

Anisha Sekar

Behind the Mask

April 14, 2023

Barr: Good afternoon. Today is April 14, 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 Anisha Sekar. Ms. Sekar, most recently, has been the founder and Chief Co-Product Officer at MoneyHash, but she's also had a number of other positions throughout her career. Today, she's going to be speaking about her long COVID experience as well as her work to help others like herself as a patient advocate. Thank you very much for being with me.

Sekar: Thank you so much for taking the time.

Barr: Absolutely. Would you briefly describe what your life was like before COVID-19, and what the acute phase of your illness looked like?

Sekar: Absolutely. Pre-COVID, I had an incredibly busy and active lifestyle. At the time, I was a senior product manager at a financial services company and then moved on to co-found a startup also in the finance space. I was distance running and doing marathons. This was of course during the 2020 lockdown, so less of that, but I was really involved in mutual aid for my community and taking classes on the side, just spending a lot of time doing a lot of different things. When I caught COVID-19, I was living alone, and so I went through the acute phase by myself. I remember a Zoom call with a friend of mine whose mother was a nurse before I got sick. He was saying that she learned from the other nursing staff to flip the patients over, so they were lying on their stomachs and that helped their breathing. I was by myself in my apartment, kind of struggling to breathe. When I called my doctors, they said to stay home from hospitals and that it was probably just anxiety. I remembered what my friend told me and laid on my stomach for as long as I could. It was a terrifying experience.

Barr: When was this?

Sekar: Oh, I'm sorry. This was early June of 2020. Onset was June 7 of 2020—tail end of the first wave. I'm an earlier adopter—not exactly the kind that I wanted to be, but it was pretty early on. It was at a time when not a lot was known, and we were kind of left to figure things out by ourselves. I made a full recovery from my acute symptoms after about two weeks. That lasted for maybe three or four weeks—almost a month. That's when I had my first crash, which led to all of my symptoms returning and was in retrospect the onset of my long COVID symptoms.

Barr: Can you describe what some of your long COVID symptoms were or are? What made you think that you could have this post-viral disorder, which is now known as long COVID, but was not so widely known at the time?

Sekar: My worst symptoms were, and continue to be, fatigue and brain fog. Post-exertional malaise is another major part of it. Basically, if I overexert myself, even in seemingly trivial ways like staying on a Zoom call too long or doing laundry for too long, a day or two after I will feel unable to move and feel poisoned—just like the worst flu of your life.

Barr: It's crazy because you used to run 10 miles a day.

Sekar: Yeah, it's kind of unbelievable in retrospect, but that also can happen to anyone.

Barr: Do you have any comorbidities? You're very young.

Sekar: In retrospect, I did. One thing that's been revealed throughout the course of the study of long COVID is that a lot of us had these underlying conditions that were maybe well managed or controlled, but with me and with other people, things that were previously controlled, or that we didn't even notice, have come into play. For example, I'm hyper mobile. Part of that is my joints just pop out all the time, but because I was living a very active lifestyle, my muscle tone was able to keep my joints in place. Now that I've been unable to do that, they're just popping out all over. It turns out that connective tissue disorders are correlated with long COVID as well. It's a lot of these pieces of the puzzle that weren't clear to me or to us and are becoming clearer.

Barr: Other than brain fog and fatigue, what are some of the other symptoms that you experienced?

Sekar: I'll try to keep the list short because I don't want to spend the entire time on listing all the things. I also suffer from postural orthostatic tachycardia syndrome. Basically, if I'm sitting upright or standing too long, my body isn't able to handle it. My heart rate rises, and it triggers some of my fatigue issues. I dealt pretty severely with neuropsychiatric symptoms, which were honestly terrifying at the time because we thought of COVID, and even to some extent long COVID, as a respiratory only illness, yet I was having these flashes of uncontrollable anxiety, uncontrollable anger, depression, and suicidal ideation. That didn't seem to be COVID or long COVID. We are now, of course, understanding that it is. There were a lot of GI [gastrointestinal] issues and sensitivities to food that I hadn't noticed previously. I think "brain fog" undersells the complexity of it. I want to dive into that a little more. Ed Yong had an amazing piece in *The Atlantic* about brain fog and how it takes away something essential of yourself. I used to be creative, thoughtful, empathetic, and an amazing problem solver—and sometimes I'm able to be these things now, but I have to work on it. It's not enjoyable. It's not a joy-bringing process. It's something that is terrifying because I'm confronted with the way that my brain used to work and trying to seem like it works and often failing.

Barr: Those are some really good points. Can you talk a little bit about how long COVID has affected your daily routine and a little bit more about your outlook on the future for both you as well as others who are close to you? As you mentioned in a piece you wrote, it doesn't just affect you but also your loved ones.

