

00;00;00;14 - 00;00;06;05

**Steven Molony**

Hello and welcome to Chronically Complex, the official #MEAction Podcast. I'm Steven Molony.

00;00;06;13 - 00;00;23;06

**Jaime Seltzer**

And I'm Jamie Seltzer. I'm a person with ME and ME runs in my family with my mom and sister both affected. I'm the director of Scientific and Medical Outreach here at #MEAction, and I also do research at Stanford University on ME and other chronic, complex diseases.

00;00;23;24 - 00;01;24;21

**Steven Molony**

I'm an actor, writer, and filmmaker. I'm also the guy that makes all of #MEAction's videos, and I provide a lot of voiceover as well. I don't personally live with any chronic illnesses, but I have some dear friends who suffer with myalgic encephalomyelitis and other chronic diseases. I want to be a better ally and I'm looking forward to getting to chat with the truly amazing people we're going to be bringing on to this podcast.

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00;01;25;14 - 00;02;02;18

**Jaime Seltzer**

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00;02;03;17 - 00;02;21;00

**Steven Molony**

Before we get started, I want to take a moment to celebrate #MillionsMissing from last month. People rallied outside the White House, put their bodies on the line, blocked traffic, and demanded the attention of the government and press, and people who were too unwell to attend in person made their voices heard online by advocating from home.

00;02;21;17 - 00;02;45;18

**Jaime Seltzer**

It was a big day. Over 9000 people saw the event live on Twitter. We had press coverage in the New York Times, The Hill, MedPage Today, NPR, Time Magazine, and more. And President Biden walked back his statement that the pandemic is over, in part because of the actions that everybody took that day. Activism works. Together, we made our voices heard.

00;02;46;23 - 00;02;59;16

**Steven Molony**

So as you may or may not know, #MEAction has partnered with the Mayo Clinic to discuss treatment, research, and improved community engagement for people with ME. Our guests today are doctors Stephanie Grach and Ravindra Ganesh.

00;03;00;04 - 00;03;30;25

**Jaime Seltzer**

Dr. Grach received her M.D. from the University of Illinois College of Medicine, M.S. in Physiology and Biophysics from Georgetown, and is completing her internal medicine residency at the Mayo Clinic in Rochester, Minnesota. She joined the Mayo Clinic as a senior associate consultant in the Division of General Internal Medicine just this July. Dr. Grach has a career interest in Post-Viral diseases and is dedicated to improving clinical research and educational aspects surrounding post-viral disease through her work in Mayo's respective clinics and the General Internal Medicine Division.

00;03;36;05 - 00;04;33;01

**Steven Molony**

Dr. Ganesh obtained his M.D. from the University of Wisconsin School of Medicine and Public Health and completed Internal Medicine Residency at the Johns Hopkins Osler Medicine Training Program. He is completing his MPH at the Johns Hopkins Bloomberg School of Public Health and is a consultant in the Division of General Internal Medicine and an assistant professor of Medicine.

He serves as the practice chair of Integrative Medicine and Health and medical director for the post-COVID Care Clinic, as well as on the General Internal Medicine Research Committee.

His research is in post-COVID Syndrome, treatment of COVID infection, and fibromyalgia, ME/CFS and POTS. He is involved in education both as a preceptor for the Mayo Alex School of Medicine and for the Mayo Clinic Internal Medicine Residency Program and has extensive experience in continuing medical education. Jamie here has been working pretty closely with the two of them over the past several months, right? Do you want to tell us a little bit about that?

00;04;33;18 - 00;06;37;02

**Jaime Seltzer**

Sure. So, Stephanie and Ravi and I met for the first time a couple of months ago to discuss the treatment of people with M.E. and Long COVID at Mayo Clinic, Rochester. And we started by talking about our mutual desire for change. And we knew that we wanted to update treatment guidelines and information on ME/CFS. And Ravi and Stephanie wanted people with lived experience to be part of that change.

So the three of us wrote a grant for the society to improve diagnosis and medicine, which I'm very pleased to say that we did receive that grant. Some fellow winners were Harvard Medical, Cedars-Sinai, the U.S. Department of Veterans Affairs. So some very big names, which made me feel very proud that we could say that #MEAction received that grant as well.

Even before we got the grant, we were already working together on the landing pages that Mayo produces about ME/CFS. I made a document that had the old language and proposed language with citations and references for each suggested change. And we would meet each week and go through those suggested changes until we had a document that was ready to submit.

And we've already submitted this to go through committee approval. And then we started working on the diagnostic algorithm that has also already moved on to committee approval. The entire time I was just so impressed by Ravi and Stephanie's know-how about these diseases, about their willingness and eagerness even to work together and create change. And it's just been a pleasure to work with them.

We actually have a lot of projects on the horizon, but the next thing on our docket is working on continuing medical education, and there's a lot more to come.

00;06;37;23 - 00;06;48;20

**Steven Molony**

That's awesome. Yeah, it's been really exciting to see you guys get all this work done and I'm looking forward to what's to come. So without further ado, here's Dr. Ganesh and Dr. Grach.

<Intro music leads into the episode.>

00;06;53;24 - 00;07;28;00

**Dr. Stephanie Grach**

I'm Stephanie Grach. I am a senior associate consultant here at Mayo and the Division of General Internal Medicine. I have actually been here, though, at Mayo for a bit over three years. I first started as an internal medicine resident here and decided that I enjoyed my time with the Division of General Internal Medicine and with Dr. Ravi Ganesh (who you'll hear from right after me) so much that I would stay, and it's been a great experience. I can't wait to share more about it.

