Susan Manfull: 00:00:00 <silence> Untangling Pandas and Pans is a podcast about two little known medical disorders characterized by the sudden and dramatic onset of symptoms such as obsessions and compulsions, vocal or motor ticks, and restricted eating behaviors, and a whole host of other symptoms following a strep or other bacterial or viral infection. I have [00:00:30] the privilege of interviewing some of the top researchers and clinicians in this rapidly growing area, known by various names such as immune mediated neuropsychiatric disorders, infection associated neuro immune disorders, and autoimmune encephalitis, or simply pandas and pans. My name is Dr. Susan Manfield. I am a social psychologist, the executive director of the Alex Manfield Fund, and the mother of Alex Manfield, who died at 26 [00:01:00] years old. Due to Pandos a disorder, my husband and I knew next to nothing about, certainly not that our daughter could die from it.

William Manfull: 00:01:19 This is episode nine of Untangling Pandas in Pans recorded December 19th, 2024.

Susan Manfull: 00:01:27 It's my pleasure today to welcome Dr. Warris [00:01:30] Bokari. He is the CEO and co-founder of Claimable. Claimable is a pioneering AI driven platform dedicated to assisting patients in overturning healthcare insurance claim denials. This is a subject that is familiar to many people in pandas and pans, and a very important one to know more about. Dr. Bokari has 15 years of experience in healthcare strategy and innovation. [00:02:00] He's held leadership roles at prominent organizations including GE Healthcare, apple Health, Anthem, and Amazon. He is a former national health service or NHS physician, and under his leadership, claimable has achieved an 85% success rate in overturning claim denials, empowering patients to navigate the complexities [00:02:30] of the healthcare system effectively. We are also joined by Dr. Mark Pasternak a little later in the podcast. He is the chief of pediatric infectious Disease at Mass General Hospital in Boston, and known to many people in the Boston area and well beyond.

00:02:51 He will weigh in on the need for a product like Claimable, and both physicians will comment on the [00:03:00] recent horrific killing of the United Healthcare CEO, Brian Thompson, and how it has unleashed unprecedented anger and hate directed at the insurance industry. There is also recently an announcement by the American Academy of Pediatrics that pandas and pans are indeed valid diagnoses, and the two physicians I [00:03:30] think, will have something to say about that too. Okay, Dr. Bokari, let's get started. We are here to talk about this new

product that is attracting a whole lot of attention in the Pans Pandas world and elsewhere. I'm, I'm sure as well, uh, claimable is the name of it, and I'm gonna see if I can sum it up in a couple of sentences and maybe you can either correct me or elaborate. Go for it. [00:04:00] Alright. So it claimable is an insurance appeals platform, uh, developed to help consumers or patients, essentially

00:04:10 Yeah.

00:04:11 To file appeals for healthcare claims that have been denied by insurance companies. And you use ai. Um,

Warris Bokhari: 00:04:20 You got it.

Susan Manfull: 00:04:21 And it was launched in September, 2024.

Warris Bokhari: 00:04:25 Yeah. A couple of months ago. So, yeah, you're spot on.

Susan Manfull: 00:04:29 Does [00:04:30] it feel like it was just a couple months ago?

Warris Bokhari: 00:04:32 No, uh, in the, I think it feels like a couple of months without really much sleep, uh, to be honest, <laugh>, um, it, there's just been a lot to do and, you know, we're getting flooded with inbound from a lot of different providers and patients who all need help, all from different categories actually, and a lot of things that we hadn't even thought of that people are getting denied for. It's been, it's been quite something. So [00:05:00] really shows you how broken some of the kind of payment model is as it aligns to people's like, experience of healthcare. And also for like anyone in healthcare to actually offer services. Sometimes they don't even know if they're ever gonna get paid.

Susan Manfull: 00:05:14 Yeah. Interesting. Um, so your background led you to, um, have one main basic goal, and that was to make [00:05:30] healthcare equitable. As I understand it, if we could sum it up in just a few words, uh, to make healthcare equitable by addressing unjust healthcare denials. Can you just talk a little bit about how you arrived at that goal before we get into the, uh, details of this?

Warris Bokhari: 00:05:52 Yeah, I mean, look, I, I'll say this. I mean, I grew up in England in a very kind of working class background with two disabled parents, [00:06:00] and both of them, you know, since passed, my mom died like when she was younger than I am now. So I'm 44. She was 42, which when I think when I was 15, felt terribly old. But actually now you realize how, how you now you realize

how incomplete like her life was, but she got all of the medically necessary care she needed. And same with my dad. And as I look at it, you know, that in this country it's not [00:06:30] a, it is not a given. Lots of people, you know, might suffer like really terrible outcomes, uh, you know, waiting, you know, waiting on hold for an insurance company effectively to approve the care they know they need and their physician knows they need.

