

Robert Miller Patient/Advocate

Good Day,

I want to thank CFSAC for convening a special meeting to discuss comments to the P2P report, and to recommend changes that will add teeth to the strong words in the Panel's report.

In 17 years of advocating for a stronger federal commitment to ME/CFS, I have never seen a report like this come from inside the government. The Panel was a panel of independent scientists, experts in their own fields, with no knowledge of ME/CFS, appointed by NIH to review the scientific state of our illness. The results of NIH's P2P panel mirror what patients, ME/CFS experts, and advocates have been calling for, for years. Now it's evidence based and official. NIH Director Collins, the P2P report requires change, our patient community is ready and willing. Secretary Burwell we await your leadership to improve the lives of one million Americans.

The Panel recommends translational networks or centers of excellence, clinical trials supported by NIH, more involvement by the Trans-NIH Working Group, increased immunological, neurological and genetic research, broad physician education, and more. It clearly states that ME/CFS is physiological, not psychological, that patients bear a stigma, and that the medical and scientific communities have failed over a million people.

It's time for NIH to listen and respond to its own process, and dedicate resources commensurate to this illness to finding a diagnostic test, approving treatments, training doctors and creating careers for scientists in the field of ME/CFS.

To CFSAC , I would ask you to include in your recommendations that the P2P Panel add teeth to its recommendations by urging NIH to spend at least \$25 million in the next two years, implementing the beginning of their recommendations. Without the dollars, none of these strong words will become a reality for ME/CFS patients. There needs to be a true sense of Urgency for our patient population.

To the patient community, I urge we all join together to use this report as a document of evidence, to hold NIH and our elected leaders accountable for changing the course of our illness. NIH's own report will lead it to commit more resources to ME/CFS research: NIH will have to increase funding if patients unite and make the most of this report. If we fight each other, little will change and NIH is off the hook. It is up to us to use their process to advance.

Thank You,