00;07;28;15 - 00;07;30;23

**Jaime Seltzer**

Thank you, Stephanie. Ravi, how about you?

00;07;31;14 - 00;08;05;08

**Dr. Ravindra Ganesh**

Ravi Ganesh. I am a consultant in the Division of General Internal Medicine. I've been at Mayo for about six years now and I've been in charge of the Integrative Medicine and Health section, which is where we house or chronic complex disease clinics, including fibromyalgia parts and MSD affairs. And I was fortunate enough to have Stephanie come over and do an elective with us, and we've done a couple of projects together. So she also introduced me to Jaime, and this is how we met #MEAction team.

00;08;06;07 - 00;08;06;27

**Steven Molony**

Very cool.

00;08;07;08 - 00;08;09;01

**Dr. Stephanie Grach**

It's been a fun time ever since.

00;08;10;12 - 00;08;37;02

**Jaime Seltzer**

Yes. Honestly, we work very well together, I must say. It's true, though. It's true. So, I guess from the perspective of patients, how would each of you explain your roles at Mayo kind of in context of what types of patients will you interact with, who are you helping and how?

00;08;38;18 - 00;10;08;12

**Dr. Stephanie Grach**

Yeah. So with the Division of General Internal Medicine, we see everything and anything I think we're most associated with are a quantitative medicine clinic that is in the forefront of Mayo. I think the idea that most people have about Mayo Clinic, that if you have something going on that you don't know what it is or it's really rare and you don't have a local specialist who can help you, you can come to Mayo, meet with a general internist through our division, and then we help coordinate that care while you're at our institution, connect you with the specialists or do the testing, evaluation to help figure out a better management plan. The division then branches off to different types of clinics beyond the Consultative Medicine Clinic, which includes our integrative medicine program, which has, again, the fibromyalgia, ME/CFS as Ravi already talked about. I'm currently mostly being a new consultant in that consultative medicine area and will be for the next couple of months still.

I'm also already starting to get to do work with our post-COVID care clinic, which is housed in the same area as consultative medicine, which is why I've been able to already get started there. But starting early next year, I'll be able to branch out more into the specific fibromyalgia, ME/CFS, POTS and other related clinics in those areas.

00;10;09;29 - 00;10;11;25

**Jaime Seltzer**

Excellent. And Ravi, how about you?

00;10;13;17 - 00;10;50;02

**Dr. Ravindra Ganesh**

So I've been here longer, as you can tell, from the gray hairs and all that. So I don't do nearly as much consultative medicine anymore. Most of my consultative medicine is post-COVID patients, and medical director of that clinic. I still do fibromyalgia, chronic fatigue, ME, POTS and a lot of my practice has shifted to more administrative and research.

So I'm less in the clinic these days. But these are the patients a take care of. I weigh in on policy and web pages and things like that.

00;10;51;02 - 00;11;42;10

**Dr. Stephanie Grach**

It is kind of interesting, I will say that even though I am technically in this more general consultative medicine clinic and not yet in the allocated specialty clinics, I see a ton of multi-system, complex chronic disease as part of consultation medicine. I at least once a week have a new diagnosis of ME/CFS frequently seeing new or looking for new management of fibromyalgia and POTS along with ME/CFS and similar conditions in the clinic.

So it's kind of interesting, even though I haven't differentiated yet, I feel like I'm already getting to do a lot of work in the area that I've been looking forward to doing. So it's been an interesting... fun, but very interesting, I would say experience in consultative medicine already.

00;11;42;28 - 00;12;08;07

**Jaime Seltzer**

Follow up to that. I know it's probably hard to tell because you might have been in that area at Mayo for the past three years, so basically during the pandemic. But would you say that there's been an uptick in diagnoses of ME/CFS, or is it too challenging to say so?

00;12;08;11 - 00;12;39;26

**Dr. Ravindra Ganesh**

I'm going to answer this because I did do consultative medicine pre-pandemic. I'm going to say yeah. We've had more ME/CFS coming through post-COVID. We've had both people who have post-COVID conditions who have now met ME/CFS criteria and people who are potentially on the verge and then got COVID and pushed them over. So we've had both kinds and yeah, we've seen more.

00;12;40;22 - 00;14;09;29

**Dr. Stephanie Grach**

Yeah. As far as like the increase in diagnosis and everything, I've been wondering about that too. So that was really good to get to hear from Ravi. I've been wondering how much of this is related to having more recognition, especially with Long COVID. How much have we already been recognizing or are patients just coming forth more because they're learning that their symptoms aren't normal and deserve further investigation?

I think one of the best parts of being in concentrated medicine or being here in division of general internal medicine is that we get to not only give those new diagnoses of ME/CFS or help them with managing along with the other conditions, but we also get to play the role of making sure we're not, that there aren't other conditions that we're missing with it.

And so I've really enjoyed that. I have a number of people who come in. Yes, they are diagnosed with ME/CFS, fibromyalgia, POTS, etc., but they have multiple other conditions that get to be seen by our specialists and just as thoroughly investigated. So I think that's been really valuable getting to see it at this level, being able to be someone who can not only diagnose these conditions but can differentiate them out to make sure any other underlying or contributing, especially pain drivers, anything like that can also get addressed while they're here.

00;14;10;25 - 00;14;21;15

**Dr. Ravindra Ganesh**

And this is why I made sure she did con med because I love being a mean mentor, but you have to be an excellent clinician in order to do ME/CFS work. You can't miss things you can fix.

00;14;22;05 - 00;14;25;20

**Jaime Seltzer**

Yes. That is spot on.

