

Testimony of Natalie Hakala
Collegiate Middle Distance Runner and Long COVID Patient
House Committee on Energy & Commerce- Subcommittee on Health
April 28, 2021

On July 4th, 2020, I was diagnosed with Covid-19 after spending a weekend camping with my friends. The day I got tested, I had a slight headache and a tingling feeling on my skin when it would touch things. It was aggravated by activities such as leaning back in my chair or the brush of my T-shirt. The following day I had a more intense headache directly behind my eyes, making it difficult to focus.

Not only were there these intense physical symptoms, but the emotional toll was one I was not prepared for. There was the initial fear of being a Covid patient and how my community would view me. I was mainly scared about what that would mean for my family. I was terrified of infecting them. The entire two weeks, I was sick; I was outside and far away from my family. I used one bathroom that I cleaned after and was only in my bedroom to sleep. I had gloves and a mask on at all times inside, and I did not touch anything. My whole goal was to limit the exposure to my family. I had an air mattress outdoors where I would take naps and a small table to eat on apart from my family. I used paper plates and plastic utensils so nobody had to touch what I had touched. Outside and far away was the only place I felt comfortable enough to relax without the fear of accidentally infecting my family. I was so worried because my younger brother and mom have ulcerative colitis, and my parents are both over 50. I knew I would be okay because all I had heard was that you are sick for two weeks, and it does not affect the young and healthy as negatively as it does the older and those with comorbidities.

As the first week continued, I lost my sense of smell, and my taste shortly followed. I still had a very consistent headache and weird tingly feelings on my skin. By the end of the first week, I began having body aches, and a day later, my fever began. This fever did not feel like a usual fever from the flu would feel; it was all-encompassing it felt like my veins were on fire. This is when I truly began to understand how deadly Covid could truly be, especially if it was someone who was not as young, healthy, and in shape as I was. I remember clearly thinking, "thank goodness this happened to me and not my parents or brothers or grandparents," because I was the one who had no health issues. My fever continued to melt me from the inside out as I was hot and cold all at once. It lasted for four days, and on the last night with a fever, it was so challenging to sleep comfortably. Once it was broken, I only had a few days left of quarantine, and my taste and smell were returning, so I thought the worst of my trials were over.

To understand how disabled I become, you need to know where I was. One year prior, I started my senior year of college in the best shape of my life. That cross country season, I got a personal record (pr) in the 5k and 6k races and finished in the top 5 for my team—something I had never accomplished in all my years of college due to various hip injuries. I was running 40 miles a week with 5-10 hours of cross-training (biking or swimming) to help take the impact of mileage off my body. Starting my track season in the spring, I consistently got prs in practice for

the 200 and 400 meters. I was the fastest 800 middle distance runner my D2 college had. I had goals to finish at the top of my Conference and qualify for Nationals. When my season was canceled, I continued training and continued to work out. I dropped my mileage from 40 miles to around 25-30 miles a week once I started working in the summer following my virtual graduation. I got a job at a local orthopedic center where I was a cast technician. I would run 4 miles before work and then help with casting patients until around 5 pm. My casting job required me to hold up legs while a team member placed the casting material, or I did the wrapping of the cast material. I would remove casts and splints and sometimes place splints. I would go up and downstairs to get to the different casting rooms and make the beds for patients. Once I was diagnosed with Covid, I took time off from work and received Covid pay for the two weeks I had off.

After I was out of quarantine, I was very excited to leave my house and go for an easy jog around my neighborhood. I had planned to do an easy two miles; I made it 200 meters before I was gasping for air and felt my heart beating out of my chest. I knew something was wrong, so I walked home and tried to get my breath back and my heart rate under control. I brushed it off as just not having moved for the last two weeks and being overly tired.

