

**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;16 - 00;00;23;10**  
**Jaime Seltzer**

And I'm Jaime 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;00;45;15**  
**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.

But before we get started, let's give a shout out to our sponsors. This episode is brought to you by Outside In Theatre. Outside In is an evolving force in equitable and transformative storytelling through multi-platform theatrical experiences. Outside In produces daring, dynamic and authentic work that speaks to intersectional communities and amplifies content created by and for unrepresented voices.

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**00;01;25;18 - 00;01;59;14**  
**Jaime Seltzer**

This episode of Chronically Complex is also sponsored by the Goodman Center. The Goodman Center is devoted to helping you reach more people with more impact in person in proposals online, wherever. They accomplish this through speeches, workshops and webinars. They've been helping good causes large and small since 1998. #MEAction had the pleasure of working with the Goodman Center for our #MillionsMissing 2022 storytelling campaign, and we can tell you what amazing work they do to help your stories have an impact.

Check them out at [thegoodmancenter.com](http://thegoodmancenter.com). Our next guest is David Tuller. David Tuller obtained his doctorate in public health from UC Berkeley. He is a senior fellow in public health and journalism at UC Berkeley's Center for Global Public Health. He was a reporter and editor for ten years at the San Francisco Chronicle and served as health editor at Salon.

He has also written articles about public health and medical issues for The New York Times and the policy journal Health Affairs. Since 2015, he has been investigating scientific, methodological and ethical problems with research on myalgic encephalomyelitis/chronic fatigue syndrome, or ME/CFS. His ongoing series on this issue Trial by Error can be found on Virology Blog, the Science site posted by Vincent Racaniello, a microbiology professor at Columbia University.

The entire series can be found at [virology.ws/mecfs](http://virology.ws/mecfs). Welcome, David.

<Theme Music plays>

**00;03;08;07 - 00;03;30;28**  
**David Tuller**

So basically I was a journalist or I am a journalist. I've been a journalist for many years, 40 years. Then I was a reporter at the San Francisco Chronicle in the '90s and I covered well, I covered health a lot, including HIV and so on, but I didn't do anything about CFS at that time or ME.

I never would have heard of ME at that time. I had a friend who was diagnosed in the early 90s with what was then called CFIDS, Chronic Fatigue Immune [Dysfunction Syndrome]. That was being used in the early 90s or one name that was being used in the early 90s.

And so I was always interested in this situation. And then I was at public Health School at Berkeley in my early 50s in the early aughts. And then the PACE trial came out in 2011... So what happened was I was reporting in like 2011, 2010, starting to report some about XMRV, the mouse retrovirus that was believed to be associated with CFS.

And that was a whole hoopla for about two years. And at that time I was doing a lot of freelance work for the New York Times for their health section. So I was de facto became the Chronic Fatigue Syndrome reporter And so I wrote about a dozen stories about that whole mess. In the middle of that, the PACE trial came out.

And so for your listeners, the PACE trial is the big trial in the UK that was said to be £5 million of UK money a big very big trial, more than 600 participants the quote "definitive trial" as the authors called it, of cognitive behavioral therapy and graded exercise therapy as interventions for the illness. So this came out in 2011.

The first results. And so I hadn't known anything about it. And my editor at the time, sent me a press release. And like you do, I wrote it up in 3 hours. I didn't really know anything about the trial, and I basically took it at face value, as one normally would with a trial in The Lancet. And it wasn't until after the fact that I got pushback from patients and I started reading it, and then I started reading the patient responses and I realized it was really a terrible trial.

And I would say I mean, I personally would call it a fraudulent trial or arguably fraudulent. I'm not the person who determines these things, but from my perspective as a public health professional, they did a lot of things you absolutely cannot do in trials. And so from my perspective, it's a fraudulent trial. That's my opinion. I couch that with all sorts of things because I've been sort of vaguely threatened with legal stuff and, you know, that sort of-- I'm not the person who gets to pronounce that a trial is, in fact, fraudulent ultimately.

But in any event, it was clear that it was a mess. And so then I started reporting on it, and I figured it was a one-off because I wrote a 15,000 word investigation and published it on a science site that was respected. And I just assumed that the study would be exposed as well, fraudulent.

And, you know, suddenly it was like, Oh, okay, well, that happened and nothing happened. And so then I kept writing about it and it just ended up kind of being my job, actually, because I was originally just doing it on the side while I had my Berkeley position, which was to run a program, a master's program in public health and journalism, because I'd gotten my doctorate in the meantime and I was running this program, and then the funding for the program ran out about a few years ago.

And then it sort of went from like, I guess, a public service project I was doing on the side to something that I sort of ended up finding ways to fund thanks to patient generally generosity and so I've continued in my Berkeley position. But this is my primary work is to basically look at this research, and bring my critical thinking skills to bear on really bad research.

And so basically for me, it's kind of been like a sweet spot between my journalism background and my public health background, where I can take my public health knowledge and epidemiologic understanding and apply it sort of in a journalistic way to this terrible research. And that's really what I've tried to do, mainly.

**00;07;46;26 - 00;07;51;27**  
**Steven Molony**

Could you tell us a little bit more about the kinds of research that you criticize on Virology Blog?

**00;07;52;20 - 00;08;08;28**  
**David Tuller**

Yeah, So I started off just doing the PACE trial and, you know, I mean, it took a year between-- I went to England and I met with some PACE participants and I tried to talk to the investigators. They wouldn't talk to me. Well, I did talk to one of them briefly, but she wouldn't talk to me about-- Anyway, that was a whole other thing. But I did talk to one of them briefly. I had email exchanges with them, but they wouldn't respond to my questions about the really egregious flaws of the PACE trial. So that ended up being a 15,000 word piece that ran over several days. And I think they had tried to ignore me.

And The Lancet ignored it, you know. But then it started to get press attention. And I basically just kind of kept doing follow ups because then I just saw like, you know, there was a commentary with the PACE trial that was completely ridiculous, you know, that was published by their colleagues and that claimed people met a strict criterion of recovery, which everybody knew was, you know, ridiculous.

Basically, it was a lie. And so there were so many other-- and then I went back and looked at the previous study that had for years been also funded by the Medical Research Council called the FINE Trial, and that was published the year before. But once it had no results, they basically didn't find any advantages to the interventions they were testing.

That was a PACE trial that was more for homebound patients because the PACE trial was for patients who could get to the clinic. So by definition it was for moderate and not severe patients. So the FINE trial was an attempt to apply the same modality, essentially cognitive and behavioral interventions to a more severely impacted group that needed to be treated at home.

And the FINE trial was touted. They were funded around the same time in 2003, and they were touted.

