

Public Comment
CFSAC | December 2014
Eileen Holderman

Good afternoon. My name is Eileen Holderman - I am an advocate for ME, GWI, and other neuroimmune diseases. My public comment for CFSAC is a letter I wrote to Secretary Burwell expressing my strong opposition to HHS's initiatives to redefine ME/CFS - the IOM and P2P.

October 22, 2014

Dear Secretary Burwell:

I am writing to state my opposition to the Health and Human Services (HHS) initiatives - the Institute of Medicine (IOM) and the Pathways to Prevention (P2P) - to redefine Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS).

Nearly 1 million American men, women, and children, and over 17 million worldwide, suffer from the neuroimmune disease, ME/CFS.

I join multitudes of advocates, patients, caregivers, ME/CFS researchers and clinicians, and other stakeholders, in opposition to IOM and P2P. There are numerous reasons for my/our opposition to these initiatives to redefine this disease, many of which I list as follows:

*** We do not need more Government-sponsored clinical and/or research definitions for ME/CFS.** Our ME/CFS experts already developed a research and clinical definition called The Canadian Consensus Criteria (CCC). HHS has created numerous erroneous definitions (i.e. Fukuda, Reeve's Empirical, etc.), which include innumerable people in the patient population that do not really have ME/CFS - and this has terribly harmed patients with ME/CFS. HHS's IOM and P2P seek to, yet again, create more definitions for ME/CFS which will further harm patients.

*** We do not need HHS bureaucrats who are not ME/CFS experts to redefine this disease.** Fifty ME/CFS expert researchers and clinicians already reached a consensus on a research and clinical definition for ME/CFS - the CCC - which they have been using for 10 years and for which they have agreed to refine as necessary. The 50 ME/CFS experts sent former Secretary Sebelius a letter urging her to refrain from reaching out to groups such as IOM to redefine ME/CFS and urged HHS to adopt the CCC in all Government agencies. Again, IOM and P2P use mostly, and in some circumstances, entirely, non-ME/CFS experts - actions which will harm patients. Please click on the [link](#) to read the Experts' Letter to former Secretary Sebelius.

*** We do not need another Government-sponsored name for this disease.** In 1969, The World Health Organization (WHO) acknowledged and coded the name of the disease

- Myalgic Encephalomyelitis (ME) - which is the name used and endorsed by most nations, experts, and patients around the world. In 1988, HHS renamed the disease Chronic Fatigue Syndrome (CFS) knowing that a name already existed for the disease and knowing their new, unscientific name would harm patients. Again, HHS/IOM aims to create yet another name for this disease - possibly Chronic Multi-Symptom Illness (CMI) - the name IOM alluded to for ME/CFS in their earlier VA/IOM report - and a name that will further harm patients.

*** We do not need more Government waste of taxpayer dollars on corrupt initiatives to redefine a disease that has been correctly defined.** ME/CFS receives only \$5 million a year from NIH in research and causes billions annually in lost productivity due to high rates of disability from the disease. ME/CFS experts established research and treatment centers around the country through private and institutional funding that need Federal funding for their research - but don't receive it. Instead, IOM and particularly, P2P, ignore the ME/CFS experts' biomedical research in favor of non-experts' psychosocial research, resulting in treatment recommendations of CBT, GET, and anti-depressants, instead of recommendations of anti-virals, immune modulators, and other biomedical treatments. This tactic will save Government and insurance companies big money! As IOM and P2P bury 30 years of biomedical research and over 5000 peer-reviewed scientific publications on ME/CFS, HHS will save huge sums of money because they will not have to fund biomedical research or pay for long-term disability and other Government entitlements for patients with ME/CFS. And Government related health insurance companies will save massive sums when they deny ME/CFS patients the biomedical tests and treatments they need.

*** We do not need more Government misinformation about ME/CFS disseminated to health care workers, health insurance carriers, the public, and the press.** Our ME/CFS researchers and clinicians have published a case definition - the CCC, 2 Diagnostic and Treatment Primers, over 5000 scientific papers, video lectures, PowerPoints, books, and resource guides about the disease. National and State patient advocacy organizations have published materials online and in hard copy with reliable information for patients and their caregivers. Yet, IOM and P2P are charged with publishing their reports, which HHS will use to "educate" doctors, nurses, health insurance companies, the public, and the press. HHS's dissemination of the erroneous information from IOM and P2P will gravely harm patients.

My letter of opposition to HHS's IOM and P2P is part of the ongoing protest which includes:

CFS Advisory Committee (CFSAC) recommendation urging the use of the CCC, ME/CFS Experts' Letter calling for the CCC, Advocates' Letter calling for the CCC, petition signed by over 6000 stakeholders calling for the cancellation of the IOM Contract and calling for adoption of the CCC, Facebook, Twitter, Thunderclap, letter, email, and phone campaigns calling for the CCC and condemning IOM and P2P, meetings with Congressmen, protests and demonstrations, media coverage, collaborations with Gulf War Illness patients, Freedom of Information Act (FOIA) requests, and even a

lawsuit filed against HHS and NIH for non-compliance with an IOM FOIA, resulting in a Federal-Court finding of the Government's violation of Federal law.

My opposition to IOM and P2P is a complete rejection of these initiatives to redefine ME/CFS. HHS should not consider my letter of opposition as participation or buy-in - because it is not. This is a letter of opposition for the public record.

Thank you for your attention.

Eileen Holderman
ME Advocate
US citizen

cc: Francis Collins (NIH), Thomas Frieden (CDC)