## **CDC Report to the HHS CFS Advisory Committee**

June 29, 2017

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## **Progress Report on ME/CFS Webpages**

Summary of Roundtable Meeting posted (under Meetings & Workshops)

Summary of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) Roundtable Meeting on September 26, 2016
CDC held a roundtable meeting on September 26, 2016 with stakeholders composed of ME/CFS patients, advocates, clinicians with ME/CFS expertise, healthcare professional organizations, medical educators, researchers/foundations, and other government agencies. The goal of the face-to-face meeting was to provide an opportunity for individuals to share thoughts on how the Institute of Medicine (IOM) Report could best be communicated through materials and content on the CDC
website.
website. Roundtable Meeting Summary Report 🔂 [PDF -216MB]
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Roundtable Meeting Summary Report 🔂 [PDF -216MB]
Roundtable Meeting Summary Report 2 [PDF -216MB]         Appendix 1 - Participant List 2 [PDF - 27KB]

- Sections for general public ready for posting when CDC webpage format is changed
- Pages for Health Care Professionals in preparation

## **Stakeholder Engagement and Communication Call** (SEC)

- 9<sup>th</sup> call held Thursday, May 25, 2017 at 3:00 pm 4:00 pm EDT
  - Name changed from PCOCA to avoid confusion with other CDC calls, but same format
- Invited speaker Robert K. Naviaux, MD, PhD, University of California, San Diego School of Medicine
  - Metabolic Features of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)

## **Observance of May 12<sup>th</sup> ME/CFS Awareness Day**

- CDC Feature, developed jointly with NIH https://www.cdc.gov/Features/cfsawarenessday/index.html
- **Blog on Public Health Matters**

CDC Features Data & Statistics

### https://blogs.cdc.gov/publichealthmatters/2017/05/me-cfs/

### **CDC** Features

CDC > CDC Features > Diseases & Conditions

ME/Chronic Fatigue Syndrome Awareness Day

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### May 12 is ME/CFS and Fibromyalgia International Awareness Day Learn about myalgic encephalomyelitis/chronic fatigue syndrome.

Myalgic encephalomyelitis (ME) / chronic fatigue syndrome (CFS) is characterized by substantial disability that affects daily activities and is accompanied by profound fatigue that is not relieved by rest. While varying by person and affecting many body systems, symptoms include severe fatigue, unrefreshing sleep, problems thinking and concentrating, pain, and worsened memory. Post-exertional malaise (PEM), a distinguishing feature of the illness, is the worsening of symptoms after physical or mental activity.

Scientists have not determined the cause or causes of ME/CFS. Although second in upper ME/CEC affects people of all arms including



Public Health Matters Blog

# Posted on May 12, 2017 by Elizabeth R, Unger PhD, MD and Christine Robinette Curus, MD, MPH, FAAP f 🍸 🕂

about this page, enter your email address.

What's this?

u do if you were point along with your life, pot what seemed like a common. Bu-like illness, but never restained your health? couldn't go to work, care for your family, or even leave your bod for months - or even years - as a result? Perhaps worse - what if this happened to your child? Then imagine doctors saving there is no treatment or our even a known cause for the liness that is upending your life or your child's. Sadly, this is the reality for many people who have Musicir Enceptulormelitis/Charmic Excisue Surdrame (ME/CES)



# MCAM Methods Paper Selected as Editor's Choice (Open Access)



EDITOR'S CHOICE

Multi-Site Clinical Assessment of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (MCAM): Design and Implementation of a Prospective/Retrospective Rolling Cohort Study

Elizabeth R. Unger; Jin-Mann S. Lin; Hao Tian; Benjamin H. Natelson; Gudrun Lange ...

Abstract 
View article Supplementary data

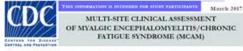
Am J Epidemiol (2017) 185 (8): 617-626. DOI: https://doi.org/10.1093/aje/kwx029

### **Presentations Since January 2017**

- 7th Invest in ME Research Biomedical Research for ME Colloquium, May 31–June 2, London, UK
  - "CDC Multisite Study and Future Plans"
- Federation of Clinical Immunology Societies (FOCIS) Symposium Insights into the Immunology of Chronic Fatigue Syndrome
  - Organized by Joseph Breen (NIAID) and Vicky Whittemore (NINDS)
  - "The Public Health Problem of ME/CFS"