PACE authors always said this is our sister trial and blah, blah, blah. Because they were sure it would prove what they thought they were going to prove. And basically the trial had, you know, there were no benefits to the interventions in the published results post the intervention.

And they tried to spin it as a success and they did post-hoc analyses and they tried to-- But anyway, it was a failed-- I mean, it wasn't a failed trial, it showed that this didn't work. And when the trial was published, they completely forgot about the listening audience. They forgot about the FINE trial and didn't even mention it in the text, although they'd spent five years touting it as their sister trial.

So this is just wrong. This is just complete ridiculousness that you cannot hide previous research just as if it didn't exist. And they're continuing to do that. I mean, one of the PACE authors just published a systematic review of, you know, and cited the interventions and cited the NICE guidance from 2007 rather than the NICE guidance of 2021, even though she submitted the paper to the Journal a month after, you know, in November 2021, and that's a month after NICE published its new guidance.

So you can't do that. You just can't do that and a journal can't publish something like that. But in this case they did. And in this case I wrote a letter to them about it and they rejected the letter because they said I didn't write anything. My concerns were not sufficiently novel, quote "insufficiently novel for the journal to publish." unquote

**00;11;30;16 - 00;11;34;15**  
**Jaime Seltzer**

There are a couple of things that we probably want to clarify for our layperson audience who may not know about this stuff.

**00;11;35;16 - 00;11;39;29**  
**David Tuller**

Yes, please, I know that I'm probably saying things that are shorthand or that, you know, whatever.

**00;11;40;15 - 00;12;13;05**  
**Jaime Seltzer**

It's really good. And I love that for people who are familiar, you're giving us the story.

There are two points of clarification that I'd like to make, and let's do the easiest one first, which is that the NICE guidelines dramatically changed recently and that they stated that graded exercise therapy and cognitive behavioral therapy were no longer recommended for people with ME in the UK in particular, that CBT should only be used in a supportive way rather than as curative.

But let's go back even further to the PACE trial and let's go ahead and list some of its many flaws so that our audience really understands why this is not an acceptable thing to use as evidence that graded exercise therapy and cognitive behavioral therapy are actually effective interventions. And if you miss any, I'm sure I'll catch them.

But go ahead.

**00;12;39;28 - 00;12;58;14**  
**David Tuller**

There's two things that I'd like to say about that, and it's very complicated because it took me a year of reading the trial and talking to people, you know, and I had other work to do at the same time. But I mean, basically it took me a year to kind of absorb all this in my head and figure out like what was actually wrong with the trial.

So one thing overall is not research misconduct, but it's just a function of the structure, of the design of the trial, which is that by definition it's understandably very difficult to blind participants to what intervention they're receiving when it's not a pill. Right? If it's a pill, you can make a pill that looks like it, even though you can't replicate the side effects of the pill with a placebo, you can sort of replicate the pill taking experience.

So the patients really don't know unless they go get the pills analyzed. They can't be sure which whether they're taking the actual pill or whether they're taking the placebo pill. Right. But you can't really do that in a trial of psychotherapy or graded exercise therapy. I mean, they have a manual that says this is what you do. You know, you kind of know which group you're in, so you can't really blind those treatments.

So that's sort of understandable. And so Pace was an unblinded trial. And the problem is when then you pair that unblinded nature of the trial with outcomes which are subjective outcomes, where you're just asking people to fill out questionnaires to say, well, yes, I feel better, or no, I don't feel better, which is essentially what questionnaires are.

Whether they're about depression, whether they're about this, whether they're about social functioning, whether they're about anxiety, whether they're about physical function, or whether they're about fatigue, which is the two main ones in the PACE trial, physical function and fatigue. You're answering questions which require a subjective answer, so maybe-- how many times can you walk up the stairs in a row?

You know, that sounds like an objective question, but it's not. It's like you're remembering, Oh, I can do it five times or I can do it one time. And your answer is going to be influenced by all sorts of things apart from how many times you can actually do it. So questionnaires can be fraught with bias. And so that won't matter if you give people pills and you don't know which they have the medication or not, and they don't know whether they have the medication or not, you might be able to rely on subjective outcomes because they don't know whether they got the medication or not.

Right. But in this case, they know that they got the treatment and they were told in the PACE trial, in the manuals and by the instructors who also had manuals, that cognitive behavioral therapy is known to make people better and people improve. And they're told the same about graded exercise therapy that previous research has shown that this makes people better.

So basically people are given an intervention in which they are told the intervention will make them better. The other people are not given that intervention. They're given an intervention in which they're not told that it will make them better or they didn't get an intervention at all except for meeting a doctor once or twice.

So you don't have to be brilliant, you know, to figure out that at the end. If you ask people at some point after the trial, within two months of the trial, did you get better? Can you do more? And you have them fill out a questionnaire and the therapist might be in the other room while you're filling out the questionnaire.

Or you might, you know, you're aware of the therapist is going to maybe see your questionnaire and you like the therapist, even if you didn't feel better or you wanted to feel better. So you think you feel better or you just you know, you're a good test taker. You did well on your your college tests and you want to get right answers.

You know that you're that kind of person. So you fill it out so that it looks good for the study. There's all sorts of reasons why if it's an unblinded study and everybody knows what they were in that subjective outcomes are a real problem.

**00;16;31;21 - 00;17;05;06**  
**Jaime Seltzer**

I'd like to interject something right there too, which is that the nature of the CBT that was being offeredâ€”patients were getting implicit and explicit messages that if you believed you would improve, if you changed your way of thinking, then you would improve. So if the if the message that the therapist is sending you along is that if you buy into the therapy, you will improve, and then at the end they ask, So how do you feel after the therapy?

You have been trained to say Yes, in a way.

**00;17;08;08 - 00;17;33;10**  
**David Tuller**

Right? Yes. I mean, basically the interventions train you to report better on a questionnaire, and that's essentially what the study did. It encouraged people perhaps to increase their answers by one or two points on the various questionnaires. So that's an overall problem with the study. And you wouldn't accuse anybody of research misconduct because it's an accepted study design.

However, it really is not one that can provide a lot of useful information because it becomes impossible to interpret whether the positive results that you may find, if you get them, have to do more with bias and have to do more with patients being told during the therapy that this will make them better and their kind of response to that as opposed to the actual improvements.

That's why you want to have objective outcomes. Now, that's very difficult with something like Chronic Fatigue Syndrome or ME, where you don't have a biomarker, you don't have an HIV test where you can say yes or no, or a coronavirus test, yes or no—you're positive or negative. You have this or you don't. We unfortunately don't have that. So that means diagnostic criteria are based on symptoms and some medical tests.

And, you know, by definition, you know, a bit fuzzy around the edges.

**00;18;27;08 - 00;18;29;00**  
**Jaime Seltzer**

They did have actimeter, didn't they?