00;14;26;23 - 00;14;36;01

**Steven Molony**

Absolutely. And relating to both of that, like through the course of your guys's careers, how did you become interested in ME/CFS and Long COVID?

00;14;36;13 - 00;15;23;23

**Dr. Ravindra Ganesh**

So for me it's a little bit different, right? Because I trained on the East Coast and there are other places on the East Coast that don't really believe in these conditions. So my training med school residency was kind of a vacuum when it came to chronic persistent conditions. But when I went to private practice, I started seeing patients who were struggling and this kind of fueled the interest.

I did some learning on my own when I was looking to come back to academics because I missed teaching. The fact that the Mayo Clinic had a clinic for this was actually one of the major draws.

I think I'm quite possibly the first person that came to the interview and said, I want to work in the fibromyalgia and ME/CFS clinic. Stephanie may have been the second.

00;15;26;21 - 00;15;27;27

**Dr. Stephanie Grach**

And that's why you're my mentor.

00;15;28;16 - 00;15;33;00

**Jaime Seltzer**

Well, I'm very grateful that both of you made that decision.

00;15;33;15 - 00;15;34;23

**Steven Molony**

Yeah, absolutely.

00;15;36;04 - 00;18;20;15

**Dr. Stephanie Grach**

So for me, how that started was I... So, similar kind of experiences when I was going through medical school training, had this idea of patients that had chronic pain. They would get the diagnosis of fibromyalgia and then whenever I'd ask, okay, what do we do for them? People would say there's nothing really you can do. At best, you'd have someone who would try to support them through their symptoms with some pain medication, non-opioid medication, or helping with therapies.

Others would just say, Oh, well, it's all in their head. And so it's unfortunate that that can still happen in this day and age. But what really got me interested was when I came to Mayo and I had a patient with fibromyalgia that I was about to see who had had it for a decade. Nothing could help them.

I went to one of my staff attendings who is a consultant here in the Division of General Internal of Medicine that I get to work with while I'm here. And when I came to him, I said, Hey, what do we do for this? He said, Well, here's the pathophysiology of fibromyalgia. This is why we think these medications can help.

Also, here's another medication that's being looked into. And why don't we try this on them? And for the first time in a decade, that patient had improvement in their fibromyalgia symptoms. And I thought that was amazing. That's why I took the initiative to set up an elective with the Division of General Internal Medicine, which is how I met Ravi. And all of that happened at that same time I was doing the elective.



Got to be with the fibromyalgia clinic, getting to see, I think, my first case of ME/CFS really in-- or at least what I recognized as it-- on my elective.

That was also the time that I watched a certain documentary that a lot of people know potentially in the community called Unrest. So I was all at once having these exposures to patient populations that I was realizing we weren't doing enough or looking into enough. And I thought that that was such an interesting idea to pursue that area of medicine.

And the more that I did in it, the more I fell in love, because it's getting to learn from people who have a whole 'nother experience that I haven't gotten to learn about just from my training in medicine. It's been really great to continue to be a part of it.

00;18;21;12 - 00;18;30;14

**Jaime Seltzer**

And so you you did a little internship with Bateman, correct? Would you like to talk about that a little bit, Stephanie?

00;18;30;16 - 00;20;27;18

**Dr. Stephanie Grach**

Yeah, so, as part of my interests in ME/CFS and getting to learn more on top of what I had already been learning and my time with Ravi in the post-COVID clinic certainly being some of a contributor that-- and spending a little time in our fibro, ME/CFS clinic, I had heard that there was an excellent clinician who was considered to be a leader in the area and so with my third year elective, wanted to do a rotation at the Bateman Center.

Absolutely amazing. In terms of reaching out, they automatically said, yes, here's some different materials that we have that you can look at before you come here. Everyone was amazing when I got to the clinic, always very excited to have me in to see, for example, their NASA lean test and watch how that was done or watch how they would manage ME/CFS and its related conditions.

It was a very good experience because I think I was able to see a lot of patterns and see, okay, based on patterns I'm seeing what management direction do I want to go? And again, coming from this same feeling that I had before with my patient with fibromyalgia, this idea of, Oh my gosh, look at all these potential things that we can start doing even more and implementing with our patient populations as we were already starting to do.

And so just getting that sort of validation from another center even-- in an area where there is really not much as far as official guidelines and recommendations, or at least there hasn't been in the past, just really valuable to be able to see that from another group and clinician that was well respected and trusted in the field.

00;20;28;18 - 00;20;46;14

**Jaime Seltzer**

Well, now we move on to the challenging round of our questions. Ravi, so some people with ME/CFS might have had a negative experience at Mayo in the past. What was your impetus for pushing for change?

00;20;47;01 - 00;22;04;18

**Dr. Ravindra Ganesh**

I think as the science has changed, I don't think that necessarily our program changed. There was a point in time where a lot of the thought process around ME/CFS was not as energetic and neurologic disease, but more... There was a lot of psychological undertones that were attributed to it, kind of led by a lot of studies out of the UK.

And I think that there was a lag time in terms of, you know, how the emerging science was interpreted and changed into practice by our ME/CFS clinic. And when I came on staff and I started learning about it, I realized that there was a gap in terms of what we were doing and what the science is saying. And there are some kernels of truth to some parts of it, right?

I mean, if you do have a lot of adverse life events and if you do have a lot of stressors, it makes everything worse. That's not the cause of it. Right? So, you know, it was completely... the protocols were misguided.

00;22;05;22 - 00;22;11;28

**Steven Molony**

Was there anything about Long COVID that changed your personal view about chronic post infectious diseases?