As the week went on, I tried to return to work and could only do half days because I was so exhausted. I found myself getting out of breath more and more frequently. At work, I found it challenging to go up and downstairs. I had to take more breaks than I used to, and thankfully my work was more than accommodating with me. During my lunch breaks, I was taking naps, and as soon as I returned home, I had to lay down and sleep for at least 30 minutes. On July 31st, I scheduled a primary care visit because I knew something was not right. I was diagnosed with pneumonia and was given a variety of medications to help with that. The following Monday, I went back to work.

On August 6th, I got home from work and just laid down on the couch. I found it very difficult to breathe and felt as if there was something just sitting on my chest. While at work that day, I was casting a patient's arm and was barely able to finish because I felt like I could not breathe. My mom came home, saw me struggling to breathe, and decided to go to the emergency room. I got looked at by doctors with lots of tests being done, but every test came back normal. I was sent home since they did not know what was wrong with me.

I called out of work the next day, and I have not returned since. I spent most of my days sleeping, and I was having difficulty walking across my kitchen to get myself a glass of water. I was at my PCP (primary care provider) again and received some pain medications to help with the sharp pains I was having in my chest.

On the morning of August 16th, I woke up at 4:00 am with severe chest pains, and I tried everything I could to make it go away, and nothing was working. By 6:00 am, I went and woke up my mom to have her take me to the hospital. Once again, all of my tests were coming back normal. But this time, my oxygen saturation was in the low 80s, and my white blood cell count was slightly elevated, so they admitted me for observation. They ran some more tests to look at

my lungs and heart, and everything was still looking completely normal. I was still testing positive for covid, so I was placed in the covid wing, where all of the people there were still contagious even though I was out of my infectious phase. Many of the doctors did not want to come into the room to talk with me; most of the visits were over the phone or very brief conversations because they did not want to be in the same room as me. Luckily, they let my mom stay with me, and since she is a Physician Assistant, she was able to advocate for me about which medications may be helpful.

While in the hospital, we noticed how my heart rate would change rapidly and respond inappropriately to the stimulus, demonstrating signs of tachycardia. For example, I would be lying down in my bed, and my heart rate would be around 70 beats per minute, where usually my heart rate would be in the 60s because I was in such good shape from running. Then I would sit up, and my heart rate would increase to 90s. I would get to a standing position, and it would again jump into the 120s. Walking the three to four steps to the bathroom would have my heart rate anywhere from 130 to 150 depending on how long I was standing for. Due to this, my mom advocated for me to be put on a beta-blocker and a heart anti-inflammatory. I started metoprolol and colchicine even though the cardiologist never came into my room and listened to my heart.

I was discharged from the hospital on August 19th because they could not diagnose me, and my oxygen saturation was back up to 97 while walking slowly. I spent the next few weeks just lying on the couch and listening to the tv because watching it made my headache much worse. I had to have my brothers make and bring me meals because I was too exhausted to do that small amount of movement. I had more appointments throughout August and September, but it did not feel like any real change was being done because the doctors did not know what to do to help me other than try and manage my symptoms.

On September 29th, I had a cardiac MRI where it showed fluid around my heart. I was diagnosed with pericarditis, costochondritis, pericardial effusions, and some pleurisy. I was still having difficulty breathing and moving around my house. Doing small acts of daily living was extremely challenging; sometimes, just taking a shower felt like too much work because raising my arms and washing my hair was too exhausting for me. I was still having stabbing chest pains, and when those weren't present, I had a dull ache throughout my chest, and taking deep breaths was very uncomfortable.

In October, I finally got a wheelchair to help me move around, so I wasn't always in my house. My mom pushed for me to start cardiac rehab to help get me up and moving around more, hopefully. It would also allow my cardiologists to see my heart while I was moving. By the end of October, I was able to watch a little tv without a severe headache. Still, I found myself only able to re-watch shows because following a plotline I did not know was too much for me to keep track of, and I found myself both exhausted and forgetting what happened right before in the show.

My first cardiac rehab appointment was on October 27th, and I was able to walk for 8 minutes, but at the 4-minute mark, my oxygen saturation was at 84%. It went back up to 97% after a

minute of a break. During the walk, I had shortness of breath, achy chest pain, and sharp pains throughout my rib cage. These symptoms continued after exercise. I continue to go to cardiac rehab once a week.

