Comments on:
Draft Executive Summary
NIH Pathways to Prevention Workshop: Advancing the Research on Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome

The report adequately addresses many issues that are important to ME/CFS patients and also contains some helpful recommendations. I want to express my thanks to the authors for understanding the gravity of the situation, the massive disease burden and suffering on the part of the patients, and the neglect and lack of funding the research field has suffered from for decades.

The draft report lists a number of needed actions (for example lines 212-276) which I endorse.

It also says:

7 Limited
8 knowledge and research funding creates an additional burden for patients and health care
9 providers.

216 Department of
217 Health and Human Services (HHS) agencies should coordinate research efforts to
218 promote efficiency and effectiveness

376 There is a role for new and ongoing policies to spark innovation and fund new research.

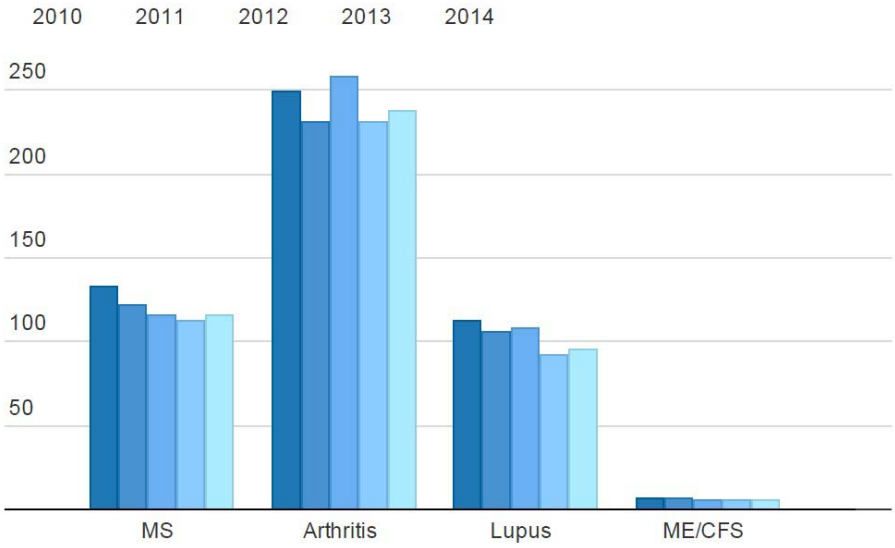
However, perhaps the most crucial section is currently missing from the report, namely recommendations on how NIH needs to take active measures to increase funding for biomedical ME/CFS research. Without NIH setting aside funds for ME/CFS through specific RFAs, none of the recommendations in lines 212-276 will stand a chance of transpiring.

The lack of funding set-aside for ME/CFS research at NIH and other funding bodies is the main reason the field is so immature and there still are no biomarkers, stratified subgroups and effective treatments.

The following graphs (courtesy of authour and blogger Jørgen Jelstad, see http://debortgjemte.com/2014/05/20/me-forskernes-kroniske-pengemangel/) are a good illustration of the current situation and the vast gap between the disease burden in ME/CFS and the funding levels into the disorder.

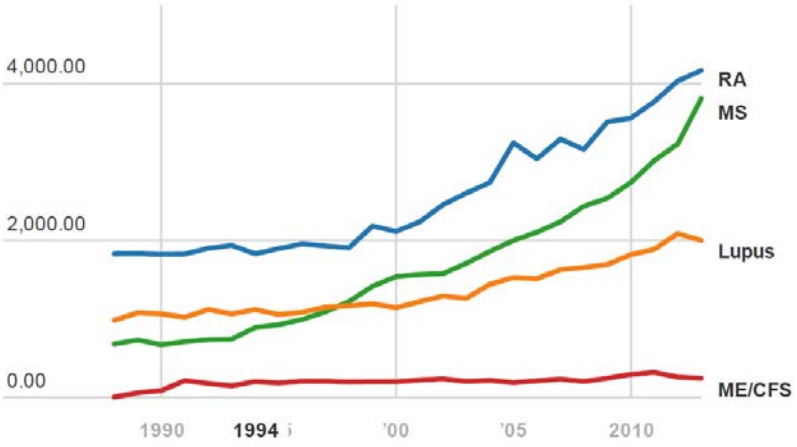
Money for research 2010-2014 (in millions)

In 2014 NIH gave 115 million dollars for research into MS, 237 million dollars for arthritis research and 95 million dollars for lupus research. In the same year ME/CFS only got 5 million dollars. 1 year of funding for MS would finance 23 years of ME/CFS research.

