Rebecca Letts
Oral History
July 21, 2023
Interviewed by Gabrielle Barr, Archivist, Office of NIH History and Stetten Museum, NIH

Barr: Good afternoon. Today is July 21, 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 Ms. Rebecca Letts. Ms. Letts is a Long COVID patient as well as a Long COVID advocate who is affiliated with the NIH's RECOVER program [Researching COVID to Enhance Recovery]. Today she is going to be speaking about her Long COVID experience as an individual, as well as some of her advocacy work. Thank you very much for being with me.

Letts: Thank you so much for having me.

Barr: Yes, it's very exciting to get to talk to you. To begin, would you briefly describe what your life was like before COVID-19 and what the acute phase of your illness looked like when you and your family fell ill in March of 2020?

Letts: Before COVID, I was a busy stay-at-home mom in a small town in California. I played a big role in coordinating and leading local volunteer groups. I was really outdoorsy and active. I loved hiking and camping, taking my kids on outdoor adventures, and all sorts of adventures. One of the two summers before COVID, I had taken my kids on a month-long tent camping trip up the Pacific coast all the way into Canada. Just myself and my kids because my husband couldn't come with us. My days [were] packed with all sorts of events and interests and obligations. With my volunteer organizations, I coordinated and planned a lot of events for our town, and schools, and scouting organizations, and that sort of thing, fundraising events, and just fun things.

I was really active, but the only health issues I had were allergies. I had some severe allergies that stemmed from a year before COVID, I had to have a hysterectomy because of severe pain. That was medically necessary. From that I had a systemic allergic reaction because they gave me the wrong antibiotic. For the whole year before COVID, they were trying to figure that out with all these severe allergies I had, which turned out to be undiagnosed mast cell activation syndrome, which you'll hear about in the whole Long COVID journey.

The difference between before COVID and after COVID was dramatic. Even after my surgery, I planned a giant school event and was there the whole day, with 30,000 steps, and doing all of these things regardless of having a surgery and having all of these allergic reactions. The difference was still huge—post COVID and pre-COVID. Then my acute phase of COVID was really early on in March 2020, before we even knew what COVID was in our small town on the central coast of California. My youngest son actually brought it home the last day of in-person school in March. He was under the weather and then he had really unusual symptoms that we didn't connect it to COVID at all. I took care of him in my room because he was vomiting throughout the night. My husband moved to another part of the house so that it wouldn't affect his work. I was taking care of him. By the end of the week, I had stereotypical COVID symptoms. So I went into quarantine.

At first, I was really sick with—well, actually, not at first, because it took me several days. I had things that I didn't connect at all with an illness—severe GI [gastrointestinal] issues and the loss of appetite for multiple days. I just I didn't think I was sick at all. And then I got fatigue and body aches and chills. I realized I was sick and went into quarantine. The next morning, I woke up with—I couldn't breathe, I started getting a low-grade fever. And it got worse from there. But the first four days were nowhere near as bad as starting six days in. It was so bad. It was like having boulders sitting on my chest. I couldn't breathe without the use of my inhaler for my allergies.

I had reached out to my doctor who didn't reach back. I just heard from the COVID testing people who said I couldn't get a COVID test because I hadn't been out of the country. I hadn't seen anyone who was out of the country and hadn't seen anyone who had a positive COVID test. I could not get tested. They said to only go into the hospital if my lips turned blue. We thought that I might die. It really felt like I was going to. My husband wanted me to make a video of myself for my children. My children at that point were 8, 10, and 11. I could not make a video. It was just the idea of it was just making me so scared. I was so sick. I could not breathe. My fever had risen. I think I was not mentally able to process what was going on either really. I just was in the illness thinking that I couldn't keep going. That lasted about four days. One night I didn't even sleep because I wasn't sure that I would wake up.

Barr: That's so scary.

Letts: It was. It was really scary. Throughout that, I sent a couple of messages to my doctor and didn't hear anything. I did feel like we were on our own. But on the 10th day of after my fever, my body aches and chills, and not being able to breathe started, I woke up and it felt like the boulders were gone. I still was having chest congestion and breathing issues and all the other symptoms, the body aches, the chills, sore throat, a bunch of things. But I felt relief like I was going to maybe survive. I thought okay, now I'm going to get better. Until then I always had illnesses that you have, you get sick, and then you get better.