00:06:42 And that is by no means equitable. So I think I came to the US because the opportunity to actually do things and innovate in this country, like the American dream is real. Like you can change things here. It's actually really difficult in a country that's as kind of traditional as England to like really [00:07:00] play with like the pieces of healthcare. But in this country, they'll let you do it. And, and that's great. We've always had like less regulation, which has meant more innovation except when the things that are let to be unre, uh, allowed to be unregulated, start harming patients at scale. And that's where we've arrived with health insurance. So I got very, very curious about the way healthcare worked, and then I've kind of like interrogated that problem from like lots of different aspects. So I worked at General Electric and worked across the healthcare division and kind [00:07:30] of all aspects from like, you know, big MRI scanners to anesthetic machines, to working on cell and gene therapies and all sorts of things which are like very, you know, modern and changing cancer care.

00:07:41 And then, you know, I was at Apple, which you would think is the most progressive company in the world and could do almost anything in healthcare, but the problem they solve is actually quite different. It's health, which is amazing, but it's not actually in the area under the curve for, you know, healthcare GDP. [00:08:00] So if you think about like what the US spends on healthcare, it's like pretty much 20% of GDP goes to healthcare. If you focus on health, you're really not looking at anyone who, you know, uses a lot of healthcare. You're not actually improving that experience for them. But what you might be doing is keeping people out of that area under the curve. But it, that is a very different problem. Um, so then I ended up at Anthem, which is like, how does a guy like me end up at Anthem?

00:08:27 And it's a great question, especially given my current position, [00:08:30] <laugh>. Um, I think it's sincerely, um, you know, we were, we were told we could do anything we wanted, like, more or less within reason to like reinvent the face of health insurance. And it was a great mission actually. I got to hire

health economists, user experience, uh, you know, designers, uh, data scientists, machine learning people, brought in a lot of people Apple and all over. And we got to work, we basically started looking at [00:09:00] different healthcare problems that really, really impacted like minority groups and, and, uh, you know, people were very financially vulnerable and, and, and, and started just devising interventions to help those patients. And some of it made a really big difference. We did one in asthma that kept something like close to 50% of patients outside a hospital in a Medicaid population. And that was really significant. It's just as, yeah. And yet to see that be deployed as a product. But, you know, it's something that could [00:09:30] meaningfully keep people like me and I'm asthmatics not a prop. Uh, and that's, it's air tagged because it's so damn expensive, <laugh>.

00:09:39 But yeah, I mean, it, it would help keep people like me outta a hospital. And so it was important. Uh, and then we worked on a bunch of other things for like to lower the cost of medications for patients as well. Then Covid d hit and the complexion of like US healthcare completely changed. I think it's like easy to forget, but that job basically disappeared. It ended up being, yeah, [00:10:00] look, there are now 15 people who all s experts in healthcare and digital health, and you're all gonna compete for like the $5 we're willing to spend on this. And it just got really stupid really quickly. Um, so in the end, like I'll, I'll skip over Amazon because it's not very relevant, but I ended up like taking a long view across healthcare and just realizing that everybody's doing anything but solve for fundamental problems of healthcare access.

00:10:27 And, you know, the, there's a lot of [00:10:30] ink given to proselytizing the problem in media, right? You can pick up the New York Times and you can go to the opinion pages and it's just full of, it's full of essays about how healthcare is broken, but there is no permission structure in this country, but allows people like me generally to kind of say, I'm just gonna change it. And so I sat around for a while thinking like, who do I need to ask? And I called Elizabeth Rosenthal, I was like, yeah, and she's a long time hero. And I asked her like, you know, [00:11:00] is it okay if I do this? She was like, kind of like, have at it because she didn't see anything coming from, from the government anytime soon. So that took me down this path of like realizing that this is big inequity in denials, no one solving it, and wouldn't it be great to just start helping by helping? And so if you can help one patient, great. And then if you can figure out how to help 500 patients, great. And if you can figure out how to help 5,000

patients and just keep going. And we attracted like-minded [00:11:30] individuals who like became my co-founders, who have all, they're all like fully formed adults. They've lived real lives, um, and they've, they've experienced, like, they're kind of inequity inherent in like adult life, right? It's

00:11:44 Hard mm-hmm <affirmative>.

00:11:45 Um, and similarly, you know, the people who've joined us like very much care about this problem. They could be anywhere. They could be, you know, selling, you know, selling Pokemon cards online or whatever, but [00:12:00] this is the problem that they're preternaturally, you know, talented and uniquely, you know, suited for solving. And so that's where we are.

Susan Manfull: 00:12:08 So that's so interesting. Going back to Apple, for example, you develop strategies for, uh, change in some aspects of healthcare, apparently, right? And you even tested them, but you

00:12:21 Yeah. Yeah.

00:12:22 But you didn't have the opportunity to actually apply them on any kind of large scale.

Warris Bokhari: 00:12:30 [00:12:30] Um hmm. How would I answer this? I, I think if I zoom out and just, and talk about big tech because it's safer, um, I don't think any of these companies are really gonna solve any of the problems within, like, inherent within healthcare as we experience it today. Now, they might create like great devices that keep you healthy

00:12:50 Mm-hmm <affirmative>.

