Michael Sieverts

Behind the Mask

March 27, 2023

Barr: Good afternoon. Today is March 27, 2023. My name is Gabrielle Barr, and I'm the archivist at the Office of NIH History and Stetten Museum. Today I have the pleasure of speaking with Mr. Michael Sieverts. Mr. Sieverts is an expert at the National Science Foundation. He's also a study participant in Dr. Avindra Nath's long COVID observational study. Today, he's going to be speaking about his long COVID experiences. Thank you very much for joining me.

Sieverts: Well, thank you. I'm glad to have this opportunity.

Barr: Definitely. When did you come down with COVID-19 and what was your experience like when you were dealing with the acute disease?

Sieverts: I was in the very first wave of people to get COVID. I got sick almost three years ago to the day. March 18 of 2020 was the day I came down with a fever. That was right in the beginning. It was so early on that my doctor didn't believe I could possibly have COVID. But I had a high enough fever and it lasted long enough that after a few days, he agreed that I should get tested. That was pretty early in the testing regime. It was still when you had to get proof from your doctor to get tested. It was on the third day that Arlington County, Virginia, had the drive-thru set up for testing. I did that and I got a positive on March 24. At that point, my doctor just thought it was like a bad flu, but that I would get over it—it might be worse than the average flu, but it wouldn't be anything noteworthy beyond that. I just went in thinking that. It took about two weeks for me to get the fever behind me. I had a fever generally about 101-102 degrees that I could manage with fairly rigorous doses of Tylenol and ibuprofen. Then around the first of April, the fever finally started to wane. I was pretty weak and tired, but I said, "Okay, I'm getting better—whatever that was is behind me and now I'll start to get better." For about a week or two, I thought I was getting better. I was starting to exercise again and go for short walks, and I was even doing some work in the garden. That was when one day I just got a really serious tightness in my chest—I really thought I was having a heart attack. My chest was so tight, I could barely breathe. I just had to lay down for a while. I thought it went away. Then I started to do just a tiny bit more and it came right back. I went in the house and just assumed I was having a heart attack. I mean, I'd never experienced anything like my chest being that tight or being so short of breath. I called my doctor, and he said it probably was not a heart attack. He was already aware of how sometimes people who have COVID have this happen when they think they're getting better. It's sort of a second punch of COVID. I thought that was that, and I would put it behind me. The doctor's office did have me come in to do an EKG [electrocardiogram] and a chest X-ray, so they confirmed it wasn't a heart attack and wasn't pneumonia. It was just something where I had to give myself extra rest and from there just see how I improved.

I didn’t improve. It was several months of just feeling really lousy all the time and very tired with a kind of tiredness I've never experienced before—where you constantly feel like you have a lead blanket on top of you. And always dizzy, always nauseous. After three or four months, by then there was enough information circulating that something strange has happened to people who had COVID. People aren't getting better. Because of that I was able to put my experience into some context and say, “Wow, this might be something pretty strange. This might not just be me taking a while to get better.” There was a really good article in the Washington Post at the end of May by someone who'd been a Washington Post science writer named Brian Vastag. He and his wife, Beth Mazur, both had had infection associated illnesses before. Brian had had meningitis, and I forget what his wife had. They both never recovered—they both ended up with these prolonged infections. ME/CFS is what the term is—myalgic encephalomyelitis/chronic fatigue syndrome. Your body never regains the ability to do any kind of exertion, you're just constantly wiped out and have to really limit your days. I saw that article and Brian had been in the NIH study under Dr. Nath for ME/CFS. That was what led me to start poking around the NIH website and say, “Okay, what’s there and how can I learn more about this?” There's an email box for that ME/CFS intramural study, and I just sent an email to that. I've sent emails to generic inboxes before and figured it would probably take a while before I hear anything back. I heard back the next day. They wrote and said the ME/CFS study isn't taking any more patients, but we'll be starting a study of long COVID patients sometime this fall. I said, “Great, put me on the list.” From there, I just checked back every couple of months with the contacts. I was the first or second person to enroll in that study.

Barr: That's really great. Have your symptoms changed over time with long COVID?

