

Comments on the P2P Report, ME/CFS – Marion Vogel

I wish to thank the members of the Panel for your efforts in drafting a report which usefully addresses many issues that are important to ME/CFS patients.

There is much to be commended in this report, for example the sections listed below:

Lines 7-9: "ME/CFS results in major disability for a large proportion of the people affected. Limited knowledge and research funding creates an additional burden for patients and health care providers."

Line 32: "ME/CFS exists."

Lines 38-43 – that the Oxford criteria be retired

Lines 45-47: "Patients are typically underserved, and clinicians have a poor understanding of ME/CFS. We heard throughout the workshop that ME/CFS can affect anyone. Education, financial security, and social standing will not prevent the disease."

Line 52 – the lack of inclusion of the severely affected (housebound) in research

Lines 63-64 – the lack of research dollars from the public sector – *This is the fundamental problem!*

Lines 68-70: "Patients usually have to make extraordinary efforts, at extreme personal costs, to find a physician who will correctly diagnose and treat ME/CFS symptoms" – *Very true!*

Lines 76-78: "Over the last 20 years, minimal progress has been made to improve the state of the science for patients with ME/CFS, and the public and provider community is frustrated. Patients want their concerns to be heard, a meaningful recovery (not just incremental improvement), and a cure."

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: "There is a role for new and ongoing policies to spark innovation and fund new research"

As a close relative, I fully support this text, and I would like it to stay in the final document.

However, I believe that perhaps the most important issue of all is not highlighted in the report, and this needs to be changed.

In lines 10-11, you state:

“Unfortunately, ME/CFS is an area where the research and medical community has frustrated its constituents, by failing to assess and treat the disease and by allowing patients to be stigmatized.”

Rather than the research community, it is the NIH and the CDC which have frustrated the ME/CFS community. (In fact, the NIH and the CDC have frustrated expert ME/CFS researchers, as well.)

CDC keeps communicating information which is not correct, such as the statement that exercise is a recommended treatment regime for ME/CFS (this may be true for persons suffering from general fatigue for various reasons, but for ME/CFS patients exercise often is detrimental, as shown by biomedical research).

NIH has not answered repeated calls for the urgent need to raise funding levels for biomedical research into ME/CFS. ME/CFS is given 20 times less money than other diseases with a similar profile (if counted in dollar per afflicted person per year 60 times less). Unless this is changed through set-aside funds for biomedical ME/CFS research, no progress will occur within the ME/CFS field, and no help will reach the long-suffering patients.

Thank you for considering my comments and thank you for your work.

Kind regards,

Marion Vogel