

# 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

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National Institute of Neurological Disorders and Stroke

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**Steve Zullo, Ph.D.**  
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# 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

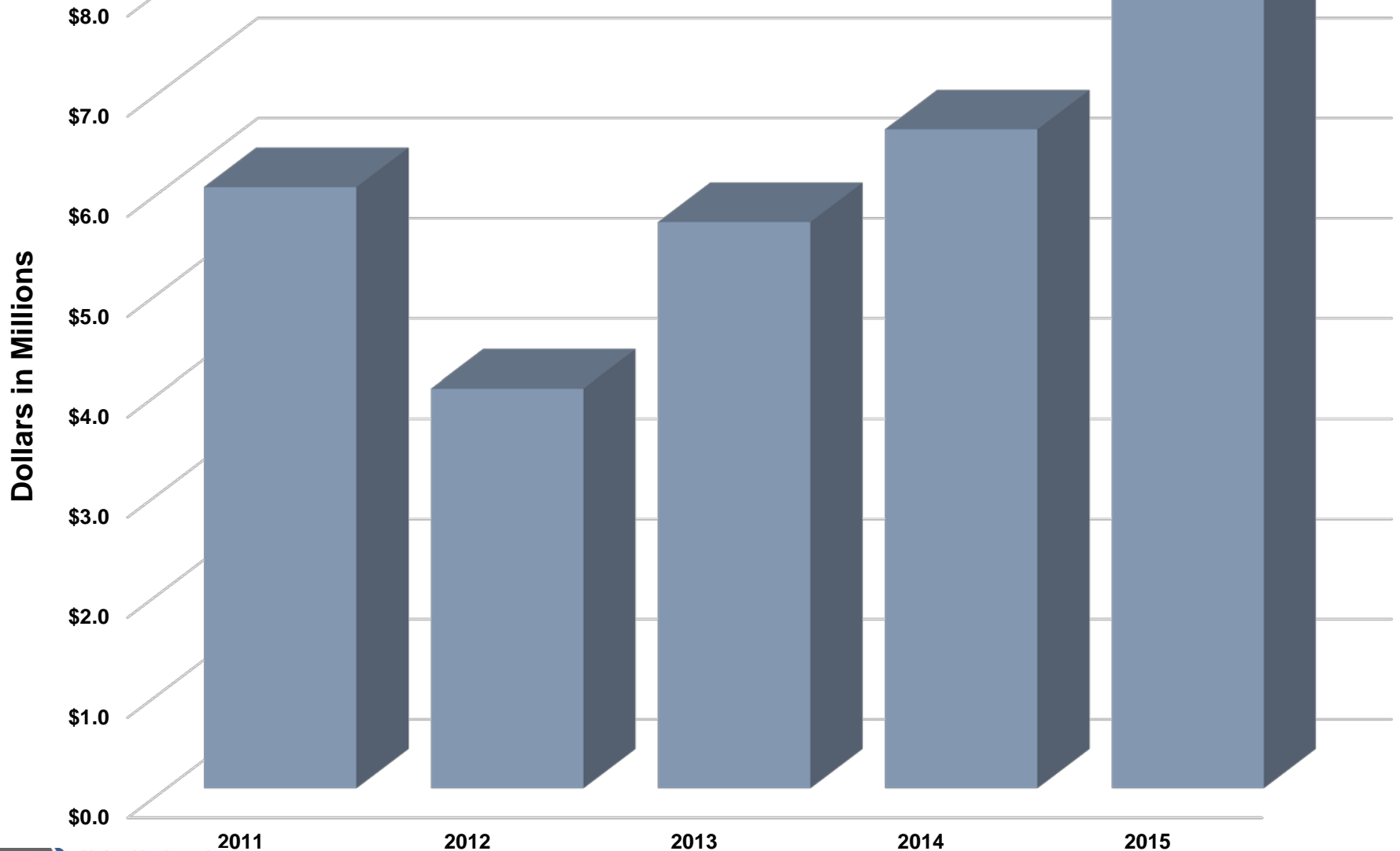