Sieverts: Not really. I'm in the group that has had these severe symptoms that have lasted, for me, three years. I've got better ways of managing them [now]. Just having better awareness of them helps me manage them. I'm fortunate that I can live a very limited life where I was far enough along in my career that I retired but was able to still work part time. As for family responsibilities, my kids are grown so I can live a life that stays within the limits that I have to have. But I'm quite limited day to day.

Barr: Can you speak a little bit about how you've managed your severe symptoms over such a long period of time especially as there's not really a cure for any of these things?

Sieverts: Right. It's just about managing the symptoms. For example, from where I'm talking to you, I'm in a bed and I have big pillows behind me. I have a bed table that has a laptop computer on it, so whatever work I need to do can be done from basically a reclined position. One of the things about ME/CFS is it becomes very hard to stand or sit upright for prolonged periods. That’s a form of dysautonomia, where your autonomic nervous system just isn't functioning properly. That's the biggest adaptation I've made—I just have a way to be reclined most of the day. Then I found that I do better on a particular diet—a low histamine diet keeps my symptoms from getting triggered. I just live very quiet days. I just do very little. If I have to do anything significant in terms of writing or reviewing things, I generally will have about two hours a day that I can put into that and then I just have to be very quiet the rest of the day. I can read or listen to things, but I am not able to drive any distance. I can drive a mile or so and get a few groceries, but for the most part I consider myself primarily house bound. Not bed bound, but I consider myself house bound. I can do okay around the house, but I leave the house very infrequently.

Barr: Will you discuss the different aspects of the study from your vantage point—from the different types of testing and examinations that you have gone through to the various personnel you've been engaging with and all the different visits that you have made over the course of the study so far?

Sieverts: I've probably made about six or eight visits to the Clinical Center so far. What this study has done for me is it has really helped me understand what I'm dealing with and given me a good sense of validation. When I'd see my own doctors, my own doctors didn't know anything about this. They were skeptical that it was even anything beyond depression. They were really very willing to discount it as being something else. Once I started to have all these results from the NIH studies, it would change the conversation with them— "Oh, that's really valuable, I'm really glad you shared that with me." The first set of things I did weren't that interesting for me. When the study started, the initial phase of it had a lot of blood tests, a relatively short autonomic function test—that's a test on a tilt table—and the brain MRI. None of that showed anything noteworthy about me. The team sort of suspected that, and that was true for some of the other patients in the study. Then they changed the study protocol. The main difference was they added a longer tilt to it. They made the tilt table test a full 40 minutes instead of five minutes. When I did that, I only made it 30 minutes before I fainted. I was about to faint, and they had to stop the test. That was the first test I did that told me something was different about me. All I was doing was going from lying down to being vertical. I just couldn't do that. I could tell that I was suddenly starting to sweat, and I got very flush. I could just tell I was getting pale. They had to stop the test. Then I was able to recover. That diagnosis meant I had this thing called orthostatic hypotension. My blood pressure crashes. That was useful information for me because I already knew that I couldn't walk very far. It wasn't that I got tired, it was that I got very dizzy. I couldn't walk any distance without getting really dizzy. If I sat up for too long—even just sitting up at the dinner table—I would get very dizzy. I knew something was up. That test helped me understand why I can't walk more than a couple minutes before I get dizzy—something's gone wrong with my blood pressure. That was useful. Then there were tests of spinal fluid. That's just really hard to do. I mean, getting the spinal fluid draw is a very difficult procedure because they're sticking a needle into your back.

Barr: That's scary. Was it painful?