Then, in the next week, I didn't get better. I started getting worse with other symptoms, which was really strange to me. I kept updating my doctor, and she did get back to me then and said, "It's odd that you're not getting better. You should come in." She did not see me. She ended up having me go to urgent care. She actually did look in the door and see me, but she did not physically treat me or do anything that was doctor-like. I saw an urgent care doctor who told me I had allergies.

Barr: That's so cold. Had she been your doctor for Long?

Letts: A few years. I felt pretty neglected. So the urgent care doctor thought I had allergies. This was three weeks in, maybe three and a half. They did chest X ray and said I had pleurisy in my chest. And they did a COVID test then, but it was negative. And my doctor did call me after and said, "Well, you don't have COVID. I don't know what's wrong with you, but you didn't have COVID." And even then that doesn't make sense because it's been three and a half weeks. So wouldn't it be negative? But very few people knew much then. Most people seemed to think that if you had COVID, and you were still sick, you should still have a positive test. But not my doctor. So that didn't make sense to me. I was reading every study that was coming out by that point, and I knew that it would probably be negative.

Barr: At that time who of your other family members had COVID, too, and that you are caring for them?

Letts: As soon as I got sick, I was alone in a quarantine. My youngest son had been sick first. We had not made the connection with COVID at all, because he started out with just not feeling well a little bit. With kids, sometimes they just don't feel well. You kind of just go along with life. It was a different world before COVID. And that was the world. Then he broke out in this chickenpox-like rash that was also not presented as COVID symptoms, right? Rashes were not listed yet. And still aren't listed enough. It was a really weird rash. It was chickenpox-like, except it didn't itch, it hurt. And it didn't end up scabbing. And several days into that he started vomiting profusely. Then he was lethargic for days. He didn't actually get better. He's my Long COVID kid. It went from there to chronic migraines, and some fatigue, and chronic nausea, GI problems, and then went on. I'm sure you'll have another question about that later. It progressed to other conditions and symptoms.

Once I got sick, he moved to his room. And then nobody else got sick at that point. He was alone in his room. I was alone in my room. This is the really odd thing—our family stayed in a household quarantine. My husband was really careful about things coming in and things going out. They did the quarantine of items going in and out. Then my room was quarantined. There was a literal five-day quarantine of things coming in and out of my room to the rest of the house, which is I know a privilege to be able to do that. We only have two bathrooms in our house. I feel bad for the rest of the house. Having to use the same bathroom for a lot of the last three and a half years actually. When I had a fever, it wasn't a high fever, but it was a low fever that did not go away. We weren't sure when I should come out of quarantine. My doctor was not helpful at all. She said, "You could just come out of quarantine. You're not contagious, it's not COVID."

We weren't sure because I was still very sick. I felt very sick. I was actually getting sicker, not better. I still had a fever. I missed my middle son's birthday. I missed Easter. My middle son's pet died. I could not comfort him. I could not attend the pet's funeral. I mean, that can sound trivial, but it was not trivial at the time.

Barr: But you're the mom, you want to be there.

Letts: He was sobbing. He had just turned 11. He was sobbing. And my husband was trying to do everything. But he didn't know all of the instinctual mom jobs. There was one point when I was trying to figure out what's going on in the house. He was cleaning up the pet cage—it was a bearded dragon—while my daughter and other son were trying to comfort my son in the living room. I called my husband. I said, "You need to be with our son who is sobbing." He's like, "Oh, I'm trying to help with the cage, so he doesn't have to do that." I'm like, "Our daughter should not be the one who is comforting a child." I have years of things I have missed—events. I just had my fifth to seventh COVID infection and ended up with a really long quarantine. So, it was very reminiscent of the first one.

