Public Comment

Anonymous

Dear CFSAC Members:

Thanks to all of you for your service on this committee to benefit ME/CFS patients. Special thanks to the FDA for the Drug Development Workshop held in April. It involved ME/CFS patients and advocates in a productive exchange of ideas. I am hopeful that other agencies will follow their fine example, especially CDC and NIH as they work to develop new case definitions. I would like to offer the recommendations I believe should be given highest priority.

1. **Hold a stakeholders' workshop to reach a consensus on case definition.** This should be done immediately. We need to achieve consensus on the appropriate case definition so that research, treatment development and patient care all take into account what has been learned since the 1994 Fukuda case definition.

2. **NIH should fund ME/CFS research commensurate with the magnitude of the problem, and issue an RFA specifically for ME/CFS.** CDC has estimated there are one million Americans affected by this debilitating illness. At present, NIH spends about $6 per patient on research. That is woefully inadequate given the suffering caused by ME/CFS and the billions of dollars it costs the economy.

3. **NIH should issue a $7-10 million RFA for outcomes measures, and biomarker discovery and validation.** We need to attract researchers. Fund it and they will come!

4. **Pool resources to create Centers of Excellence, using physical or virtual locations.** This would give patients easier access to ME/CFS experts and facilitate research.

5. **Remove the CDC Toolkit for healthcare providers from the CDC website.** It does not offer the best clinical practices and can even be harmful to patients. I hope that your High Priority list will include the recommendations that hold the greatest promise for accelerating research and alleviating patient suffering. Again, I thank you for your dedication and commitment to helping ME/CFS patients!