**00;18;29;14 - 00;18;54;26**  
**David Tuller**

Yes. Well, so what happened was you find proxy measures that will measure function but aren't measuring physiological, you know, blood things and something like that if you want to find an objective measure. So they had four objective measures that they included in the trial and one objective measure that they dropped from the trial at an early stage for ridiculous reason. Really, they lied in their response to a patient about that. And they said it was-- Well, let me go over these one by one. Is this not too much detail? This is what you want?

**00;19;05;10 - 00;19;05;28**  
**Steven Molony**

This is great. Keep going, yeah, it's great.

**00;19;06;01 - 00;19;16;19**  
**Jaime Seltzer**

It's very interesting to hear it all from the person who's done probably arguably the most research into this, out of anybody else, so we're waiting with bated breath.

**00;19;16;19 - 00;19;34;08**  
**David Tuller**

If anybody said to me ten years ago, you know, oh, you're going to be the chronic fatigue syndrome reporter, you know, or something, I would've been like, "What?" You know, it would have been like, "Huh? What are you talking about?" But anyway, here it is. And it's been a fascinating project.

And I think, you know, it's interesting. People just assume that I have ME or I have CFS or I have someone I know, I mean, I have a friend, but it wasn't like I had a, you know, I'm not Ron Davis, you know, whose son is very sick. I've just been astounded by the incompetence and the stupidity of these people and by their efforts to pretend that their work is great. And it just kind of really caught my interest. And one of the flaws was really what kept me going. But I'll go over the objective measures.

So basically I had four objective measures. One was a six minute walking test, which is a standard measure of how disabled people are, how far they can walk in 6 minutes. One was a step test, like on a step stool. Is that what they're called? A stepladder? Or step stool like you step up and down, you know, and that's considered a fitness test.

And then they had a measure of employment status, whether people worked more or less hours than they have or whether people were on or off, you know, social benefits for disability, whatever those would be in England. And so those were there for objective measures.

They'd also started off with another objective measure called an actimeter, which Jaime just mentioned, which is, you know, like a Fitbit or a thing you put on your ankle or on your wrist or somewhere.

I think these were ankle monitors and you walk around with it for a week and it measures how many steps you take. So they started off with that as an introductory measure. And they initially intended to use that as an objective measure because after all, at the end, that's a pretty objective measure of how far do you move?

And what happened was they dropped it from there when the protocol was published and a patient asked them, Tom Kinlan (I think it was Tom) asked them in question, you know, correspondence, why did they drop that? It would seem thatâ€™s a good measure. And they said what â€œWell, we have four other objective measures and we dropped that because we decided it was too much of a burden for patients to have to wear it at the end of the trial.

That's an absolutely ridiculous, stupid lie because basically they were making patients wear it at the beginning of the trial, so presumably half the patients would be cured at the end of the trial. So it would actually be less of a burden to them at the end of the trial to wear it than at the beginning. So if they really wanted to prove that people were moving more, they would have kept it.

What happened was a Dutch study from their colleagues, there were a couple of Dutch studies that included this as a measure, and they didn't include the measures when they actually reported the initial subjective results. This is a problem with this entire body of literature that when they do have objective results that contradict their subjective results, they tend to downplay them or hide them in some way, like not reporting them until years later, like the PACE authors did with three of their objective findings.

But in any event, this Dutch team found that the actimeter measures did not match their subjective measures of reports. In other words, they had no results on the actimeters and that got reported to the PACE team. And in some of the trial minutes, it says, oh, the Dutch team found that this didn't work.

And then therefore, this means that this isn't a good objective measure. So they decided that because the objective measure did not match the subjective measure, it was the subjective measure they had to believe and not the objective measure. So they dropped the actimeters from the trial as an objective measure and they lied about why they did it in correspondence.

I mean, there's not really...you know...

**00;23;04;16 - 00;23;16;16**  
**Jaime Seltzer**

I'm always blown away by these kinds of things, right? Like you must live in a near constant state of frustration and disbelief.

**00;23;17;03 - 00;23;40;08**  
**David Tuller**

Yes. It's been very, very frustrating. And at first I thought I was going insane and I kind of felt like I had a secondary glimpse of what patients must go through because I would call up editors and I'd say, you know, I was still often trying to get this with regular editors. And I would say chronic fatigue syndrome, and you could hear their eyes rolling in their head, you know, over the phone because nobody wants--

"Oh, here's this Tuller again, calling with this chronic fatigue syndrome stuff," you know. And so, I mean, I did feel like I was going insane because I'm like, what do you mean, you did this?" You know, and I mean, we haven't talked about the flaws, but I mean, I'm like, how could this be? And it is, you know. Anyway, so.

**00;24;00;23 - 00;24;11;26**  
**Jaime Seltzer**

We did not even mention that they moved the thresholds for recovery mid trial, such that some people who entered the trial would have been recovered at its end.

**00;24;12;25 - 00;24;47;06**  
**David Tuller**

So basically the one flaw that has kept me fascinated with this. And it's like an Alice in Wonderland thing is the physical function scale where the problem is so obvious. And it makes no sense. Basically what they did to go into detail about what Jaime was saying, which just makes the trial, you know, ridiculous on its face, is that after collecting data, they changed their outcome measures.

And you can do that under some circumstances. But it's a problem when you weaken all of the outcome measures and that as a result, all your results look much better than they would have had you stuck with your original outcome measures. That's not a good look for researchers, really. And the fact that they weakened all their outcome measures was obvious.

It wasn't like it was complicated. The way they explained what they did was they lowered thresholds.

So what they did was one of their two primary outcomes and their two primary end criteria, they had scales for physical function and scales for fatigue on the scale, for physical function. It goes from 1 to 100. I'm sorry, 0 to 100. So 100 is you're in perfect shape.

Most people, even with some disabilities, will score-- you know, the curve on that is very much skewed toward the healthy end. So people answering these questions can, you know, can you lift this? Can you walk up the stairs. I don't remember what the questions are, but things like that.

**00;25;45;27 - 00;25;52;18**

**Jaime Seltzer**

But they're all very basic. They're all very basic questions. And if you say you can't do even one or two of them at all, you're disabled.

**00;25;52;28 - 00;26;29;24**

**David Tuller**

Right. So basically they ended up with entry criteria at 65 or below on the scale represented serious disability enough to get into the trial. So in order to get into the trial, you had to have a score of 65 or below to qualify as disabled for physical function. So when they started the trial, when you look at the protocol on that scale, they rated-- when they talked about how they would assess the findings, a 75 on that scale was considered, quote, improvement on that scale.