So let me go on about why it was a long one. When I came out of quarantine—after a while, we decided I better come out of quarantine before my other son's birthday. I hugged all my kids and everything. Within a week, my middle son was sick. It seemed like a normal illness. It was a sore throat, cough. He didn't feel good. He gets really emotional, especially when he's younger when he gets sick. He cried all over my husband. Within four days of him getting sick, my husband got sick with COVID symptoms. He was not able to have a positive test for that. But he lost his smell and taste. He had tight-chest type breathing for months afterwards. We assume that it was COVID as well. But my husband had those symptoms. My youngest son had test results that indicated that it was also COVID. He had lung function tests later in the fall and cytokine and other tests later. All of his conditions indicate that it was COVID and the same with myself.

So we were diagnosed with Long COVID and had a history of COVID in the next year. It was hard for people in March 2020 to get tests. It was a long journey to prove that we had Long COVID as well.

Barr: Can you talk about some of your Long COVID symptoms a little bit. I cut you off, sorry. You had started to describe you had pleurisy in your chest.

Letts: Well that's almost minor compared to everything else. It's actually kind of a dreaded question. Often new people with Long COVID will go on to support groups and ask, "What are your symptoms?" And it's just like, "Oh, I'm just gonna leave right now." But it is important to talk about it so that people recognize what it's like. Sometimes it's mentioned that with Long COVID you can have over 200 symptoms. A lot of us have over 200 symptoms or have had at one time or another 200 symptoms. I often have up to 100 symptoms a day. When I talk about symptoms, I'm going to talk about the worst ones, the ones I'm thinking of right now, the primary ones. My brain doesn't work, I'll be talking about ones that pop into my head or ones I've written down. But first of all, pain. I have so many kinds of pain. I have small-fiber neuropathy, which itself encompasses a lot of different kinds of pain, migraines, GI, so gastrointestinal pain, joint pain. It feels like my bones hurt, my veins hurt, my eyes, my face, my lymph nodes. I have Costochondritis [chest pain from inflammation of cartilage and bones in the rib cage] which is something I started early. But I still get reoccurring. And I have so many other kinds.

Then one of the next really bad ones is malaise. I feel like I am sick all the time. When I got sick in March 2020, I have not ever gotten better. I have not had a day that I have not felt sick. On a good day, it's like I have the flu. Basically, I feel like I have the flu all the time—at least the flu. And then on other days, I have all the symptoms of malaria. And I have to still go on with my day.

One more really bad symptom is post-exertional malaise. That means that just doing, thinking, or feeling too much can make my symptoms get worse in the future. It can be a couple hours later, or it can be within the next couple of days. And it can last a variable amount of time. It can last the rest of the day, or it can last weeks or months. It often makes my malaise worse. I will do something, have too many appointments, in one day. And then for the next week, I will be really ill and not be able to get out of bed. My pain will be higher.

My other chronic conditions, that either were triggered by Long COVID or exacerbated by Long COVID, are worse for that time period. For example, ME/CFS [myalgic encephalomyelitis/chronic fatigue syndrome] is the one that with the post-exertional malaise. For that one, I can feel like I'm actually ill with COVID or, like I said malaria for that time or a really bad flu. However you want to look at it. A lot of my symptoms that I've been having in the past from other more recent COVID infections, just keep adding to my malaise, my post-exertional malaise. Like right now, I had another COVID infection and each time I do too much, my lung congestion keeps coming back. That's new actually, because I haven't had that in years since my first couple of COVID infections. It's getting reinfected and that's really frustrating. But I'll also have other COVID infections that were more neurological—I got tics from Omicron and stuff. Sometimes that will come back with post-exertional malaise. It can vary.

Sometimes it'll all come back at once if I do too much, and I'm just a complete mess. That can be hundreds of systems that just get worse. Then of course, there's fatigue—I always have fatigue, but that definitely gets worse with post-exertional malaise. My ME/CFS is what I consider moderate. On good days, that can be mild where I can do things and I can ignore the fatigue. But it's really not even so much fatigue because when it gets too severe because I did too much, it's more like paralysis—both my mind and my body. It can be hard to even move my hands. I get stuck in different positions, or my brain gets stuck. It can be physical or mental or both. It's often at the end of the day if I did too much or if I did too much on multiple days then it could be a whole day where I'm stuck. I often need help to do basic things. If I've done too much for a couple days and then by the time I need to get ready for bed I can't. I won't always know that that's going to happen. Sometimes I'll just be in a place where I'm getting ready for bed and then all of a sudden I'm just stuck sitting somewhere—totally awake and not able to move. If I don't have my phone with me, I can't tell anybody. I have to wait for someone to find me.

