March 28, 2023

To: Chair, Tina Liebling

I am Suzanne Wheeler, President of the Minnesota ME/CFS Alliance, U.S. Army Veteran (UH-60 Blackhawk helicopter pilot) and mom of three young women. I live in New Hope, MN and am a person living with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS).

As COVID-19 and its variants continue to affect Minnesotans, long COVID is emerging as a crisis. Many individuals with Long Covid also receive the same diagnosis as me (ME/CFS) which is life altering – some are homebound/bedbound, unable to work or care for their own families. Current resources at the Minnesota Department of Health are inadequate to address the impact of long COVID, which may have affected up to 20% of all infected Minnesotans, including children, adolescents, and young adults. Disproportionate impacts have been felt by Black, Indigenous and other nonwhite communities, as well as low-income, rural, disabled, and elder populations, and more data is needed to understand these impacts.

I became ill in late 2002 yet wasn’t diagnosed with ME/CFS until October 2017. During those years I continued to work in a corporate leadership role but suffered immensely with extreme levels of chronic pain and fatigue. I had a team of physicians, physical therapists, and chronic pain specialists, yet remained undiagnosed. Eventually I had to leave my corporate career due to illness and remained homebound/50% bedbound for over two (2) years. It was through Stanford University Medical Center in Palo Alto, CA that I was finally diagnosed and receive treatment to this day. It is unfortunate to be so ill yet must travel to another state for medical care. I’m grateful that I had the means and support from family that allowed me to leave my job and travel to a physician that could help. I am writing because I do not want anyone else to have to wait for 14 years for a diagnosis. Minnesota can do better but needs consistent funding for services for the long COVID community. My story from 2019 is linked below:

<https://www.hometownsource.com/sun_post/community/new-hope-woman-with-fatigue-condition-honors-fellow-millions-missing-from-jobs-social-spheres/article_88e794b2-7d6c-11e9-af1d-5343894f40c8.html>

The Governor's budget proposes funding to raise awareness, develop consensus guidance, and support long COVID survivors and communities. I urge you to support this funding, as it is critical to Minnesota's response to this crisis. Thank you.

Sincerely,

Suzanne Wheeler

President, Minnesota ME/CFS Alliance

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