

## Nicole Heim Testimony

Chairman Sanders, Ranking Member Cassidy, Members of the Committee –

Thank you for the invitation to testify today on this important issue. My name is Nicole Heim and my 16-year-old daughter has Long COVID. In this room alone, I am sure there are countless stories about the impact of a COVID diagnosis. But one story that is rarely shared is that of our children and the devastating physical and mental long-term effects of this virus. My daughter is just one example, and I am here to share her story in the hopes that it may help other families.

In September 2021, my daughter, 14-years-old at the time, contracted COVID after an exposure in band class. Before COVID, she was a relatively healthy, typical teenage girl, excelling at school with a robust social life. She was diagnosed earlier in her adolescence with POTS, Posterior Orthostatic Tachycardia Syndrome, in which she experienced an abnormal and elevated heart rate. Her COVID diagnosis only exacerbated this issue and we saw her heart rate increase after walking up a flight of stairs from 177bpm before COVID to 208bpm after COVID. Her COVID symptoms were extensive, and she was very sick, but thankfully not hospitalized.

A month following her recovery, I received a panicked phone call from the school nurse saying my child was short of breath, her pulse was extremely high, and she was unable to move her arms and legs. This is the kind of phone call no parent is ever prepared to receive. At the time, we lived in Charles Town, W.V., so I rushed her to the local ER where she was diagnosed with hypoxia with low blood oxygen. She was transferred via ambulance three hours away to Ruby Memorial in Morgantown, W.V., where she received a Long COVID diagnosis.

Following this diagnosis, we were fortunate to be introduced to the team at Children's National Hospital here in Washington, D.C. While waiting to receive care at Children's pediatric Long COVID clinic, my daughter's testing and blood work continued. After many months of waiting and jumping through prior authorization hoops with Medicaid, my daughter gained access to the wide network of specialty doctors in the Long COVID clinic led by Dr. Alexandra Yonts, the lead infectious disease doctor at Children's. She coordinates the clinic and team that provides my daughter with care. At the time of our initial visit with Children's, my daughter was experiencing a wide range of symptoms, including extreme fatigue, low blood pressure, increased heart rate, rapid weight loss due to daily nausea and vomiting, severe brain fog, and depression. As patients of the Long COVID clinic, we learned about and enrolled in the joint Children's National and NIH Pediatric COVID Outcomes study, led by Dr. Roberta DeBiasi. This is the only study of its kind in the country, where one thousand children are evaluated for three years following enrollment to determine long term effects of a COVID infection.

Long COVID took my straight "A" honors student, talented flautist, and member of the school's marching band with an active friend group and stripped her of life as we knew it. Because of the severity of her symptoms, she is no longer able to physically participate in the marching band and is now homeschooled full-time. Instead of looking forward to a high school graduation, my 16-year-old is working slowly on her GED from home.

The mild depression and anxiety she struggled with prior to COVID has only been intensified and has led to increased panic attacks and hospitalization for suicidal ideations. We so frequently

hear about the physical effects of Long COVID. Without a doubt it significantly impacted my daughter's life. Unfortunately, we rarely discuss the mental health impact of COVID. It is especially concerning when considering our children. Having a chronic illness as an adult is difficult, but it's more challenging and takes a much greater toll as a child. So much of our children's lives revolve around school, extracurricular activities, sports, and friends – activities that continue for my daughter's peers but are no longer a part of her normal life.

After two years with Children's, and through extensive testing and blood work, physical therapy, supplements, and daily medications, her GI symptoms, stamina, heart condition, and brain fog are manageable and under control. Although my daughter has improved, we are still experiencing new symptoms and struggling each day to adjust to this new norm, including a recent discovery that she has micro clots which now requires her to be on daily blood thinners. We are optimistic that she will fully recover one day but remain concerned that her current treatment regimen may be necessary for the rest of her life. Clinics and studies like those done at Children's are crucial to understanding this infection and its unique impact on our children. Unfortunately, fewer than a dozen pediatric Long COVID clinics exist across the country to help affected children. Children's National's approach is unique in that each pediatric patient meets with their whole team of specialists back-to-back during a single coordinated clinic visit. But I have heard other clinics focus just on rehab or pulmonology. I would urge the committee to meet with the hospitals running Long COVID clinics to better understand the level of services they provide. With increased research, I am confident that treatments can be found.

