

Dr. Leonard Jason
Behind the Mask
March 7, 2023

Barr: Good afternoon. Today is March 7, 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. Leonard Jason. Dr. Jason is the director of the Center for Community Research, and he's also a professor of clinical psychology and community psychology at DePaul University. Today, he's going to be speaking about his work with long COVID, particularly with his affiliation with NIH's RECOVER [Researching COVID to Enhance Recovery] initiative. Thank you very much for being with me.

Jason: Happy to be so.

Barr: My first question is will you please share how your training and years of studying Myalgic encephalomyelitis or chronic fatigue syndrome [ME/CFS] prepared you for examining long COVID?

Jason: ME/CFS has multiple triggers. There's many reasons for people developing MECFS. Sometimes it's viral, like an Epstein-Barr virus. Because I've been studying the pathways into MECFS, it was natural to start studying long COVID because that's caused by a virus and some people do not recover and those people generally are referred to as long COVID.

Barr: You have some personal experience with dealing with these post-viral, post-infection syndromes yourself, having dealt with it after a bout of mono. How has that influenced your research on this topic?

Jason: When I got mono and had difficulties dealing with it, I saw the consequences when you have very little energy and very high levels of fatigue. That was a kind of an experience that I had that gave me a more compassion for those people who have had this illness.

Barr: Definitely. When did you join the Commonalities with Other Post Viral Syndromes Task Force of the RECOVER initiative, and how did you get involved in the first place with RECOVER?

Jason: Well, it's about February of 2022 that the committee came together, and I was in ME/CFS expert on the Illinois Hub. I was recommended from the Illinois Hub to serve on one of these committees.

Barr: Will you discuss the backgrounds and other areas of expertise of your colleagues on this task force?

Jason: Yes. They have a lot of particular experience with commonalities like ME/CFS or mast cell or other types of chronic illnesses like fibromyalgia. They had a lot of those experiences.

Barr: Will you describe some of the key objectives and responsibilities of this task force and what your role has been?

Jason: Our role has been to look over the RECOVER initiative, all the hubs and the protocols, and to comment if we can on ME/CFS or other commonalities that occur. My specific expertise is with MECFS, so that's where I've made most of my comments.

Barr: Do you see the protocols throughout their development? Have you had the opportunity to look at them before they ever were launched?

Jason: They were developed in the summer of 2021, and I did see them in March or April of 2022. I did have a chance to look over them I looked over the adult and the child protocols very closely.

Barr: Are people very willing to incorporate these comments into their studies?

Jason: It's very complicated process, RECOVER. There's multiple committees, and each one has to give its kind of consensus and kind of ratify the other. There's been two initiatives that I've been working on. One is to get specific ME/CFS questions into the protocol so that you can make a diagnosis of ME/CFS, and I've been working on that for a year. Those recommendations are going up to the executive committee from what I understand, and hopefully they'll get approved so at least the adult study, if all goes well, will have the questions that are needed to make a diagnosis. The pediatric study I haven't had as much success on. The other thing is I've asked to get an ME/CFS cohort to be studied independent of long COVID, and while they have given me permission to do that, they have not provided funding for that so that's the next effort. My part will be to see if I can find funding for bringing in a new cohort of just ME/CFS patients to compare to long-haul ones.

Barr: You mentioned looking at both adult and pediatric protocols. How common is it to have pediatric cases of long COVID and MECFS, and do they look different in adult and children populations?

Jason: There are some differences. Some children might have more difficulty, particularly the younger ones, in being able to articulate what they're experiencing, and if family members aren't supportive, it could be more difficult for them to get recognition as to why they don't feel well to go to school. So yes, there are some unique challenges youth have, but youth have less other comorbid illnesses than adults have. In some ways, they're a better group to look at because you have all the other issues of multiple diagnoses.

Barr: Definitely. What have been some areas of discussion within this group and some of the different opinions that have been expressed with people coming from different vantage points on this task force?

Jason: The task force has been united in the necessity to have questions added to the adult and pediatric protocol. There hasn't been much kind of controversy there. The task force has also been united in wanting to get a ME/CFS cohort, so there haven't been really too many objections. I think the biggest issue has been when we've gotten out of our commonalities group, when it's gone to other higher-level groups. Those groups have brought up issues such as you're adding questions to a protocol, or you have a study that is not exactly a long COVID study, so you need to seek your funding from other sources.

Barr: How often does your task force meet, and how often do you meet with some of the other groups that are part of RECOVER?

Jason: We had been meeting every two weeks for the first year. Now we basically have begun meeting once a month, and my subcommittee that I'm part of – the diagnostic subcommittee – we meet about once a month. I would say about twice a month I meet with those groups, and then I have ancillary meetings with other groups who asked me to. For example, the treatment group wants to use one of my questionnaires, so they have had a meeting with me in several discussions about what's called the

DePaul symptom questionnaire PEM (post-exertional malaise), so I've been in discussion with them. There's a variety of different activities, and I do have a chance to talk with people from other areas.