Sekar: Yeah, absolutely. It has upended my life to a degree that I couldn't have imagined. I'm no longer working. I had to resign from my job due to long COVID. I had to step back from my volunteering. Physically, I'm much more dependent on either automating things or breaking up tasks so that they're more manageable or relying on my partner for help. For the most part, I'm largely house bound. I spend most of my time in bed or on the couch. I'm able to leave the house to go to the coffee shop down the block, but that's generally it. My life is based out of my home in a way that continues to be true even as restrictions are lifting and more people are going outside.

Barr: What prompted you to publish “A Practical Guide to Long Haul COVID”, which has been referenced many times by other long COVID groups and advocates? Will you discuss some of the battery of tests, treatments, and lifestyle changes that you've endured as well as some of the practical advice that you have for others?

Sekar: Absolutely. I mentioned earlier that it was like a puzzle piece, and that's really what it felt like, especially at the time. This was a post-viral condition that not many of us had a name for. Not many of us could talk as having a cohesive set of symptoms. There was also so much fear around whether my organs were working or if I have blood clots. I was very lucky to find a supportive primary care provider who was willing to run tests and was willing to believe me when I said it wasn't just anxiety and depression. What I wanted to do with that guide was to share with people everything that I've learned from other sources, including the Body Politic Support Group, and from existing experts in ME/CFS [myalgic encephalomyelitis] and dysautonomia, and put it all in one place, because I had to cobble all that together myself. When you're sick and you're trying to figure out if this is even real or if this is just in my own head—and on top of that, trying to figure out what to do about your illness—it is so overwhelming and exhausting.

Barr: How long did it take you to compile it? It's quite extensive.

Sekar: Oh, my gosh—about three months. This is another one of those “Man, my life is so different” moments because pre-COVID, it probably would have been something that I would write in two or three days. Having to pace myself and only being able to do 15 or 20 minutes a day, it took a lot longer. But it was also something that was incredibly clarifying for me and a way to take this horrible experience that I've been through and hopefully bring some good to others who are unfortunately suffering the same thing.

Barr: One of the things that you emphasize in this piece as well as others is the cost of all these treatments and tests, and not everyone in this country is lucky enough to have those resources. Can you share a little bit about your thoughts on that given that this disorder affects so many different parts of the body and it's unclear?

Sekar: Absolutely. So many different factors of long COVID make it a financial nightmare. The first one, again, is that uncertainty—some treatments work for some people, some don't. It's very hard to get a couple of days' worth of a prescription just to see if you can tolerate the side effects. It's very hard to find a doctor who's in-network who listens to you and believes you. Even more than that, rest is a key treatment for long COVID, especially early on, and rest is so expensive. You need paid sick leave; you need FMLA [Family and Medical Leave Act]; you need to find a way to take care of people you have responsibilities over if that's applicable to you. All

of that costs money. As pandemic related protections are ending with the public health emergency, I worry that it's just going to get worse. I'm incredibly lucky to have the financial resources to pursue treatments and also to prioritize my own health instead of working myself into such a state that I'm even sicker. It is really demoralizing to see that becoming less and less of an option as time goes on.

Barr: Definitely. How did you become involved in NIH's RECOVER [Researching COVID to Enhance Recovery] Initiative and what committees have you participated in?

Sekar: I found out about the NIH RECOVER Initiative through the Body Politic Support Group and the Patient Led Research Collaborative, which is an outgrowth of that focused on research and scientific advocacy. I am on the Quality Assurance and Data Integrity Committee as well as the Communication Subcommittee. My background as a... I'm sorry, brain fog setting in. My background in tech, and prior to that, studying computer science and statistics in college, and then also being in a product role that is very communications and narrative focused, definitely play a role in that. Especially with the data committee, I'm asking questions like "What are we trying to see within this data and what are we missing with what we're getting in?" Questions like "Within our attrition rate, are there certain demographics that are more likely to be missed? What populations are excluded when we see certain patterns on diagnosis and symptoms?" I'm asking those meta questions of what the data is telling us and what we should be caveating. With the communications group, I'm just taking scientific literature and taking this large initiative and breaking it down into things that make sense to everyday people and are digestible—and also toeing that line between being honest about what we've learned and not being confusing. That means being very upfront about study limitations. That means being clear that this is incredibly a work in progress and for all that we have learned there is so much that we have yet to know.

Barr: For both the communications and the study committee, do you just see the aggregate or big picture or are you privileged to see particular studies, and do you get to make comments on those?