00:12:51 But if you're already sick, these companies are not solving that problem. And the, the huge burden in American healthcare is how you treat [00:13:00] sick people. And I agree, we have to keep people healthy, but it doesn't stop the near term problem from being solved.

Susan Manfull: 00:13:07 In this case, though, you are, you developed a, a strategy, you developed a product, and you are able to apply it with the hopes that you can change.

Warris Bokhari: 00:13:16 Yeah, absolutely.

Susan Manfull: 00:13:17 Yeah. Okay. So you're doing what you thought you were gonna be doing earlier in your career.

Warris Bokhari: 00:13:22 Yeah. Look, the, the, the, the real, the reality is, is that if you go to a big company, you kind of have to do big company things. [00:13:30] And Scott Galloway talks about this, uh, <laugh>. He talks about people who are bad at being employees, and, um, and that means you're an entrepreneur. So, uh, and there's like Gretchen Rubin's the Four Tendencies, and I, I have two of the worst ones, which is like, one I question everything. And two, I'm quite rebellious. So, um, and, and I'm, I'm certainly, I'm certainly not minded to be, um, uh, you know, I want, let's just say I'm implacable when it comes to like, some of these problems. Like, I, I, [00:14:00] I want 'em to be solved and I'm impatient about finding solutions. So I, I'm just gonna keep tunneling on that until I figure it out. And, and the best way to do that is start a company that allows you to kind of, you know, scratch that itch whilst getting the feedback of like, working with patients every single day.

Susan Manfull: 00:14:17 Great. Um, well, we're gonna move a little more into claimable and Sure. We're going to be welcoming Dr. Mark Pasternack into this conversation. Thank you for joining [00:14:30] us. Dr. Pastor Neck, who is the chief of pediatric infectious disease at Mass General Hospital, and he's been working with Panda and Pan, or people with Pandas and pans diagnoses for well over a decade. And, uh, Dr. Pastor, I thank you for coming, uh, to join, uh, Dr. Bo and I because I, in a few minutes, would love to hear your thoughts about this new product [00:15:00] and really the importance of, of having it. So what I'd like to do now is to provide kind of the backdrop using some statistics that you provided Dr. Boari the last time that we talked. And, um, of course, this would be just to put things in perspective for some of our listeners who don't follow this, um, this, this subject very closely. Uh, and that would be that one in five claims are [00:15:30] denied. And that's across the board, that's not just for Pandas and Pans, which means approximately the 850 million denials a year after, uh, out of 5 billion claims. Correct?

Warris Bokhari: 00:15:47 Correct. Yeah.

Susan Manfull: 00:15:49 That's quite a large number. And so, needless to say, this leads to delays in care, uh, for about 60% of these patients, [00:16:00] correct? Correct.

00:16:02 Who

00:16:02 Are denied the, the treatment. And some patients just abandon their attempts to, to get the care completely. Also, it's been found that, uh, right around 50% report that they, uh, that their care, their health that is, uh, worsens as a result of, of having this, uh, this denial. Mm-hmm <affirmative>. Um, so the great part [00:16:30] about what you're doing is if the patient invests just a minimum of 30 to 40 minutes, um, in, in time, in 30 seconds to generate a letter that, um, they have an appeal through claimable. Yeah. And that thus far the success rate is right around 85%. Yep.

00:16:53 Correct. Changes a little every day. But yeah, it's, it's, it's thereabouts

00:16:57 And it takes about 10 days for [00:17:00] a response,

Warris Bokhari: 00:17:01 About 10 days. I mean, we've, so like averages are, you know, distortable by extreme. So we've had like some, which were, I I kid you not approved within two hours. And we've had some that took like, you know, well over, like, took over a month. And I think some of it depends on whether someone submits as urgent. Some of it depends on where, like, how hard the practice manager at the doctor's office is gonna, is gonna help them fight. That tends to lead to faster overturns. Or if a patient actually takes [00:17:30] the appeal and then markets it to the insurer and starts emailing executives inside the insurer and saying like, Hey, I've got a patient complaint. And the other thing that drives like the fast outcomes is that we copy every regulator. So, so, you know, if you just e if you just send this to the appeals address, I think it gets denied, to be honest, like most of it, because they think they can get away with it, no one's watching.

00:17:52 But if you, if you start sending it to like the Department of insurance, the governor, the Attorney General of the Department of Labor, um, suddenly [00:18:00] people start getting interested because they start reading these really unique stories, which is, you know, in pans and pandas are really heartbreaking, awful stories of, you know, families that have been like really impacted by the decline of a child. They're under extreme financial hardship, you know, um, they, they might have kids who can't sleep in the same house anymore. They might be losing their homes, they might be getting divorced, have gotten divorced, and they're dealing with like acute, effectively acute psychosis in a child. And, [00:18:30] and they've got nowhere to go. And the insurance company's just like, yeah, whatever. But the, but when it goes to, you know,

the Department of insurance, the governor, the Attorney General, they start investigating.