And then 85 on that scale was considered recovery for that scale. Now, not recovery overall for recovery on that scale, because they had multiple measures on which you had to have recovery scores in order to be fully considered recovered for the full trial. But on that measure--

**00;26;48;06 - 00;27;07;17**

**Jaime Seltzer**

Wouldn't you think that it would make more sense to (maybe this is a naive question) to do percentage increase rather than... suppose somebody, you know, entered the trial with exactly 65 and... Oh, I suppose, I suppose. But let's say that they entered the trial at like 40.

**00;27;08;00 - 00;27;08;09**

**David Tuller**

Mm hmm.

**00;27;09;12 - 00;27;22;15**

**Jaime Seltzer**

They would have recovered more if they had managed to reach 85 than somebody who had entered the trial on 65. So wouldn't we think that improvement would be more important for the individual patient?

**00;27;22;21 - 00;27;50;03**  
**David Tuller**

They have different ways of measuring things, they had improvement and they had a recovery and they published the different sets of data in different ways. And they also had a measure for, you know, they might say-- you take the averages and say, well, people might-- in a trial like this, not necessarily this one, but they might say, yes, the average is increased by more than a clinically significant amount, even though in the end they were still disabled, it would have been people in that category.

And so they presented their data in multiple ways, including in sort of average increases in the measures. But also they were supposed to give us a measure of what, you know, what percentage had recovered on this measure at 85%. So, you know, there's a problem with all of these in all the ways you do these measures.

When you do averages, you're not getting the outliers. So you don't really know how many people did or didn't get better. So averages have their own limitations because then you might get the average increase was great, but that might be because three people did fantastically and everybody else just kind of did, you know, not so well. But in any event, in this case, they were the recovery on this threshold was supposed to be 85 and up.

So if you scored 85 and up, you were said to have recovered for physical function. When they published the initial PACE trial in 2011, they had changedâ€¦ Well, by the time-- forget that. By the time they published a paper on recovery, the recovery threshold for physical function had dropped to 60. So in other words, you could enter the trial being severely disabled at 65 on that scale.

You could get more disabled on that scale or subjectively more disabled on that scale and end up with a score of 60. But for the purposes of the PACE trial, you would still be considered recovered for physical function. I mean, that is completely nonsensical. It's just like you can't be you can't have breast cancer and not have breast cancer at the same time.

I mean, you can't be recovered and disabled on a single scale at the same time.

**00;29;28;13 - 00;29;39;24**  
**Jaime Seltzer**

And I want to emphasize, too, just how disabled that that is. A score of 60 on physical function is terrible. You're extremely disabled at that value.

**00;29;39;24 - 00;30;15;22**  
**David Tuller**

And they call that value. They called that the normal range, which is a statistical value. But they actually did what they knew was the false statistical test for the data set that they had, which I wrote about at great length and doesn't really bear going into here. But they knew that this was not a normal range that they constructed a not a normal range, which again, is the statistical understanding that they constructed it as if their underlying data set was a normal bell shaped curve when their underlying data set, which was sort of the range of responses on this questionnaire, is much more skewed toward the healthy end curve.

So we could use a very, very we expand that quote, normal range and they ended up with 60 as if that's normal and it's not it's extremely disabled. So they were basically--

**00;30;25;19 - 00;30;47;25**  
**Jaime Seltzer**

Let me interject again, just for our listeners at home who may not understand that when you say like normal statistically. So that's a term in statistics. Right. And I will also add that there are a lot of researchers who apply whatever statistical method will give them the results that appear to be the most advantageous for them rather than the statistical methodology.

That's actually appropriate for the case.

**00;30;50;15 - 00;31;09;02**  
**David Tuller**

Right. A normal range does not mean normal in the healthy sense. It's normal range is a statistical term and it can't be understood to mean, oh, that's a normal thing. But that's what the PACE authors did, because when they presented the PACE trial in 2011, one of the lead authors said, Oh, this many people got back to normal.

Even within this bogus, the normal range already was fraudulent. And then she made it further fraudulent by claiming people got back to normal, which was a complete mis--

**00;31;20;11 - 00;31;25;20**  
**Jaime Seltzer**

Perhaps she misunderstood. Perhaps she misunderstood the technical term.

**00;31;26;06 - 00;31;46;04**  
**David Tuller**

I'm not convinced that that particular researcher is the smartest of the bunch. But yes, in any event, all the media from the PACE trial initial presentation was patients getting back to normal, which to the normal person means recovered. The whole thing is a scam and a sham. And so theyâ€|

**00;31;46;09 - 00;31;52;03**  
**Jaime Seltzer**

Isn't there a logical fallacy name for like using a term that has like another meaning?

**00;31;52;17 - 00;32;23;24**  
**David Tuller**

It's a misnomer. It's a misnomer in this context. It's sort of a misnomer, but maybe there's a different term. But but that main flaw about the physical function scale and that impossibility and their insistence that this was okay and the insistence of the Lancet, that this was okay and the insistence of every single person in the British establishment and the CDC and everywhere else that this trial was okay, notwithstanding the fact that people could get worse on an outcome measure and be considered recovered, you know, that by definition makes the whole trial ridiculous.

You can't publish crap like that. And they did. And, you know, they've never taken responsibility for it and nor have the journals, nor have those who supported it, nor has the CDC, which defended the PACE trial until it disappeared. And then never explained why it disappeared except to blame patients for misunderstanding what the CDC meant when they used the terms cognitive behavioral therapy and graded exercise therapy.

Nobody misunderstood anything. Everybody understood perfectly well what the CDC--

**00;32;52;27 - 00;33;08;15**  
**Jaime Seltzer**

No, although people are are much more likely to when they know that they have made an error, it's a lot easier for them to remove evidence of that error and fix the error, and never say anything again.

00;33;10;10 - 00;33;12;02  
David Tuller

Often, that's easier. That's true.

00;33;12;15 - 00;33;14;16  
Jaime Seltzer

Yes. Easier. We'll use the word easier.

00;33;15;03 - 00;33;31;11  
David Tuller

But you know, I mean, I feel this personally, but with the CDC and the CDC is the country's lead public health agency, I have a doctorate in public health. I'm a public health professional as well. You know, mainly I'm a journalist, but I mean, I pose as a public health professional because I have an academic post in the public health faculty of Berkeley.

I'm really offended as a public health person. These are this is terrible public health. When you make a mistake, you acknowledge it and you apologize for it and you do what you can to rectify it. And you don't accuse people of misinterpreting what they did not misinterpret. And that's what the CDC has done throughout this episode. Maybe they're doing better research now and maybe they're doing some better stuff now and maybe, you know, there's still this problem, but obviously it's better than it was.

But this is bad public health and I'm offended not just as a human being, but I'm offended as a public health professional.

00;34;03;15 - 00;34;16;29  
Jaime Seltzer

I'm offended as a human being as well. I will say that I think that it was bad practice. I'm glad that they've changed their recommendations and that now they talk about post exertional malaise and the fact that you should not push yourself.