Sekar: I'm part of some of the manuscript working groups. For certain papers coming out, I might be involved with essentially providing a patient perspective. As a patient, I would expect that the study design might need XYZ caveats. Or when we're framing the conclusions, I would recommend that we phrase it in this way, so that it's very clear that we're saying what we want to say. I've been lucky enough to see some of the upcoming manuscripts, and it's really amazing to see that work coming out—absolutely.

Barr: For some of the communications teamwork, how have you applied some of your financial and inspirational expertise? In the past, you've done TED talks and you've done things on social media—how have you applied that to long COVID?

Sekar: The biggest thing is that nothing happens in a vacuum. When we're putting out a study and we're asking for participants to register, that's all happening in the context of—I'm sorry, I'm going to have to take a second to think... It's all happening in systems. We want to make sure that we're being upfront about what we're able to do and what we can't do, and when information is coming in and coming out, making sure that it's properly contextualized. Part of my expertise, and what I'm hoping I bring to the table, is not just coming out with simply

what we found in a couple of bullet points, but also what it means and what you need to keep in mind—here's how you can take this and maybe apply it to broader set of principles.

Barr: What do you feel that you have learned through your engagement with RECOVER as well as through your long COVID journey, both as a patient but also as a person who is involved in a number of groups?

Sekar: My biggest personal learning is that I had a lot of profoundly ablest beliefs and still do. It's absolutely a work in progress to unlearn that. Learning to focus on access as something that should be a right was something that I had and am continually having to learn. The other thing that I have learned is that we, as a long COVID group, are incredibly, incredibly privileged to have a body of knowledge to work off of from existing post-trial conditions. The ME/CFS community is one example. They had every right to be angry at us for coming in late and getting so much attention and so much funding, and yet they embraced us with open arms. I've been so privileged to be connected with some people in those areas who are giving what such little time and energy they have to share their wisdom. I'm just in awe of it. Going back to the systems thing, the biggest thing that I have learned throughout this entire journey is that long COVID didn't come out of nowhere. There are long histories of post-viral illnesses. If we do things right, we have the opportunity not to just help people with long COVID but help people with a range of conditions. That's what we should be using our platform for. It's not just long COVID. It's for anyone who could benefit from this research.

Barr: Definitely. What have you found most frustrating so far—obviously, the brain fog with you personally—as part of the research process into long COVID and treatment?

Sekar: There's a lot of bias around illnesses that are difficult to track by normal tests, especially illnesses that disproportionately impact marginalized groups. There's a lot of dismissal, and there's a long history of that. What has been frustrating is that those biases can even creep into current research—so funding things that have been both debunked and are incredibly alienating to the community, like cognitive behavioral therapy or graded exercise therapy—things that come from the idea that you're sick because you're not trying hard enough. It is incredibly frustrating to see that even decades after the initial trials—which have since been debunked—promoted those ideas, that it is still so deeply pervading the way that we view people with long COVID and the way that long COVID should be treated.

Barr: Yeah, definitely. What do you think should be some next steps for RECOVER as well as for the long COVID community?

Sekar: For RECOVER, we need to look at treatments. We all need answers, and we need them yesterday. This isn't just for RECOVER; this is for the global everyone. We need to work to make sure as public health emergencies end, access still remains—we still keep mask mandates in health care settings, and we still provide sick leave to people. Going back to what I was saying earlier about the expenses of treatment and even rest being a treatment, we need to make sure that people don't have to be healthy to survive. For the long COVID community, we are very, very lucky to be in a time historically where we can be online—social media didn't really exist 20 or 30 years ago—so we can remain vocal. We can remain a part of the overall disability and post-

viral illness community and use our volume and the current attention on us to lift everyone up. That's the best thing we can do with our voices.

Barr: Is there anything else that you would like to share about your experience with long COVID or your work with RECOVER?

Sekar: Long COVID is incredibly amorphous as we understand it now. Knowing that, we all need to come from a place of curiosity and belief of our patients if people are coming in. Speaking of my experiences very early on, if people are coming in and saying, "I did not have this experience, and now I am having it and it is bad and I need help", that is all you need to hear as a clinician. If you are hearing from your patients that they're trying a treatment and it's not working, that needs to be your baseline. At a higher level with RECOVER and these initiatives, listen to the community and listen to the people who have been doing this work for decades, because they're an incredible body of knowledge that we are very privileged to have access to. And we need to be listening.

Barr: Definitely. Well, thank you so much for all your work, especially considering your own condition. I really appreciate it and I wish you and others only the speediest of recovery.

Sekar: Thank you so much. Thanks for taking the time on a Friday evening and I hope you have a fantastic weekend. It was great talking to you.