00:18:40 I can tell you in, uh, Logan Coulter's case, which was the first Pans case we did that, picked up the, I think the department of the department of Insurance in Idaho sent him a letter saying they're actually gonna start investigating Cigna. And so be it. [00:19:00] Great. Have at it. Um, there was another case in Kansas City this week. It's been a busy, busy couple of weeks where the Department of Insurance, and I think the Attorney General looking at Blue KC for, you know, denying a 23-year-old for necessary care for her, um, her, uh, blood disorder. And, and, and it's like super interesting. So sometimes, sometimes when we get approved, it still triggers an investigation and sometimes when we lose, it still triggers an investigation. [00:19:30] But the idea is to like start curbing, uh, these harmful insurance practices. And if we act together as a community, we can do that. So it is important to say that, you know, what we ended up doing for Pans Pandas we did for free, and it will, as far as we can, it will remain free that the goal is for it to, to be a free product for Pans Pandas. And that was really because when I spoke to like 15 families, I think in that weekend, it just became [00:20:00] really clear they'd been through so much

00:20:01 Mm-hmm <affirmative>.

00:20:02 And, and it just didn't, there was just no desire for us to like, you know, wanna attach a payment model to that. We just wanted it to be something that we built with the community. The goal is for these letters to get better and better. So, you know, there, we, we want to change even from what we have now, how the letters have built. So that's in progress to make them stronger. Um, I've been working with quite a few families to tweak their letters in interim, uh, to make sure they're [00:20:30] as strong as possible. And, you know, we're taking, uh, United Healthcare who are very topical right now to task over denying April Beck, who's a mom in Georgia, whose daughter Emily's, um, you know, still waiting for an outcome from United Health. So, um, you know, major media, I won't say who, but is covering that story. I can tell you that one of the big TV stations is in like, big TV networks is interest in covering that story, and on and on and [00:21:00] on it goes. So, you know, this, the longer they delay, the worse it gets.

00:21:04 Mm.

	00:21:04	So, um, and, and we, we wanna put so much pressure on these insurers that they actually, ultimately, they stop doing this and the way to do it's with a huge volume of cases.
Susan Manfull:	00:21:16	So I'd like to hear a little bit more about that, but maybe tell us just a little bit more about Logan Logan's case, because I think, if I recall correctly, he is what got you interested in Pandas and [00:21:30] Pans. He,
Warris Bokhari:	00:21:31	He is, so, first of all, like Logan is actually how I first met Mark <inaudible> over email. Uh, and so lo and it was like the first time since medical school I'd actually heard of Pan. So I think there was a, there was like a book, pediatric Secrets or something that mentioned it. And I remember reading about something similar to that some years ago. Um, Logan, Logan Coulter, his case came to me on LinkedIn. I got tagged into it. And then someone called me at 4:00 AM [00:22:00] on a Saturday morning and said, Hey, you've gotta see this, like, maybe you can help. So by 6:00 AM I've reached out to Logan and we're on. And then we're very shortly on the phone, and then I'm on the phone with him and his wife Mary, and they're giving me the whole story. And then be, you know, then I'm like in the midst of like writing an appeal manually and pulling all of the evidence.
	00:22:20	I'd find Mark Mark's paper that he wrote with Jenny Franco at Stanford, and, you know, all of the great work they've done. I'm like, oh, this is fantastic. There's actually like, [00:22:30] really great, there's like a really great standard of evidence that I can base this around. It shows that IVIG is necessary or, or would be beneficial in, you know, a preponderance of cases. And so we, we wrote a really strong appeal and we managed to get that submitted, and we got him overturned in four days. But it was with a lot of help from our friends. So, um, I wrote Mark Cuban, uh, mark Cuban, then put it out on LinkedIn. [00:23:00] He then retweeted it on Twitter, and we started making videos about Logan's daughter, Gianna. And then Harold Perino, who was in the TV show lost mm-hmm
	00:23:11	<affirmative>.
	00:23:13	His daughter, um, had pants. And him and his wife were instrumental in lobbying to change the law here in California, uh, because no one could meet with Newsom. Newsom wasn't taking meetings apparently. But when, when Harold Perino, um, came knocking, it suddenly became very [00:23:30] apparent that they were going to meet with him, and they changed the

law. And then Jeremy Rena got involved. So before we knew it, we had something like well over a million eyeballs on Logan Coulter's case. I think, you know, I spoke to Diane Sawyers people at one point, like TBD to what happens there. But like, there was a lot of attention on the fact that like, all of these celebrities on, on Instagram were like, you know, really going after Cigna. Um, so, you know, Angie Harmon got involved, um, a and a bunch of other people. [00:24:00] It was really interesting to see.