I think that's good and I think so too. The comeback the PACE trial-- that was the central flaw that kind of really kept me interested. And the other thing that I think we should mention is that the investigators were all advising disability insurance companies and, you know, basically that these interventions would get people back to work even in the absence of any evidence that was, in fact, the case.

And so they did not disclose these conflicts of interest to participants in the trial.

And even though they had promised, I think this is a big problem, but they've always, you know, fluffed it off and The Lancet looked it off and everybody sort of ignored it. But they basically promised in their protocol to follow a human rights declaration called the Declaration of Helsinki, which was designed to protect human rights subjects.

**00;35;06;26 - 00;35;17;14**  
**Jaime Seltzer**

And everyone has to take this, by the way, everyone has to study that declaration. If you've ever taken IRB training in the UK, in the U.S., you definitely know about that. If you are informed.

**00;35;17;18 - 00;35;38;23**  
**David Tuller**

Right and now you know and things have changed since 2005 when they started the PACE trial. So things have gotten much more stringent with conflict of interest declarations and so on so no and nothing probably in UK law at that time would have forced them to disclose these potential conflicts of interest to. I mean, it was a squishy area.

They disclosed the things when they published their articles, but not in the consent forms. However, they agreed in their protocol to follow the Declaration of Helsinki, and the Declaration of Helsinki is fair and you put in your protocol, you're going to follow this and this and this, you know, ethics provisions, and that's how you get your money. You get your money by promising things in your protocol.

So they promised in their protocol as a you know, as a function of their promises that they made to receive money, that they would follow the Declaration of Helsinki, which is very, very explicit. And at that time, it's been updated over the years. But at that time it was already very explicit that researchers had to disclose any possible conflicts of interest and any institutional creations.

Those are very broad terms. That means what it says these people had active institutional affiliations with government agencies and disability insurance companies, and they had active possible conflicts of interest with those same entities. And did not disclose to participants. When I raised this with them, they gave all sorts of bogus reasons why they didn't have to comply with it.

But it's all crap. It's all nonsense. They violated the protocol by not disclosing to people, and that's a real serious ethical violation that they violated their protocol and they didn't make these disclosures. I think all the data set should be thrown out, but that's just me.

**00;36;59;16 - 00;36;59;24**  
**Jaime Seltzer**

Hmm.

**00;37;00;08 - 00;37;16;24**  
**Steven Molony**

So you've been doing this a long time and you've been really outspoken. I wanted to revisit-- you mentioned that you've received several vague legal threats over time. And I would love to hear a little more about that if you can expound on that at all.

**00;37;17;08 - 00;37;38;16**  
**David Tuller**

Oh, sure. Yeah. Well, basically, I consider, you know, these people always claim that anybody who criticizes them is harassing them and, you know, engaging in bad faith behavior and all this kind of stuff. So, you know, I consider the behavior towards me to be a form of harassment. They've harassed me. I publish things. I haven't accused them personally of anything.

You know, I haven't personally accused their research of things. And I say that their research is unethical. I don't call them names, you know, or I mean, I have maybe a little bit, but basically I call it obnoxious. You know, I have and I've torn up their papers at conferences and stuff, but that's no, you know, I mean, I'd say everything I say is pretty much in fair common category.

And some of my work I consider sort of to be like academic performance art and some sort of, you know, a little provocative in order to get attention because otherwise nobody would pay attention. Plus, I'm an American. I can get away with things that people working the UK establishment could not do because, you know, there's more deference paid there.

So I don't have to care about deference and they can't... But anyway, that's like when I first published my big thing. Virology Blog immediately got, you know, from the public relations people at Queen Mary University, which was where the lead author was university about, you know, I was causing Internet abuse, I was triggering Internet abuse, and I was triggering reputational damage.

So, you know, I consider those legal threats. I mean, that's legal language you send to somebody to make them worried that they're causing problems.

It's not my fault if their bad things cause people to send them nasty emails, you know, if they're horrible behavior in terms of research causes them to get terrible emails, that's really too bad, you know?

But it's it's not my fault. And if they cause reputational damage because I've accurately described their terrible research, that's often not my problem. That's their problem. I consider those legal threats. subsequently, one researcher, you know, subsequently over the years. I mean, then I had, you know, Reuters wrote a piece which basically made me seem like some guy, you know, the first version, didn't mention that I'm an academic position at Berkeley, that this work is my academic project.

It mentioned my crowd funding, which I do twice a year at this point. It made it sound like money goes directly to my pocket, like I go around the world just having my hand out and taking cash from patients as opposed to the fact that my money is crowdfunded directly in donations to Berkeley.

I don't see a cent of it. It goes to my department and my department pays me my salary and benefits like any other academic at Berkeley. I just happen to be crowd funded. Rather than having \$100,000 from a foundation. Foundations have their interests too. You know, everybody who funds you is going to have some interest. Yes, I'm funded by patients.

You know, these people are funded by their colleagues in academia who also have their interest in supporting their crap. So everybody has interest in who funds them.

**00;40;23;23 - 00;40;25;16**  
**Jaime Seltzer**

Or they're funded by the Department of Work and Pensions.

**00;40;25;23 - 00;40;46;11**  
**David Tuller**

Or they're funded by the Department of Work and Pensions, which obviously has an interest, it wouldn't fund you if it didn't think that your project was going to get people back to work. So basically they've accused me of conflicts of interest and then, you know, the worst I thought was that... And so I had, you know, a couple of what I would consider hit pieces written about me for inaccurately portraying my academic status.

And I don't care about my academic status particularly, I became, you know, an academic means I got my doctorate when I was 57. So this is not like, you know, oh, I'm, you know, whatever. But I mean, they treated me like I was a patient.

They treated me as badly as they were treating patients because they could treat patients like that.

And they thought they could treat me like that, too. And it doesn't really work because, you know, I'm at Berkeley. The other thing is that the University of Bristol, which has a very, I'd say, ethically and methodologically challenged faculty member named Esther Crawley on its premises, you know, whose work I have critiqued fiercely and who I have made fun of in some ways.

But, you know, not in, you know, her research is terrible. So she publicly started to publicly accuse me of libelous blogging. When I responded and asked her to explain this, what was libelous, she refused to answer me. In the meantime, it later turned out-- And then I went to a lecture of hers, and I asked her why she had accused me of libel without, you know, explaining it.

And then I got asked to leave the room after she ranted about my work and how you know, unprofessional I was and that she thought she needed to call the police about me and that I'd been sent a cease and desist letter by her university, which wasn't true. It turned out not to be true. So I left the room very calmly.

