



University of Minnesota Masonic Children's Hospital

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Dear Chair Wickland 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, where I've been treating children with COVID related illnesses since April 2020. 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 or will develop, lingering illness. Children at all ages and from all backgrounds, regardless of their medical history are at risk for *Long Covid* however as true for all chronic illnesses, those from disadvantaged communities who historically have less access to care are the ones most affected. *Long Covid* is a post-infection syndrome, a group of conditions that manifest themselves by persistence of pathology following acute infection, usually viral. 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. 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. 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. ME/CFS is the most common cause for long term school absences. The pathology seen with *Long Covid* is very similar to other post-infection syndromes and beyond ME/CFS, and many patient also suffer from symptoms reminiscent of postural orthostatic tachycardia syndrome (POTS), fibromyalgia, pediatric acute-onset neuropsychiatric syndrome (PANS), mast cell activation syndrome (MCAS), and others. *Long Covid* is projected to at least double the number of Americans suffering from such diseases.



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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 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-infection syndromes have long been a significant blind spot in the field of medicine. These chronic illnesses have been misunderstood for generations, and controversial theories have associated the debilitating symptoms with a variety of debunked ideas such as female hysteria, teenager school refusal, mental illness, and others. Unfortunately, the usual sporadic epidemiology of these conditions has also been a major obstacle to research. SARS-CoV-2 and the COVID-19 pandemic have provided a unique, once in a generation opportunity tackling some of these challenges and establishing a program to monitor long COVID. It is also possible to combine clinical care with much needed observational and hypotheses driven projects as 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. With appropriate coordination, collaboration, and funding we can study the effect of SARS-CoV-2 on a large cohort of children in Minnesota. A study that no doubt will have implications on the scientific understanding of post-infection syndromes in all populations everywhere in the world.

I'm happy to continue this conversation and explain in more details each concept and my suggestions for the practicalities of such endeavor.

A handwritten signature in black ink, appearing to read 'Bazak Sharon'.

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