I also have POTs [postural orthostatic tachycardia syndrome], which is a dysautonomia, an autonomic dysfunction. I get a whole range of symptoms but the most obvious to the outside world is fainting or really bad dizziness and temperature-regulation dysfunction. I have no ability to regulate my own temperature, or very little actually because I have some. I have issues if it's too cold or it's too hot. I often dress very unusually. I'll wear a ton of clothes in the winter. Even when other people are in T shirts, I'll be in several layers of wool and gloves because it's too cold for me. Then in the summer, I will be inside in the air conditioning when other people are enjoying the sunshine. It can be really difficult because I have pre-syncope [feeling that you are about to faint] all the time. Even just stressful situations can make me very, very lightheaded and I don't get enough blood in my head. I don't think very well a lot of the time. I have difficulty with social interactions because you need more blood in your head to do that. I have found that getting IV fluids on top of all the other medication that I'm on for POTS and other conditions helps. So that's a recent thing. It basically boosts how much fluid is in my body totally so my heart more easily can pump blood throughout my body including to my head. So that's part of why I can do this interview right now.

And cognitive impairment is a huge one. A lot of people call it brain fog. I don't really feel foggy, so I don't like to call it brain fog. It is more like there's something actually wrong and missing kind of, but it's not all the time. It can vary how much and so I have executive dysfunction really badly. I have to do a lot to overcome that. I don't remember things at all. I have to write down everything and have a ton of reminders. Things have to be in front of me for me to remember. It's not even a matter of importance, because I forget important things all the time. I don't know. It's really a horrible one. On top of all of the other stuff, you lose who you are, and how you can live. I used to remember all the details with my volunteer jobs before—it was kind of an extension of actual jobs that I used to have of program managing and event planning and stuff where I had so many details, and I could remember an entire calendar. Now I have none of them. Nothing is in there. I am lucky when I can just remember how to find the information I need. That's the best I have now. I have a hard time not helping with things. I am still doing some local volunteer work, as much as I can do virtually.

Barr: It's in your nature.

Letts: But it's really, really hard. It's also a little thankless when it's this hard.

Barr: I had a question about why you've had so many COVID infections. Is that common among people with Long COVID? Do you have an idea of why?

Letts: I think for a lot of us, it is common. My immune system is dysfunctional now. I catch things really easily. I catch lots of things really easily. Plus I have children in school. We didn't get any new COVID infections when there was virtual school. We had limited infections when the kids wore masks in school. We did get some. The kids were in virtual school for a year and a half, I think. And they didn't get any new infections. They didn't even get colds, which was amazing. And, of course, then I didn't get anything besides my chronic illness, which was enough, but it was a good because then I could tell what was post-exertional malaise. It was easier for me to understand my illness.

But then when they were back in person in school, they got Delta within the first week-and-a-half of school starting. They got Omicron within the first week of school starting after Christmas break. They got another Omicron [infection]—that was actually on a family vacation. It wasn't school that time. We thought it was safe because we were just all together. But you know, some people travel and that happens.

The following year, unfortunately, PCR tests [polymerase chain reaction tests, which detects RNA from the virus) were really hard to come by. We got so many illnesses from school. That's when I don't know how many COVID [infections] I had. We had four confirmed before then. We had so many illnesses last year, two of which I think might have been COVID. I have never tested positive on—except for maybe once—but I think maybe I haven't ever tested positive on the antigen tests. They just don't work on me. So I have to get a PCR test. I have to either get a PCR test or depend on my family to test positive around me.

Last year, they just weren't testing enough with the illnesses that we're all having. It was hard for me to go get PCR tests at the exact right time, because I have to take them at exactly the right time. This [COVID infection] I just had, I had actually gotten some of those at-home PCR tests in preparation. I took it on the first day I was sick and had a positive result and that was the only way I got this one. And I was able to get antivirals. Last year I got sick so much and I was never able to get antivirals, because I didn't know for sure if I had COVID. I'm not sure, but for some of them my body reacts the same way COVID does after the fact.