And at this point I heard from her university that they had filed complaints with Berkeley about me, and they were discussing my behavior. So I talked to my supervisor and they were like, yeah, we got these complaints. We don't really know what to do with them because they don't say you did anything wrong.

They just don't like your behavior. They're like, What is your behavior? I said, Well, I went to her lecture and I asked her a question, and I had a video of, you know, my very polite asking of the question and my very polite leaving the room when asked and her going on and on about ridiculousness and saying things that weren't true, like I got a cease and desist letter.

So, you know, basically Berkeley ignored this because they felt like they didn't understand the complaint. And, you know, I considered that harassment. You know, I consider that harassment because they were trying to threaten my employment because I wrote things they didn't like about their star grant maker. You know, we call it rainmaker. She's a rainmaker. She brings in a lot of grant money.

So they don't want to do anything about it, even though you know, her work's terrible. So I've had some harassment that way. But it's actually been kind of fun. I mean, I can't really you know, let me put it this way.

I'm, you know, I mean, I'm fine. I mean, everything's fine with me and I haven't suffered from it.

And it hasn't caused me problems in the sense that the way it would patients or the way if I was a researcher in the UK or work at a university that supports me, they think I have academic freedom even on my tenure. So everything's good with me.

**00;43;46;17 - 00;44;10;03**  
**Jaime Seltzer**

Well, so I had a feeling that the Esther Crowley thing would have been the answer. But just in case it isn't, what is the most absurd Monty Python sketch esque thing that you found out as the result of your labors in investigating ME research issues? I'll just throw a few things out there to give you some ideas. Get the old juices running.

Is it the FND stuff? Godwin's Law and Nazis, The Lightning Process... Just a few choices for you to choose from.

**00;44;19;15 - 00;44;40;14**  
**David Tuller**

I'd say it's an Esther Crowley situation. I'd say that, and it's the lack of response from the journals. I'd say that, well, first of all, every time something would happen and I'd mention to Vincent Racaniello, who's the host of Virology Blog, and I'd say, Now they did this. We'd be like, "They didn't what?" You know, "They said what this time?"

I mean, it's so ridiculous. And you get astonished each time that this person is in this position. So what Esther Crowley did in one of her studies of the lightning process, which, you know, is just I mean, we don't know that much here in the in the U.S. it's basically you will yourself better and they say it's your, you know, you're engaging in neuroplasticity and your restructuring, rewiring your mind and you do it in three days and, you know, you just say, no, no, no. You know, it's sort of like--

**00;45;14;27 - 00;45;20;07**  
**Jaime Seltzer**

You shout stop at your symptoms. And then they stop and then you spin. You spin a few times in place.

**Steven Molony**  
That's how it works, right?

**00;45;20;07 - 00;45;35;26**  
**David Tuller**

And I choose the life I love, and I don't choose to be sick. And it's a lot of affirmations which are all very, you know, that can be helpful for anybody. I don't dispute that. But anyway, I don't think it will cure your serious illness in three days, But there's a lot of testimonials.

So anyway, Esther Crawley was doing a study of this in children and she basically so basically when you do a study, you register the trial, then you recruit people and when you register the trial, you mention your outcomes, what they are, and that's what they're supposed to be. And so she did something where she recruited half the patients for what she called a feasibility trial, and that had its own outcome measures.

And then when she recruited more than half the patients, she got permission to extend that into a full trial. So she recruited another less than half the people. At the same time, if she changed it, she changed the outcome measures based on the data from the first half of the trial. So she changed the data midway through. I mean, the outcome measure, she swapped primary and secondary outcome measures midway through, and then she published the trial in a BMJ journal without mentioning any of this stuff that she'd changed the outcomes part way through.

She wrote it up as it was a completely prospective trial with everybody pre-registered when it was not. It was a complete lie. So I did a whole thing, made it clear that this is what she had done. There was no disputing it. The Journal spent a year and a half investigating it when it took me, once you saw what was done, it took about all of 10 minutes to see that this was really not right.

And then they published a 3000 word correction instead of retracting it.

**00;47;05;07 - 00;47;06;18**  
**Jaime Seltzer**

So basically another paper.

**00;47;07;08 - 00;47;31;16**  
**David Tuller**

Essentially. I mean, that's an unheard of, you know, I mean, I've never seen a 3000 word correction. Every section was corrected practically. And in terms of this outcome swapping, which they did with full knowledge of which was the better outcome, because they have the first half of their results, you can't do this. This is fraudulent. You can't change your outcome measures midway through and just not tell anybody.

You can't do it. You can't.

**00;47;33;04 - 00;47;43;10**  
**Jaime Seltzer**

She was interpreting it as not being midway through because she was interpreting the other study as the beginning as a separate study, except for when she needed to think of it as being part of the same study.

**00;47;43;23 - 00;48;16;04**  
**David Tuller**

Yes. And then she had rationales for why they changed the outcome measures. And the thing is, if she had told the Journal in the beginning that half the patients were recruited after registration and that they had done the trial would never have been published in the first place because it violates all the major journals agreed in, I don't know, 2005 or some, you know, a long time ago not to publish any papers that were not registered where all the patients were recruited after registration.

This trial did not meet those criteria. So anyway, she lied about that on the paper. The paper, the BMJ, treated it like an oversight sort of. Oh, it was confusing, you know, whatever. And then when they asked them, did the fact that you saw the results before influence your decision to change the outcome measures to the more attractive ones that you got?

Oh, no, no, no, it didn't. So the editor's note So not only was there a 3000 word correction, there was a 1000 word editor's note essentially explaining in twisted language why they did not retract it. The reason was we asked them and they said that didn't influence them. The whole point we have things structured to prevent bias is because we don't know we're being influenced by it.

So you don't accept the researchers work that they were not biased by looking at their results before they were supposed to, and that you don't take their word that they they just violated the principles. So they allow them to republish it with the exact same results rather than forcing-- republish it with the outcome measures swapped so that they would have had negative results for their primary outcome had they actually followed their protocol.

So this is a standard practice of these people. They swap outcome measures, they change things all the time. If you look at all these trials, many of these trials, they do similar things. But that was the most egregious and the most egregious decision on the part of a journal not to retract it as well as The Lancet.

I mean, The Lancet, I mean, all the journals, I have no respect for them at this point that remain in this domain. I can't really speak for other areas. But in this domain, the major journals or many major journalists have really been atrocious.

**00;49;54;06 - 00;50;00;06**  
**Jaime Seltzer**

Well, I mean, look at how long it took The Lancet to retract Wakefield's. But anyway.

**00;50;00;19 - 00;50;18;29**  
**David Tuller**

And I imagine that's one reason why Richard Horton doesn't want to deal with PACE because he came out swinging when PACE was publishing, slamming patients and defending the trial in ways that showed he didn't really understand what the trial was doing. And he's kind of, you know, basically now out there crusading about bad science. But he won't look in his own backyard.

