

Anonymous #5

Dear Sirs,

I would like to thank you and congratulate you for having written a Draft Report which recognizes the reality of ME/CFS and its biological origins. There are many parts of the report which I fully support and approve of, such as the following lines:

(Please note that I am using the line numbers of the 389-line version of the report.)

Lines 7-9

Line 32

Lines 38-43

Lines 45-46

Line 52

Lines 63-64

Lines 68-72

Lines 76-78

Lines 82-86

Lines 104-105

Lines 127-129

Lines 142-159

Lines 184-185

Lines 186-187

Lines 212-269

Lines 294-300

Line 376

I would like to request that the above mentioned sections remain in the final document.

Here are some things I think could be improved in the final document:

- it could be made even clearer that ME/CFS is an organic disease, affecting multiple systems of the body. You state "this is not a psychological disease in etiology" (line 92-93), which is very true, but the phrasing could be taken by some to mean that while ME/CFS is not psychological in origin, it can be perpetuated by psychosocial factors. This is not any more true for ME/CFS than for MS, RA or Parkinson's, but sadly this view has been promoted (mainly by UK psychiatrists). I therefore ask you to clarify further in the report that ME/CFS is an organic, multi-system disease

- please mention the severely affected more. It has to be clarified and stressed how extremely debilitating ME/CFS can be

- it could be made clearer that further research needs to be focused on those with the most severe cases of ME/CFS, in particular those confined to their homes or even to their beds. This will require extra funding as these patients are not able to physically go to a research facility themselves (line 52)

- make it clear that PEM, not fatigue, is the cardinal symptom of ME/CFS (e.g. lines 59, 95)

- not only the Oxford criteria but also e.g. the Fukuda criteria are too broad, not requiring PEM as a mandatory symptom of ME/CFS (line 58)

- while it is true that there are no diagnostic tests for ME/CFS there is certainly a well-defined set of criteria that should be endorsed for use in further research, namely the Canadian Consensus Criteria (CCC) (lines 40-43 (in part), 366). No more time or money should be spent on further fine-tuning these criteria, which already are specific enough to narrowly define ME/CFS, that could instead be spent on actual research.

- most important of all: More funding for biomedical research is needed, and must be provided by NIH. This could be made even clearer by making comparisons with NIH funding of research of other diseases of similar severity and/or prevalence

Best regards,