Barr: Before we move on to your work with RECOVER, how do you manage your own health issues with caring for your loved ones both when they're sick, but also on a day-to-day basis? I mean, you're still the mom and you have ideas of what you want for your kids and what they should be doing, and knowing how a household runs. How have you dealt with that?

Letts: That's been really hard. I've had to give up control and power. I used to be the default parent, the person in charge of the household, and now my husband is. I'm lucky that I have a husband who is willing to do that and can do that. He has taken time off of work to do that. We make a lot less money. We were never wealthy. He works halftime and we just try to save money and try to live frugally because I can't do all the stuff for the kids, and I can't be the person in charge of all of the household stuff. I can't cook dinner most days. I can't do the dishes. I can't clean the house, can't walk the dog. I can't even be the person who is on the kids for everything every day. I do a lot. I do as much as I can. We have an arrangement that I have to communicate if I can or can't do something.

Our kids do a lot, too. They're not little now. The youngest, the long hauler, is 12 now and my eldest is turning 16. They do the yard work. They do a lot of the dishes. They do their own laundry; they do the cleaning, and they're willing to help. A lot of the stuff is actually just supervising them. My job mainly is to be a mom to them, be there for them emotionally, and make sure that I troubleshoot problems.

Barr: Is your son who's the long hauler doing better now, or is he still contending with a lot of health issues like you are?

Letts: Both. He is doing better. The difference is very dramatic, but he's had a difficult journey. He's actually gotten worse from reinfections. So, like me, he got POTS and ME/CFS, but they're much milder. But with one of his Omicron reinfections, he developed PANS [Pediatric Acute-Onset Neuropsychiatric Disorders], which is a really horrible condition. Its main thing is brain inflammation that causes behavioral changes. It basically changes a kid's personality completely. It can disrupt the entire family. It's not something that goes away for a long time, so he still has it and he's always on the brink of flares.

We worry about new illnesses because new infections can cause it to flare again. He can get really bad. He had an illness last year, which may have been a flu or something like a flu, where he went from being almost a normal kid one day—with some of his chronic symptoms and was functional at school–to having a complete meltdown at school and being a runner. He was running away from staff, looking for things in his backpack frantically. It can look like a severely autistic child when they're flaring. They can also be a danger to themselves. They rage. They regress. When he was really bad in spring of 2022—I don't even know if he remembers a lot of that spring—but it was like having 100-pound toddler who wouldn't listen. He was not a compliant 100-pound toddler. He would often hit and try to do damage. He was destructive. For weeks, he would only watch Marvel movies. He couldn't do any schoolwork. He couldn't talk.

Barr: Is this common among children with Long COVID?

Letts: It's not uncommon. It's not the most common, but it's known enough that when he developed it in a reinfection, I knew what it was because of being in Long Covid Groups or Chronic Illness groups. Because of that, we got help much faster than most people would. I kind of knew what I was looking at. It's something that happens overnight after a new infection. It happened about three or four weeks after he had COVID, which is normal with immune system effects. He had Tourette's-like symptoms. We were taking video of him and sent it to the pediatrician. None of his doctors knew what they were seeing, but I said, "Could this be PANS?" And they said, "It could be. We can refer you to the PANS doctor in our institution." So they did that. He got a diagnosis when we saw the doctor. It's one of those things that can take many, many years to get diagnosed in a normal circumstance, because not that many people know about it.

Barr: I've never heard of it.

Letts: You might have heard of PANDAS [Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infections]. Pandas is a subset of PANS but with strep. There are some treatments. We're still waiting to see if he can get IVIG [intravenous immunoglobulin], but we haven't heard anything. He's on different kinds of medication for anxiety and sleep. He got a vaccination for the different kinds of strep antibodies because he was a little bit high on those.

He's doing much better in that he was able to go to school this year and was mostly functional. But he has waves where if his other chronic illnesses are flaring, PANS will start to flare, especially if he's fatigued, or he's fighting an illness. Then he goes into this chanting kind of episode. He is not always rational, and he'll do behaviors that are very immature, like many years too young for him. He will act like he doesn't have empathy and have a rage behavior, and he won't be good at following directions. It's just a number of behaviors. He'll be obsessive about different things as well. That can be different for every child with PANS—what they're obsessive about—but OCD [obsessive-compulsive disorder] is part of the symptoms.

