

**Public Comment**  
**CFSAC | December 2014**  
**Joseph D. Landson, sick for ten years**

To the committee:

Thank you for hearing me, if in fact you do.

We were asked to address the new Working Group topics of a Patient Registry and a Center of Excellence for ME/CFS.

I heartily approve of a Patient Registry. We already have several, and one more can't hurt. However, here are my questions: Will we use the research resulting from that registry to understand ME/CFS better, or will we throw that research away? I ask because the Pathways to Prevention (P2P) evidence review has thrown away a lot of promising work. Will the registry define an actual patient population, or will it use every broad and vague definition ever devised, as P2P also did?

In sum, the Patient Registry will only be helpful if it defines an actual patient population, and produces research reflecting that population, rather than reflecting some preconceived notion.

I approve of a Center of Excellence, too. This committee has already recommended such centers at least twice, so I hope the third or fourth time will be the charm.

Here are my questions: Will this Center of Excellence replace the existing Centers that currently dominate ME/CFS? In other words, will it replace the Centers of Ignorance, still using discredited psychosocial approaches to explain away the illness? Will it replace the Centers of Arrogance, still ignoring, belittling, and dismissing advocate concerns about the management of ME/CFS? Will it replace the Centers of Cynicism, still treating ME/CFS more as a public relations problem than as a biomedical one?

The Center of Excellence won't do much good, unless it replaces those other Centers.

This is Joe Landson, signing off from the Center of Disillusionment.