

Centers for Disease Control and Prevention (CDC) Atlanta GA 30333

December 23, 2015

Ms. Mary Dimmock

Dear Ms. Dimmock:

Thank you for forwarding a letter on behalf of myalgic encephalomyelitis and chronic fatigue syndrome (ME/CFS) advocacy organizations to Dr. Richard Kronick of the Agency for Healthcare Research and Quality (AHRQ) and Dr. Thomas Frieden. We understand that AHRQ is responding to you separately. The Centers for Disease Control and Prevention (CDC) appreciates you sharing your and your partners' concerns regarding our agency's ME/CFS guidelines and the Pacing, Graded Activity, and Cognitive Behavior Therapy: a randomized Evaluation (PACE) trial. CDC is committed to advancing our understanding of ME/CFS using the best available science.

While concerns about the PACE trial have been raised, its findings in combination with the 2015 ME/CFS Institutes of Medicine (IOM) report and the National Institutes of Health Pathways to Prevention (P2P) meeting recommendations have provided significant new insights. However, more research on the nature of the illness, its causes, and subgroups is still needed. Because available data is limited, CDC remains focused on creating partnerships to better understand ME/CFS and on collaborating to develop better diagnostic tools and effective treatments. Currently, we are in the process of establishing a partnership with stakeholders from government agencies, the CFS Advisory Committee, medical professional societies, medical educational organizations, ME/CFS clinical experts, and ME/CFS advocates and patients. We will work with these partners to revise our website and to prepare new educational materials that incorporate the most recent information.

Thank you again for reaching out to share your and your partners' concerns about this important public health issue. We are hopeful that the momentum generated by the IOM report and P2P recommendations will help advance the current science around ME/CFS and lead to new developments. We look forward to working with you and your partners on our ME/CFS efforts going forward. If you have questions or further concerns, please contact Dr. Ermias Belay, Associate Director for Epidemiologic Science within CDC's Division of High-Consequence Pathogens and Pathology, at <a href="mailto:ebelay@cdc.gov">ebelay@cdc.gov</a> or 404-639-4655.

Sincerely,

Inger Damon, M.D., Ph.D.

Director, Division of High Consequence Pathogens and Pathology National Center for Emerging and Zoonotic Infectious Diseases

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