

Lucinda Bateman

Behind the Mask

March 1, 2023

Barr: Good afternoon. Today is March 1, 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 Dr. Lucinda Bateman. Dr. Bateman is the medical director at the Bateman Horne Center (BHC). She's also the education director of the BHC MERC [Bateman Horne Center Medical Education Resource Center] Initiative. Dr. Bateman has also been a very big part of NIH's RECOVER [Researching COVID to Enhance Recovery] Initiative. Today she will be speaking about her efforts with that. Thank you very much for being with me.

Bateman: You're welcome.

Barr: Will you please share how your medical training and experience with caring for patients with myalgic encephalomyelitis, also known as chronic fatigue syndrome, prepared you for addressing the issues with long COVID?

Bateman: Sure, I'm happy to, and I'll also help you pronounce that incredibly hard word. I'm a general internist, and so I have a lot of experience with chronic illness management. Early on in my career, I started seeing patients with chronic fatigue syndrome, which is what we called it then. Then I got interested in studying post-viral syndromes, particularly what we call ME/CFS, which stands for myalgic encephalomyelitis/chronic fatigue syndrome. That's why we say "M.E." instead of the whole word. I've been diagnosing and managing these patients since the mid-1990s, actually. In 2000, I left general internal medicine and opened a fatigue consultation clinic. Then in 2015, I started a nonprofit, specifically for advancing clinical care and science for ME/CFS and related conditions.

Barr: Can you talk a little bit about that as well as your approach? I've read that you really like to see patients as the whole patient not just their disease. Also, part of your philosophy is that just because diseases are a mystery doesn't mean they can be ignored. That really relates to long COVID as well.

Bateman: Exactly. For years, I've been dealing with patients with really debilitating multi-system illness, and yet we lacked a sort of specific diagnostic test. The best way I've discovered to manage it is to take a little more time, really do close collaboration with patients, bring them back frequently, and really work with them to adapt to their illness. After working with so many patients, there's absolutely no question that they have a real and debilitating illness. I have so many patients that are mentally very stable and don't have mental health problems. It becomes really clear that these illnesses stand alone, even though they can be impacted by the way our emotions deal with chronic illness. As soon as long COVID came along, we started seeing tremendous similarities as early as the middle of 2020.

Barr: In 2020, you already started addressing the need to further examine long COVID given, as you said, the many similarities with chronic fatigue syndrome, which you and others have said may develop after people have infections—kind of like long COVID with those who have COVID. Nearly three years later, what do you see as some of the similarities and differences between long COVID and chronic fatigue syndrome?

Bateman: There are many similarities, particularly if the long COVID patients are more severely ill and have been sick longer. I started reading about long COVID in the summer and fall of 2020. Then we opened a clinic early in 2021 and started bringing in patients, studying them very carefully—specifically to try to understand how their presentation might be similar to the illnesses we studied in our clinic. We've had an opportunity. Many of those patients became sick in March of 2020. By now, we've had a chance to track many patients—a year, two years, and getting close to three years after the onset of their long COVID condition. Now there's a lot of federal studies going on to understand how broad of symptoms and debilitation people have and how many people are going to get better in six months and twelve, etc. It may take us some time, but we've got a little jumpstart from the patients we've seen in our clinic.

Barr: What have you seen with some of the patients that you have examined personally?

Bateman: Well, they're very sick. We have seen patients with, I would say, significant cognitive impairment, and who very commonly have dysautonomia or problems with orthostatic intolerance—that means trouble being upright without developing all kinds of symptoms. Many, many patients have exertion intolerance, and post-exertional malaise. That means they get illness relapse from trying to do too much activity whether it's physical activity or cognitive activity. Their bodies don't seem to handle physiologic stressors very well. We're hoping to study the chances of recovery and what to do for patients early in the course of their illness and learn from long COVID so that we can help all ME/CFS patients.

Barr: What do you do for those patients right now to help them with their situations?

Bateman: Oh, there are so many things that can be done. Helping them recognize the parts of their illness and helping them learn how to pace their activity—that means slowing down and doing activities a little more carefully. All of your activities, so you don't relapse your illness and cause a flare of symptoms. We can teach people. We can help people with pain and with disordered sleep and give them tools to help them with cognitive impairment. Most importantly, there are many things that can be done to help orthostatic intolerance.

Barr: Can you speak a little bit about a particular study you were part of where you looked at the orthostatic challenges and the hemodynamic and cognitive issues that result in patients with long COVID, chronic fatigue syndrome, and healthy controls?