I feel so grateful for the treatment my daughter is receiving at Children's, but I know there are many other parents and children struggling, not only with the Long COVID diagnosis but also to find some symptom relief. In reflecting on our experience, my recommendation to this Committee and our health care system is simple – do more to increase awareness around pediatric Long COVID. My daughter had many medical appointments and interacted with many providers before receiving a diagnosis. I believe this contributed to the severity of her symptoms and a delay in appropriate treatment. Like medical screening tools used for depression and suicidal ideations, there should also be a screening protocol for providers and patients to help identify Long COVID. I would tell any parent today that if their child's existing conditions worsen or they develop persistent and/or new symptoms after COVID, they should contact their doctor to discuss Long COVID.

We should also allow physicians caring for Long COVID patients to have telemedicine appointments in states that they are not licensed in for both initial visits and for follow-up visits. This is very important because most states do not have a pediatric Long COVID clinic. And even in areas where there is a Long COVID clinic, families like mine have to travel for several hours to make appointments. Finally, my daughter's care was partially delayed because of the long prior authorization requirements of our state's Medicaid program. If there were less hurdles like these, it would help patients get to clinics faster.

I look forward to a day when doctors not only know more about Long COVID but can also quickly identify patients to provide timely treatment. I hope studies, like those at Children's National Hospital, are continually supported to lead to new treatment options for patients like my daughter. Thank you for the opportunity to share our story, I've done so in the hopes that it can

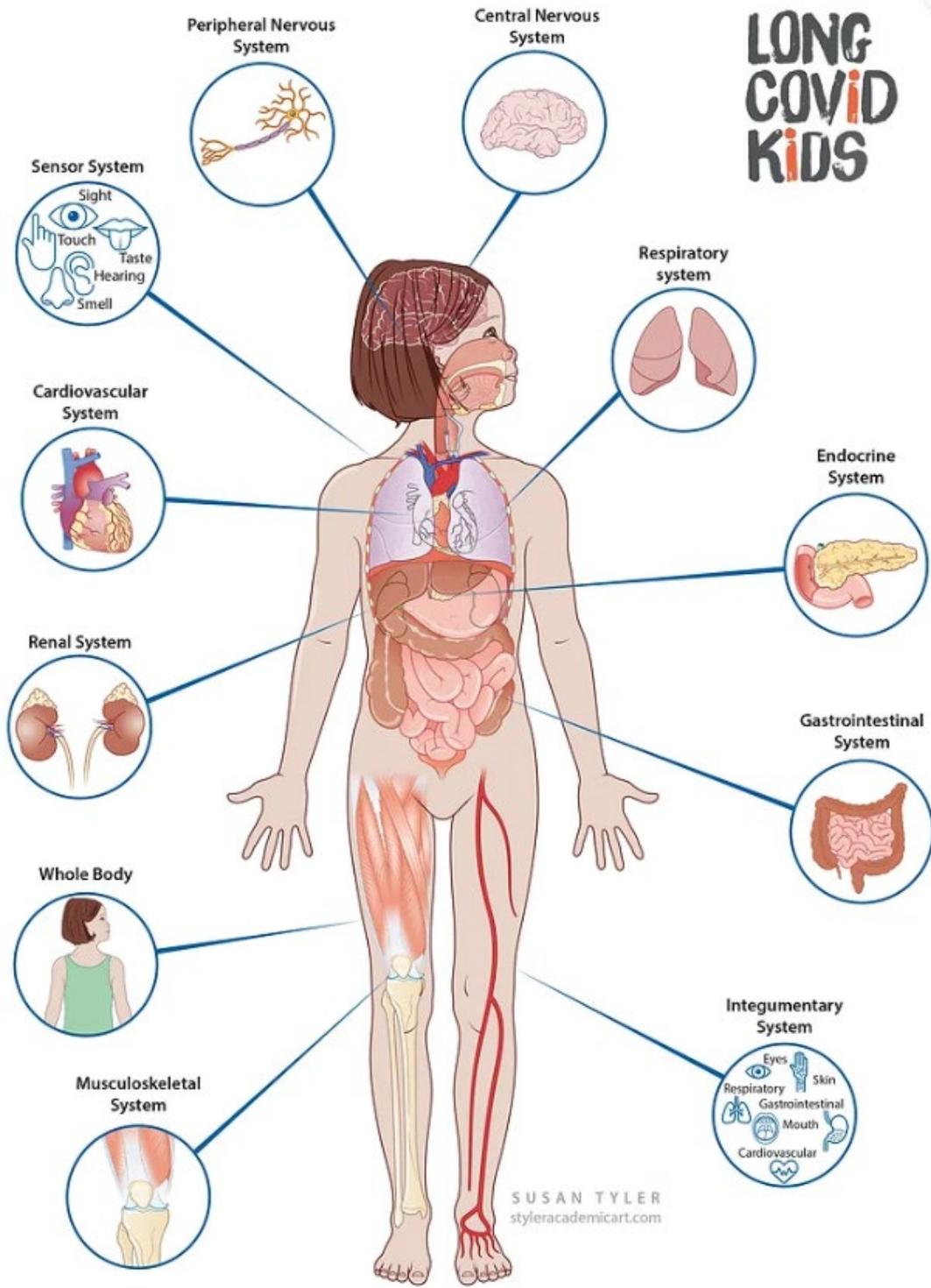
help many other families, and I'd like to offer myself as a resource to this Committee and our health care system as we continue to address Long COVID. I look forward to our discussion today.

