

Public Comment, P2P Draft Report, ME/CFS

Thank you for your work. I hereby submit my comments to the P2P Draft Report on ME/CFS

Referring to lines:

273-275: 'Studies investigating homeopathy, non-pharmacologic, complementary, and alternative medicine treatments are needed'

and referring to lines:

116: 'should be used as a component of multimodal therapy'

303-306: 'We believe ME/CFS is a distinct disease that requires a multidisciplinary care team (e.g., physicians, nurses, case managers, social workers, psychologists) to optimize care. Thus, properly training that workforce is critical'

350: 'Future treatment studies should evaluate multimodal therapies'

370-371: 'We believe there is a specific role for multimodal therapy'

I would like to suggest the following changes:

As the report states, patients often choose 'alternative' treatments because there are no approved drug treatments for ME/CFS. This should be remedied by focusing on research which can validate effectiveness of conventional medical treatment—i.e. biomedical research into disease mechanisms and clinical drug trials.

It is clear that ME/CFS patients do not receive substantial help from behavioral treatment modalities or alternative medicine (or else many of us would be much better today!)

It would be a mistake to spend precious research dollars on complementary medicine or multimodal treatment, when there is such a dire need for biomedical ME/CFS research.

Please remove the above mentioned suggestions, and instead make strong, specific and numerical recommendations that NIH increase its funding into ME/CFS to levels proportionate to the needs of the patients (that would mean a 20fold increase in funding).

Yours sincerely

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