00;22;12;10 - 00;23;04;00

**Dr. Ravindra Ganesh**

The thing that changed my view the most about chronic post infectious diseases with Long COVID was that as everyone on this call knows, there is more money available for Long COVID than anything else. So I could convince my research department to let me run tests I wouldn't be able to run otherwise.

So we found cytokine abnormalities which have been mentioned in every other single chronic, persistent illness. We found PET scan changes.

We're finding some changes that are enough to make other people take us seriously. And we've gotten a good number of collaborators on board to kind of help us work through this. And our hope is that the energy from this and the science leaps that we'll make going forward on Long COVID translate and people will have the same energy to help us work on ME/CFS.

00;23;04;00 - 00;23;14;29

**Jaime Seltzer**

That is a wonderful answer that brings me to my next question. So tell us a little bit about your work with #MEAction and what we've accomplished so far.

00;23;15;10 - 00;23;16;09

**Dr. Ravindra Ganesh**

Stephanie, you want to lead?

00;23;17;12 - 00;25;29;27

**Dr. Stephanie Grach**

Yeah. So it's been a really great year. I still remember when we first talked with Jaime and Ben, and I'm sure both sides were probably a little like... I imagine both sides were probably a little bit nervous like, "Oh, how is this going to go? Is it what we're hoping for?" and I, at least on my end, I think it was everything that I was hoping for and our collaboration has allowed already for us to make changes that are in process that will be accessible to clinicians, but also soon to patients.

One of the things that we're working on right now with a recent announcement involved with it is a grant even together that will allow us to improve diagnosis of ME/CFS, really making sure that other clinicians are able to access criteria, access learning materials, understand what tests to order to make sure at the very least that we're not misclassifying other syndromes and other conditions as ME/CFS. We want to make sure that we are diagnosing them properly and then also giving them the management recommendations on things that can be done and when to connect with the specialists and to our clinic.

And really looking forward, I think, to that coming about because the platform that we're using for this is used by physicians, especially within the Mayo system. But there's some access outside as well.

For me, I know I'm using it on a daily basis, probably multiple times a day. And I think that goes for probably most of the physicians here.

It's a highly utilized resource. And so I think that was one way that we were able to think of what's a way that we can really make effective change, and I think that's going to be a good one.

00;25;31;18 - 00;26;54;00

**Dr. Ravindra Ganesh**

So there's an internal care process model for physicians and I think it also helps in raising the possibility that somebody could have ME/CFS a little bit earlier in the workup so that we don't do some of the things that could potentially make make a patient do worse. You know, like, we wouldn't necessarily send them to PT while we're working them up while we're thinking about what actually is happening here. The other things that we're doing this part, this collaboration is we're updating the front facing Mayo webpage for ME/CFS to be more in line with the scientific process.

Something to remember about Mayo is that Mayo's not a speedboat, it's an aircraft carrier. To make changes takes a while, but once it happens, it's there. And the last thing we're doing together is we've gotten Jaime to work with us on a concise review on ME/CFS, which is essentially a primer for physicians on how to treat.

And I think this may be one of the first major articles on ME/CFS, that has the voice of a patient and an advocate prominently featured in it. So I think that will make a huge difference.

00;26;54;10 - 00;27;44;11

**Dr. Stephanie Grach**

And I think it's really exciting. I really wanted to highlight too what you said about-- especially with the care process model, making sure that we are helping clinicians recognize before they're having patients do extra things that could even lead to harm. Really, also taking ME/CFS out of-- you know, potentially other providers who may not be as familiar with it, taking it out of their mind as a diagnosis of exclusion and really making sure they know now there is diagnostic criteria.

We have cardinal symptoms with post exertional malaise, really highlighting that this is a specific thing to look for before simply just running the gamut, making them go through, for example, physical therapy or other exercise-based tests before reaching that conclusion.

00;27;44;11 - 00;27;49;05

**Steven Molony**

How do you think all of this fits with how you see Mayo's clinical strategy going forward?

00;27;49;14 - 00;28;17;23

**Dr. Ravindra Ganesh**

Mayo's clinical strategy is, you know, to provide high quality care to patients going forward. I think that moving our ME/CFS treatment and education protocols forward to provide scientifically sound advice and guidance patients is in line with our strategy and I think we're doing the best thing we can for the brand this way.

00;28;18;11 - 00;29;47;21

**Dr. Stephanie Grach**

I think recognizing especially with our, like, we are known for the needs of "the patient come first" and recognizing that there is increasing evidence, data, understanding in a field where we can really make sure we are putting the needs of the patient first in a fairly sizable patient population is something that should be important. I really do think that the institution sees it that way.

I've, even in my short time here, I've talked with leadership members who are saying, "What can we do to better access or provide resources," even to patients, whether it's us seeing them in GIM here in Rochester or elsewhere. I really do get the sense whenever I talk with others in leadership that they're supportive, and I'm really thankful for that.

I'm sure part of that is because Ravi has already done a lot of that hard work for me. And again, I think there's something to be said too when there's more recognition funds with what has happened with the pandemic. So I have maybe some extra luck with that. But I think everything was already kind of moving this way.

And now we'd like to keep that going and really make the most out of it because I think it's going to end up benefiting a lot of people, especially with the impact of our institution.

00;29;48;14 - 00;30;30;18

**Dr. Ravindra Ganesh**

And I think I'd like to latch onto something Stephanie said there. Having small centers of excellence, and I'm not even sure we are a center of excellence, tell the truth. I don't think anybody is a true center of excellence for this. But having centers of excellence serves a very small amount of patients.