Barr: How did you become involved in NIH's RECOVER Initiative, and can you talk a little bit about how you became a part of the Integrative Physiology Task Force and what your role has been?

Letts: I was recruited to help with RECOVER back at the very beginning, right when they realized they needed to pull on representatives. The president of the COVID-19 Longhaulers Advocacy Project was one of the people who was asked to recruit some individuals. She asked me because she knew that I had a Long COVID kid and that I had Long COVID myself and that I had a number of associated conditions and was knowledgeable about a number of aspects of Long COVID. Plus, I had had Long COVID since March 2020. A lot of us who have had Long COVID since then have educated ourselves and also have experience fighting our battles with the medical system and speaking up for ourselves. She needed some pediatric representatives, so she recruited me. I started helping at the beginning of the planning stages. We did that in June of 2021.

Then when they started the next stages and needed representatives for task forces and committees, they asked me to register, sign up, and they did pick me. I'm in a couple of different groups. I'm in the Integrative Physiology group. I'm also in the NCEG [National Community Engagement Group] in one of the subcommittees. You'll have remind me what NCEG stands for.

Barr: We can look that up.

Letts: I've also been helping with publications. That's an ongoing thing right now. I think that'll probably be going on for a while. I'm not sure the task force is because they're reorganizing, and I have to read through that. But with the Integrative Physiology Task Force, it's a group of research doctors from many different institutions in different disciplines. For the last year or so, we have been helping finalize some of the research tests that are needed in the RECOVER project for tier two and tier three testing protocols. They're usually tests that multiple specialties are involved in. Multiple specialties get together and discuss what triggers are involved with the tests—like what symptoms will trigger people needing to do that test for research purposes; how many people will be doing the test; and a lot of the details about that. Also, we discuss a lot of things in relation to RECOVER in terms of issues that are in a cross specialty and important to testing protocols. That's what we've been doing so far. There's been some talk about white papers.

Barr: Sorry, I cut you off.

Letts: No, go on.

Barr: Go ahead. No, you were saying.

Letts: I didn't know what I was gonna say.

Barr: About the testing protocols. Can you talk a little bit about that? What kind of recommendations you all have made with that?

Letts: Well, it's really important that the representatives are there because we actually have experience with the tests and [are] also patients who have it, who are on one side of taking the test, both in a clinical situation and in research situations. It can be really helpful when you have a roomful of research doctors because they not only have their perspective as a research doctor, but they often have it just from their specialty. When the patients are there, and the representatives, they—I have my own perspective from taking the tests. I'm actually a RECOVER participant; my son is a RECOVER participant. So we go to the sites; we know what it's like to participate, but I've also done a lot of these tests as a patient. I'm on countless support groups where a lot of people discuss these tests. I know what happens across the country with these tests, often more so than the individual PIs.

They'll be talking about autonomic testing and saying whether it's normal to have nitro with tilt table tests [a test to evaluate unexplained episodes of lightheadedness, dizziness or fainting; nitroglycerin may be administered to elicit a fainting response.] They would all say that it's abnormal and that you shouldn't do that. And the other patient rep and I will say, "It's odd then that all over the country, people are getting tested with nitro." It's not a good experience. People don't like it. It's actually a very bad experience. I can say, from both my experience and from the experience of people across the country, and in other countries, I would not want to have that as part of the autonomic testing if that's the choice. I can give my perspective on something in particular. There's been other situations where they're like, "Should we do this test? Is this even applicable to past patients?", I can say, "Well, that condition that that test tests for is actually very common anecdotally in Long COVID populations." It might be a useful test to get interesting research results for another sort of test. There can be many ways that my information can be useful.

Barr: Recently, there's been a lot of comment that some of the RECOVER tests caused more harm than good in some of the patients, [they] make people too tired, or it's just not right for a patient's condition, given the state that they're in. What are some of your thoughts, and how has it influenced how you have advised how tests should be made up or changed?