**00;50;18;29 - 00;50;20;26**  
**Jaime Seltzer**

Very few people are willing to do that.

**00;50;21;09 - 00;50;27;01**  
**David Tuller**

I always had a dog. We always looked in the backyard for his poop. You know.

**00;50;27;05 - 00;50;27;10**  
**Jaime Seltzer**

Nice.

**00;50;27;14 - 00;50;29;02**  
**David Tuller**

You know, you do that. That's what you do.

**00;50;29;18 - 00;50;56;09**  
**Jaime Seltzer**

Of course. You know, I think that there are fewer people than I used to believe who are actually interested in determining what the truth is rather than what would just benefit them the most, were it true, especially in light of the pandemic, unfortunately. So my last question is what do you see as the ultimate goal of your work?

And do you have anything to promote? Your fundraiser or anything like that?

**00;51;03;12 - 00;51;24;29**  
**David Tuller**

Yeah. So basically my you know, I started out this it was a one off this, this all evolved on its own kind of thing. I mean, I'm not like a big entrepreneur. I'm not like, you know, I'm not really, you know, I was a newspaper reporter and then I was at Berkeley, and then I started this project, and then I needed to find a way to keep making money or I couldn't continue the project because, you know, I needed.

So I started crowdfunding. And then lo and behold, to my amazement, I never I mean, you see Iâ€™m technologically inept that I would be crowdfunding and be able to do that and make it work is kind of astonishing to me in that there's enough people out there, you know, that put their faith in me and do this. It's kind of very humbling and so I never intended to make this, you know, I mean, such a long project.

But it just seemed to me that at the time I realized that I was in a position to do this because I could and I had an academic position. So I sort of had some credibility that I could sort of pull something together where it was clear that there weren't any other scientific voices from outside the community speaking out on this stuff.

So I saw that as my initial goal and my initial goal was to get the PACE trial retracted, I quickly realized that was not possible. So my goal just became to completely discredit the PACE trial. Then my goal became to have the-- I was thinking, I'll do this until the new NICE guidelines came out. Right Then the pandemic happened and that got delayed because that would have been like four or five years since

I started the project. Then, you know, so then I felt like the NICE guidelines came out. I thought like, okay, I'd done what I could. You know, and I sort of thought, oh, maybe I'll do a book or something like that. And then I thought, Well, I see all this Long COVID stuff happening and I see that the exact same people are using all their bad research and citing it to make the similar argument.

That's completely ridiculous about Long COVID or at least those Long COVID patients who have a similar cluster of symptoms that looks very much like ME or CFS, right? Sort of the that cluster of nonspecific symptoms that we're all familiar with. And so I saw the same people. I thought, Oh no, I can't, you know, I sort of have a certain, I don't know, something that I can do and that I can sort of and I saw this whole bleeding into, you know, medically unexplained symptoms.

And now this paper like this one recently that said that POTS was psychogenic.

**00;53;29;26 - 00;53;45;01**  
**Jaime Seltzer**

That's just astounding too, right? Like that has autoantibodies. You can measure that. That has tilt table testing. It's just it is absolutely astounding what people will do to try to expand the area that their field will cover.

**00;53;45;13 - 00;54;08;06**  
**David Tuller**

I found what's astounding about that, it's again, I'm not a doctor or medical person or a scientist or biologist, but I just go on the logic of some of these things and their logic was, you know, just, you know, they had an association and they interpreted it as a causal relationship in the opposite direction of what a normal person would do.

So it just doesn't make any sense. I mean, they basically told people that people who had POTS and people who don't have POTS, they told them both they were going to get, you know, they told them 20 seconds before they were going to be having a tilt table test. People with POTS. No, that's unpleasant feeling. So they got greater anxiety and so they had a high heart rate.

So the other people didn't have a high heart rate, was being tilted that wasn't particularly unpleasant for them because they didn't have POTS.

**00;54;38;23 - 00;54;42;06**  
**Jaime Seltzer**

Or they didn't even know what a tilt table was. So they were like, okay.

**00;54;43;01 - 00;55;08;25**  
**David Tuller**

They didn't have any expectation. So they found that people anticipated an unpleasant sensation and they interpreted that to mean that therefore, when they were tilted upright and they had even more heart rate going, that it was psychogenic because it was based on the anticipatory anticipation of feeling bad rather than they actually feel bad. And they posited that the people had a previous episode of being sick or, you know, recently had been sick.

And after they got sick, they got up and were dizzy. And so they got imprinted from that one experience, not because they have POTS but that experience so terrified them that now whenever they stand up, they have this anticipatory thing that was there, that was their paper.

**00;55;24;14 - 00;55;35;13**  
**Jaime Seltzer**

It takes a special kind of brain to to come up with that explanation. I just sometimes I really I actually don't understand.

**00;55;35;13 - 00;55;49;18**  
**David Tuller**

It takes a special kind of interpretation to interpret everything in the more complicated way when there's a simple explanation, which is that the people with POTS understandably were anxious about having being tilted, and so they were anxious.

**00;55;49;18 - 00;55;51;18**  
**Jaime Seltzer**

Because it causes increased symptoms.

**00;55;51;21 - 00;56;10;27**  
**David Tuller**

Of symptoms. Why wouldn't you have an anticipatory anxiety response? That's the logical explanation. But they interpreted it backwards, you know. So yeah, I wrote a letter about that and that would be published, you know, with some, you know, eight or nine of us, I think, signed the letter. So that'll be published next month. But you know, it's constantly vigilance.

And sometimes I wonder, does it have any effect? Because I feel like I'm still doing the same thing over and over. I have to believe that my persistence has had an effect and that my... well, I have to believe that my work has had an effect because otherwise, why keep doing it? But I sort of wondered, is there a continued effect?

And I've sort of tried sort of expanded into this other area because it's obviously so connected to ME/CFS And there's this whole area of medically unexplained symptoms that seems to open itself up to bad epidemiology and bad science.

**00;56;51;08 - 00;57;18;06**  
**Jaime Seltzer**

And illogical thinking. I think that you have made a difference and I think that it's probably very hard for you to tell because what you end up seeing and working on is often the worst of the worst people who have no logical reasoning ability and start from their conclusion and work their way backwards to something that they think makes sense to them.

The rest of us are are pleading with them to understand Occam's Razor. I think that that's going to call it a day for us. Yes, Steven? Do you have any any final questions?

**00;57;31;11 - 00;57;47;24**

**David Tuller**

Oh, so, you know, the one thing I mean, I don't know if I should promote this or not, but I mean, I do crowdfund to support my work. It's what I dislike doing is, you know, I really wish I didn't have to crowdfund. And that there was another way to just get a big grant.