Sieverts: The first time it went without a hitch—it wasn't painful at all. No issues, and it went very smoothly. The second time I had it done, it was a day when I already wasn't feeling well. While they were doing it, I could feel nerve sensations running down my legs. I got really nervous, and they had to stop and then they rescheduled it. The next time I did it, they did it with a really fancy X-ray fluoroscope so they could just guide the needle perfectly. The standard way to do it is you just hunch over and arch your back and sort of hold yourself still in a ball and the doctor guides the needle in that way, but with the fluoroscope, I just have to lie on my stomach and lie still. That was much easier. It's a tough procedure. You're just worried that that needle is going to prick your spinal nerve and that'll be that. My blood tests never showed anything of note about me, and they ran lots of blood tests. It was never anything. I was amazed by how much blood was being drawn in those standard tubes. They were also drawing blood just to store so that years later they could analyze the results. I really do appreciate the people in that department. They're really good. Drawing blood is not easy. The people in the Clinical Center are really skilled. With the spinal fluid analysis, suddenly I had results that showed really major issues with systemic inflammation and things that are similar to what people with Parkinson's or MS [multiple

sclerosis] might have. Again, it's not reassuring to have that—but it is validating. It just helps. It gives me information I can share with my own doctors and say, "Okay, this is what I'm dealing with." It really helps to sort of think about things that might help. There really are no treatments yet. When I read about things that help with neuroinflammation, like some supplements, I can talk to my doctors about whether it might be helpful given what I'm dealing with. That has been a plus. That has been really valuable for me.

Barr: Are there any other tests that you're scheduled for? Do you have to be seen every year to see how you progress?

Sieverts: I'm not sure. I know that the team is figuring out the next steps for that study. There were 12 or 13 of us in the original group. They've added about 20 or so more, but the first group of us did one year and a second year—so we've done one year of follow-ups. That group under Dr. Nath isn't sure what's going to come next because some of the stuff they were expecting to see, they didn't see, and they've seen things that they weren't expecting to see—so the original design of the study doesn't make sense to continue as it is. They're thinking about what to do next and what makes sense for this research. The last time they were very straightforward with me about what they found and that this doesn't match what they were hoping to find. But they know there's something there worth studying.

Barr: What were some of the things they were expecting and what were some of the things they have seen that they were not expecting?

Sieverts: The main thing they were really expecting to see were significant things in the brain MRIs. And they didn't. Part of that is because they didn't have a brain MRI from before COVID. There are some studies that have that—there's some biobank in the U.K. where they have that and where you can see some differences. But just my own [current] brain MRI in isolation by itself doesn't show anything noteworthy. That's the main thing. They were expecting that to be a valuable measure, but it hasn't been—whereas the other things, especially the spinal fluid information, I don't think they were expecting to see as much, and they've seen a lot. That's where it is. For me, I just enjoy spending a day asking lots of questions and just getting time with the different labs. Everyone's figuring this out. People, especially in Dr. Nath's lab, have known about these conditions like ME/CFS for a while, but this is the first time that they've been able to have a group who had the same virus, and the same experience, and be able to follow this group with the same virus around the same time and see what happens in them over time. That's made it really valuable.

Barr: Were there particular people you developed a rapport with having gone so many times?

Sieverts: Yeah, I definitely have. There's Sarah Moore, who is sort of the point person for a lot of the patients—whatever our days entail, Sarah's the lead for getting us around. Then there's the whole team in Dr. David Goldstein's lab that do the autonomic function testing—they've been great. And if I could say Janna last name, I'd say it. It begins with a "G" but right now I'm blanking on how to pronounce it. [It's Gelsomino.] That team is always just very attentive and very clear in explaining things to me, so I really appreciate that. The first year, one of neurologists, Brian Smith, was really invaluable to me—first just explaining everything to me, but then also giving me suggestions for things to discuss with my own doctors, like what kind of therapies might be useful or

what the test results really mean. It's always been clear that the doctors at the Clinical Center can't treat me. I don't go there for treatments, I'm just there to do research—but I can learn from them about things that can help me with my own treatment. They've been very forthcoming with useful information and useful things to discuss with my doctors.

Barr: Do you know any of your fellow study participants, and have you gotten to talk to them about their experiences?

Sieverts: I know one other person who lives in DC. When CBS did a story about Dr. Nath's study, I went out and was part of that. Even before that, NBC did a report on it, and a different patient was in it. I was able to find her through Facebook and direct messaged her. Then we found out we were in one of the online support groups together. We haven't talked in a while, but we talked a lot at first just comparing experiences. It's always nice when you find someone who's going through this very strange thing in a similar way. That was really helpful. Through all my other work, I have connected with people who are in the ME/CFS study in Dr. Nath's lab, and just through this work in support groups, we've become pretty close. We know all the same people, so we talk and just compare our experiences with the study.

