

CDC Report to the HHS CFS Advisory Committee

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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.

[Roundtable Meeting Summary Report](#)  [PDF - 216MB]

[Appendix 1 - Participant List](#)  [PDF - 27KB]

[Appendix 2 - Meeting Agenda](#)  [PDF - 91KB]

[Appendix 3 - Presentations](#)  [PDF - 1.4MB]

[Appendix 4 - Roundtable Meeting Discussion Handouts](#)  [PDF - 71KB]


- 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)

- 9th 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 12th ME/CFS Awareness Day

- CDC Feature, developed jointly with NIH
<https://www.cdc.gov/Features/cfsawarenessday/index.html>
- Blog on Public Health Matters
<https://blogs.cdc.gov/publichealthmatters/2017/05/me-cfs/>



CDC Features

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ME/Chronic Fatigue Syndrome Awareness Day

ME/Chronic Fatigue Syndrome Awareness Day

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 more research is needed, ME/CFS affects people of all ages, including

Public Health Matters Blog

America's Hidden Health Crisis: Hope for Those Who Suffer from ME/CFS

Posted on May 12, 2017 by Elizabeth R. Ungar PhD, MD and Christine Rubenstein-Cutts, MD, MPH, FAAP

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What's this?



What would you do if you were going along with your life, go what seemed like a common, flu-like illness, but never regained your health? What if you couldn't go to work, care for your family, or even leave your bed for months – or even years – as a result? Perhaps worse – what if this happened to your child? Then imagine doctors saying there is no treatment or cure, or even a known cause for the illness that is impacting your life or your child's. Sadly, this is the reality for many people who have Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS).

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

American Journal of
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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 ▼](#)

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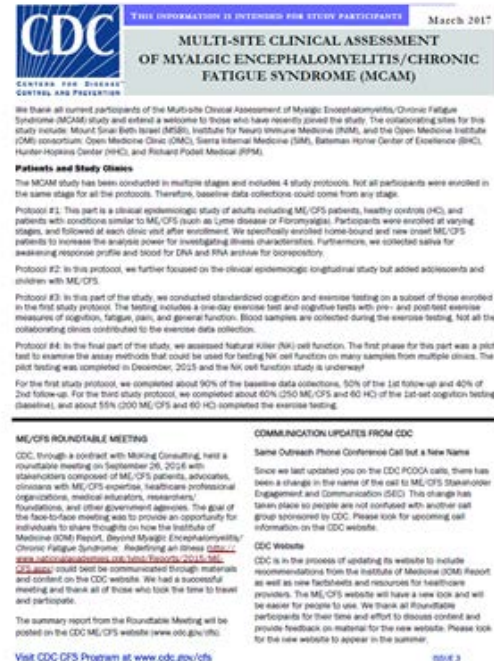
Am J Epidemiol (2017) 185 (8):617-626. DOI:<https://doi.org/10.1093/aje/kwx029>

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



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/CFS 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.