Creating an echo model where we can have multiple centers that can tap into knowledge and resources serves more people.

I think that, honestly, with the amount of people who had ME/CFS before COVID and the amount of people are going to have ME/CFS after COVID, we need to really create a wider net of people who can appropriately care for these patients.

00;30;31;16 - 00;30;35;13

**Dr. Stephanie Grach**

Addendum being with Dr. Bateman, and you, of course.

00;30;35;13 - 00;30;36;16

**Jaime Seltzer**

Yes. "Addendum being," of course.

00;30;36;16 - 00;31;06;09

**Dr. Stephanie Grach**

Got to look out for her. We've actually all gotten to talk too and she's fantastic. But really, yeah, again, how do we make more of those opportunities happen, right? Because I think, you know, Ravi's right. That really hasn't been an option at most times. And certainly, you know, Dr. Bateman, even with her team meeting the needs of Utah alone is overwhelming. So what can we do to expand that sort of reach?

00;31;07;27 - 00;31;30;25

**Dr. Ravindra Ganesh**

And don't take what I said wrong, right? I mean, when I think about a center of excellence, I think about, you know, being able to provide meaningful, drastic life change. I mean, you know? So, I would like us all to be able to have better treatments before we could be considered centers of excellence. That's all I was saying.

00;31;30;26 - 00;32;42;21

**Jaime Seltzer**

I agree with that, yeah. I would add, too, that the care is complicated, right? And so I want to acknowledge that that is an incredibly important goal. And at the same time that getting us there requires a monumental medical education effort. And I know that treatment, in conjunction with our methods, is attempting to make medical education a little more accessible.

Treating patients with these chronic, complex illnesses is a stretch, it's a reach, it's an ask. So it's just as much information as we can possibly get them. But also the resources too, right?

The resources at Mayo are-- you send somebody to this different department and they'll be able to walk downstairs and have an appointment in 2 hours.

That's that's my personal experience of having been there, whereas not every hospital system is thus equipped. So it's tough. There are still obstacles in the way, but we are certainly closer than we were three years ago by a lot.

00;32;42;26 - 00;33;02;26

**Steven Molony**

Speaking to that monumental effort in education, Jaime, I'm always fascinated by the reasons behind why people got into the line of work that they're in. And so I'd like to hear a little more about that and whether or not these new initiatives tie you closer into why you got into medicine.

00;33;04;05 - 00;33;50;12

**Dr. Ravindra Ganesh**

So from my perspective, I got into medicine because I like the science of it. I'm a nerd. No two ways about that, right? Chronic complex illnesses present a scientific frontier that's not understood. There's no clear treatment options. There are things we can do to make symptoms better, and there are things we can do that will help. But, you know, thinking about exactly what process is causing this and finding targeted therapies is very much out there.

So as a nerd, it speaks to me. As somebody who likes patients, and likes relationships and likes people getting better, it also speaks to me. So I'm happy with what I do.

00;33;50;27 - 00;33;54;09

**Steven Molony**

Very cool. I'm a nerd as well, but I'm the video game kind of nerd.

00;33;55;03 - 00;33;56;25

**Dr. Stephanie Grach**

Oh, are you playing anything good right now?

00;33;58;08 - 00;34;06;11

**Steven Molony**

I'm currently playing-- I never played anything in the Yakuza series, so currently, I'm playing Yakuza 0. And it is a good time.

00;34;06;25 - 00;34;16;28

**Dr. Stephanie Grach**

Okay, very nice. We're-- well, I'm having my fiancée play Horizon Zero Dawn, so we can get to the sequel.

00;34;17;11 - 00;34;20;14

**Steven Molony**

Oh, it's so good. I haven't played the sequel yet, but I love Zero Dawn.

00;34;20;21 - 00;34;30;12

**Dr. Stephanie Grach**

It's amazing. So I'm just waiting for him to finish. So then we can enjoy the next one together. But I'm enjoying watching him enjoy it because those are just fabulous games.

00;34;30;22 - 00;34;32;11

**Steven Molony**

You're going to have to give us a follow up on how all that goes.

00;34;32;11 - 00;34;44;05

**Jaime Seltzer**

We have had many nerdy conversations over the course of our work. I think part of the reason that Stephanie and Ravi and I all get along so well is that we are the same brand of nerd at heart.

00;34;44;05 - 00;35;07;10

**Dr. Stephanie Grach**

We are. And yeah, that's absolutely part of-- well, that's certainly part of why I enjoy medicine. I think that's why I love consultative medicine in particular right now, and seeing everything that I do along with these conditions. And I would say for me it's part the nerd and then more the human aspect is why I got involved. So that's why I think we balance each other out, Ravi.

00;35;07;20 - 00;35;08;13

**Dr. Ravindra Ganesh**

Yeah.

00;35;08;28 - 00;35;17;28

**Dr. Stephanie Grach**

That's why we work so well. You've got a little bit more of the science, I'll have a little bit more of the humor and I'll have more of the optimism. You have a little bit more-- you said today was an "Eyore day?" I think so.



00;35;17;28 - 00;35;19;08

**Dr. Ravindra Ganesh**

Yeah.

00;35;20;23 - 00;35;22;19

**Steven Molony**

We all have Eyore days, don't we?

00;35;23;04 - 00;35;44;28

**Jaime Seltzer**

It feels like it's been a bit of an Eyore week. I don't know if it's something in the air. I know that from my own research, right, the geeky aspects of this, I know that sudden weather changes play with people's neurology. So the huge heat wave followed by the temperature dropping like 30 degrees really seems to have set people into a spin.

