National Center for Emerging and Zoonotic Infectious Diseases

CDC Report to the HHS CFS Advisory Committee

Ermias Belay, MD

Associate Director for Epidemiologic Science

Division of High-Consequence Pathogens and Pathology

ex officio Member CFSAC

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Progress Report on ME/CFS Webpages

- Sections for general public were updated May 2018
  - Reflect input from advocacy community
- Voice of the Patient section initiated May 2018
  - Features stories of patients living with ME/CFS; will be expanded
- Section for Healthcare Professionals is in production phase
  - Expected launch by June 2018 CFSAC meeting

Stakeholder Engagement & Communication Call (SEC)

- 11th call Thursday, May 10, 2018 at 3:00 pm - 4:00 pm EDT
- Invited speaker – Faith Newton, PhD (Professor of Education, Delaware State University)
  - ME/CFS: The Invisible Disease and its Educational Implications for Young People
- First SEC using webinar format as an option
- Transcript, audio file and slides will be posted on CDC ME/CFS web page:

Behavioral Risk Factor Surveillance System (BRFSS)

- ME/CFS included as state-added questions by 5 states in 2014, continued by 3 states in 2016
- Proposal to add ME/CFS module presented to BRFSS conference April 2018
  - ME/CFS module (3 questions) accepted as new optional module for 2019 survey
  - Advocacy support helped [Call-to-Action: Urge your State Health Department to Track ME!"]
- Preliminary results of the BRFSS 2014/2016 data will be presented at the 2018 Council of State and Territorial Epidemiologists conference (June 2018, Florida)

Additional Plans for ME/CFS Surveillance

- Active National Surveillance in Schools – planned start fall 2018
  - Procurement opportunity to be posted on FedBizOpps.gov website
  - Activities include collecting data on conditions causing chronic school absenteeism and educating school nurses about ME/CFS
- Descriptive Study of Patients with ME/CFS in an Integrated Health System
  - Proposals requested from 8 eligible Vaccine Safety Datalink (VSD) project sites
  - Funds available for one site, pending application and evaluation
  - Specified activities, using data from 2006–2017, include developing an electronic case definition* to identify ME/CFS in 9-39 year olds

*Consistent with the 2015 Institute of Medicine diagnostic criteria

Collaborative Activities

- Continued active participation on CFSAC workgroups
  - Pediatric Education, Medical Education and Clinical Trials Working Groups
- Finalized Research Collaboration Agreement with American Institutes for Research to use MCAM data
  - FDA Drug Development Tool Qualification Program
- Developed ME/CFS Landing page on the Center for Parent Information and Resources (CIPR) website
  - Highlighting resources for parents and schools
  - Collaboration with CIPR and Department of Education

Healthcare Provider Education

- Medscape Spotlight CME
- Video of 4 physicians addressing how to diagnose ME/CFS
  - **Dr. Lucinda Bateman** (Bateman Horne Center, UT); **Dr. Natalie Azar** (NYU Langone Medical Center, NY); **Dr. Nancy Klimas** (Nova Southeastern University, FL); **Dr. Jose Montoya** (Stanford University, CA)
  - Taping late summer 2018, launch planned November 2018
- Medscape will conduct evaluation of program

Additional Plans for Education

- Roundtable 2018 – Stakeholder engagement about educational needs for healthcare providers and information patients what their providers to know
  - Small group phone calls
  - In-person meeting late summer/early fall in Atlanta
- Educational services for healthcare providers serving pediatric population
  - Planned contract for services with a chapter of the American Academy of Pediatrics
  - CME event, webinars, articles in chapter newsletter about ME/CFS

December 2017 CFSAC Recommendations

Update on those directed to CDC

CFSAC recognizes that treatment of patients with ME/CFS needs to be personalized, and that ME/CFS treatment is in evolution. Given the urgency of the unmet healthcare needs of patients with ME/CFS, CFSAC recommends the dissemination by the HHS of the treatment recommendations in the 2014 IACFS/ME Adult Primer and in the 2017 ME/CFS Pediatric Primer.

- CDC has included links to the 2014 IACFS/ME Adult Primer and the 2017 ME/CFS Primer under “Resources for Healthcare Providers”

CFSAC also recommends that the CDC continue to move forward with the June 2017 CFSAC recommendation to create a plan for developing clinical practice guidelines for ME/CFS. These treatment guidelines need to fulfill evidence-based standards, such as GRADE, as applicable, and/or IOM’s standards for developing trustworthy clinical practice guidelines, and need to be developed in a collaborative and transparent manner.

- CDC supports the need for guidelines and will continue to update CFSAC on progress and plans.

Since it is crucial that the terminology, diagnosis and treatment recommendations for ME/CFS be consistent across all federal agencies, CFSAC recommends that all outdated federal websites or outdated material provided by federal agencies be removed or updated as quickly as possible and by no later than the end of 2018.

- English and Spanish copies of the ME/CFS brochure and Toolkit had been removed from CDC’s website but were still accessible through archives maintained in CDC Stacks. These have now been removed from CDC Stacks as well.

CFSAC further recommends that the materials provided by HHS, the VA and the DoD are to be regularly reviewed and updated as warranted by the research and consensus expert opinion.

- The CDC Website will undergo annual review to assure information is current.

Given the shortage of qualified healthcare providers with expertise in the treatment of ME/CFS, CFSAC recommends that the agencies within the HHS:

- Provide funding for CME/CE training conferences/programs on ME/CFS led by experts for MD, DO, NP, PA, Nurses, Social Workers, Psychologists, Psychiatrists

- CDC is working with MedScape to provide a Spotlight CE activity for healthcare workers. Other educational activities are planned focusing on nurses and pediatricians.

Given the shortage of qualified healthcare providers with expertise in the treatment of ME/CFS, CFSAC recommends that the agencies within the HHS:

- Continue school health and pediatric ME/CFS educational initiatives as recommended in January 12-13, 2017 in person CFSAC meeting

- In collaboration with CDC and Dept. of Education, the Center for Parent Information and Resources (CIPR) website now has landing page highlighting resources for parents and schools who are supporting students with ME/CFS. http://www.parentcenterhub.org/me-cfs/

Given the shortage of qualified healthcare providers with expertise in the treatment of ME/CFS, CFSAC recommends that the agencies within the HHS:

- Continue outreach to professional medical societies, internet medical provider information websites (e.g. UpToDate), and internet “public” medical websites (e.g. Mayo Clinic, Healthwise) to inform them of new information on the CDC and other federal agency websites

- CDC invited representatives of these groups to participate in the next Roundtable process addressing medical educational materials

CFSAC recommends that all materials published or distributed by HHS take special care to address negative provider attitudes and disease stigma, such as by:

Using a standard description of the biological, multisystem nature of the disease, relying on the IOM report (2015), IACFS/ME Adult Primer(2014) and the ME/CF Pediatric Primer (2017) and Stating explicitly that individuals with ME/CFS are suffering with a chronic disabling biological illness and are neither malingering nor seeking secondary gain.

- CDC web pages use a standard description of ME/CFS relying on the 2015 IOM report and emphasize ME/CFS is biologic illness.

Thank you

https://www.cdc.gov/me-cfs

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