### **Other Programmatic Activities Since January 2017**

- Continuation of Multi-site Clinical Assessment of ME/CFS (MCAM) Study
  - Third Newsletter prepared
  - NK cell testing initiated
  - Continuing follow-up
- Supplementing MCAM
  - Two new announcements FedBizOps
  - Populations under-recruited in current clinics
    - Pediatrics population
    - Ill comparison population



We base all current participants of the Wellohit Donard Assessment of Mongain Encentrationywiths (Donard Falgue S Syndrome MCMM study and network a anticipants to those with have intendity private the study. The collaboration string the the study results. Moncal Since Beh Issues (Brillion, Linitade for Yeway) remulties detailed that the Open Medicine Mollow (2001) concertaint: Open Medicines Class (2005), Sama Islanda Medicine (2006), Samana Intrine Oneter of Excellence (BHC), Harden-Hospina Classif (2006), Sama Islanda ISMA).

#### **Patients and Study Clinics**

The MCAM study has been conducted in multiple stages and includes 4 study protocols. Not all participants were excited in the same stage for all the protocols. Therefore, baseline data collections could come from any stage.

Potocol F1: This part is a linked epidemiologic study of adults including MU/CFS patients, healthy controls (HC), and patients with conditions similar to MU/CFS (such as Used desaise or Foromorphics). Participants were encoded if varying studys, and followed leans of encir with the monitomics: We see boothood in ordinate for the encoded MU/CFS patients to nonset the examine provide provide the second structure for the encoded with the second MU/CFS patients to nonset the examine provide provide the second structure for corrections. We content for the encoded with the seasoning responsible on orthin and 3000 for CFA and FAM structure for correction.

Protocol #2 in this protocol, we further focused on the clinical epidemiologic longitudinal study but added addresorerts and shifteen with ME/CPS.

Prictool SL Is this pert of the study, we conducted standardized optition and exempts tating on a student of those excelled in the first study protoco. The tetrage nucleuse a version even and and optitude test which you and potential exercise measure of diographic, tragger, pain, and general function. Blood tategies are objected during the exercise testing. Not all the obligation contributed to the eventse data solution.

Protocol #4: In the final part of the study, we assessed features Killer (NA) will function. The first phase for this part was a plot tant to examine the assess methods that could be used for balang NK cell function on many samples from mattple clines. The plot thering was completed in Developed (2013) and its NK cell function study is underward

For the first situate protocol, we completed about 90% of the baseline data codectores, 50% of the List follow-up and 40% of 2nd follow-up. For the third shadp protocol, we completed about 60% CI50 ML/OS and 60 ML/OF and 60 and 51% CI60 ML/OS and 60 M

### ME/CFS ROUNDINALE MEETING

### Same Outreach Phone Conference Call but a New Name Since we last updated you on the CDC PCOCA calls, there has

COMMUNICATION UPDATES FROM CDC

The summary report from the Roundtable Meeting will be posted on the CDC ME/CPS website (www.odc.gov.tho.

Visit CDC DFS Program at www.odc.gov/cfs

been a change in the name of the cast to ML-OTS Standorde Diggeneret and Communication (SEC). This change has taken place to proper am on to confused with workser cast group sponsored by CDC. Please including cast information on the CDC website.

(DC) is to be proceed of aparting its version to include momentations from the institute of Makona (DOI Report as well as new facibilities and resources for freethrouse provides. The MC (DS) vectors will have a new lock and will be assert for people to use, we transval it Rewritisher performs for the MC (DS) vectors will have a new lock and provide restricts on material for the new existing. The Rease took for the low existing to papers in the name.

## **Collaborative Activities**

- Active participation on CFSAC workgroups
  - Pediatric Education Working Group
  - Medical Education Working Group
- ME/CFS Common Data Element Project
  - Collaboration with NINDS
  - Co-funded by CDC and NINDS
- FDA Drug Development Tool Qualification Program
  - Sharing MCAM data to advance work for Qualification for Clinical Outcome Assessment (COA) DDT#080: ME/CFS/SEID

### **Progress on CFSAC Recommendations**

- Continuing dialogue with National Association of School Nurses and U.S.
   Department of Education (DOE)
  - Follow-up with Center for Parent Information and Resources (CPIR), recipient of a cooperative agreement from DOE
  - CPIR has drafted ME/CFS landing page in collaboration with CDC including links to
    - CDC ME/CFS website
    - DOE and CPIR resources about educational and health services for eligible students with ME/CES related impairments

## Thank you

For more information, contact CDC 1-800-CDC-INFO (232-4636) TTY: 1-888-232-6348 www.cdc.gov

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