Letts: I do have opinions about the RECOVER focusing on exercise and graded exercise therapy [physical activity is gradually increased over time regardless of how the patient is feeling] and mental health and cognitive behavioral health and substance use in some of their recent literature and studies. I do think that they're not listening to the patient communities well enough. I feel like the patient communities are very clear about—there is extensive past research about ME/CFS and POTS that has already been done.

It would be really beneficial to start at a point where some of that [work] has already been done and not from scratch. Yet, that seems to be ignored. There are some things that we really don't want RECOVER to focus on, both for the way it looks to the greater world that really respects what comes out of NIH, to also what is a good use of resources and funding. We're desperate. We are living in a situation where we really need help. It feels like RECOVER isn't taking that seriously. They say they are, but the actions aren't saying the same thing.

Barr: What are some of those things? There's the graded exercise and substance-abuse questions, but are there other things that you think they should not be focusing on as much?

Letts: I think it can be subtle. In some of the manuscripts, there can be a subtle emphasis on mental health in a way that makes it look like [long pause]—Sorry, I'm a little bit slow—it can look like you're blaming PASC [post-acute sequelae of SARS-CoV-2] on either lockdowns, or mental health, or the pandemic. That just needs to stop happening. We see it in random media articles, but it needs to not come out of academic or scientific works. It's really frustrating if our names are on a manuscript, and we're fighting so hard to get the manuscript to be accurate, and it's full of little things like that. If I read something like that—in a big media news source—I will immediately stop reading it because I won't respect it. And yet something with my name on it is like that. That's not okay. RECOVER needs to be better than that.

There is to be no blame on mental health, even subtly. People need to understand that. It's an insult because I had no mental health problems until Long COVID—until way into Long COVID. And, of course, I get mental health questions at every doctor's appointment, and of course, I've been extremely sick for three and a half years. I'm going to have some mental health issues. I'm not ashamed to say that. Who wouldn't? But none of this is caused—it's not in my head; it's not caused by anxiety. It's not anxiety. It's a physical condition. We need a physical solution. We need treatment. No amount of yoga, or tai chi, or therapy is going to make us better. Therapy has its uses. Therapy is important, but it's not a solution to Long COVID.

Barr: Can you talk a little bit about what your role and work has been with the other two RECOVER committees that you're involved with—the publications and the NCEG committee?

Letts: The NCEG subcommittee, we were kind of working on a—I'm sorry, what's the word? You can tell I'm slowing down—when you review something. Evaluation for representatives and their groups so that we can tell whether committees and task forces are working well with their representatives. We're also working on a representative—it's not like album, but a place where we could find each other with contact information.

Barr: A directory?

Letts: Yes, a directory? Thank you. This is my charade portion of the interview. [laughs]

Barr: No problem.

Letts: We talk a lot about issues that representatives have in RECOVER and try to solve them basically and try to make them feel better and have fewer issues. I'm on a committee for publications with manuscripts. What they do is they send an email with several manuscript titles and descriptions and then they ask if you want to be involved in any of them, and you rank them. Then they get back to you as a representative, and let you know what ones you're on. Then you start having meetings with the PIs and other representatives. You read over the manuscript and review it. You can do it at different levels. You can do it at a level where you're very involved and you're helping write it; or one where you're reviewing it in depth and helping edit and do some of the writing; or a bunch of different rankings below that. I'm on several right now, and there were a couple that I was on before that are in the peer-review process.

Barr: That's great. What do you think should be some next steps for RECOVER as well as on the Long COVID community?

Letts: I think we do need help. We need treatment and recognition. It's really important—and I think a lot of us wonder if this is going to happen at this point—but it's really important for there to be information conveyed to the country about Long COVID and the risks involved. The only way to avoid getting Long COVID is to avoid getting COVID. And yet, there is no risk mitigation. It's on you whether you wear a mask, but nobody else is wearing masks.

For people like me, who have a dysfunctional immune system because of COVID, we're just going to keep getting worse. I'm not getting better because I get new conditions and symptoms with every COVID infection. As much as I wear masks, no one else is. I go to the hospital every week and my doctors and people working directly with me wear masks, but no one else in the hospital is. No one at any of my doctor's office is except for my actual doctor. No one in the pharmacy is. So places with sick people and immune-compromised people coming to the same places don't have any protection. We're just going to keep getting worse.

