



December 9-10, 2014

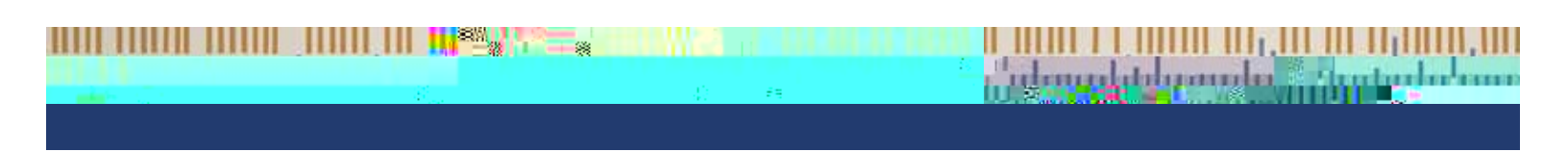
Sponsored by:

Trans-NIH ME/CFS Research Working Group
Office for Research on Women's Health (ORWH)
Office of Disease Prevention (ODP) National Institutes of Health (NIH)

Summary

On December 9–10, 2014, the National Institutes of Health (NIH) held

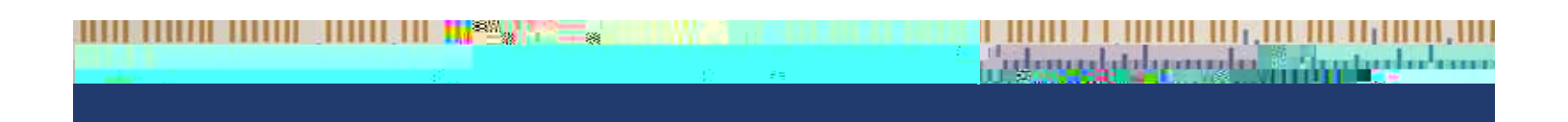
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agencies, patient advocacy groups, and patients and their families, have a shared responsibility for meeting the needs described herein, and thereby improving the lives of people living with ME/CFS.

Background

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) is a chronic, complex, and multifaceted disease characterized by substantial reduction or impairment in the ability to engage in pre-illness levels of occupational, educational, social, or personal activities; post-exertional malaise; unrefreshing sleep; and at least one of the



limits generalizing the results of current studies. Some instruments used to evaluate ME/CFS are not validated, are inappropriate, and may be misleading. All of these issues contribute to inconclusive research results and a lack of definitive knowledge about incidence, prevalence and potential causes and treatments (Green et al., 2015).

Specific Research Focus Areas: The following research priorities were identified by the federal partners:

- Invest in bench-to-bedside research. Research that provides detailed analysis of multiple measures in large numbers of individuals with ME/CFS would help investigators to



Through a contract with the Center for Advanced Professional Education, the CDC developed a set of videos for the [MedEdPORTAL](#) focusing on the doctor-patient interaction and pediatric/adolescent ME/CFS. This resource could be expanded to include additional ME/CFS materials. It would be important also to develop educational materials for other health care providers including nurses, physician assistants, etc.

- Developing educational materials with broad stakeholder collaboration: Individuals with ME/CFS, advocates, medical professional and educational organizations, clinicians with expertise in ME/CFS, and government (HHS ex officio CESAC members) could work together to develop educational materials. One way to foster collaboration between academic centers and the federal government is to identify grants and funding opportunities for development of educational programs and materials for health care professionals and for individuals with ME/CFS and their caregivers.

Opportunities for Collaboration Among Federal Agencies, Resource Development, and Next Steps:

Developing ME/CFS educational materials offers several collaborative opportunities:

- Working together on educational materials would help promote communication among stakeholders and improve dissemination of educational materials to the health care provider community.

- Educational materials should incorporate the recommendations from the IOM ME/CFS report.
- Topic/delivery method needs for continuing medical education (CME) resources should be assessed as they relate to ME/CFS.
- Educational materials should communicate consistent messages and the federal partners should present accurate, evidence-based, and up-to-date information on ME/CFS.
- Stakeholders should partner on agency-developed CME courses and reach out to primary care providers to promote these resources. The optimal outreach strategy will need to be determined.
- The HHS Health Resources & Services Administration (HRSA) supports community health centers that seat sen agey cd