00;35;44;28 - 00;35;49;00

**Steven Molony**

I have not wanted to move in, like, yeah, probably two weeks.

00;35;49;16 - 00;35;57;10

**Jaime Seltzer**

Steven does not have ME, by the way. So this is like a statement from a person who's basically healthy. Don't want to speak for you, Steven.

00;35;59;01 - 00;35;59;25

**Steven Molony**

No, yeah, that's true.

00;36;00;09 - 00;36;06;29

**Dr. Stephanie Grach**

And my cat is shedding like crazy now, apparently because of also the weather change. So now there's just all types of effects going on.

00;36;07;16 - 00;36;24;23

**Jaime Seltzer**

Yeah, actually, one of the strangest things about this call is that I have not seen a huge floofsome cat tail the entire conversation because usually Stephanie's cat is part of our conversations. One of our scientific collaborators made very important contributions to the field.

00;36;24;27 - 00;36;27;04

**Steven Molony**

Oh, wow, we would love to get-- what's your cat's name?

00;36;27;13 - 00;36;28;01

**Dr. Stephanie Grach**

Chulo.

00;36;28;18 - 00;36;29;27

**Steven Molony**

We would love to get...Chulo? On the mic. Absolutely.

00;36;33;16 - 00;36;40;24

**Dr. Stephanie Grach**

Yeah, it was his name-- I adopted him when he was nine-years-old. It was already his name when I got him. I'm like, "You know what? I'm going with it."

00;36;42;08 - 00;36;45;01

**Steven Molony**

We did the same with our dog.

00;36;45;01 - 00;36;46;22

**Dr. Stephanie Grach**

He's 12 now, and he just acts like he's 3.

00;36;46;22 - 00;37;02;25

**Jaime Seltzer**

Well, you know what I feel like, you know, we've come to the end of our list of questions, but I feel like we have a little bit more time for conversation. So I'm curious if you have anything to ask either of us or that you would like to bring up that we have not mentioned as of yet.

00;37;03;13 - 00;37;09;18

**Dr. Stephanie Grach**

Now, I am curious, what were your thoughts before you met with me and Ravi for the first time?

00;37;10;03 - 00;39;31;07

**Jaime Seltzer**

I'll tell you something funny. So obviously you guys have heard that my experience at Mayo was mixed. I had some excellent clinicians.

I remember my neurologist was absolutely amazing and I had other people that were dismissive. And I remember very early on that when somebody asked me if they thought that I might have something idiopathic, although they didn't quite put it that way.

They said that they could send me to the CFS clinic if they found nothing. And, of course, over the course of my time at Mayo they found many things, but at the time that ruled out CFS to them. So my impression of Mayo as an institution was just as mixed. However, I knew Stephanie from Twitter and that makes all the difference.

I was not particularly wary of speaking to Stephanie because I had seen her posts. She obviously followed me. And you get a bit of a different impression when you're following somebody on social media. Sure. We all use these social media constructs, but I would say that I'm a little bit more free with what I say on Twitter than what I would necessarily say in a scientific collaborative discussion.

So if Stephanie had seen all my tweets and still wanted to have a conversation with me, she was probably going to be cool, but I was actually quite surprised by how well we all got along and how fast we moved. I have often been, you know, you guys describe Mayo as a behemoth. Let me tell you, there's nothing that moves slower than a university institution with--

I don't think they believe in deadlines. I don't think that anything is pushing them from behind. You can be working for three years in the same team and they don't produce a thing. Over the past several months, Stephanie, and Ravi, and I have completed two things: our website suggestions and our diagnostic and management algorithm, and we've already started writing the concise review.

And already discussed what we're going to do for the CME. That's what, guys, three months? Is that even three months? Something like that.

00;39;32;11 - 00;39;33;05

**Dr. Ravindra Ganesh**

Just about, yeah.

00;39;33;29 - 00;39;41;17

**Steven Molony**

From the sidelines, way, way, sidelines, it's been awesome to witness all the work that you guys are accomplishing. It's exciting.

00;39;42;06 - 00;40;17;22

**Jaime Seltzer**

And the fact that we're accomplishing things together also helps build trust because we see, I think they see from my end and I certainly see from their end that there's genuine devotion to the project and to the ideals behind the project. And I have been moved multiple times to think that together we are going to change the lives of patients who end up at Mayo Clinic, Rochester. And I believe I'm understating it when I put it that way. So thank you.

00;40;18;17 - 00;41;16;16

**Dr. Stephanie Grach**

Oh, no, thank you. You know, that's the thing is, especially now that I'm in a clinic, even though it's not the dedicated clinic, I'm still seeing this all the time. And that's even more of a drive for me, right? The sooner that we have these things done and out and ready and out to patients and out to clinicians, the sooner that means potentially improving the experience of someone going through the system and improving their outcomes.

So, going back to education that we had touched on briefly, too. Coming from the residency program, which was phenomenal, I loved it here. Granted, I mean, I had ranked Mayo number one for my residency program because I really enjoyed the culture. Probably also because I liked the fact that we were given free lunch every weekday. That might have been a big factor.

00;41;16;16 - 00;41;18;00

**Steven Molony**

You can't argue with free lunch.

00;41;18;00 - 00;41;21;03

**Dr. Ravindra Ganesh**

So spoiled. I did not get free lunch.

00;41;21;24 - 00;41;35;07

**Dr. Stephanie Grach**

Oh my gosh. I will take the spoiling. I loved that. Gave me less time to have to think about what I was going to eat for the day, and more time to think about what am I going to do to improve patients experiences, right?