00:24:02 Uh, and then Cigna like started disabling comments on all of their social media <laugh>, because they were getting, they were, they were basically getting so much pressure for what they were doing. So, uh, in the end they ended up reversing it, um, you know, which was, which was great. And they also paid for all of the out-of-pocket costs for the culture family, so, which is fantastic. Mm-hmm <affirmative>. So they, they ended up with a really good outcome. You know, I, I keep, I talk to Logan like every couple of days. Like we, we, like, I've made a new friend [00:24:30] <laugh> from, from doing this, which has been, which has been great. Um, and so, you know, I keep up with him. It's like, it as, you know, it's not a straight line puff. And then there was another family in Indiana who like, don't wanna be public necessarily, but, you know, there was a case that we submitted.

00:24:46 It was interesting, it got denied. Um, and then I looked at the denial letter <laugh>, and I was like, wait, they used adult emergency medicine to, to review this case. That's a joke. [00:25:00] So we basically reformulated the appeal. We wouldn't, didn't even submit it as a second level appeal. We just said, Anthem, you got this wrong. And sent it to the board of Anthem, like literally to their board of directors and said, like, you, you know, from the, the mother of Senate. And basically said like, you guys have gotten this wrong here. Like, here's why you're wrong and this is what you need to do. And within about three days-ish, I wanna say three, four days, um, [00:25:30] they had approved it. And every single time they kept trying to kick it to a low level person. And you know, the mom would ask me like, what do I do now?

00:25:37 And I'm like, well, just keep copying the executives. Like, just keep bringing them back in. Don't let them, don't let them avert their eyes like this. This is a situation that they need, they need to be aware of. Because at some point the execs are just like, get this off my desk. And, you know, I think one has to be careful for calling people like executives out publicly on social

media in [00:26:00] this day and age. Mm-hmm <affirmative>. Um, be that as it may, they're accountable. Uh, and I think there's a right way of involving them, which is like, you don't understand for consequences. Your plan is happening on everyday people. And so we're gonna show you, because you're gonna receive this in a mail, you're gonna get it by fax, and if necessary, you're gonna get it by email. Um, and at some point you might take a greater interest in how your business works.

Susan Manfull: 00:26:28 Well, that it sounds [00:26:30] like that's going to be the case if, um, you have anything to do with it.

Warris Bokhari: 00:26:35 Yep.

Susan Manfull: 00:26:36 Let me bring Dr. Pasternak in now. So, um, mark, I know that you've had a lot of experience with insurance denials, and I'm wondering, I guess what I'd like to hear, let me just start with a broader question. Why do you think a product like Claimable is so important and has so much [00:27:00] potential? And I, I don't mean to put words in your mouth, Wade. Do you think that that's the case and why?

Dr. Mark Paster...: 00:27:05 I do think it's the case. I, I think, um, I, I inherited the IVIG ordering end of the practice. Uh, not long after I started, we had an, an immunologist in our Pans Pandas group, uh, who was quite familiar and, and, uh, experienced in writing IVIG orders. 'cause she was treating a lot of children with, uh, antibody deficiency. [00:27:30] And, uh, she would see these children and they, they were sending her basically just to write the IVIG orders and she would do it. So my job was easy. I did the sort of other stuff, and she would do the IVHU. Then she, she left Boston and took a job in Florida and I was left holding the bag. The allergy immunology group refused to replace them because they were very, um, bottom line focus group. And they said, you know, she didn't generate that many RVU for all the work she did, <laugh>.

00:27:57 They went, no, I'm serious. They wanted someone who would see kids [00:28:00] with runny noses and asthma and, and all the quick and easy things and, and generate a lot of procedures and stuff. And I said, we need an immunologist here for the complicated cases that we deal with. And he just would not fight. And I had no recourse. I couldn't force one on him. So I became the IVIG orderer and I <laugh> I met with failure, uh, sort of like a baseball player, you know, baseball player is an all star. He succeeds three times outta 10 <laugh>. And, uh, [00:28:30] I was not an all star. I probably, uh, I think they called

them Mendoza Alliance of like 150 or, I don't know. I was not doing very well, but occasionally I would get success and I, the treatments were more often than not helpful. Uh, and then I had one patient, believe it or not, um, whose appeals for, whose requests for IVIG were denied multiple times over three years.

00:28:55 The child was a disaster. He was a high school student who couldn't go to school, uh, brilliant, [00:29:00] uh, but sat at home and worked remotely. He could not be in a classroom. The noise, the lack of commitment of his classmates, just the chaos, uh, just he couldn't focus. And, and he was so debilitated, he wouldn't eat or get dressed or do anything without his parents' permission. He would ask them, can I take a bite of my cereal? Can I put on this shirt? Can I, can I wash my hands? After three years, I finally got his order approved. I wrote a 10 page [00:29:30] single space letter the longest that I've ever done. Now I got it approved. And he received one infusion of IVIG and has been normal for three years.

Susan Manfull: 00:29:40 Wow. Oh my gosh.

