

Testimony before the Select Subcommittee on the Coronavirus Crisis
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Thank you for having me here today.

My name is Hannah Davis. I'm a co-founder of the Patient-Led Research Collaborative¹ and admin at the Body Politic Support Group². The Patient-Led Research Collaborative is a team of Long Covid patients with a wide range of research, policy, design, and medical backgrounds who did the first research on Long Covid in April 2020. I got COVID in March 2020 in New York City. My first symptom was that I couldn't read a text message; an hour later I took my temperature and realized I had a low-grade fever. 2 years later, I still have severe cognitive dysfunction, memory loss, tremors, peripheral nerve damage, clotting markers, immune system abnormalities, dysautonomia, which is dysfunction of the autonomic nervous system, and myalgic encephalomyelitis, or ME/CFS, a disabling and complex neuroimmune condition. I still have difficulty driving and reading, a complete loss of executive function and short-term memory, and I still have not recovered. Before I got sick I worked in machine learning and artificial intelligence, but I haven't been able to return to that kind of work. I'm considered a mild COVID case by every definition.

We know a lot about Long Covid. It is a complex biomedical condition spanning multiple organ systems, affecting all age groups. Almost every study shows a prevalence between 10-30% of COVID cases. Research to date has found microclots, poor cerebral blood flow, dysfunction of the blood vessels, ongoing immune dysfunction, disruption to the blood-brain barrier, connective tissue issues, and hundreds of other findings. Several promising theories about the cause of Long Covid include viral persistence especially in certain tissues, clotting and coagulation issues, dysfunctional brainstem signaling, immune dysregulation leading to reactivation of other pathogens and viruses, changes to the microbiome and virome, connective tissue damage and hypermobility-related issues, and autoimmunity, or a combination of all of these³.

Last month, the US Census released their data showing that an estimated 7.5% of all US adults currently have had Long Covid for at least 3 months.⁴ That's 1 in every 13 adults in the entire country - not just those who had COVID. Women and socioeconomically disadvantaged patients are most at risk, though every demographic is affected. We know that not being able to rest in the first few weeks after onset increases the risk and severity of Long Covid, which means people without appropriate accommodations and people who are forced back to work or who must resume or continue unpaid household or caretaking labor are at increased risk, as is anyone who didn't get documentation of their COVID test who cannot substantiate or does not know their need for rest.

¹ "Patient Led Research Collaborative."

² "Body Politic Support Group."

³ Proal and VanElzakker, "Long Covid or Post-Acute Sequelae of COVID-19 (PASC)."

⁴ U.S. Census Bureau. Household Pulse Survey, 2022. <https://www.cdc.gov/nchs/covid19/pulse/long-covid.htm>

There are many misunderstandings about what Long Covid is, in part from lack of public education on it. 76% of Long Covid cases happen after a mild or asymptomatic non-hospitalized onset⁵; the incidence is higher in hospitalized patients, but because there are so many more non-hospitalized patients, the vast majority of cases happen after a non-hospitalized infection. Many did not have respiratory symptoms or low oxygen levels⁶. Many people assume that Long Covid is a continuation of COVID's acute symptoms, where we now know that it's actually a delayed onset of multisystemic symptoms. We now know that there is often a delay of several months between COVID onset and the start of neurological symptoms, and this delay is more likely in younger patients⁷. We have seen that Long Covid can happen after reinfection in those who fully recovered from their first infection. We know that vaccination can reduce the risk of Long Covid a little, but that Long Covid still happens in fully vaccinated people, with one study showing 9.1% of triple vaccinated people got Long Covid after the Omicron BA.2 wave⁸.

We know that between half to three quarters of Long Covid patients develop ME/CFS, dysautonomia, or both⁹. ME/CFS is one of the world's most disabling illnesses, with a quality of life worse than end-stage renal failure, cancer, stroke, rheumatoid arthritis, and multiple sclerosis¹⁰. 75% of people with ME/CFS can't work, and 25% are bedbound. Only 5% recover. Consistent abnormal findings in ME/CFS include diminished natural killer cell function, T cell exhaustion and other T cell abnormalities, mitochondrial dysfunction, vascular and endothelial abnormalities including deformed red blood cells and reduced blood volume, exercise intolerance, impaired oxygen consumption and a reduced anaerobic threshold, abnormal metabolic profiles including dysfunctional energy metabolism, altered brain function including neuroinflammation, reduced cerebral blood flow, and brainstem abnormalities, abnormal eye and vision findings, and reactivated viruses (including EBV (also known as mono), shingles, and others)¹¹.

