

Rachel Beale, MBA
Testimony before the Health, Education, Labor and Pensions Committee
January 18, 2024

Chairman Sanders, Ranking Member Cassidy, and Members of the Committee, thank you for inviting me to testify today. It is an honor to be here.

My name is Rachel Beale and I live in Sedley, a small town in Southeastern Virginia. I live with my husband, Steven, who has joined me here today, my daughter, and two sons.

I tested positive for COVID on March 17, 2021. I was sick with COVID for two weeks. I had a high fever and intense body aches. Although I didn't feel well, I managed my COVID at home. After my fever went away, I tried to return to my normal life. I worked as a Human Resources (HR) Director at our local community college. I loved my job, but I soon realized I was struggling. Even after my initial COVID infection, I continued to experience extreme fatigue, chronic pain, and neurological issues, to name a few. Before COVID I was very healthy, I didn't expect to have problems recovering.

When I realized I was struggling, I visited my primary care doctor. My doctor told me I needed more time to recover, I was stunned when he took me out of work for two weeks. I was very stressed about missing more work and worried that I would fall behind. But two weeks turned into two more weeks, and eventually my doctor diagnosed me with Long COVID in May 2021. I was lucky to have a primary care doctor that believed me and believed my symptoms. I know not every person with Long COVID has the same experience.

My Long COVID symptoms persisted beyond May 2021. I tried to go back to work part time, but I just couldn't do it. For the first six months of my illness I was on short-term disability. I tried over and over to work, but I could only manage an hour before I would start getting headaches and feel sick. Six months after I was diagnosed with COVID, I was transitioned to long-term disability. At this point I was separated from my job.

As someone who has helped countless employees on short-term disability and has transitioned some to long-term disability, I knew this would happen to me. I used to have the very same meetings with employees. There is nothing that prepares you to hear the words that you no longer have a job. I loved my position at the college; I loved my career in HR. Having to stop working because of my health has been devastating.

I had a very full life before I got sick. Long COVID has affected every part of my life. I wake up every day feeling tired, nauseous, and dizzy. I immediately start planning when I can lay down again. There are many days when I sleep all day. On my good days I get about 2-3 hours of energy.

I have had most of the symptoms of Long COVID. The fatigue and chronic pain are the hardest to manage. It can be debilitating. I also have neurological issues, the executive function part of my brain seems to be affected the most. Being sick for so long has made my depression and anxiety worse. I've had low times, when I don't feel good I get depressed. I was just diagnosed with fibromyalgia, triggered by Long COVID. Yet another illness for which there is no cure.

In December 2021, I filed my initial application for Social Security Disability Insurance. I have been denied twice. I am now waiting for a hearing date with an Administrative Law Judge. Long COVID is recognized by the Americans with Disabilities Act. It should be easier for someone with Long COVID to be approved for SSDI.

I feel very fortunate to have a supportive family. My husband has good health insurance. My doctors, procedures, and most of my therapy has been covered. I'm thankful for that. However, the copays add up. Sometimes we can't pay for them on time.

My kids have grown accustomed to me being sick. We plan things around how I feel and my energy level. If there is something coming up, like a birthday or a holiday, I try to get as much rest as I can before the event. I know that I will have a crash for the next few days. I won't be able to do much just sleep. Sometimes it takes several weeks for me to get back to my baseline. For example, coming to testify today has been a huge effort and I know that I will need several days to recover. We've gotten used to this lifestyle and living within my physical limitations.

When I think about what comes next – I just don't know. Full recovery seems out of reach for me. I've been sick for almost three years. It feels like there hasn't been much progress in Long COVID research. I hope that Congress can help with that, to move the research forward. But for now, I'm just trying to make peace with my situation. It makes me sad to think about my future. This may be as healthy as I get.