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**Re: Comments to Inform the Strategic Plan for Research on the Health of Women**

Dear Dr. Caviston and ORWH agency partners,

Please consider this letter as public comments and recommendations regarding the NIH-Wide Strategic Plan for Research on the Health of Women. These comments are submitted on behalf of the Solve ME/CFS Initiative (Solve M.E.) and the community of people affected by Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), Long COVID/Post-Acute Sequelae of SARS-CoV-2 infection (PASC), and other post infection diseases.

We applaud the NIH Strategic Plan for Research's focus on advancing rigorous research that is relevant to the health of women. The increasing rates of PASC and related conditions such as ME/CFS and POTS constitute an emerging chronic health crisis- one that will disproportionately impact women. **The study of post infection diseases is a critical emerging need in research and should be prioritized in the Strategic Plan for Research on the Health of Women.** This is a timely opportunity to modernize the plan and reflect the changing scientific landscape of the study of the health of women.

Studies in the U.S. estimate that 10 to 30 percent of COVID-19 survivors develop long COVID<sup>1</sup>. Often referred to as "Long COVID", these symptoms, which can include fatigue, shortness of breath, "brain fog", sleep disorders, fevers, gastrointestinal symptoms, anxiety, and depression, can persist for months and can range from mild to incapacitating. Studies confirm that "female patients were more likely to experience long covid-19 syndrome over their male counterparts<sup>2</sup>."

We can also look at existing research about ME/CFS to extrapolate what the long-term impact of PASC will be on women's health. ME/CFS is a chronic, complex, neuro-immune disease that profoundly limits the health and productivity of millions of individuals. About 80% of cases of ME/CFS are reported to follow an acute infection (like COVID-19) and 75% of ME/CFS cases are in women. The causes of ME/CFS are unknown and there are no FDA approved drugs or treatments for the disease. 89% of people who get ME/CFS end up losing their job as a result of the disease. Experts are predicting significant increases in cases of ME/CFS following COVID-19<sup>3</sup>. As outlined by the U.S. ME/CFS Clinician Coalition, **"Over the course of one year, that [increase] would at least double the number of Americans suffering from ME/CFS...a remarkable event in the history of a chronic illness<sup>4</sup>."**

In addition to enhancing the research efforts in post-viral conditions, **increased efforts to disseminate information about PASC and ME/CFS are critical to improving the health of women.** We applaud

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<sup>1</sup> <https://www.gao.gov/assets/gao-22-105666.pdf>

<sup>2</sup> <https://www.tandfonline.com/doi/full/10.1080/03007995.2022.2081454>

<sup>3</sup> [www.washingtonpost.com/health/could-covid-19-cause-long-term-chronic-fatigue-and-illness-in-some-patients/2020/05/29/bcd5edb2-a02c-11ea-b5c9-570a91917d8d\\_story.html](http://www.washingtonpost.com/health/could-covid-19-cause-long-term-chronic-fatigue-and-illness-in-some-patients/2020/05/29/bcd5edb2-a02c-11ea-b5c9-570a91917d8d_story.html)

<sup>4</sup> Komaroff, Anthony L., and Lucinda Bateman. "Will COVID-19 Lead to Myalgic Encephalomyelitis/Chronic Fatigue Syndrome?" *Frontiers in Medicine*, vol. 7, 2021, doi:10.3389/fmed.2020.606824



# Solve M.E.

the Strategic Plan's goal to promote training and careers to develop a well-trained, diverse, and robust workforce to advance science for the health of women. We emphasize that this training should include accurate information about complex, chronic illnesses that are frequently missed or dismissed in the medical community- particularly post infection diseases.

The increase in cases of ME/CFS and other post infection chronic illnesses following COVID-19 coupled with the devastating economic impact of ME/CFS could create a serious health and economic crisis which will hit women the hardest. **ME/CFS and PASC research and medical education must be strategic priorities.**

I hope these comments are helpful and that you will consider PASC, ME/CFS, and other post infection diseases in the development of the next NIH-Wide Strategic Plan for Research on the Health of Women. Please don't hesitate to contact me or my organization if there is any way we can assist.

Sincerely,

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