Bateman: Yes, this was very fortunate that we were able to collect this data. Before the COVID pandemic, we had a five-year NIH grant working with Jackson Labs to enroll 150 ME/CFS patients and 150 healthy controls. We also split those ME/CFS patients into people who've been sick for less than three years and people who had

been sick for more than ten years. We were just finishing up with analyzing that data and being able to publish some of that data when we were starting to recognize long COVID. Early in 2021, we got some extra add-on funding from the NIH to recruit long COVID patients right away into the same study. We brought a comparison group of long COVID patients and did the very same things we've done in the ME/CFS study. One of the most important things was doing orthostatic testing. We did cognitive and orthostatic testing. We were able to put those findings together in a paper that we published in late 2021. We were really able to get the message out that there's a lot of orthostatic intolerance and circulation issues in patients with long COVID and that we should be identifying them—and also to call attention to it in ME/CFS as well.

Barr: How many more women have long COVID than men in the study? Are more women prone to issues with long COVID and other diseases like it?

Bateman: Yes. We know it's true that there's a slight predominance of maybe two thirds or three quarters in ME/CFS in women and the balance are men. It looks like it's quite similar in long COVID. We're not sure why that is. It's really just a subset of long COVID—not the people who are hospitalized and severely ill, because that's actually slightly more male patients, but the kind of middle-aged and higher functioning people who really got mild COVID and then went on to have chronic problems. It is much more like the scenario that happens in ME/CFS. That's the first thing. The second thing is that women volunteer for research more than men. The third thing is if studies aren't very big, sometimes we just study one gender because it gets harder to analyze since their science is different, right? There are a few studies where sometimes we just do all women in a pilot study, and then we can enlarge that study to include more male patients. But mostly, it's really just the distribution of this illness.

Barr: What has been your role as part of the NIH RECOVER Initiative? How and when did you join the Clinical Trials Steering Committee?

Bateman: We started out at our clinic tagging on to a grant application for the RECOVER Initiative for the science side before the clinical trials part started. We were able to be a small part of that initiative. You'll be interviewing Dr. Suzanne Vernon, and she's been our representative more so than me on that side of the RECOVER Initiative, even though I'm following pretty closely what they're doing, of course, and we're reviewing the papers. In April of 2022, I was invited by Amy Patterson, the Senior Oversight Committee Co-chair of the Executive Committee for RECOVER. She's the person over this whole project—the clinical trials, committees, etc. This has also given me a chance to serve on working groups under that. That has given me a really great opportunity to be part of developing protocols. They particularly want my input based on my clinical experience with other post-viral syndromes and ME/CFS, plus our experience with long COVID patients as well.

Barr: Will you describe some of the goals of the committees that you serve on and your responsibilities?

Bateman: It's hard because it's constantly evolving. Sometimes I'm shifting around because I have kind of an advisory role, but I've been able to be part of the Developing Protocol for Viral Reactivation Committee—they've got new names now, but in the beginning, that's what they were called—to help them develop this kind of

generic protocol for testing interventions for the virus and viral reactivation. I'm not playing a primary role, but mostly, I'm there to help say what I think about the protocol, how it might work, how patients will handle it, and the best ways to test patients with exercise intolerance. It's really challenging for this group.

Barr: Can you speak about some of the discussions that this group has had? You help review studies, ensure there's a wide range of trials, enforce time limits for the studies, and other things like that for this really new disease. Can you speak about some of the discussions that these groups have had?

Bateman: It's complicated, and it's got many moving parts. There are many different working groups. There are working groups on the science side, collecting observational data and biomarkers, and they do some crosstalk. There are different working groups that come together on the clinical trials side. It's changed as time has gone on. Basically, these working groups have experts in the field all try to come together on a committee to bring their expertise and really work through what might be the best way. It is super challenging. The biggest challenge in designing these treatment trials is we're trying to design trials for an illness we don't understand very well and don't have any established treatments for, so we're bringing together people who have expertise in other fields, and we're all relatively new to understanding what makes people with long COVID impaired and how we go about improving that. It's taking longer than everybody thought, both the public and all the researchers. There's an urgency to get this going because we know how important it is—but we also have to do it right. Every time committees come together, they all say, “Well, what about this? What about that?” and go back to the drawing board. We want to be able to make these trials worthwhile, because the protocols are being developed in a way that, as large multi-site trials throughout the country, they will hopefully enroll thousands of people [in these trials]. They'll take the first drug they're going to study and implement the protocol. Then hopefully, each drug they want to study, they can use the old protocol and just maintenance adapt it to the new drug. It's worthwhile to do the investment upfront and then things will move more quickly.

Barr: Has long COVID evolved since it originated in 2020 with COVID changing with the variants and less people getting critically ill? Have you seen a difference? How has that been reflected in some of the protocols that are being developed?