Barr: I imagine most of your meetings are virtual, but have you all had the opportunity to meet in person or at any kind of convention?

Jason: It's been all virtual at this point.

Barr: Today, what do you think that the task force has learned, and what are some aspects of long COVID that you hope can be explored further in both the short term and the long term?

Jason: Well, we're currently writing a white paper, and I'm the lead author. That's basically trying to look at how ME/CFS research over the last three decades can inform long COVID work. That paper is almost written. It will be sent off to a journal, a special issue of a journal, and what we have learned is that ME/CFS has multiple triggers, long COVID has one primary trigger, but if the consequences are similar in terms of people being ill for long periods of time, then it's possible that there might be initiating factor in SARS-CoV-2 but the maintaining factors might be different. Again, the key question is why some people get a virus and recover and others get a virus and don't recover. What are the genetics? What's the lifestyle? What's the biomarkers that help one make those distinctions?

Barr: Definitely. What do you think that RECOVER can do for patients with post-infectious disease like long COVID that other programs have not been able to do at this point in time, and how do you think scientists, clinicians, and patients can sustain the momentum that RECOVER has sort of catalyzed?

Jason: There's a real problem with momentum. The RECOVER trial has basically – I think it's struggling with funding right now with the President [Joseph Biden] mentioning that the pandemic is over, and they have different venues. It looks like it might be more difficult to get kind of funding for these initiatives, so I think that is going to be something that could limit for example more treatment trials needed for patients.

Barr: Can you talk any more about some of the other challenges that your group and RECOVER has faced or will possibly face?

Jason: I think to me the biggest challenge is making sure you can differentiate those who have or do not have ME/CFS, and the only way you can do that is if you use validated questionnaires. That's needed to basically make sure that if you're going to have subtypes and you're going to look at subgroupings to make sure that those diagnoses are accurate. Right now, we still don't have the key questions in either protocol, the adult or the pediatric, so until those things occur, I will be nervous about just asking a person whether they have ME/CFS. I don't think that's sufficient, and it's often not accurate.

Barr: We're going to turn now to your personal research with long COVID. Will you speak a little bit about a study that you were a part of that looked at COVID-19 symptoms over time and compared those symptoms to ME/CFS patients and what some of the findings were?

Jason: We've got several studies going on now, but one has really basically found that people with long COVID seem to, from the beginning to six months later, have a reduction in symptoms whereas the ME/CFS groups tend to maintain their symptomatology. The one area that seems to be not necessarily reduced is the neurocognitive problems. They seem to be maintained in a long COVID group.

Barr: Yeah, I had a question about that. Why do they linger so much longer than the other symptoms?

Jason: Well, it could very well be that the brain is implicated in what the virus is doing, and it's just harder to find where the damage is. That's my guess, and that's leading to the neural cognitive issues. It could very well be that the virus is still kind of in the brain. Again, it's just harder to do these types of autopsies. It's easier to look at the blood and to sort of see if the virus is in the blood. It's, as you probably imagine, harder to get tissue from the brain unless a person has actually died.

Barr: Yeah. Why does it seem that long COVID patients recover relatively quicker than ME/CFS patients do?

Jason: It's maybe not completely recoverable but having a lessening of symptoms, and this is not surprising. If you have people who have been affected by the Epstein-Barr virus which causes the majority of ME/CFS, initially you have about 10 percent of people who are sick for six months, but at one year and two years those rates go down considerably. So again, there's a natural trajectory of people beginning to recover, and those folks who don't recover are the ones who probably will get the label of ME/CFS. Once you have ME/CFS, it means you've been sick for a while. What that suggests is that either the virus or whatever has attacked you or the host or the autoimmune response that the host is having is making you different from other people who have recovered.

Barr: In several of the studies, it seems like there have been more patients with existing ME/CFS diagnoses than long COVID. Are you and others planning on revisiting some of these studies to include more patients with long COVID to make a more equitable comparison?

Jason: We're estimating that about one and a half million people probably have ME/CFS in this country, and as you probably recognized, a number of people that have been affected with COVID and have not recovered is far more than that. We're still trying to get accurate estimates of how many people have not, but certainly this is a pandemic that has affected a large portion of the population, so we expect numbers to be much larger.

Barr: Can you speak a little bit more about your collaborative work that examines whether the DePaul symptom questionnaire which assesses the frequency and severity of common symptoms with ME/CFS could be used to diagnose and monitor symptoms in patients with long COVID?

