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Dear Chair Liebling and Committee Members,

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My name is Bazak Sharon MD. I'm the medical director of the pediatric COVID clinic at the University of Minnesota. I've been treating patients with COVID since April 2020. So far I have seen more than 100 children with complaints of variety of persistent, and often debilitating symptoms. This experience gives me an excellent vantage point to explain *Long Covid*, its clinical presentation, and its impact on individuals, communities, and society, particularly children and their families.

So far over one million children in Minnesota have been infected with SARS-CoV-2 and it is estimated that 10,000-50,000 of them have already developed, or will develop, lingering illness. Children at all ages and from all backgrounds, regardless of their medical history are at risk for *Long Covid* and as true for all chronic illnesses, those with less access to care are the ones most affected. *Long Covid* in children, as well as in most young adults and many other patients at all ages is a post-viral syndrome, a group of conditions that manifest themselves by persistence of pathology following acute disease or developing sometime after asymptomatic infection. Patients experience a spectrum of symptoms and present with a variety of syndromes that may cause chronic disability. Extreme fatigue is often the most debilitating symptom and myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) can be considered the 'prototype' of these conditions. ME/CFS is a complex disease that is characterized by overwhelming fatigue and causes substantial loss of physical and mental stamina. It debilitates patients and many cannot maintain their regular daily activities, cannot work, function as they used to, and some are bed ridden and lose their mobility. But ME/CFS not only incapacitate individual patients, but it also represents a substantial burden of families, communities, and the economy. The estimate annual direct and indirect economic costs of ME/CFS are between \$17 and \$24 billion. In children, beyond the physical symptoms, social isolation and family stress are common. Those with ME/CFS often report lower quality of life as compared to other illnesses such as diabetes, epilepsy, and cystic fibrosis. Education is often a major concern and ME/CFS is the most common cause for long term school absences. It is not surprising that some people infected with the COVID-19 eventually develop a debilitating chronic fatigue. The pathology seen in patients with *Long Covid* is very similar to other post-viral syndrome and in addition to ME/CFS, some patients present with symptoms reminiscent of postural orthostatic tachycardia syndrome (POTS), fibromyalgia, pediatric acute-onset neuropsychiatric syndrome (PANS), mast cell activation syndrome (MCAS), and others. Post-acute COVID-19 is projected to at least double the number of Americans suffering from such diseases. Appreciating the association between *long covid* and ME/CFS allow

us to understand and predict the enormous impact that chronic sequelae of SARS-CoV-2 infection is having and will continue to have on children across Minnesota.

This association between *Long Covid* and ME/CFS also represents an opportunity to tackle these challenges in two fronts. First, we can build on the knowledge and experience we have about the diagnosis and management of ME/CFS to design the optimal response to *long covid*. Model for effective management include increasing access to healthcare, educating primary care providers and providing resources, promoting clinics to provide coordinated, holistic, and individual care. Mental health, integrative medicine, and designated physical therapy have shown great promise, but unfortunately availability of such services and equal access to them have been a major challenge, that should be addressed. Second, ME/CFS and other post-viral syndromes have long been a significant blind spot in the field of medicine. These chronic illnesses have been misunderstood for generations before becoming controversial in the age of evidence-based medicine. But even after scientific theories have emerged to explain fatigue and other chronic illnesses as sequelae of acute infection, the sporadic epidemiology of these syndromes has been a major obstacle to research. SARS-CoV-2 and the COVID-19 pandemic have provided a unique, once in a generation opportunity to combine clinical care with observational and hypotheses driven projects to study chronic illness and its association with viral infection. The same concepts that are so important to effective management (access to care, educating primary providers, promoting coordinated care) can also serve as the foundation to longitudinal studies on a large cohort of children infected with SARS-CoV-2 in Minnesota, with implications on the scientific understanding of post-viral syndromes in all populations everywhere in the world.

Based on my experience in treating children with post-infection syndromes for many years, and more recently those infected with SARS-CoV-2 infection allow me to identify specific concepts that are described in brief above. I'm happy to continue this conversation and explain in more details each concept. And how I think policy, legislation, and public funding can promote them.



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