August 8, 2017

The Honorable Paul D. Ryan
Speaker of the House
United States House of Representatives
Washington, DC 20515

The Honorable Nancy Pelosi
Minority Leader
United States House of Representatives
Washington DC 20515

The Honorable Rodney Frelinghuysen
Chair, Appropriations Committee
United States House of Representatives
Washington, DC 20515

The Honorable Nita Lowey
Ranking Member, Appropriations Committee
United States House of Representatives
Washington, DC 20515

The Honorable Tom Cole
Chair, Subcommittee on Labor-HHS-Education Appropriations Committee
United States House of Representatives
Washington, DC 20515

The Honorable Rosa DeLauro
Ranking Member, Subcommittee on Labor-HHS-Education Appropriations Committee
United States House of Representatives
Washington, DC 20515

Dear Speaker Ryan, Minority Leader Pelosi, Chairmen Cole and Frelinghuysen and Ranking Members DeLauro and Lowey:

I write you today on Understanding and Remembrance Day for Severe Myalgic Encephalomyelitis to urgently express the National Organization for Women’s support for the restoration of funding and continued investment in research and related programming for Myalgic Encephalomyelitis (ME), historically known as Chronic Fatigue Syndrome (CFS). Currently, the House Subcommittee on Labor-HHS-Education has zeroed out the only line item for ME/CFS research in the Fiscal Year 2018 budget, H.R. 3358. This cut in ME/CFS research and investment is especially disheartening considering last week’s breakthrough study from Dr. Jose Montoya of Stanford University which could pave the way for a definitive blood test for ME/CFS. Now is not the time to cut ME/CFS research programs.

The National Organization for Women (NOW) is the largest organization of feminist grassroots activists in the United States. NOW has hundreds of chapters and hundreds of thousands of members and supporters in all 50 states and the District of Columbia.

Based on information from ME/CFS patients and their supporters who are NOW members, our organization asks you to restore, strengthen, and accelerate federal efforts in ME/CFS biomedical research and clinical education now. Since the disease was first investigated by the CDC in the 1980s, federal agencies have failed to adequately conduct basic research or invest in the field to enable the necessary scientific understanding or clinical trials of ME/CFS. Furthermore, the extended lapse in the ME/CFS research landscape has allowed the disease to be stigmatized and misrepresented as psychological for many years. This lack of concern, lack of urgency, and improper allocation of resources has historically occurred in relation to diseases that primarily affect women, and it must end. We need to make up for lost time and take the appropriate strides to address the heavy burden of this horrible disease.

This incredibly debilitating disease destroys the quality of life and livelihood of up to an estimated 2.5 million people in the United States; more than HIV/AIDS and MS combined. ME/CFS costs the U.S. economy between $17 to $24 billion annually. However, as the Institute of Medicine (now the National
President Toni Van Pelt

Thank you for your attention to this critical issue. We look forward to your response.

Sincerely,

Toni Van Pelt
President
National Organization for Women

Academies) notes, there has been “remarkably little research funding” to date to discover its cause or possible treatments. If we were able to find a cure or effective treatment for ME/CFS, it would save the U.S. billions of dollars annually.

We are asking for:

1) The restoration of funding for the Chronic Fatigue Syndrome line item in the CDC’s Center for Emerging and Zoonotic Infectious Diseases, currently funding a CDC multi-site study, medical education initiatives, and investments in the field of ME/CFS biomedical research.
2) The inclusion of ME/CFS as an eligible program area for the Congressional Directed Medical Research Program’s Peer Reviewed Medical Research Program, and
3) Additional language in the FY 18 appropriations process providing guidance to the NIH to increase investment in ME/CFS biomedical research for ME/CFS.

A recent study published in the Journal of Medicine and Therapeutics estimated the World Health Organization (WHO) disability adjusted life years (DALY) measurement for ME/CFS and determined that, in comparison to other illnesses, NIH research funding for ME/CFS should be $188 million per year, over 25 times higher than the current $7 per patient per year that is currently being allocated by the NIH, who’s recent budget estimates anticipate a $2 million reduction in funding for ME/CFS in FY 18. This is a criminal underfunding of a disease affecting millions of your constituents and it must be rectified.

Additionally, ME/CFS is too prevalent (affecting up to 2.5 million Americans) to qualify for subsidies and government incentives offered to pharmaceutical companies for rare disease research. Yet, it is not prevalent enough to represent a large enough market share for private sector investment. ME/CFS research is “lost in the middle” and relies almost entirely on public funding for research investment.

We believe that the higher prevalence of ME/CFS in women is a contributing factor resulting in the stigmatization experienced by patients and the failure of research investment commensurate with the burden of the disease by federal agencies. As you are aware, there is a long, documented history of gender bias in medical research and ME/CFS is one of many diseases negatively affected by this trend. Terms like “mass hysteria,” "conversion disorder," and "Raggedy Ann syndrome" belittled patients and clearly undermined the seriousness of this terrible disease, where women are the vast majority of those who suffer.

We urge Congress to seize this opportunity to quickly advance diagnosis, treatment, and a cure for ME/CFS, by restoring and expanding funding in research and education programs at a level commensurate with other similarly burdensome diseases unaffected by stigma or gender bias. Doing so will spur research at a time when many scientists believe that major discoveries are imminent, as well as bring new investigators into the field.

Congress must take urgent and immediate action to reverse the damage of the past and provide renewed hope for millions suffering today.
cc:
Carol Head, President, Solve ME/CFS Initiative
Dr. Janine Clayton, Director, NIH Office of Research on Women’s Health
Dr. Walter Koroshetz, Director, National Institute of Neurological Disorders and Stroke
Dr. Vicky Whittemore, Program Director, Synapses, Channels, and Neural Circuits, National Institute of Neurological Disorders and Stroke
Dr. Avi Nath, Clinical Director, Neurosciences Program, National Institutes of Health
Dr. Elizabeth Unger, Chief, Chronic Viral Disease Branch, Centers for Disease Prevention and Control
Dr. Emias Belay, Associate Director for Epidemiological Science, Centers for Disease Prevention and Control
Secretary Tom Price, Department of Health and Human Services
Rep. Susan Brooks, Co-chair, Congressional Caucus for Women’s Issues
Rep. Lois Frankel, Co-chair, Congressional Caucus for Women’s Issues
Sen. Chris Van Hollen
Sen. Bob Casey
Sen. Al Franken
Sen. Michael Bennet
Sen. Chris Murphy
Sen. Elizabeth Warren
Sen. Tim Kaine
Sen. Maggie Hassan
Sen. John McCain
Sen. Ed Markey
Dr. Susan Wood, Associate Professor, Director, Jacobs Institute for Women’s Health, George Washington University School of Public Health and Health Services

i “Cytokine signature associated with disease severity in chronic fatigue syndrome patients” Montoya, Jose et al. Proceedings of the National Academy of Sciences, July 31, 2017
iv Ibid. Page 2
v Ibid. Page 9