CURRENT ACTIVITIES OF THE TRANS-NIH ME/CFS WORKING GROUP

Chronic Fatigue Syndrome Advisory Committee (CFSAC)

Vicky Whittemore, PhD
Program Director
NINDS, NIH
**Trans-NIH ME/CFS Working Group Goals**

**Short Term Goals**
**FY16-FY17**

- Complete detailed portfolio analysis
- Develop inventory of available biospecimens and linked phenotypic data for use in research
- Coordinate with investigators involved in NIH intramural ME/CFS study
- Initiate collaboration with CDC Multi-Site ME/CFS Study
- Issue Notice soliciting Administrative Supplements
- Initiate Common Data Elements Project for ME/CFS
- Develop plan for communication with and engagement of ME/CFS stakeholders
- Issue Request for Information (RFI) to solicit input on areas of research priorities
- Release Funding Opportunity Announcements

**Intermediate Goals**
**FY17-FY18**

- NIH staff attend IACFS conference in 2016 and participate in grant workshop
- Work with FDA to develop clearly defined endpoints for treatment trials and interventions
- Assess clinical trial readiness and potential treatment and intervention trials for ME/CFS
- Leverage CDC health care provider educational materials
- Stimulate and support rigorous research on ME/CFS
- Increase number of training grant applications (F, K, T categories) submitted to NIH

**Long Term Goals**
**FY18-FY22**

- Support meritorious clinical trial applications for ME/CFS
- Continue to stimulate and support rigorous research on ME/CFS

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**NIH**
National Institute of Neurological Disorders and Stroke
Common Data Elements Project

- Develop content standards that enable clinical investigators to systematically collect, analyze, and share data across the research community.

The CDE Project is a resource to help clinical investigators employ standardized data collection techniques as they design and conduct new clinical studies and clinical trials. The use of CDEs in investigational research will help:

- Reduce the time and cost needed to develop data collection tools
- Promote standardized, consistent, and universal data collection
- Improve data quality
- Facilitate data sharing
- Improve opportunities for meta-analysis and comparison of results from different studies
COLLABORATION WITH CDC MULTI-SITE ME/CFS STUDY

- Capitalize on expertise of clinicians involved in CDC study
- Identify areas of collaboration between CDC and NIH efforts
  - Biospecimens
  - Database
  - Standardized measures
CREATE NEW KNOWLEDGE

- NIH Intramural ME/CFS Study
- Stimulate and support investigator-initiated research across NIH Institutes, Centers and Offices
- Issue Notice soliciting applications for Administrative Supplements to NIH-funded grants to expand and enhance research on ME/CFS
COMMUNICATION AND ENGAGEMENT PLAN FOR ME/CFS STAKEHOLDERS

- Issue Request for Information soliciting input on research priorities for ME/CFS
- Develop plan for communication with ME/CFS stakeholders
- Engage ME/CFS stakeholders in discussions about research priorities
FUNDING OPPORTUNITY ANNOUNCEMENTS

Coming soon!

Trans-NIH ME/CFS Working Group