

# Executive Summary and Recommendations for the Dissemination of ME/CFS Medical Education

CFSAC Medical Education Working Group

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Kaplan Clinic Chronic Fatigue Syndrome Advisory Committee

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Washington, DC

## **Committee Members**

- Dr. Gary Kaplan (Chair)
- Dr. Theodore Ganiats (AHRQ)
- Charmian Proskauer (CFIDS/ME & FM)
- Dr. Elizabeth Unger (CDC/CVDB)
- Dr. Robin Curtis (CDC)
- Terri Wilder (Community)
- Donna Pearson (CFSAC member)
- Mary Dimmock (Community)
- Dr. Drew Helmer (VA/WRIISC)
- Emily Taylor (SolveME)

## Background

Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS) is a debilitating disease that affects between 836,000 and 2.5 million Americans leaving them severely impaired for decades<sup>1</sup>. The economic cost of the disease is approximately 17-24 billion dollars in direct and indirect costs<sup>2</sup>. Despite a patient population larger than those with Multiple Sclerosis, ME/CFS remains among the least funded and researched illnesses. The National Institutes of Health (NIH) Pathways to Prevention (P2P) workshop<sup>3</sup> in 2014 as well as the Institute of Medicine (IOM) Report<sup>4</sup> in 2015 made valuable contributions by acknowledging the existence of ME/CFS as a distinct medical disease, as well as clarifying diagnostic criteria. Research since the IOM and P2P conference has further elucidated potential biological markers for diagnosing the illness. With better insight into the biology of this disease, new treatment strategies are being proposed. Studies are ongoing with regards to appropriate treatment protocols. Despite these advances there remains a significant problem with the medical profession's ignorance and stigma regarding this disease. There is a significant shortage of healthcare professionals who have the expertise in diagnosing and managing ME/CFS. The IOM report (2015) stated that fewer than one-third of medical school curricula and less than half of medical textbooks include information about ME/CFS. The IOM also noted that patients reported "being subject to hostile attitudes from their healthcare providers" and concluded that the biggest barrier to dissemination is not lack of knowledge but negative attitudes, which must be addressed for successful dissemination. As a consequence of the

lack of knowledge and the medical stigma, the ME/CFS community is severely underserved by the medical community.

At the January 2017 in-person meeting<sup>5</sup>, the Chronic Fatigue Syndrome Advisory Committee (CFSAC) established a medical education working group. This working group was charged with formulating a series of recommendations to the Secretary of Health on how to improve education for healthcare providers on ME/CFS.

### **Mission of the Medical Education Working Group**

The working group defined the following objectives to meet this goal:

- Provide a wide array of extensive and easily accessible ME/CFS education trainings, resources, and tools to healthcare providers (MD, DO, NP, RN, PA, Social Workers, Psychologists and Psychiatrists)
- Disseminate clinical guidance, best practices
- Identify potential mechanisms to expand the base of healthcare providers able to diagnose and care for persons with ME/CFS
- Include continuing education options to incentivize participation and specialist support for healthcare providers inexperienced in the field

One of the major challenges identified by the working group is continued misunderstanding and far-reaching controversy regarding published and researched treatment protocols for ME/CFS. If we are to disseminate information, we must have agreement on what information is most appropriate to make available to clinicians. At this time, given the controversies in the field, the working group has concluded that the best source of treatment guidelines for ME/CFS is expert opinion of

clinicians with long experience in treating patients with ME/CFS. To address this challenge we are proposing that CFSAC adopt the following recommendations:

**1. Content of Educational Material**

**1a.** 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<sup>6</sup> and in the 2017 ME/CFS Pediatric Primer<sup>7</sup>

**1b.** 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 use by primary care clinicians

**1c.** These treatment guidelines need to fulfill evidence-based standards, such as GRADE (Grades of Recommendation, Assessment, Development and Evaluation), as applicable, and/or IOM's standards for developing trustworthy clinical practice guidelines, and need to be developed in a collaborative and transparent manner

**2. Dissemination Strategies**

**2a.** CFSAC recommends that all educational materials disseminated by the HHS, VA and DoD for healthcare providers and for the general public be

informed by the findings of the IOM, the IACFS/ME 2014 Adult Primer and 2017 ME/CFS Pediatric Primer

**2b.** 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. One example:

- The content provided by the CDC for the MedEd Portal needs to be updated to align with these standards