## Long Term Goals

FY18-FY22

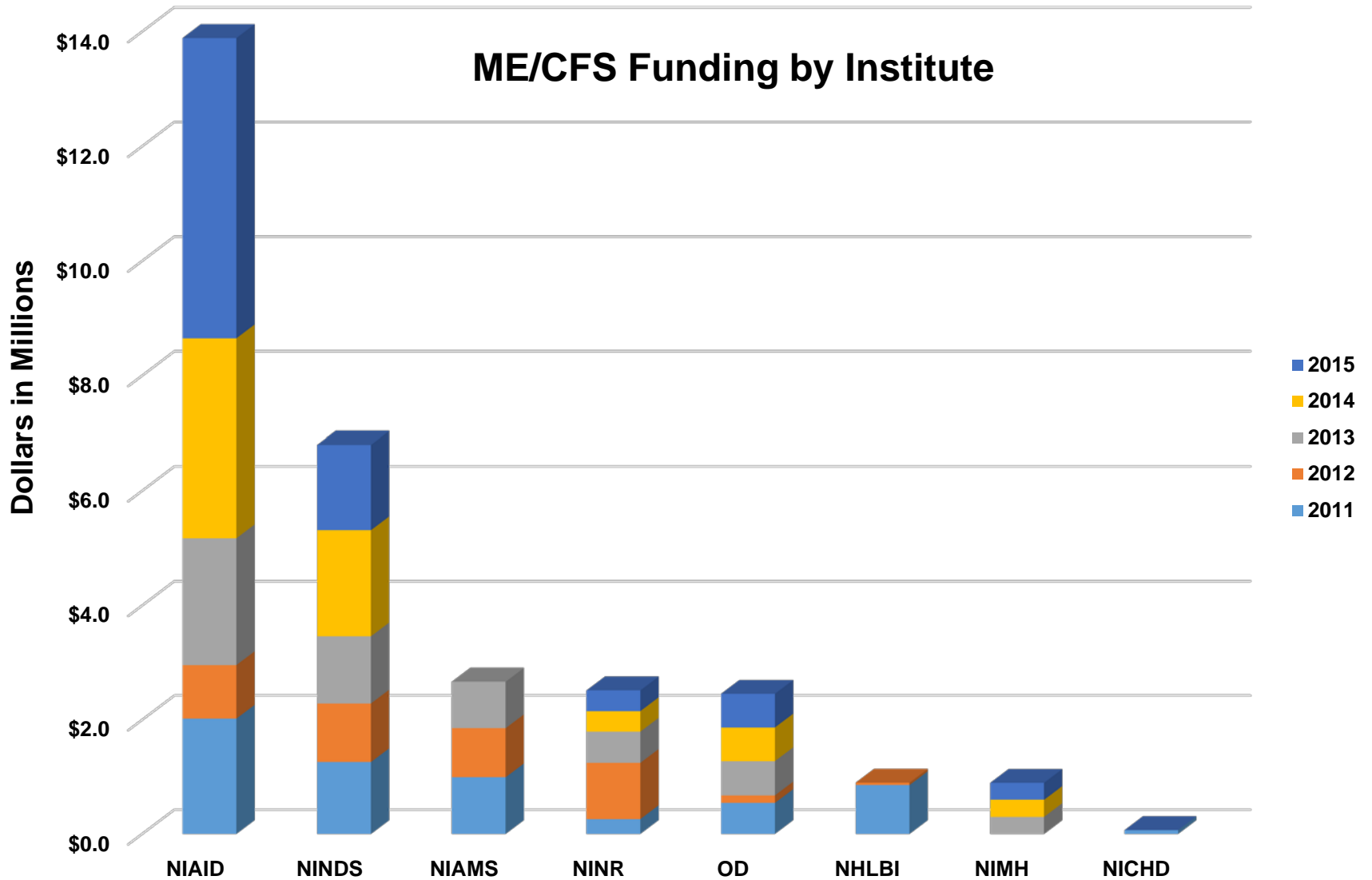
Support meritorious clinical trial applications for ME/CFS  
Continue to stimulate and support rigorous research on ME/CFS

# NIH Portfolio Analysis

## ME/CFS Research by Funding Year



# NIH Portfolio Analysis



# COMMON DATA ELEMENTS PROJECT

- 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!