⁵ "Patients Diagnosed with Post-COVID Conditions: An Analysis of Private Healthcare Claims Using the Official ICD-10 Diagnostic Code."

⁶ Davis et al., "Characterizing Long COVID in an International Cohort."

⁷ Apple et al., "Risk Factors and Abnormal Cerebrospinal Fluid Associate with Cognitive Symptoms after Mild COVID-19"; Davis et al., "Characterizing Long COVID in an International Cohort."

⁸ "Self-Reported Long COVID after Infection with the Omicron Variant in the UK - Office for National Statistics."

⁹ Haffke et al., "Endothelial Dysfunction and Altered Endothelial Biomarkers in Patients with Post-COVID-19 Syndrome and Chronic Fatigue Syndrome (ME/CFS)"; Kedor et al., "Chronic COVID-19 Syndrome and Chronic Fatigue Syndrome (ME/CFS) Following the First Pandemic Wave in Germany – a First Analysis of a Prospective Observational Study"; Mancini et al., "Use of Cardiopulmonary Stress Testing for Patients With Unexplained Dyspnea Post-Coronavirus Disease"; Larsen et al., "Characterization of Autonomic Symptom Burden in Long Covid."

¹⁰ Falk Hvidberg et al., "The Health-Related Quality of Life for Patients with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS)."

¹¹ Committee on the Diagnostic Criteria for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, Board on the Health of Select Populations, and Institute of Medicine, *Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome*; Bateman et al., "Myalgic Encephalomyelitis/Chronic Fatigue Syndrome"; "Index of ME/CFS Published Research"; Seltzer and Thomas, "ME Research Summary 2019"; Eaton-Fitch et al., "A Systematic Review of Natural Killer Cells Profile and Cytotoxic Function in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome"; Curriu et al., "Screening NK-, B- and T-Cell Phenotype

Despite the severity of the illness and its significant overlap with Long COVID, only 6% of medical schools fully teach post-viral conditions like ME/CFS¹², and very few providers and researchers are familiar with these conditions or their presentations in Long Covid. There are about two dozen ME/CFS experts in the US, but very little collaboration with or funding of these experts, and we are wasting time reinventing the wheel, with research exploring hypotheses that were disproven decades ago.

Similarly, many providers, even some Long Covid clinics, don't know that outdated treatments like graded exercise therapy cause high rates of harm in patients with ME/CFS and can cause patients to worsen and even become bedbound.

Multiple misconceptions about the accuracy and use of COVID diagnosis tools have tainted studies and caused enormous issues for long haulers. PCR and antibody tests are often required for entry into Long Covid clinics, for time off from work, for further care for Long Covid issues, and as a requirement for participation in Long Covid research. By the CDC's numbers, however, most Covid cases are not documented by PCR: in the first wave, only three percent of cases were documented, and to this day only twenty-five percent are confirmed¹³. Additionally, PCR tests have extremely high false negative rates¹⁴ and are less accurate in women and people under 40¹⁵. Rapid at home tests are similarly inaccurate and unreported.

Further, there is widespread misinformation that everyone who gets COVID makes COVID antibodies (also known as seroconversion). After infection, 22-36% of people don't make detectable long term antibodies at all¹⁶ and others lose them over time; this is more likely in people who had an initially mild illness, with 61% of mild patients having no antibodies at eight months, compared to 29% of severe patients¹⁷. Additionally, 80% of people who lose antibodies

and Function in Patients Suffering from Chronic Fatigue Syndrome"; Mandarano et al., "Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Patients Exhibit Altered T Cell Metabolism and Cytokine Associations."

¹² Peterson et al., "Coverage of CFS within U.S. Medical Schools."

¹³ CDC, "Cases, Data, and Surveillance."

¹⁴ Kucirka et al., "Variation in False-Negative Rate of Reverse Transcriptase Polymerase Chain Reaction–Based SARS-CoV-2 Tests by Time Since Exposure."

¹⁵ Levine-Tiefenbrun et al., "SARS-CoV-2 RT-QPCR Test Detection Rates Are Associated with Patient Age, Sex, and Time since Diagnosis."