Jason: If you want to find out whether patients with long COVID have ME/CFS, you are best to use a questionnaire that basically just doesn't look at the occurrence of somatic symptoms like fatigue. And the reason for that is these somatic symptoms, whether it's sleep problems or fatigue or pains, are very common in the general population, and if you just look at occurrence, you're not going to be able to discriminate ordinary issues that are not burdens to the person. They shouldn't meet a threshold. What you really need is to look at how frequent symptoms occur and how severe they are, and if you do that, you can better find out whether the person commits a threshold. In a sense, if you have something that's not very frequent but very severe like maybe a migraine once every two months, it's not going to probably be a burden. It probably shouldn't be counted. If you have something that's very frequent, like every day, but it's very mild like a pain in your toe, again, that's not going to limit you and you probably shouldn't be counting that as a symptom. It's only when the symptom frequency is at least about half the time in at least severity of moderate that we should be thinking about it being counted.

Barr: What are some other questionnaires and tools used for similar conditions that have been or are currently being evaluated to look at long COVID patients?

Jason: Well, there's dozens of questionnaires that have been published. Most of them when you look at factor analytics studies, you find some difficulties. Either the number of items to persons or the number of items per factor have had problems. Basic psychometric properties of most of these questionnaires – most of whom just look at occurrence of symptoms – has some psychometric limitations, so we do think that the questionnaire has to be not too long, it has to be focused on the right symptoms, and you need to have thresholds as to whether they're a burden or not. I would say most questionnaires don't have those characteristics in the long COVID area.

Barr: Will you comment on some of the treatments for long COVID such as mindful meditation and how that can be beneficial for patients with long COVID and other post-infection syndromes?

Jason: We've recently written a review paper on all the different kinds of research on meditation with different chronic illnesses, and it does seem that meditation does have positive effects to lots of biological factors. We think that meditation is probably one of the better treatment approaches, because it doesn't have a lot of secondary negative aspects. We certainly recommend meditation, and and if you can believe we're actually writing a grant proposal to look at meditation as a treatment approach with long COVID.

Barr: I thought it was very interesting in the paper that there's a right way to do the meditation for it to work correctly. Can you go more into that?

Jason: Well, the main thing with meditation research is that you want to do it enough to sort of have this effect translate not just into how you feel but also the biology of the body, and we basically think that over eight weeks – that's probably the minimum time for an intervention to occur that would be weekly. And I think that the interventions that are just for a couple hours are going to have less likelihood of bringing about long-term change

Barr: Can you comment on people being guided through meditation in person versus online?

Jason: There's not a lot of research on that, but we do think that meditation could be done by trained masters who could be guiding people through meditation even with groups. We do think that it's possible, and probably more efficient to reach people particularly those who can't travel to a place where there's a teacher.

Barr: Definitely. What are some of the other angles of long COVID that you are currently exploring or hope to examine more in the near future?

Jason: We have a very large data set of about 4,500 college students that we have blood samples on, and we have questionnaires that they filled out called the DePaul symptom questionnaire and other markers. Then we kind of watched those students in terms of who developed infectious mononucleosis, and then we compiled them further as to why some recovered, and some didn't. This is called a prospective longitudinal study, and the reason these data are unusual is that we have data prior to illness, prior to infection, so we can look at predictors of what are the characteristics of people prior to a trigger that might make them more likely to not recover from that viral insult versus those people who do recover, and that's research we're currently following of a large cohort of students over six or seven

years that we have data on prior to the pandemic, prior to them getting mono, and or trying to determine which ones have gotten COVID and how that's affected them.

Barr: You also have other areas of interest including domestic violence, addiction, and smoking cessation. Have you done any COVID-related research with any of those other passions of yours that you study?

Jason: I do study substance use addiction, substance use disorders, and I've been studying recovery homes, particularly one called Oxford House, for many years. We did look at the first year of the pandemic, and we looked at Oxford Houses around the country. There's over 3,000 of these houses, and people can live in these houses as long as they want as long as they don't take alcohol or drugs, and they're all self-governing so there's no professional staff. We looked at these houses to see who had been infected – this was before the vaccines came out. We found that if you lived in an Oxford House versus the geographic area around the Oxford House, you had less likelihood of getting infected. That was suggesting that high-risk people who have substance use disorders, if you can find settings that are healthy and healing, you can reduce the likelihood of acquiring this SARS-CoV-2.

Barr: In addition to being a scientist, you're also a person who's been living through this pandemic the past three years. What have been some challenges and opportunities for you as an individual that the pandemic has presented?

Jason: One of the challenges is that a lot of people kind were not going to schools, were not going to university settings, so some of the research that we have been doing on violence prevention, for example in the Chicago Public Schools, we had to stop. And even people for a while were not coming to my research center. Everyone is working from home, and when you're doing basic research and you don't have oversight of what everyone's doing, that's a certain challenge. That's been a downside. Of course, having the increased mental health problems that have occurred because of the pandemic has affected our population. On the other side, because of this pandemic, I think the illness of ME/CFS is now more legitimized and people now are less likely to think it's just all in the mind, because there's so many people that have gotten sick.

Barr: Is there anything else that you would like to share about your all COVID research and experiences?

Jason: I think that's about it, and I thank you for going through these questions.

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