Addendum:

I have included attachments to my testimony to further inform the committee of all the ways children are being affected by Long COVID. These graphics are pulled from [longcovidkids.org](https://longcovidkids.org).



# LONG COVID KIDS



SUSAN TYLER  
styleracademicart.com

## Whole Body

- Pain
- Tiredness and Weakness
- Fatigue
- Insomnia
- Excessive sleepiness
- Insomnia
- Flu-like symptoms
- Post Exertional Symptom Exacerbation (PESE)
- Self harm/Suicidal thoughts
- Food restriction
- Weight loss or Weight gain
- Difficulty regulating temperature
- Dental and gum problems

## Musculoskeletal System

This system provides the body with support, stability and the ability to move. It consists of bones, joints, ligaments, muscles, tendons, cartilage and bursa

- Joint Pain
- Muscle Aches
- Swelling
- Joint redness
- Connective tissue disorders

## Cardiovascular System

This system is made up of the heart and blood vessels

- Chest pain/tightness
- Myocarditis
- pericarditis
- Heart Palpitations
- Increased Heart Rate (Tachycardia)
- Bradycardia and arrhythmias
- High or low blood pressure
- Fainting
- Oxygen desaturation
- Inflammation
- Blood Vessel Damage
- Coagulopathy (Excessive bleeding or clotting)
- Microangiopathy (Covid toes)
- Nose bleeds
- Anaemia

## Renal System

This is a group of organs that work together to store, release and produce urine

- Acute kidney injury
- Urinary frequency
- Urinary hesitancy

## Sensory System

This is part of the nervous system and is responsible for processing information from our senses

- Tinnitus
- Earaches
- Noise sensitivity
- Nasal congestion
- Loss/Change of smell
- Phantom Smells
- Loss/Change of taste
- Loss of appetite
- Difficulty swallowing
- Red eyes/Conjunctivitis
- Blurred vision
- Light sensitivity

## Peripheral Nervous System

This system consists of all the nerves branching off from the brain and spinal cord

- Pins and Needles
- Numbness
- Swollen hands/feet
- Dysautonomias, eg. POTS
- Fainting
- Tics and twitches
- Tremors
- Difficulty regulating temperature

## Central Nervous System

This part of the body is made up of the brain and spinal cord. It takes in information from the body, processes it and then produces the body's responses.

- Brain fog/cognitive disturbances such as poor concentration, confusion, short term memory problems and memory loss, word finding difficulties or word repetition
- Mood changes
- Depression
- Anxiety
- Headache and migraine
- Lightheadedness
- Dizziness
- Unexplained irritability
- Tics and twitches
- Stuttering, swearing, vocalising
- Behavioural changes
- Difficulty regulating temperature
- Tremors
- Sleep issues
- Suicidal thoughts

## Respiratory System

The respiratory system is the network of organs and tissues that help a person to breathe.

- Shortness of breath
- Wheezing
- Breathing Pattern Disorders
- Chest Pain
- Cough
- Sore throat
- Throat clearing
- Throat tightness
- Voice changes

## Endocrine System

The endocrine system consists of a number of different glands and organs which produce and regulate hormones to control many functions of the body.

- Hormonal imbalance
- Menstrual changes
- Menstrual pain/cramping
- Worsening premenstrual syndrome
- Testicular pain

## Gastrointestinal System

This system is responsible for processing foods, absorbing nutrients, and eliminating waste.

- Abdominal/Stomach pain/cramps
- Bloating
- Diarrhoea
- Nausea/Vomiting
- Gastric Reflux
- Food restriction and weight change

# Integumentary System

This is an organ system consisting of the skin, eyes, glands, hair and nails. It protects the internal body from the outside world.

- Fever
- Swollen Glands/Lymph nodes (throat, under arms, groin)
- Reduced antibody reaction
- Histamine Intolerance
- Mast Cell Diseases
- Pallor (Pale skin)
- Skin rashes
- Skin flushing
- Itchy skin
- Excessive sweating
- Peeling skin
- Red/cracked lips
- Hair loss
- Ulcers