Barr: Can you speak a little bit about what your experience has been like being a part of different long COVID groups and organizations and how you share your experience with others and get information?

Sieverts: I do quite a bit on that because I have a background in the federal government, including in federal research funding. I've been able to help understand what's going on and what NIH is funding, the status of NIH's funding, the different dimensions of what's going on with the research study, who the awardees are, and just keeping track of that. I am actually, just through the advocacy work, involved with others at NIH on the extramural side. It's probably very annoying to some of them because of all the questions I asked. I do a lot of work with the advocacy community. A lot of it does relate to NIH because NIH is doing the most significant work on long COVID research at this point. I'm on the board of a group called the Long COVID Alliance. I'm also a member of a group called the Patient-Led Research Collaborative. They've done some really significant work on long COVID research and published some of the more significant papers on it.

Barr: They do a lot with RECOVER [Researching COVID to Enhance Recovery].

Sieverts: In addition to the intramural studies under Dr. Nath, I'm in RECOVER through Howard University. Howard University is the local site for the adult population.

Barr: Have you encouraged others to be a part of studies?

Sieverts: Oh yeah, I always do. Whenever I have the chance, I encourage people to be part of the studies, both because you learn about yourself and because it's so important to the science and keeping it moving forward.

Barr: Before your experience with long COVID, had you ever been part of a scientific or medical study before personally?

Sieverts: I've been on the researcher side. I've never been involved in biomedical science before, but I've done a lot on just overseeing major projects. I studied physics as an undergraduate, and I've mostly been doing science policy as my career. I've been involved in different dimensions—some related to public communication, some related to budgeting and planning activities. I've been fairly immersed in a lot of different aspects of science over the years.

Barr: What do you hope will be accomplished on a larger scale with long COVID?

Sieverts: I really do hope that there are fundamental advances in understanding how our immune systems can go off track. I mean, that's basically what's happened to me and a lot of others. We go through this viral infection—for some people, it's a bacterial infection, like Lyme—and something happens that fundamentally changes your immune system, and your immune system can't get back to normal. My immune system thinks I'm really sick. I mean, all these things that are going on with me are basically my brain thinking I need protecting. It's making me really tired, so I don't do anything exhausting. It's not letting me be energetic. It's saying, "Okay, you need to be quiet, you need to shut down." Even some of these issues with food that I have—it's a form of protection. It's like my immune system is reacting to things that it thinks are a danger. To me, those reactions are irrational. It shouldn't be reacting that way, but it is—and that's a lot of immune reaction. A lot of autoimmune issues are just your body perceiving something as a threat that's not a threat. That's what's happening. That's where some of the most interesting and significant work can come from, because by getting better able to understand that and hopefully manage that and treat it, it would be relevant to a wide range of things, not just long COVID. Long COVID is just the latest in a long history of things where your immune system gets knocked off course by some kind of infection or other disruption.

Barr: Is there anything else that you would like to add about your COVID and long COVID experiences?

Sieverts: The main thing is just that I'm glad you're reaching out to us because for me, being able to get out to the Clinical Center, even as a subject of study, is very informative. It's been incredibly useful to me. Just getting to know the people at the Clinical Center and the staff has all been very valuable—and the people have been great resources for me.

Barr: Thank you for participating in our project and thank you for being so enthusiastic about advancing care for others—not just yourself. It's really admirable.

Sieverts: It does remind me of one thing. I remember when I was reading the consent form for the study. There's a question that says, "Will you benefit from this research?" And the answer is that you will not benefit from this research, because we're just learning. Most of my career, being at the National Science Foundation, I've had to spend a lot of time justifying basic research—research that has no practical ends, and you're just doing it for the sake of doing it. I read that question and said "Oh, that's my wheelhouse. That's a good fit for me." I'm good at research where you can't predict the benefits!