I was slowly improving because I could make my small breakfast in November and get up to get my water. I could watch an entire tv show without a severe headache, but I was still noticing the brain fog. I was forgetting words frequently and could not remember what I was doing mid-activity. I would become confused as to why I was standing in the kitchen when I had walked in there to get water. I still had chest pain and had to sit down and take frequent breaks. Showering was still the one big activity for the day, and I would often have to sit down and catch my breath afterward while I waited for my heart rate to calm down and for my breath to return. At cardiac rehab, I was able to walk for 10-15 minutes, and I would occasionally drop my oxygen, but it was becoming less frequent.

In December, I made much more significant improvements. I walked for 30 minutes at cardiac rehab without feeling incredibly out of breath and was not lying on the couch all day after a big day of movement. I still had sharp pains and chest aches, but I could take deeper breaths, and breathing felt more manageable. I was able to read for the first time in December; granted, it was only books I had previously read, and I had to reread pages and sentences a lot of the time because I would forget what I just read or what was happening. But I was able to do it, and that was a very exciting thing for me.

January is when I started working an online job where I only had to work for 5-10 hours a week, and through this health care company, I got my covid vaccination. I tried slow jogging in January. It was something I could do, but the next day I was still having an increase in chest pains and feeling overly exhausted. I still had fatigue and found myself very exhausted after doing too much movement. I started wearing compression socks to help my blood circulation because I found my feet and hands extremely cold and occasionally blueish-looking. When I wore my compression socks or leggings, I felt much better fatigue-wise and found it easier to be standing for more extended periods of time. I got my vaccination at the end of January, and I was on the couch like I was in September for the entire week following my shot.

This same type of reaction occurred after my second shot in February. After receiving my vaccination and recovering from the shot, I made much more extensive improvements. My energy was slowly returning, and I did not use my wheelchair at all anymore. I was able to walk for 60 minutes by the end of March. I was slow running for a max of 2-minute intervals, which I did for a maximum of 5 times by the end of March as well. I could do a spin bike workout for 30 minutes. I felt like I was returning to my old self just because I could finally do a small workout.

Currently, I can run for a maximum of 15 minutes continuously. I can read new books, and I have started taking two new classes at my local community college. I am unable to focus on my homework for long periods and still find myself getting exhausted and having chest pains; if I do too much movement. Sometimes a headache will follow a stretch of too much thinking and focusing. My brain fog seems to be improving the more I use my brain, but it took a very long

time for me to use it like I used to. I still find quick thinking challenging, and my reaction times are significantly slowed, which can be seen on my Sunday tennis drills with my family. They play slower for me so I can try and get my left-right brain moving once again. I have not been able to return to my previous cast technician job because that would be too much movement for me at this time.

I am very fortunate that I have improved, but that would not have happened had I not had the time and space to truly rest my body and allow it to recover at the pace it needed. I have seen other Long Haulers try to push themselves too early in the process, and they end up in more pain than when they started. I am also very fortunate to still be on my parents' insurance. As a recent college graduate, I do not have the funds to pay for all my medical bills that occurred from my hospital stay, many appointments, and frequent testing for my heart and lungs. I am very supported by my family, and I would not like to think about what would have happened had I not had their support. I am currently living at home, unable to work more than 5-10 hours a week. Granted, I am helping out with coaching a team and taking two online classes, but that still does not amount to a full-time job. Had I not been at home during this difficult time, I would not be recovering the way I am. I would be in massive amounts of debt, unable to work to pay the medical bills, along with being unable to pay for food and housing. I am also very fortunate because I had people who believed me when I said I was not feeling well. All my doctors and family members listened and understood that something was not right with me. Not everyone has that type of support from their caregiving team, and I am fortunate to have had people in my corner helping make sure I got what I needed and when.

Thank you for listening to my story.