00;41;35;10 - 00;41;38;26

**Jaime Seltzer**

There you go. Sell it, Stephanie.

00;41;38;26 - 00;43;12;27

**Dr. Stephanie Grach**

But having been with the residency for three years and interacting with my co-residents and medical students, learners, I know that the lack of knowledge about ME/CFS about multi-system complex chronic illness is not intentional, nor is it necessarily desired by learners. I think learners really want to know about these conditions. It's just really hard when you go into the room, when you examine, and then come back after you've talked to the patient and your attending says either, "I don't know," or like, "Yeah, that's probably nothing."

That's hard for a learner to know what to do with. They can't move forward unless they take that individual responsibility to. And I think what's kind of cool here is that there are people who want to take that individual responsibility. But when I took opportunities-- so for example, doing morning reports for a clinic on fibromyalgia or even just talking with colleagues on the side about ME/CFS and what I was learning or Long COVID, my colleagues were incredibly receptive.

They were excited. They were like, "Oh, wait, let me try this with my own patients. Let me try this counseling that I learned from your lecture." And I'd have people come back and tell me afterwards, like, "I did what you said and it worked. And like for the first time, I didn't have like this awful feeling after working with a patient and not being able to do anything for them, because I actually could do something for them." And that's a really exciting feeling.

00;43;13;07 - 00;43;50;19

**Jaime Seltzer**

We all want something in that toolbox, right? Like, we don't like the idea of not knowing what to do and especially when we feel like we are in our wheelhouse or we should be. Being faced with uncertainty can feel very threatening in a way. So it's good to have that information ready for people. And I want to emphasize, too, that the diagnostic and management algorithm that we talked about in the CME that we hope to work on.

We intend to make this available not just for Mayo clinicians, but more broadly so that anybody should be able to access it.

00;43;50;21 - 00;44;42;22

**Dr. Ravindra Ganesh**

And I think that's particularly huge, right? So we have made some changes to the internal environment, you know.

Stephanie doesn't know this, but before her time I made it that everybody who did consultative medicine had to rotate through fibromyalgia and chronic fatigue first so that the idea gets presented at the time of the initial consult that this could be fibromyalgia or ME/CFS and it's not an afterthought at the end if we didn't find anything else.

We've worked to get this material into curriculums for the medicine residency, the Sleep Medicine Fellowship, and we've tried to increase knowledge that way, but this is a great opportunity to work with a group that has knowledge and understanding of the patient aspect of this and can help us get this outside of Mayo. So we really relish the opportunity.

Thank you, Jaime.

00;44;43;19 - 00;44;44;15  
**Jaime Seltzer**

Thanks.

00;44;44;25 - 00;44;54;22  
**Steven Molony**

What do you think people living with ME, Long COVID, and other associated diseases-- is there anything that you would like those people to know from your position working at Mayo?

00;44;54;26 - 00;45;11;12  
**Dr. Ravindra Ganesh**

From my perspective, you know, we have a bunch of nerds who are interested in trying to improve the science. And, you know I think, like Stephanie said, you know, building the right team is important because she's better with people than I am.

00;45;11;29 - 00;45;14;03  
**Dr. Stephanie Grach**

I don't know about that. You're pretty great around here.

00;45;16;18 - 00;45;19;23  
**Jaime Seltzer**

You guys are both pretty personable, I wouldn't sell yourselves short.

00;45;20;21 - 00;45;26;22  
**Steven Molony**

I'm charmed. I'm sure all of our listeners are charmed as well.

00;45;26;22 - 00;45;36;21

**Dr. Stephanie Grach**

Well, if only they could see Ravi's red glasses. That's the big thing around here. People always know his glasses when he leaves them in the work room, they're like, "Ah, Ravi was here."

00;45;37;15 - 00;45;58;27

**Jaime Seltzer**

I thought that you were going to say, that's how everyone knows Ravi is personable because he's chosen colored glasses. And I was like, that's an unusual statement, but I actually kind of agree with it. People who choose colorful things to wear intend to display themselves as outgoing and friendly. And so I think it's a it's a good choice.

00;45;59;14 - 00;46;00;09

**Dr. Stephanie Grach**

See? You're a natural.

00;46;00;09 - 00;46;06;00

**Jaime Seltzer**

[Laughing] So is that your message to patients? About the glasses? Because I think we might have found our way outside of the question here.

00;46;06;01 - 00;46;10;24

**Steven Molony**

I think that's what he was driving toward. I think that was the main--

00;46;10;24 - 00;46;12;01

**Jaime Seltzer**

Gotcha. Gotcha.

00;46;12;13 - 00;46;27;27

**Dr. Ravindra Ganesh**

Yeah, no, I mean what we want people to know is that there's a team. We're thinking, we're fighting, we're trying to do our best to deliver good quality care and more importantly, we're trying to learn, which is why we're here.

00;46;28;19 - 00;46;45;22

**Steven Molony**

That's invaluable. Yeah. Awesome. Well, thank you so much, you guys.

I'm so appreciative for you joining us here, and I'm really grateful for the work that you're doing. And I can't wait to see how this partnership continues and how we all can grow together.

00;46;46;16 - 00;47;00;14

**Dr. Stephanie Grach**

Thanks so much, Steven. Thank you, Jaime. We're, again, it's so great to be on here and getting to continue the collaboration. It's just really exciting. I think things are going the right way and that's how it should be.

