Open Letter to Secretary Azar

The Honorable Alex Azar
Secretary U.S. Department of Health and Human Services
200 Independence Avenue S.W.
Washington, D.C. 20201

April 9, 2019

Dear Secretary Azar:

We are activists for the neuroimmune disease Myalgic Encephalomyelitis (ME), which strikes about one million American men, women and children and millions worldwide and we are requesting a meeting to discuss and resolve the vital issues of proper disease name, criteria, medical guidelines and education.

For decades, the U.S. Department of Health and Human Services (HHS) has enacted policies that have harmed patients with ME. Specifically, the Centers for Disease Control and Prevention (CDC) have created faulty definitions for the disease - systemic exertion intolerance disease (SEID) is the latest example - that have negatively impacted, and will continue to do so, diagnosis, treatment, research, education, media reports and public policy.

For the past year and a half, our Twitter initiative—#TeamTweetStorm—has advocated for numerous issues affecting the ME community, focusing on criteria and education. Our initiative has urged HHS and global health agencies to utilize our experts' definition, the International Consensus Criteria (ICC), and our experts’ primer, the International Consensus Primer (IC Primer), to ensure accurate diagnosis, treatment, research and education. We have also called for HHS to stop the implementation and dissemination of SEID. #TeamTweetStorm has galvanized a global coalition of advocates and influenced government health agencies and public policy around the world.

Additionally, #TeamTweetStorm inspired advocates to organize a petition demanding that HHS utilize the ICC and the name Myalgic Encephalomyelitis. Currently, the petition has gathered close to 6,000 signatures from clinicians, researchers, advocates, patients and caregivers.

We know HHS has met with organizations who purport to represent the ME community. However, those organizations do not represent ME as defined by our experts nor do they share our mission of implementing the ICC and IC Primer in all government research and education. Furthermore, those organizations, along with CDC, an agency with a history of creating harmful names and definitions, are promoting and disseminating the government-sponsored criteria, systemic exertion intolerance disease (SEID), yet deceptively are using the name Myalgic Encephalomyelitis.

We adamantly oppose CDC's campaign to implement, disseminate, promote and code SEID. In 2012, experts and advocates launched a massive protest that is still ongoing, against HHS's campaign to redefine and rename the disease. Despite the mass protest and the Advisory Committee's (CFSAC) recommendation to use our experts' definitions (CCC/ICC), HHS forged ahead and created a new name and definition, SEID. We oppose SEID for the following reasons:

- named and defined by our experts years before
- wasted one million dollars creating another non-expert name and definition
- diverted funds better used for biomedical, scientific research
- created new "disease" with efforts underway to create new "disease" code
- uses one symptom as the name of the disease
- acts as simple checklist for a complex disease
- focuses on one common symptom of fatigue
- lacks specific neuro-immune and cardio symptoms
- mandates a six-month wait before diagnosis
- omits important medical tests to aid in diagnosis
- allows primary psychiatric and other disorders into the cohort
- broadens patient population to include variety of unrelated conditions

For over three decades, patients with Myalgic Encephalomyelitis have suffered the consequences of HHS's policies of creating demeaning names, faulty definitions and harmful medical guidelines for the disease that have resulted in loss of: health, job, money, credit, education, home, healthcare, disability benefits, family, friends and life itself.

HHS must use proper name, criteria, medical guidelines and education and stop using SEID in all government programs. SEID was created to subsume and bury ME as indicated by the reasons shown and the very name of the report, *Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness*. If HHS persists in their harmful policies and their SEID campaign, the effects will be destructive to ME patients in America and around the world.

Therefore, we ask for equal access to our government's officials as you have given other organizations. Please reply via email and let us know when you will meet with representatives from #TeamTweetStorm to resolve the issues of using the ICC and IC Primer, instead of SEID, and so we may deliver our petition to you.

Sincerely,

Eileen Holderman
@TurnItUp4ME

Gabby Klein
@GabbyKlein1

Hardcopy sent via USPS