Barr: Are you involved in any other Long COVID advocacy activities or groups?

Letts: Yes. I help with a company called Eureka, which is a private company that's privately funded. I'm a patient advisor. They're a pretty cool company. They have put up a lot of different kinds of treatments that Long COVID patients use. Patients can register and put up their own treatments and review them and then other patients can see them and read all the reviews. Then you put up all of your associated conditions like ME/CFS, POTS, mast cell activation syndrome, fibromyalgia, EDS [Ehlers-Danlos Syndromes, a group of 13 heritable connective tissue disorders].

You can be grouped with people who have similar conditions as you and see what medications other people are taking, and how well they worked for different symptoms. You have all the symptoms; you have other conditions. This company has also pulled up all of these therapeutics and medications from Reddit. They have thousands of them that they pulled, and you can look at it and see how effective they are as well. It's a goldmine of information. They're building it. They listen to the patients in terms of how they're editing it. I think it's still in beta. It's really phenomenal. The CEO's mom has a form of dysautonomia [failure of parts of the autonomic nervous system that control involuntary functions like breathing], which my mom passed away from. They're really in it just for the patients to help them and it's all free and everything. They help with that.

Basically, I'm kind of all over the place. With my brain, I can't keep track of what I'm doing so much. I am part of a lot of different groups—I'm a member. If they asked me to be part of some talks or some meetings, and I'm available—and it's something I feel I have the energy to do, or almost have the energy to do it—I will say "Yes," and try to do it. I'm a member of all the normal Long COVID [groups]—I don't know, a bunch of different things.

I try to help out with a lot of different things. I do a number of different surveys and studies. Did I write anything down? Let me see. [Looks down at notes.] No, I think—it's actually a problem that I can't remember everything. I was trying to write down all the things I'm involved in. I have an extensive calendar where I put down everything that I am obligated for—that I say I want to do. But sometimes it's a surprise, like there'll be a study that I sign up for, and then they contact me and say, "You're eligible." And I'm like, "Oh, this one's interesting." It can be disturbing not knowing—your brain not working.

Barr: No need to worry about that. This is one of the last questions. What do you feel that you've learned through your engagement with RECOVER as well as through your Long COVID journey as both a patient but also a patient advocate?

Letts: I think the medical system has to be reworked. It's not serving chronic illness patients well. Something needs to happen maybe starting in med school, maybe earlier, to teach medical providers the importance of actually listening to patients. My only doctors who function as doctors work with me. The other ones I've had, I've had to stop seeing because their ignorance was too high—was as high as he goes, unfortunately. I mean, I've had neurologists who insisted that Long COVID was not neurological, that nothing about it was neurological.

Barr: Yes, it's been proven that it is.

Letts: I was just like, "Yes, it is." I moved on to my different neurologist who's part of a Long COVID clinic. That's the level of ludicrously. I've had to learn how to talk to doctors and not get steamrolled by them. Unfortunately, the doctors I have are the exception now, not the rule. I feel that something needs to change. But what I've learned with RECOVER, is that it's really important to remember "Nothing about us without us."

Chronic illness brings me new horrors all the time. Often, life is not worth living for myself, at least. It's a good thing I have others to live for. There has been something very special about the Long COVID and chronic illness communities though. As I lost faith in the world, and even with much of my personal world, I also saw the best of people and I still call them my people. The Long COVID community and the chronic illness communities have been real fighters with this.

Barr: Definitely. Well, is there anything else that you'd like to share? You shared so much, and I really appreciate it.

Letts: My last thing is that I think it's important that hypermobility [loose joints] be looked at when it comes to Long COVID and chronic illness because more people than they realize, I think, have hypermobile Ehlers Danlos Syndrome [causes generalized joint hypermobility, joint instability, and chronic pain]. I think that's going to be a risk factor for a portion of people with Long COVID. Yet it's one of those things that doctors don't think of looking at. I wish that primary care doctors actually—that it was one of the basic things that they looked at that and doing orthostatic testing, like just with everybody, especially after COVID.

Barr: Well, thank you so much for this wonderful interview and for relaying your experience. I really, really appreciate it and admire all the work that you do considering all your symptoms every single day, so thank you.

Letts: Thank you.