Bateman: It's a constantly moving target—and we knew that for COVID, and we're learning that with long COVID too. The definition of long-COVID initially included almost everybody who didn't get better in a month or in three months, depending on who defined it. We know that lots of people get better, but we don't know who or why yet because we don't have big enough studies. The people who are engaged in the trials also change every six months or every year because they may have started out as early onset disease. Later there are people who've been sick for three years—some got the first variants; some got later variants; some got vaccinated and some didn't. All those variables might change—how long people are sick and what is driving their illness and what they'll respond to. It's a major scientific challenge. It's going to take everybody's effort, and I believe there's an earnest and very extensive effort going on to try to get it right.

Barr: Can you talk about some of the subsidiary studies from some of these larger, multi-site studies that are happening—some of the tissue sample work and things of that nature that are related but different? Are you a part of helping plan those?

Bateman: Not as much, because that's on the RECOVER observational cohort. There are two sides. There's the observational cohort that's studying what the illness looks like. It's super detailed. They look at tissues and cultures and they test people. They test their brains, hearts, and lungs, and they test for orthostatic intolerance. These are really complex trials going on. They're different in different places. But over time, we're going to get a lot of information about illness. Then there are the clinical trials that are really trying to decide how to divide up this complicated illness. There are trials that are trying to look at exercise intolerance and fatigue. There are trials trying to look at neurocognitive impairment, trials looking at sleep, trials looking at the idea that there might be viral reactivation or persistent virus going on, and trials looking at autonomic dysfunction and orthostatic intolerance. I'm not sure I even hit them all. They are trying to find ways to approach that heterogeneity that occurs in ME/CFS too, but also in the long COVID populations.

Barr: What do you feel that you and others have learned so far? How do you hope the work that you and others are a part of will evolve in the coming months and even years?

Bateman: That's a complicated question. What I've learned, honestly, is how hard it is to attack a complex problem like this—how much work it is. So many people need to be involved, and yet the more people that are involved, the more complicated it gets, but if you don't have the breadth of people, you don't bring all that expertise together. I've had an appreciation for how that can be really frustrating because everybody can't always agree, which is healthy— [it leads to] healthy discussion about the right way to do things and going back to the drawing board and trying again and revising things. There has been some really good communication among all these experts, which is super needed. One of the problems in ME/CFS is the knowledge about it is very compartmentalized into silos, and there's no medical home. There's no specialty of medicine for ME/CFS. Who do they go to? Did they go to a rheumatologist or a neurologist? None of those fields really feel comfortable with saying it's their disease. That's happening with long COVID, too. We need incredible crosstalk among all the specialties, areas of medicine, and science to be able to understand how the science interrelates.

Barr: Will you speak a little bit about how the Bateman Horne Center became involved in and partnered with the RECOVER Mountain State PASC [post-acute sequelae of SARS-CoV-2 infection] Consortium, a coalition of researchers and healthcare systems in Utah, Colorado, and New Mexico?

Bateman: The Mountain State PASC Consortium is one of the sites of the big observational cohort of RECOVER. It's the one in my local area. Our nonprofit is affiliated with the University of Utah. As soon as we heard there was a competitive grant system for being part of the RECOVER Initiative, the University of Utah and some other related institutions in Utah and nearby in Colorado—I can't go through everybody in the consortium—joined together to be part of the grant. We're sharing data and it's one project as a group, as a consortium. This has been really fun. I know the University of Utah has the adult cohort. They also have a study for obstetrics and pregnancy. I'm trying to remember if they have the pediatric cohort or not; I'm not sure. Each of these

consortiums bring their expertise and have proposed in their grants what they want to study and what aspects of long COVID they want to look at. Then it's all part of one big consortium under the RECOVER Initiative that will all share data and analyze data. Everybody can analyze their individual data, but all the data will come together so that in the end, we'll have a very rich, rich compilation of all of this scientific data.

Barr: How is the Bateman Horne Center contributing to that in particular?

Bateman: The grant applications were really complicated and expensive. By the time the grants had been accepted, it had been pared down and made lean so that they could afford us, and it could fund all the different consortiums. At Bateman Horne Center, our main role has been recruiting patients. We helped in designing the application by giving some input. Mostly, we already had a bunch of long COVID patients in clinic and a big list of long COVID patients we were including in research. It was a great way to jumpstart the enrollment of the Mountain States PASC Consortium because we just contacted all of our patients and invited them to enroll in the research initiative. The University of Utah has a long COVID clinic and probably each of the other institutions have long COVID clinics. That has allowed the enrollment to grow. Then the scientific studies are variously based at these different academic institutions.

Barr: Education is a very big thing for you all at the Bateman Horne Center. How has that factored into your work with the Mountain State PASC Consortium effort?

