



Solve ME/CFS Initiative

Leading the Fight to cure ME/CFS

Solve ME/CFS Initiative Statement on President Trump's FY19 Budget Proposal

Negative implications for ME research and science, including ME funds at the CDC eliminated again.

February 15, 2018

This week, the Trump administration released its [fiscal year 2019 budget proposal](#). Ideally, this proposed budget would reinforce Congress' measured steps to support medical research as a national priority. Unfortunately, the proposed budget once again zeroes out funding for the Chronic Fatigue Syndrome program at the Centers for Disease Control and Prevention (CDC), cuts funding for key biomedical and scientific research agencies, eliminates healthcare research agencies, and proposes a substantial restructure of the National Institutes of Health. These changes, if implemented, would be devastating for ME/CFS research, ME/CFS clinical care and education efforts, and biomedical research more broadly.

Centers for Disease Control and Prevention (CDC)

The President's FY 19 budget, again, proposes the elimination of funding for the Chronic Fatigue Program housed within the National Center for Emerging and Zoonotic Infectious Diseases at the CDC. The elimination of this funding would shut down the Multi-Site Clinical Assessment of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (MCAM) and the fledgling medical education projects underway at the CDC. The budget also contains a proposed 12% cut to the Centers for Disease Control (CDC). Again, these projects are critical first steps for improving clinical care for an estimated 2.5 million Americans with ME/CFS. The loss of these programs could delay improvements in ME/CFS clinical care by decades.

National Institutes of Health (NIH)

The administration's proposed budget also freezes funding for the National Institutes of Health (NIH) while simultaneously adding three new institutes and agencies into the NIH. The proposal outlines a new structure for the NIH which would incorporate the National Institute of

Disability, Independent Living, and Rehabilitation Research (\$104m annually), National Institute for Occupational Safety and Health (\$350m annually), and the Agency for Healthcare Research and Quality (\$470m annually). We are extremely concerned that this new proposed structure adds substantial obligations to the NIH (\$924m annually), **but is accompanied by no additional funding.**

If these proposed changes took place, we anticipate the NIH would cease any new programs in ME/CFS research and could even eliminate the programs and initiatives already in place on account of the budget shortfalls. Those programs include: four recently funded NIH Collaborative Research Consortia, an Intramural study on ME/CFS at the NIH campus, and many other grants and supplemental awards currently underway. It would devastate the ME/CFS research space to lose these programs.

SMCI Fights Back

Fortunately, congressional leaders have stated their commitments to strengthen medical research and increase funding at the NIH. **SMCI will be actively educating and collaborating with members of Congress on behalf of people with ME/CFS** as the FY 2019 budget process unfolds. Our first trip to Washington DC is in March and our team will advocate for the restoration of Chronic Fatigue Syndrome funding at the CDC and, separately, including ME/CFS in medical research programs housed in the Department of Defense. We will also lead our second annual ME/CFS Advocacy Day on Tuesday May 15 to enable our community to directly share their story with members of Congress.

To learn more about the Solve ME/CFS Initiative's advocacy priorities, read our organization's [Policy Advocacy Statement](#).

About the Solve ME/CFS Initiative:

The Solve ME/CFS Initiative (SMCI) is a non-profit disease organization that works to accelerate the discovery of safe and effective treatments, strives for an aggressive expansion of funding for research that will lead to a cure and seeks to engage the entire ME/CFS community in research. Through scientific research and advocacy, SMCI serves patients and researchers alike, serving as an information center for the entire ME/CFS community, and enabling SMCI to make an even stronger case for federal government ME/CFS spending, by generating verifiable and large data sets with reliable metrics.

Our Vision: A World Free of ME/CFS.

Our Mission: Make ME/CFS understood, diagnosable, and treatable.