



CDC Report to the HHS CFS Advisory Committee

January 12, 2017

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Publications and Presentations Since May 2016

■ Publications

- Multi-site clinical assessment of myalgic encephalomyelitis/chronic fatigue syndrome (MCAM): Design and implementation of a prospective/retrospective rolling cohort study. *Am J Epidemiol* (in press)
- CDC Grand Rounds: Chronic Fatigue Syndrome – Advancing Research and Clinic Education. *MMWR* 65:1434-1438, 2016 doi: 10.15585/mmwr.mm655051a4
 - Generated 7 e-mails to corresponding author, 2 from clinicians

■ Presentations

- IACFS/ME Biennial Conference
 - Workshop on multi-site study (7 presentations)
 - Panel member in Discussion Session - “Nothing about us without us”: How community-engaged research can accelerate progress in the field of ME/CFS
- Solve ME/CFS Webinar – Update on CDC’s Public Health Approach to ME/CFS
- Posters at 3 National meetings
 - Experimental Biology 2016, American Public Health Association Meeting, 2016 Joint Statistical Meetings

Other Programmatic Activities Since May 2016

- Roundtable meeting with ME/CFS Stakeholders – September 26, 2016
- ME/CFS Outreach and Communication Call – June 23, 2016
 - Invited speaker - Dr. Jarred Younger – “Current and future research on ME/CFS treatments: An update from the field”
- Continuation of Multi-site Clinical Assessment of ME/CFS (MCAM)
 - Contractor meeting held December 16, 2016; Vicky Whittemore attended
- Continued development of medical school educational initiative
 - First MedEd Portal module accepted
 - Assessment of ME/CFS (myalgic encephalomyelitis/chronic fatigue syndrome): a case study for health care providers. MedEdPORTAL Publications. 12:10527, 2016 doi.org/10.15766/mep_2374-8265.10527

CFSAC's Questions for CDC

“CDC is planning on disseminating updated medical education through a set of products that include:

- the standardized patient videos for medical schools
- an updated website
- the Grand Rounds
- Science Clips, and other products.

We request that CDC summarize its plan to develop, approve, and disseminate new medical education, to include a description of the planned products, the role of disease experts in not only the creation but also the review and approval of the final products prior to release, and CDC's plans to actively disseminate its medical education.”

CDC's Process for Development of Educational Materials – In General

- Needs assessment – stakeholders, including patients and health care professionals
- Content development– literature review, interviews with ME/CFS experts, patients
- Draft prepared – CDC personnel, including health communications experts
- Review and approval – Programmatic review and informal consultation
- CDC clearance through Office of Associate Director of Science

Note: During first stages extensive outside consultation occurs to assure content is reliable, valid and meets needs of stakeholders

Process for Standardized Patient Videos

Overview Published: *Transl Behav Med.* 2013 Dec;3(4):338-9. doi: 10.1007/s13142-013-0229-9

- Case studies from ME/CFS experts clinical records (anonymized)
 - Clinicians described an ME/CFS patient encounter, what worked, what did not work, or what facilitated assessment or positive interaction
- Focus group feedback from ME/CFS patients on their experience with the illness and with healthcare providers
- Vignette of scenario and script development
 - Incorporated health behavior theory and concepts for effective health communication
- Videos – filmed at Center for Advancing Professional Excellence (CAPE), University of Colorado Denver
- Educational curriculum
 - Developed by CDC based on published literature; incorporated qualitative input from medical student review
- CDC Clearance and CAPE pilot testing for efficacy (medical, nursing and PA students)
- MedEd Portal peer review

Process for ME/CFS Web Content –

Incorporating IOM Report Recommendations and Needs Assessment

- Process for broad stakeholder collaboration to assure IOM case definition is understood and disseminated and determine priorities for other educational materials
- Small group discussion calls to prioritize topics for Roundtable meeting
- Roundtable meeting – September 2016 – 55 individuals
 - Patients/advocates, ME/CFS clinicians, IOM committee, medical professional organizations, educational groups, research/foundations, government
- Meeting Summary prepared for posting on CDC webpage
 - Circulated for comments to participants – Nov. 14 – Dec. 12, 2016

Projected Timeline

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|---------------|--|
| January 2017 | Incorporate feedback into meeting summary
Layout/outline for web content |
| February 2017 | Post final summary of Roundtable meeting
Drafting content for web page – major changes in case definition; detailed consideration of treatment/management will occur later, but roundtable comments relating to GET and CBT will be addressed |
| March 2017 | Internal CDC review (including health communications experts) and outside informal sharing of content |
| April 2017 | Submission for full CDC clearance |

Date for final publication on web depends on extent of revisions required during clearance