I don't like asking patients for money. It doesn't feel right. I understand that for the most part, patients who support me, you know, don't resent it. They understand why I do it, and they do it because they want to. So I certainly, you know, but I do have to do it, you know, as long as I'm doing this.

And so I keep my job and, you know, keep my health insurance, which we in the US get. You know, I think it's sometimes hard in the UK for people understand like, well, it's a lot of money and they don't realize that 40% of what I collect is actually going towards my health insurance that I get through Berkeley because that's how we stupidly do things here.

So anyway, I will have a crowdfunding period in October and I understand that some people can't give and, you know, I don't charge for my work in terms of you know, I mean, some people said, Oh, do a newsletter. And then, you know, I don't want to make people pay if they can't, but I want people to give what they can.

So I've been very, very lucky. I felt very lucky that I've been able to continue this, what to me is just a fascinating project and I've met amazing people that I really care about. So, I mean, even though I didn't start with a personal stake in the same way, I mean, I have personal stake now because I have a lot of, you know, people that I care about.

But, you know, it's still a professional thing. I'm just outraged by this bad science and I'm outraged at its potential to harm people. And I don't think all the people involved are horrible people.

I just think they're doing bad science and they're trapped in paradigms or in mind spaces where they don't actually see that what they're doing makes no sense.

**00;59;24;25 - 00;59;27;12**  
**Steven Molony**

Do you know where people could find you?

**00;59;28;10 - 00;59;51;29**  
**David Tuller**

Yeah. So basically most of my work is on Virology Blog, so if we just look up Virology Blog, you'll find it. And my work is slugged under trial by error. And so there's a page where I've listed all the hundreds of blog posts, although I'm not completely up to date. And then, you know, also I do news articles for other news organizations and stuff like that.

So then you just have to do a search for my name and other things. I usually post those, but most of my work would be on and then occasionally, you know, I have commentaries or, you know, so I try to do a mix of news reporting, my blogging, speaking and, you know, some academic writing, not research per se, but commentary and things that get published, you know, have to be peer reviewed and stuff like that.

**01;00;20;16 - 01;00;23;01**  
**Steven Molony**

And what do you do your fundraising through?

**01;00;24;24 - 01;01;11;24**  
**David Tuller**

Berkeley, specifically. A Berkeley University, a University of California, Berkeley fundraising platform, it's only for campus projects. The money goes directly to Berkeley, and probably about 20 projects will do crowd funding in October. Most of them are, you know, like the the basketball team or the science club or, you know, support for Asians who are studying this or some groups doing that or, you know, whatever it is, you know, different associate association groups have raised money and I raise money for my project so they can find that if they look next month, you know, in October, it'll be running all through October.

If they just look up David Tuller Berkeley crowdfunding, it should pop up. I don't have a website for them.

**01;01;18;10 - 01;01;22;02**  
**Steven Molony**

Okay, great. Well, thank you so much for taking the time to speak with us today.

**01;01;22;17 - 01;01;42;18**  
**David Tuller**

I was really it was really fun. I enjoyed it. As I said, I don't really talk about this much outside. If anybody's watched Severance, my Outie, I don't talk about it much because my Outies are all not really-- my Innie life is all about this and I kind of go insane and my friends start talking about they're like enough, enough.

It's like they can't, you know, because I can go on and on and on in great minutia about all this stuff because it's so fascinating to me. And I know it's like a little bit of a suck on something. You know, I can't turn it off.

**01;01;54;04 - 01;02;14;12**  
**Jaime Seltzer**

But whenever we do like a really deep dive into this stuff, that's the way that it can it can turn out. I think over the years I've developed elevator pitches that explain all of these things because, you know, you're at a party and somebody says, So what do you do? And you're like, I advocate for this thing.

Oh, tell us about it. I feel like the last time that I was at a party and somebody asked me to do that, I just like went on autopilot and woke up a minute or two later finishing discussing the PACE trial. And I was like, Oh, I'm still here. And apparently my mouth is still moving. So used to doing it.

**01;02;31;17 - 01;02;40;27**  
**David Tuller**

I had a friend who was an accountant and he said the worst thing at parties was to talk to an accountant because then people will run to the other side of the room because they have like no interest in hearing what the an accountant does.

**01;02;40;27 - 01;02;42;04**  
**Jaime Seltzer**

Math phobia.

**01;02;42;18 - 01;03;07;05**  
**David Tuller**

Yeah. So anyway, I mean I again, it's been for me just a really rewarding project and you know, my other big major project was 20 years ago when I did, you know, I lived in Russia and I read about gays and lesbians in Russia or LGBT, but nobody said anything. But so that was a big project that went on for a number of years, and I was always talking about that, you know, So this is sort of my, you know, my Medicare-age great project.

**01;03;09;27 - 01;03;11;06**  
**Steven Molony**

Awesome, thank you for all the work you do.

**01;03;11;17 - 01;03;30;07**  
**David Tuller**

Oh, well, thanks. It's as I said, I'm now, you know, paid to do it, so I have no excuse not to do it. So, I mean, I you know, I mean, it's an odd position to be in because I sort of I'm not really working for patients. I'm working for Berkeley, but they're funding Berkeley, you know, for me to continue my work.

And nobody is. Again, I get accused by the PACE authors of oh, you're you're being paid to trash our research and I mean to some extent I suppose there's some validity to that. But I'm not getting paid to trash any specific research, I'm just getting paid to look at research in this field and see whether I think it's good or not.

And the fact is I was trashing PACE for two or three years before I asked anybody to pay me to do it. So, you know, my PACE bashing happens for free. So I have no perceived or real conflicts of interest at the time.

<Theme music plays>

**01;04;05;29 - 01;04;08;24**  
**Steven Molony**

Thank you so much to David for joining us on the podcast.

**01;04;09;00 - 01;04;27;02**  
**Jaime Seltzer**

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

**01;04;28;01 - 01;04;46;21**  
**Steven Molony**

This was the last episode of our first season. We'll be off in the month of February while we reflect on our first seven episodes and work on making some improvements for season two. I want to express my sincere gratitude to all of our listeners for supporting Chronically Complex. It's important to us that you find this podcast valuable and entertaining.

If you have any suggestions you'd like us to think about before we return in March, drop us a line at [podcast@meaction.net](mailto:podcast@meaction.net).

**01;04;54;19 - 01;05;02;15**  
**Jaime Seltzer**

Thanks for joining us at #MEAction's Chronically Complex Podcast. Keep reading, Writing, Speaking out and speaking up.

**01;05;02;24 - 01;05;20;25**  
**Steven Molony**

And don't forget to #StopRestPace. Happy New Year, and we'll see you next time.