Director Collins’s Response to Congress Isn’t Good Enough

In a formal House of Representatives letter of support, 55 bipartisan members of Congress called upon National Institutes of Health (NIH) Director Francis Collins to take action on myalgic encephalomyelitis (ME), commonly known as chronic fatigue syndrome (CFS).

As the letter explains, “ME/CFS is a complex, debilitating, and chronic disease afflicting 1 to 2.5 million Americans. It costs individuals, the U.S. health care system, and our economy an estimated $17-$24 billion annually. Yet, as the Institute of Medicine noted in its report, ‘Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness,’ there has been ‘remarkably little research funding’ to date to discover its cause or possible treatments.”

The letter specifically encourages 1) the strengthening of NIH efforts in ME/CFS biomedical research, 2) a reinvigorated trans-NIH ME/CFS working group housed within the National Institute of Neurological Disorders and Stroke (NINDS), and 3) additional intramural and extramural research programs. The letter, which follows a similar call to action led by Congresswoman Lofgren in 2014, emphasizes these actions must be taken in a timely manner while reporting to congress about additional ME/CFS planning and research activities.

Breaking Down Director Collins’s Response

“The complexity of ME/CFS and the need for an inter-disciplinary approach to better understand and develop treatments for this disease necessitate a trans-NIH approach…the Trans-NIH ME/CFS Working Group…is a team effort among 23 Institutes, Centers and Offices.”

Fact Check: The Trans-NIH ME/CFS Working Group was established in 1999. In 17 years, the working group produced just one RFA, issued only one batch of administrative supplements, and hosted a mere four events.

SMCI’s Response: A multi-disciplinary approach is best for ME/CFS, but there must be clear responsibility and accountability for action, progress, and funding within the NIH.

“[T]he NIH has already funded seven supplements to existing awards focused on understanding the causes and mechanisms of ME/CFS.”

Fact Check: These awards were one-time supplements only available to existing NIH grant recipients and do not include continued or sustained funding for long-term investment.

SMCI’s Response: We applaud the NIH’s supplemental funding as a first step, but the total NIH financial commitment to ME/CFS continues to be insufficient to make progress against this disease.

“The NIH is preparing two Requests for Applications (RFAs) which will support ME/CFS collaborative research centers and a Data Management Coordinating Center. These RFAs will be released once they are finalized.”

Fact Check: On October 29, 2015, Director Collins announced that the NIH would reinvigorate ME/CFS research. Since Director Collins’s announcement, the NIH has issued 362 RFAs totaling just under $2.9 billion. The last RFA for ME/CFS was issued in 2005.

SMCI’s Response: The NIH recently announced additional details regarding two Funding Opportunity Announcements (FOAs) scheduled to be published in Dec. 2016. While a first step, these actions lack the critical urgency this extremely debilitating disease merits and fall short of the significant investment needed to secure a biomarker for, understand the pathology of, research the epidemiology of, and create regional centers of excellence for this disease.

Here’s What’s Missing:
- A plan to ramp up funding
- A Request for Applications (RFA) for biomarkers or key biological questions
- Recognition of, or a plan to address, barriers to clinical trials
- A plan to progress clinical trials on drugs currently being used off label by ME/CFS patients

Here Are Our Immediate Needs:
- Specific dollar amounts and a sustained commitment for RFAs and other research programs
- The status of the planning effort to create a coordinated NIH research strategy
- Specific activities planned for FY 2017 and 2018
- Specific timelines for the working group RFI responses, the public release of intramural study protocol, and continued reporting to congress and the ME/CFS community

Here’s How to Learn More:
- Contact Emily Taylor, SMCI advocacy and engagement manager, by email at ETaylor@SolveCFS.org or by phone at (704) 364-0016, ext. 209