Dr. Mark Paster...: 00:29:41 And so I say that for people who don't believe A, in the diagnosis or B in the treatment, they should spend an afternoon with me and, and see a child like this because it, it's real and it works.

Warris Bokhari: 00:29:52 Sounds like you need to do that for the entire American Academy of Pediatrics. Oh,

Dr. Mark Paster...: 00:29:57 That's another, we'll get to that <laugh> <laugh>. So [00:30:00] I worked hard with some of the Massachusetts mothers, who I must say were remarkably effective at getting the Commonwealth to pass bills relating to in insurance coverage. So I was almost excited to write my first IVAG order after the law went into effect. And I got a denial and I was ripped. It's like I didn't understand this. And it was for a national carrier, and it was for a child whose parents were insured through a corporate self-insured program. [00:30:30] And mm-hmm <affirmative>. Spoke to the people, I think it was Cigna actually. And they laughed at me. They literally laughed on the phone when I said that, you know, this is gonna be reported to the commissioner of insurance. He said, he has no authority. He said, we're, we're a national company. The, the client is self-insured and there's, there's no they're there. And I spoke to the commissioner ma of insurance in Massachusetts who basically confirmed that self-insured companies have some sort of federal,

Warris Bokhari: 00:30:58 Um, yeah, they're covered under ERISA, [00:31:00] they're covered under the

Dr. Mark Paster...: 00:31:01 Employ. And I would love to learn more about that. But it just, I was, I was, I dunno, <crosstalk> something. I was just beyond myself.

Warris Bokhari: 00:31:10 It's not always the case though, mark. I will say that like, even like these insurers believe that's the case, and it is, sure, like legally they fall under regulation from the Department of Labor. But it's always worth in my, in my view report, like sending these appeals to the attorney general of the state, um, or the governor. [00:31:30] Because, you know, California will go to bat against any self-insured plan. New York does also, uh, depending on the state you live in, the chances are if it's egregious enough, they'll get involved. I've seen it in Missouri as well. I've seen a multi-state investigation triggered by the governor of Missouri for a self-funded plan that should be federally regulated. I've seen a Department of Pharmacy come into a clinic and card out a bunch of notes, um, you know, based on, based on, [00:32:00] um, insure, uh, PBM practices like pharmacy, pharmacy benefit manager practices. So it is, people read this stuff. Like the problem is, is the second you send it to them, they're obligated to read it. So, like, I, my advice to anyone who listens to this is if you are writing a complaint, whether you use claimable something else or your word processor, send it to, you know, as many relevant people as you think you can, because the chances are you're gonna cause a a lot of embarrassment for these [00:32:30] insurers, for their practices. This is the right way of pushing back.

Dr. Mark Paster...: 00:32:33 Right. I will say parenthetically in Massachusetts, some of the self, uh, self employer based plans have been paying for, it's been a little bit of a struggle. Yeah. But it gets through and I think they're, they're aware that they are at risk of getting shamed, uh, that the coverage is for valued employees.

Warris Bokhari: 00:32:54 Mm-hmm <affirmative>.

Dr. Mark Paster...: 00:32:54 And, um, they're making, you know, a wise business decision is to allow the coverage to retain [00:33:00] your employer. Mm-hmm. I have, I have, I have a patient from, from Maine who could not get her employer to provide coverage through their self-insured plan. And she said, if you don't do this, I'm gonna leave. And she was a senior valued employee and she left, she took another job where she was sure that the benefits would

provide coverage and they did. And her child was treated and is doing quite well.

Warris Bokhari: 00:33:22 Mm-hmm.

Dr. Mark Paster...: 00:33:23 And so all of her hard work was, was valid. And the appeal letters to a non Massachusetts New England state [00:33:30] failed. But I, I must say, uh, waris, I didn't, I didn't have the, uh, global sort of worldview and the time to, to just cc the letter 20 times to all the relevant people. But I, it's the right approach. A hundred percent. I I really think it's a, a genius, a stroke of genius.

Susan Manfull: 00:33:49 So, Dr. Pasternack you're bringing up a good point. Who is, in your case, who's writing those appeals?

Dr. Mark Paster...: 00:33:57 So, um, we've worked a kind of workaround, [00:34:00] as Susan knows, um, these things take time and it takes me away from my regular bureaucratic life. And so I get suspended at least once a year for being tardy on my charts <laugh>. And, um, it happened this summer. I was actually suspended for a month. I knew the charts were late. Um, but the, our system is so primitive that the bean counter never knew. And then they found out and they went bonkers <laugh>, and they suspended me. And, uh, [00:34:30] I caught up and that was fine. But the time to write the letters is, is I always tell patients I either, you know, my job one is to not get suspended. 'cause then I can't schedule appointments. And so if the letters are delayed, it's because I have to do the paperwork for the clinic.

