME - studies indicate between 0% and 6% of ME sufferers recover; there will not be a large population of these people to study

Line 344 - yes patients should be active in their own treatment; they are often the only ones who are!

Line 351 and 352 - yes more conferencing is needed, **but please get on with more studies and provide a widely distributed PR campaign telling doctors and the public that ME is real and very debilitating - please don't go back to your offices without telling as many as possible that this is a real, and not imaginary illness - this would be a first very helpful step in improving the quality of our lives; for doctors, governments, financial support systems, and the public to know we are not crazy or lazy!**

Line 362 - I agree, as I have noted above that education will facilitate better understanding - hence the PR campaign

Line 365 - please retire any outmoded definitions

Line 366 - agreement on a single definition may take time, please do not wait for unanimity

Line 388 - yes, your work has dignified and validated ME, but out here in the rest of the world people still think ME is hysterical nonsense - please start educating doctors, researchers and the public now! I have been doing my bit in this respect for over 25 years

Thank you very much for your work on this document, and all the work to follow. You have given us real hope for change, and I look forward to more good things to come from, the NIH! Happy New Year!

Kind regards,