Bateman: That's a great question. Yes, as a nonprofit, we have a mission to not just learn more about clinical care and provide clinical care, and not just do research and facilitate research, but also to really provide good educational resources for both patients and providers. We do that mostly through our website that we developed during the pandemic, actually, when everybody was on their computers. We've made a real point of making free accessible information that just goes out to anybody who needs to find it. As soon as we started getting long COVID information, we connected the two and put long COVID information on there. Then there's been a big effort of the advocacy community, the existing ME/CFS patients, to network with long COVID patients through Facebook groups and other kinds of groups. In fact, we recruited for our initial studies through the Utah Long COVID Facebook group—it now has 5,000 people. I've also taken every opportunity possible to participate in provider education that combines long COVID with ME/CFS. There's a CDC-funded telemedicine education program called “Echo” for medical providers, with a faculty that brings expertise among COVID and ME/CFS. We've also done a series of online lectures, available through the University of Utah, about different aspects of long COVID—how to recognize it and the comorbid conditions and how to approach management.

Barr: Do you find that Facebook has been your most successful tool in terms of recruitment? Are there other social media platforms that you're also trying out?

Bateman: As an organization, we use multiple social media resources—Facebook and Instagram—and we reach out through medical databases and some other ways too. We just try to brainstorm. That's our new MERC initiative—to continue to try to understand how we can connect programs, share education, and facilitate quicker progress in getting education about all these disorders out to practicing clinicians.

Barr: What do you hope that long COVID will do for other disorders like it in the medical field?

Bateman: Oh, I am sure it's going to help tremendously—because there's active study in COVID and long COVID, of the immune system, of the nervous system, of dysautonomia. All aspects now have 100 times more people doing basic research and clinical research and trying to look for drug development, viruses in general, and antiviral treatments. I'm confident that as our knowledge progresses, it's going to provide information that's going to help all people with post-viral and post-infectious syndromes. We saw this after the AIDS epidemic—all that money that got poured into advancing our knowledge of AIDS and treatments just dramatically increased our technology for viruses and immunology and antiviral treatments. Then it kind of came to a halt when the problem became more stable. And now it's progressing again. But we're seeing a surge of interest that way—not only here, but of course around the whole world.

Barr: What are your plans to continue working on long COVID both in the short term and long term?

Bateman: We're going to keep trying to be actively involved. I will say that our nonprofit is primarily devoted to ME/CFS and associated comorbidities. We're going to be especially interested in the long COVID patients who meet our criteria—who develop the illnesses we study—but they're often the most neglected as well and can be the most disabled. We're going to continue our educational efforts, our engagement, and research. I'm hoping that BHC will become a very active center of clinical trials. We have the ability to recruit patients and a very good clinical research staff and research coordinators. We're looking forward to good opportunities to start some of these trials.

Barr: In addition to being a physician and serving in other capacities professionally, you're also a person who's been living through the pandemic. What have been some positives and some negatives about the pandemic for you, and what have you done to cope with all those different stresses?

Bateman: You know, that's a great question. It was extremely hard. As a physician and a scientist, I thought it was formidable from the moment I heard about it. I mean, in January, I started actively reading. Then I found myself getting anxiety—not so much because it would affect me, but in the early phases of the pandemic, I felt scared for the world and what it would mean for us. That just eventually gave in to diving in and trying to be part of the solution. Most of all, the pandemic gave us a chance—and me a chance—to work remotely. That's pretty significant because ME/CFS patients are often homebound, and it's a great sacrifice for them to come to the clinic in person. During the pandemic, we really extended our telemedicine abilities to reach out to the sickest patients and make it so that it was not so onerous to come to the doctor. That's been a great advance. I hope we can figure out how to keep that going—especially since there are so few providers who feel comfortable treating these disorders. Honestly, I want that to go away, too. I want all providers to be comfortable treating all of these disorders. That's the end I hope for.

Barr: Yeah. Is there anything else that you'd like to share about your COVID-19 experiences?

Bateman: I was talking to the head of the long COVID clinic at the University of Utah. She also worked in ICU and has been a pulmonary doctor since the very beginning of the clinic. She keeps saying COVID is “the gift that keeps on giving” in a sarcastic way. But I think it's helped us expand our mind and be more interactive. There are some bad things about the pandemic, for sure, but I have confidence in our society and our government, and the people who live here, that we can all make progress through adversity. That’s the silver lining. Though, the biggest silver lining is we're going to make progress in ME/CFS!

Barr: Definitely. Thank you so much, and I wish you continued success in all that you do.

Bateman: Thank you for doing this and let me know if I can be of any additional help.

Barr: That sounds great.

Bateman: Okay. Take care.

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