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)
- 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](https://www.cdc.gov/Features/cfsawarenessday/index.html)

- Blog on Public Health Matters
  [https://blogs.cdc.gov/publichealthmatters/2017/05/me-cfs/](https://blogs.cdc.gov/publichealthmatters/2017/05/me-cfs/)
MCAM Methods Paper Selected as Editor’s Choice (Open Access)

American Journal of Epidemiology

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

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)

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.