



Robert F. Kennedy, Jr, Secretary
Department of Health and Human Services
200 Independence Ave., SW
Washington, DC 20201

Dear Secretary Kennedy,

We are writing from Patient-led Research Collaborative and #MEAction, organizations that advocate for people with Long COVID and myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). We wish to express deep concern regarding President Trump's recent executive order to terminate the advisory committee on Long COVID. In your exchange with Senator Young at your confirmation hearing, you committed to prioritizing efforts to address Long COVID. We are asking you to keep your word. Please keep the Long COVID advisory committee with the members previously selected, as they have lived experience and expertise in this area of science.

Long COVID continues to affect millions of Americans, with estimates of [20 million people](#) having developed this condition. Furthermore, about 45% of individuals with Long COVID [meet ME/CFS criteria](#), one the most underfunded and under researched diseases in the United States.

The economic impact of these diseases is substantial. Long COVID is [expected to have already cost](#) the US at least \$3.7 trillion in lost productivity based on reduced quality of life, reduced earnings and increased medical spending. The economic cost of Long COVID rivals the aggregate cost of the Great Recession, according to this estimate.

You have time to reverse course on this misguided decision. This will not be the last issue that affects people with Long COVID. Medicaid cuts, telehealth, 504 accommodations, and so many more issues hang in the balance. We urge you to reaffirm your commitment to addressing Long COVID. The health and well-being of millions of Americans depend on continued research, support and action in this area.

Sincerely,

Laurie Jones
#MEAction

Lisa McCorkell
Patient-Led Research Collaborative