¹⁶ Korte et al., "SARS-CoV-2 IgG and IgA Antibody Response Is Gender Dependent; and IgG Antibodies Rapidly Decline Early On"; Mallapaty, "Kids Show Mysteriously Low Levels of COVID Antibodies"; Liu et al., "Predictors of Nonseroconversion after SARS-CoV-2 Infection - Volume 27, Number 9—September 2021 - Emerging Infectious Diseases Journal - CDC"; Jo et al., "A Two-Phase, Single Cohort Study of COVID-19 Antibody Sera-Surveillance"; Chia et al., "Dynamics of SARS-CoV-2 Neutralising Antibody Responses and Duration of Immunity"; Van Elslande et al., "Longitudinal Follow-up of IgG Anti-Nucleocapsid Antibodies in SARS-CoV-2 Infected Patients up to Eight Months after Infection."

¹⁷ Van Elslande et al., "Longitudinal Follow-up of IgG Anti-Nucleocapsid Antibodies in SARS-CoV-2 Infected Patients up to Eight Months after Infection."

are women¹⁸, and both PCR and antibody test accuracy is worse in women¹⁹, creating barriers to care and participation in research for this group.

Finally, multiple research papers show that low or no antibody creation may actually be a feature of Long Covid, and can be used to predict Long Covid at the acute infection stage in both hospitalized and non-hospitalized patients²⁰; however, this information is not widespread.

Because researchers assume these tests are accurate and antibodies are consistent across all types of patients, many studies unintentionally include Long Covid patients in the control groups, seriously weakening their conclusions and leading to inaccurate narratives about prevalence and severity of Long Covid.

Long Covid must be considered in every step of the COVID response. Two and a half years into the pandemic, Long Covid has already impacted our workforce²¹. A large subset of people with Long Covid either can't work or need reduced hours, and many struggle to apply for meager disability benefits, if they are even deemed eligible. The financial impact is devastating and cannot be overstated. Long COVID will destroy our economy and disable a huge percentage of our society if we do not decrease new cases and prioritize help for the existing ones.

We need immediate changes. We need an urgent public information campaign on Long Covid, to explain that it happens after mild cases and to all ages, is debilitating, and requires immediate pacing and rest. We need to prioritize preventing transmission, including through data-driven mask mandates and improved ventilation, and new generation vaccines that include Long Covid prevention and impacts on Long Covid as endpoints. We need to expand and improve clinical care access and quality, including education for providers and community health care workers on Long Covid and the common diagnoses of ME/CFS and dysautonomia. We need to provide for paid leave to rest and recover from acute COVID. We need to reform SSI and SSDI, by shortening application processing times, increasing benefits, removing waiting periods, updating asset limits, making it easier to provide needed medical documentation given there aren't yet diagnostic tests, and providing free legal assistance to people who are applying. We need to provide financial assistance to the millions of long haulers unable to pay their daily costs of living, let alone medical care. We need to fund current post-viral experts and let them lead Long Covid research. And we need to expedite and fund clinical treatment trials, including anticoagulant therapy for microclotting, antivirals for both COVID and reactivations like EBV,

¹⁸ Jo et al., "A Two-Phase, Single Cohort Study of COVID-19 Antibody Sera-Surveillance."

¹⁹ Vashisht et al., "Age- and Sex-Associated Variations in the Sensitivity of Serological Tests Among Individuals Infected With SARS-CoV-2"; Levine-Tiefenbrun et al., "SARS-CoV-2 RT-QPCR Test Detection Rates Are Associated with Patient Age, Sex, and Time since Diagnosis."

²⁰ Augustin et al., "Post-COVID Syndrome in Non-Hospitalised Patients with COVID-19"; García-Abellán et al., "Antibody Response to SARS-CoV-2 Is Associated with Long-Term Clinical Outcome in Patients with COVID-19."

²¹ Bach, "Is 'Long Covid' Worsening the Labor Shortage?"; Ham, "Long-Haulers and Labor Market Outcomes | Opportunity & Inclusive Growth Institute"; "Long Covid Is Showing Up in the Employment Data - Bloomberg"; "Workers' Experiences of Long Covid: A TUC Report."

and trials for ME/CFS and dysautonomia, including mitochondrial treatments, IVIG, and connective tissue restoration^{22, 23}.

Thank you for your time.

²² "ME/CFS Treatment Recommendations."

²³ For more recommendations for research priorities, design, and oversight for Long COVID please see Patient-Led Research Collaborative's Towards a Patient-Driven National Research Action Plan: <https://patientresearchcovid19.com/wp-content/uploads/2022/06/Towards-a-Patient-Driven-National-Research-Action-Plan.pdf>