00;47;01;02 - 00;47;10;16

**Dr. Ravindra Ganesh**

It is exciting. I mean, it's, you know, 5:30 on a Friday afternoon and I'm happy to be on this podcast.

**Dr. Stephanie Grach**

Agreed.

00;47;10;16 - 00;47;26;06

**Jaime Seltzer**

Yeah, I was going to mention at some point how often-- like, we have a time zone difference and I'll be like, "Oh yeah, 4:00 pm sounds good!" And everyone's like, "Sure, sounds great..." And then, you know, we see them at home with their cats, with their children. And it just shows the devotion.

00;47;26;19 - 00;47;27;16

**Dr. Stephanie Grach**

I was going to say, I think you do it to see the cat.

00;47;31;05 - 00;47;32;29

**Steven Molony**

We're all kind of in it for the pets, right?

00;47;33;04 - 00;47;43;07

**Jaime Seltzer**

It's true. It's true. I'm allergic, so the only time I can play with a cat is through the screen, because otherwise I would sneeze and cough, unfortunately. One of those curses.

00;47;43;14 - 00;47;44;23

**Dr. Stephanie Grach**

You know, Ravi's allergic, too. But he has a cat.



00;47;48;27 - 00;47;56;01

**Dr. Ravindra Ganesh**

My cat doesn't like people she likes. She likes warmth. So she comes and curls up on me when I'm not moving. Yeah.

00;47;57;05 - 00;48;04;03

**Steven Molony**

So you're allergic to your cat, but you have the cat anyway.

**Dr. Ravindra Ganesh**

Yeah.

**Steven Molony**

Your love is stronger than your allergy. I love that.

00;48;04;08 - 00;48;06;28

**Dr. Ravindra Ganesh**

I can always take Benadryl or Zyrtec. I'm fine.

00;48;07;23 - 00;48;08;18

**Dr. Stephanie Grach**

Cora's so cute.

00;48;09;05 - 00;48;09;22

**Steven Molony**

That's great.

00;48;10;01 - 00;48;20;22

**Jaime Seltzer**

My parents had a cat for a while and it was a cat that just showed up one day for us and decided to adopt us.

00;48;20;22 - 00;48;21;09

**Dr. Stephanie Grach**

That's the best.

**Steven Molony**

I love those stories.

00;48;21;10 - 00;48;40;21

**Jaime Seltzer**

My mom and-- oh, it was delightful. But Mom and I are both allergic.

But he was a low allergy cat, so any time I would pat his head or whatever, I could just go wash my hands and it would be okay. But he was he was amazing. Al, the White Cat of Mystery, my stepdad used to call him because he would just show up randomly.

00;48;40;21 - 00;48;42;11

**Steven Molony**

Al, the White Cat of Mystery.

00;48;43;00 - 00;48;44;21

**Dr. Stephanie Grach**

You have to say the whole thing every time.

00;48;44;29 - 00;48;45;04

**Steven Molony**

Yeah.

00;48;45;06 - 00;48;47;03

**Dr. Ravindra Ganesh**

It's nice when a cat has a title.

00;48;47;10 - 00;49;04;18

**Jaime Seltzer**

Yes. It was appropriate, too. That cat had more personality than most people I've known. If he got pissed off at you, he would look at you, make eye contact, make sure that you saw his face, and then he would turn his back on you.

00;49;04;18 - 00;49;08;05

**Steven Molony**

He'd show you the butt just to teach you a lesson?

00;49;08;05 - 00;49;08;28

**Jaime Seltzer**

Just an amazing animal.

**Dr. Stephanie Grach**

Oh, my gosh.

00;49;09;17 - 00;49;13;16

**Steven Molony**

Beautiful. Thank you so much for taking time out of your days to talk with us.

00;49;14;01 - 00;49;19;03

**Dr. Stephanie Grach**

Thank you so much. I hope I get autotuned.

00;49;19;03 - 00;49;20;20

**Steven Molony**

We'll remix a song out of this for sure.

00;49;20;20 - 00;49;24;13

**Jaime Seltzer**

With just the Al, the White Cat of Mystery part, maybe?

00;49;25;04 - 00;49;26;03

**Steven Molony**

Yes. That's part of it. That's the chorus.

00;49;26;13 - 00;49;31;18

**Dr. Stephanie Grach**

Oh, gosh. Ravi was like, "She was doing so well, and then she asked for the autotune."

00;49;31;27 - 00;49;39;06

**Dr. Ravindra Ganesh**

I'm sending you back for more media training.

<Theme music plays into the outro.>

00;49;39;06 - 00;49;43;09

**Steven Molony**

Thank you so much to Dr. Grach and Dr. Ganesh for joining us on the podcast.

00;49;43;18 - 00;49;48;16

**Jaime Seltzer**

And thank you again to our sponsors at Outside In Theatre and The Goodman Center.

00;49;49;01 - 00;49;58;08

**Steven Molony**

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00;49;59;12 - 00;50;11;24

**Jaime Seltzer**

At #MEAction, we're building a global movement to fight for recognition, education and research so that one day, all people with ME will have support and access to compassionate and effective care.

00;50;12;08 - 00;50;21;27

**Steven Molony**

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00;50;22;18 - 00;50;39;23

**Jaime Seltzer**

If you have any questions, or suggestions for guests you would like to see on the show, feel free to email us at [podcast@meaction.net](mailto:podcast@meaction.net). Thanks for joining us at #MEAction's Chronically Complex podcast. Keep reading, writing, speaking out, and speaking up.

00;50;40;06 - 00;50;56;14

**Steven Molony**

And don't forget to #StopRestPace. We'll see you next time.