00:34:46 Um, but some of the home IV companies will write a letter and they send me a PDF file and I say, this won't do, you need to send me the word file so I can edit it. And then I edit the letter and then they send it along. And it's, it has a [00:35:00] fair in Massachusetts at least it's had a fair success rate in approval. I've also found that, um, I think you made this comment that the peer review process is, is is laughable in general. Yeah. Because my peer is not some retired orthopedic surgeon with a bad back who took a different job. So he could sit and listen to these complaints and read a script that says no. But when I've spoken to someone who's actually thoughtful, I use the argument that as costly as IVIG therapy may be, this [00:35:30] child has two much more dire financial concerns. One of which applies to you directly, which is that if this child has a psychiatric hospitalization or repeated psychiatric hospitalizations, your bill is gonna far exceed the cost of the IVIG therapy. So it is cost

effective for your agency to pay for the IVIG and hook, the child does. Well,

00:35:51 I've made that argument with success a number of times. But you have to have someone on the other end of the phone who, who's willing to listen. And some [00:36:00] of the people are truly not willing to listen. Um, so this second tier appeal process, uh, has on occasion been helpful, but I'm, I'm always very skeptical. I've, I've tried to set up some of these things and I, I'm told I have to provide, I think it was 12 hours of availability to speak with a peer, a a peer reviewer. And I basically canceled the week of clinic so that I'd be available. And then they never called me Not once during those 12 hours.

Susan Manfull: 00:36:29 Oh my gosh.

Dr. Mark Paster...: 00:36:30 [00:36:30] It was just, it's just punitive, uh, demeaning frustrating interaction. And so when people say I need to write an appeal, like I, you know, I get palpitations because it's like, not only is it is it time that I don't have, but it's so frustrating that that's, but that carry on because the success successes fuel the engine. You know, that it is, it is children who get IVIG and who show no benefit are in [00:37:00] such a minority in my, from where I sit that I'm happy to keep trying.

Susan Manfull: 00:37:06 Wow. I

Warris Bokhari: 00:37:08 I think that's great. I think, and I, I'm gonna use that argument. I think it's a really good argument about like kind of blunting future costs. The arguments we tend, we we've been using are the ones about, um, reducing future, um, autoimmune complications. And that children who receive I uninterrupted, IVIG [00:37:30] have like fewer, sorry, have more symptom free days over, over a following five year period. I think it's a Calabrese Calabrese paper and one by MA etal. So those, those two papers are, are, are, like I, we tend to cite those because they're good. Um, and then there's also a MeMed study, which cur I wrote <laugh>, I this a, a p thing's on my mind. Um, but I wrote them a letter yesterday [00:38:00] basically asking them why they didn't, uh, include for MeMed study from 2021 or 2024 in, in their position paper. So open-label clinical trials, which show benefit of IVIG in children for OCD symptoms as measured by standardized instrument that yes, you can criticize these studies for being small, but we're dealing with a rare disease.

	00:38:26	So like how would these be large? I, I don't [00:38:30] like, inherently these will be small studies that that's, that limitation comes with the territory. So, but we, we cite all of these studies and try and try and build a case based on the patient, but it's also the parents get really impacted as well, which is the other thing we put into these appeals. Uh, you know, parents like not being able to work like, you know, uh, some loss of income of one parent entirely and plus mounting costs if they have to pay for this, you know, um, out of pocket. [00:39:00] You know, I was talking to, I talk to April Beck every day right now, but you know, I'm in it with these families. I'm sure you are. Um, and if Emily gets sick, the nearest like provider who actually believes in pans or pandas as a diagnosis is a good nine hours away.
Susan Manfull:	00:39:17	Mm-hmm <affirmative>.
Warris Bokhari:	00:39:19	Right? They have to go from Georgia to Arkansas in order to get care. So it's not even that, like they've like two hurdles, right? Sick kid, well, three I guess sick kid, no [00:39:30] doctors in Georgia like are like pans experts or would, you know, would minister IVIG if she needed it and then have to drive that distance and then have all of that incurred cost. I mean that, that's like, that's insane.
Susan Manfull:	00:39:42	Hmm. Well, the other issue that, uh, I don't think has been brought up yet is some education. The fact that some are, are not able to a attend school. And when they finally are, they're, uh, best suited to go to a therapeutic day school, which is [00:40:00] in many cases outside of the community. So the cost to the, um, the city and the state are also, uh, elevated. Not to mention the cost on the individual because they can't attend school. And all that's lost educationally, socially that way. Um, this is a, a disorder with long tentacles that affect so many aspects of one's life and the community [00:40:30] and, um, the medical system and the impact on the, the, the doctors when the treatments that they prescribe are are not available. So, um, mark, have you had a chance to use Claimable?
Dr. Mark Paster...:	00:40:46	Not yet. Not yet. I've only known his bad its existence for what, two or three weeks we
Susan Manfull:	00:40:51	Going into this? Pretty recently
Dr. Mark Paster...:	00:40:52	<laugh>. Yes. I will promise, um, that I will reach out to you, um, with the next struggle. Um, [00:41:00] like I said, there have been sort of routine orders that are approved. And then in Massachusetts, at least in Eastern Massachusetts now, one of

the operational obstacles is nursing staffing. There's a real shortage. I don't know why, because of where they're paid. Well, and um, you know, it's satisfying work because the nurses develop a real relationship with the children and with the families, with the parents. Um, [00:41:30] it just seems very satisfying to me. And, you know, you're taking care of one patient for eight hours instead of four or three, you know,