**2c.** 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

**2d.** Given the shortage of qualified healthcare providers with expertise in the treatment of ME/CFS, CFSAC recommends that the agencies within HHS:

- Provide sufficient funding for ME/CFS Project ECHO<sup>8</sup> (Extension for Community Health Outcomes) programs
- Provide funding for CME/CE training conferences/ programs on ME/CFS led by experts for MD, DO, NP, PA, Nurses, Social Workers, Psychologists, Psychiatrists

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

### **3. Facilitation of Educational Efforts within HHS**

**3a.** 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 and the ME/CFS Pediatric Primer (2017)
- Stating explicitly that individuals with ME/CFS are neither malingering nor seeking secondary gain but suffering with a chronic disabling biological illness

### **4. Further Recommendations**

**4a.** CFSAC recommends that AHRQ work with the authors of the 2016 Addendum to the 2014 ME/CFS AHRQ Evidence Review to get notice of the addendum published in the Annals of Internal Medicine in June 2015, which contains the original article <sup>9,10</sup>

**4b.** CFSAC endorses the IACFS/ME proposal for changes to the ICD-10-CM coding for ME/CFS (Appendix2)

**4c.** CFSAC recommends that Federal Agency coordination be enhanced by:

- Creating an overall inter-agency plan to act on these recommendations
- Convening monthly inter-agency conference call to report and discuss progress on the plan
- Providing targeted agency updates on activities related to the plan at CFSAC meetings for at least the next two years

**4d.** It is the recommendation of the medical education working group that CFSAC creates a standing committee to maintain a list of all ideas relating to medical education (including the recommendations for federal agencies above, but also ideas for private or state-level activities) and review the list and action items at each CFSAC meeting for at least the next years (Appendix1).

### References

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2- Jason, L. A., Benton, M. C., Valentine, L., Johnson, A., & Torres-Harding, S. (2008). The economic impact of ME/CFS: individual and societal costs. *Dynamic Medicine*, 7(1), 6.

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3- Green, C. R., Cowan, P., Elk, R., O'neil, K. M., & Rasmussen, A. L. (2015). National Institutes of Health Pathways to Prevention Workshop: Advancing the Research on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Pathways to Prevention Workshop. *Annals of internal medicine*, 162(12), 860-865.

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4- Institute of Medicine. Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness. Washington, DC: National Academies Press; 2015.

5- January 12-13,2017, CFSAC recommendations.

<https://www.hhs.gov/ash/advisorycommittees/cfsac/recommendations/2017-01-12/index.html>

6- ME/CFS: A Primer for Clinical Practitioners, Fred Friedberg, et al., International Association for Chronic Fatigue Syndrome/Myalgic Encephalomyelitis, 2014

<http://www.iacfsme.org/portals/0/pdf/primerfinal3.pdf>

7- Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Diagnosis and Management in Young People: A Primer, P.C. Rowe et al., Front. Pediatr., 19 June 2017, <http://journal.frontiersin.org/article/10.3389/fped.2017.00121/full>

8- Project ECHO. <https://echo.unm.edu/>

9- The 2016 Addendum evaluated CBT and GET after excluding Oxford studies and downgraded its recommendations for CBT and GET. U.S. Agency for Healthcare Quality and Research. “Diagnosis and Treatment of Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome.” Evidence Report/Technology Assessment Number 219. U.S. Agency for Healthcare Quality and Research. December 9, 2014. Updated July 28, 2016. AHRQ Pub. No. 15-E001-EF [https://www.ncbi.nlm.nih.gov/books/NBK293931/pdf/Bookshelf\\_NBK293931.pdf](https://www.ncbi.nlm.nih.gov/books/NBK293931/pdf/Bookshelf_NBK293931.pdf)

10. The 2015 Annals article on treatments - pre-Addendum, recommends CBT (referred to as counseling) and GET. Smith ME, Haney E, McDonagh M, Pappas M, et.al. Treatment of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: A Systematic Review for a National Institutes of Health Pathways to Prevention Workshop. Ann Intern Med. 2015 Jun 16;162(12):841-50. doi: 10.7326/M15-0114. PMID: 26075755. <http://annals.org/aim/fullarticle/2322801/treatment-myalgic-encephalomyelitis-chronic-fatigue-syndrome-systematic-review-national-institutes>

## Appendices

**Appendix 1.** Idea grid for Tracking Dissemination Actions

**Appendix 2.** ICD-10-CM Proposal for ME/CFS

