

# RESPONSES TO RECOMMENDATIONS FROM THE CHRONIC FATIGUE SYNDROME ADVISORY COMMITTEE

REF: March 11, 2014 CFSAC Meeting via Webinar

**Recommendation 1:** The Chronic Fatigue Syndrome Advisory Committee (CFSAC) recommends that the Secretary fund ME/CFS commensurate with the epidemiologic prevalence and economic burden that this disease imposes on American society.

**Background and Response:** *Agencies have the responsibility for determining funding for all diseases and conditions, unless directed by Congress. While the National Institutes of Health (NIH) and Centers for Disease Control and Prevention (CDC) spend a portion of their annual budgets on ME/CFS each year, agencies like the Centers for Medicare and Medicaid Services (CMS) and Health Resources and Services Administration (HRSA) support families with ME/CFS through their respective health coverage programs and clinics. Also, the Food and Drug Administration works with the pharmaceutical industry to facilitate drug development.*

**Recommendation 2:** CFSAC recommends that HHS provide opportunities for dissemination of information through the development of a curriculum at all U.S.-based medical schools providing the tools needed for physicians and other medical professionals to recognize ME/CFS as defined solely by the 2003 Canadian Consensus Criteria (CCC) and to make appropriate referrals.

**Background and Response:** *HRSA supports curricula development when it is within the Agency's legislative authority. HRSA has and will continue to disseminate information developed by sister HHS agencies (e.g., CDC, NIH, etc.) about ME/CFS to HRSA grantees and partners, reaching thousands of health practitioners, educational institutions, and health professional organizations.*

*Comment by the Social Security Administration (SSA): SSA published updated criteria in Social Security Ruling 14-1p for how we develop evidence to establish that a person has a medically determinable impairment of ME/CFS and how we evaluate the impairment in disability claims and continuing disability reviews under titles II and XVI the Social Security Act. SSR 14-1p, with these criteria, is available to the public, including medical schools and physicians.*

**Recommendation 3:** CFSAC recommends that funding be allotted to the appropriate agencies that can best develop teaching modules featuring ME/CFS patients with complex presentations as defined by the 2003 CCC.

**Background and Response:** *HRSA has and will continue to disseminate information developed by sister HHS agencies (e.g., CDC, NIH, etc.) about ME/CFS to HRSA grantees and partners, reaching thousands of health practitioners, educational institutions, and health professional organizations.*

*SSA's Comment: SSA is in the process of developing Policy-in-Practice training through Video-On-Demand for its medical consultants on evaluating ME/CFS claims. The training focuses mainly on our SSR 14-1p for evaluating these claims by presenting case studies and discussions of actual ME/CFS claimants.*

**Recommendation 4:** CFSAC recommends that HHS provide funding through HRSA and other agencies to support integrative medicine programs featuring learning about ME/CFS patients as defined by the 2003 CCC.

**Background and Response:** *In September, 2012 HRSA funded the American College of Preventive Medicine which established IMPriME - the National Coordinating Center for Integrative Medicine. The purpose of IMPriME is to create a sustainable, preventive medicine-specific infrastructure to provide technical support for Preventive Medicine residency and other health professions training programs interested in incorporating evidence-based integrative medicine content into their programs. The IMPriME website (<http://www.imprime.org>) provides information on funding opportunities, curricula, and other resources related to integrative medicine. In addition to funding the National Coordinating Center, HRSA funded 12 Preventive Medicine residency programs to incorporate integrative medicine curriculum into their training programs.*

*In September 2014 HRSA funded the Arizona Center for Integrative Medicine to establish a Center for Integrative Medicine in Primary Care (CIMPC). The purpose of the CIMPC is to incorporate evidence-based integrative medicine (IM) curricula into existing primary care residency and other health professions training programs. The CIMPC is expected to contribute to the evidence-base for IM, and identify and disseminate promising practices related to the integration of IM into primary care.*

**Recommendation 5:** CFSAC recommends that HHS fund through appropriate agencies novel programs such as “Project Echo” comprised of experts and/or multidisciplinary teams with expertise in ME/CFS that reach areas where patients do not have access to adequate clinical care for ME/CFS as defined by the 2003 CCC.

**Background and Response:** *HRSA’s mission is to improve health and achieve health equity through access to quality services, a skilled health workforce and innovative programs. HRSA’s programs provide health care to people who are geographically isolated, and economically or medically vulnerable. HRSA also supports the training of health professionals, the distribution of providers to areas where they are needed most, and improvements in health care delivery.*

*For example, HRSA’s health center program funds new access points for primary care in areas of greatest need. HRSA’s National Health Service Corps program places providers in communities that demonstrate a shortage of primary care clinicians, and the Federal Office of Rural Health Policy – housed at HRSA - supports a number of programs and initiatives to address access to quality health care services in rural communities including telehealth. Furthermore, HRSA supports interdisciplinary approaches to improve the health of populations and funds the National Center for Interprofessional Practice and Education which leads, coordinates, and studies the advancement of collaborative, team-based health professions education and patient care as an efficient model for improving quality, outcomes, and cost. The center, housed at the University of Minnesota, is a public-private partnership created in October 2012 through a cooperative agreement with HRSA and four private foundations: the Josiah Macy Jr. Foundation, the Robert Wood Johnson Foundation, the Gordon and Betty Moore Foundation, and the John A. Hartford Foundation. For more information, please visit <https://nexusipe.org/>.*

**Recommendation 6:** CFSAC recommends that HHS provide funding to gather requisite data (prevalence rate/provider attitudes and knowledge, etc.) regarding ME/CFS patients as defined by the 2003 CCC through established primary care associations such as the American Academy of Pediatrics; the American Academy of Family Practice; the American College of Physicians; the American Board of Family Practice; and the American College of Obstetrics and Gynecology.

**Background and Response:** *HRSA currently partners with many primary care and public health organizations on a variety of primary care and public health issues to improve health and achieve health equity through access to quality services, a skilled health workforce, and innovative programs. Data collection is a part of our quality focus and grantees are required to report on various elements related to their specific grant.*

**Recommendation 7:** CFSAC recommends that HHS support CFSAC's efforts to continue to amend CDC website information as has been discussed previously.

**Background and Response:** *The CDC web page is designed for a broad audience and complies with regulations for accessibility and plain language. The section on pediatric CFS has been added recently. Further updates of the web page will await the report of the IOM committee.*