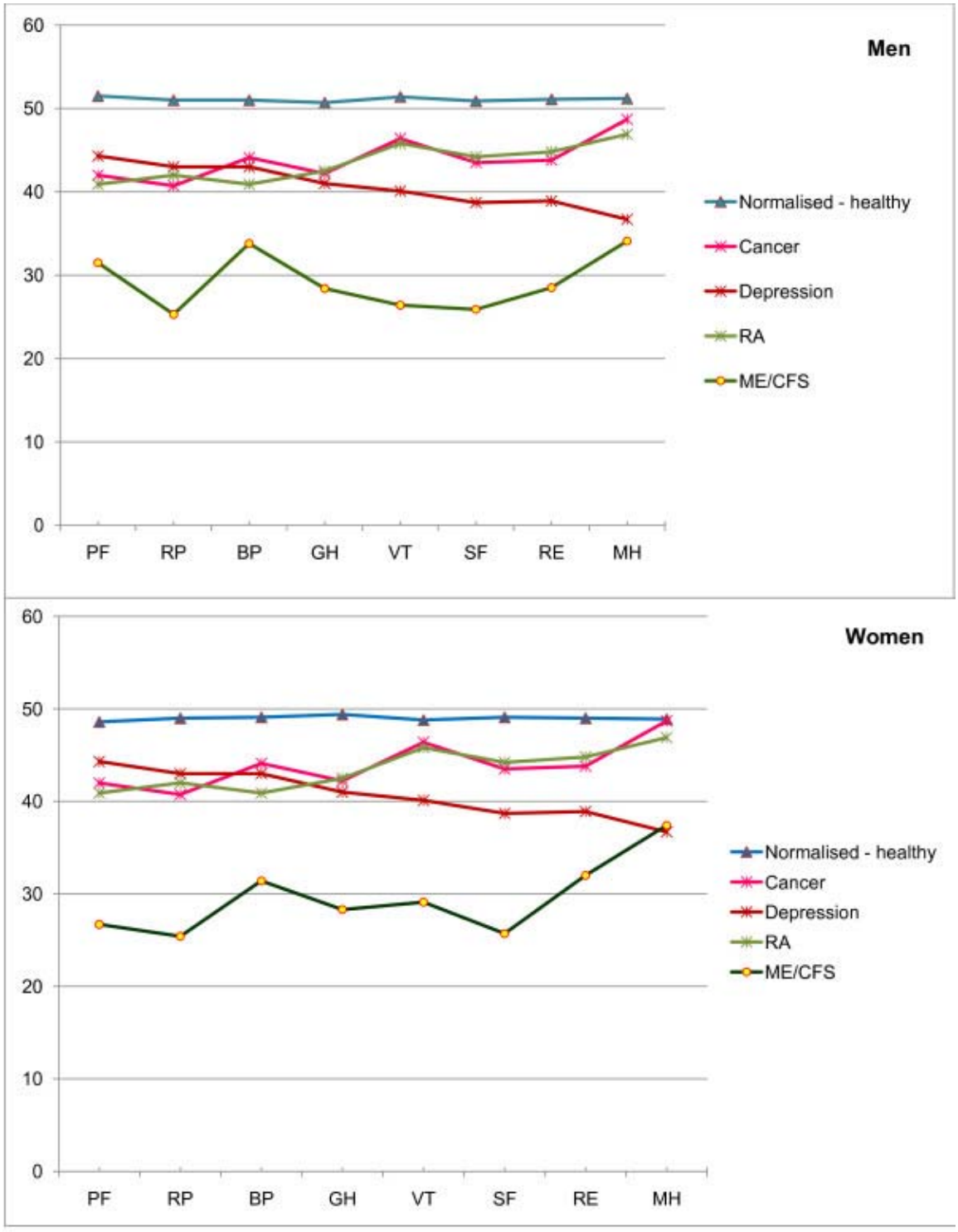


Published studies 1988-2013

The graphs show how many new studies are being published each year in four diseases. Since 1991 there has barely been any progress in the amount of published ME/CFS studies. While research into MS, RA and lupus has increased dramatically.



The following graph describes SF-36 scores in men and women with ME/CFS, other health conditions or healthy controls:



"The functional status and well being of people with myalgic encephalomyelitis/chronic fatigue syndrome and their carers"
BMC Public Health 2011 11:402

As you can see, ME/CFS patients have a higher disease burden than many other diseases. It is also a fairly common disease, with an estimated prevalence of roughly 0.4%. In the US, an estimated 400,000 patients have MS, and an estimated 1,000,000 patients have ME/CFS.

Still, available funding for ME/CFS research is more than 20 times lower than funding for MS research. MS researchers receive in 1 year what ME/CFS researchers receive in 23 years! As evident from the graphs, this–naturally–correlates with the number of published studies.

It also clearly correlates with the state of knowledge in the different diseases. In MS and arthritis there are today several lines of treatment which in many cases are effective. By comparison, in ME/CFS, the disease pathways or biomarkers have not yet been identified. There have been many very promising research leads into the etiology of ME/CFS, but almost all of them have come to a halt due to the lack of funding for large follow-up studies.

It is well known in the research community that it is very hard to receive funding for ME/CFS through NIH. We are aware of several researchers who have left the field. Researchers also report a notable difference in the level of difficulty in receiving funding for ME/CFS compared to other diseases.

It has been repeatedly requested (via the CFS Advisory Committee, the International Assocation of ME/CFS, etc.) that NIH issue RFAs for biomedical research into ME/CFS. This has not been done. When NIH held a State of the Knowledge Workshop on ME/CFS in 2011, it was generally expected that this would be followed by an RFA. This did not happen, and the miniscule levels of funding have continued.

This negligent public funding is the main culprit for the stalemate in the ME/CFS research field, and before it is amended, it is unlikely that any other recommendations or actions will lead to any discernible progress.

Therefore, it is absolutely necessary that the final P2P report includes strong and very specific recommendations that NIH bring the level of funding for biomedical research up to levels proportionate with the need, prevalence and disease burden. One recommendation should state that NIH must allocate set-aside resources for ME/CFS research, preferable by issuing multiple RFAs for ME/CFS research. (Referring here to the section ‘Future Directions and Recommendations’, starting on line 178.)

If this is incorporated into the final report, there will be hope for a future where the two first graphs above will finally report a different reality and ME/CFS patients, researchers, clinicians and carers may feel hope.

Thank you