00:41:37 You can sit and just hang out for most of the time once the IV is going in. You know, it's, it's doesn't sound like bad work to me, but there is a real shortage. And, um, so sometimes there are delays just because of staffing, which shocks me, but better late than never. I mean, it does get done, it's just a delay. But I will definitely reach out to the claimable people because, um, the company I work [00:42:00] with, I think a number of the different home companies have offered to write letters and some, I think my third grade grandson could do as well, if better. Um, spelling wouldn't be as good, but he, he would think a little more clearly this letter is like their letters were like, um, sentence pickup sticks, you know, just like jar, right? Gared bunches of paragraphs with sentences that had no relation one to the next, and references that had no relation to the problem at hand. [00:42:30] If it mentioned IVIG, they just stuck it in and it was just, that's why I needed the word file because it was embarrassing, you know?

Warris Bokhari: 00:42:36 Yeah. A lot of these things are template letters, right. Which has been the standard. And then it really relies on the family, sort of like con of the knowledge asymmetry between them and the insurance company. Mm-hmm <affirmative>. And the insurance company hides behind like their IVIG policy, um, which, you know, effectively doesn't include panto pandas because it's an off-label use. And then they say it's either [00:43:00] not medically necessary, um, investigational and experimental. Right, right. Or not, or, or not covered under formulary. So, you know, our view is request a formulary exception request for medical necessity. And so we just say to them like, we're, we're requesting an exception to your formulary process because it's not on label and it is medically necessary. And we've included this letter that came from the PANS Research, um, consortium, which, you know, summarizes the evidence [00:43:30] and cites a good like 25 peer reviewed studies.

00:43:33 So it's like a backstop, um, to say like, look, there is a consensus of sensible experts in England. We have this kind of test in medical ethics called the BOEM test, which has been, I think long superseded, but it's like starting to show my, my years

outta practice. But effectively it said like, would you, do you practice in accordance with like a reasonable standard that other people might also consider this reasonable? Like they, they called it a reasonable [00:44:00] body of medical men that you, your, your decision would conform with. So I think, you know, what we try and demonstrate through the PAN'S research letter is that a, a, you know, a group of like, well-credentialed experts agree that this is, you know, there is consensus effectively, but this is a reasonable treatment. And, and you insurer with your internal medicine, your adult internal, your adult internal medicine physician, you know, acting as your denier for hire, you dunno what you're talking about, and you should probably listen to these guys. So that's what we try to show. [00:44:30] Um, and there's also like precedent cases, which is like another really, really important thing that people ought to know. And, and the parents Pandas community is a tight community, which I love, right? Uh, I actually love that. Like all of these parents talk to each other about how to help their

00:44:48 Kids.

00:44:49 Um, so what we try to do is like every time we get a win to ask for family, if we can anonymize the case, but keep the insurer details, so then it becomes [00:45:00] precedent against that insurance company. So then we can just keep siding these cases and then we kind of get this kind of like snowball effect of, um, lots of different parents who've been approved by lots of different plans. And eventually there's overlap, right? So you can like directly cite a case and say like, Hey, I'll pick on, you know, I'll pick on Blue Cross Blue Shield Illinois because I've gotta go fix a problem with them in a couple of hours, <laugh>. But that, um, you know, you've, you've approved this for this patient before or for a similar patient before, [00:45:30] um, why not me? Like my case is actually strikingly similar. Um, you know, it meets, I meet cri, I would meet any sensible criteria.

00:45:40 Um, so we, we try to do that. And then the other, the other case like that I've seen is when a family has been authorized previously, and then they get issued a new denial, well, guess what? You have precedent against your own insurance company because if they've approved you for it before, then they should [00:46:00] approve you for it again, because now the criteria you need to meet and not initiation, which are actually a lot harder to meet, it's continuation. And for continuation, what you need to document is benefit. So you need to show that your child has actually improved. And if you

can do that, then you're well on your way to beating, you know, beating the denial. They, they really have like zero legs to stand on

Susan Manfull: 00:46:26 In

00:46:26 That case.

00:46:27 So you're starting to talk to us, um, about [00:46:30] what goes into the letter or what goes into the appeal. Could you move back just a little bit and, and walk us through the, the process you've got?

Warris Bokhari: 00:46:39 Yeah, sure.

Susan Manfull: 00:46:40 Um, the parent is, is denied or the claim is denied. So what happens or how does the process start?

Warris Bokhari: 00:46:46 So typically, like in other areas we worked in, they, you know, the parent will, the, uh, they're human. The patient will get like a letter from the insurance company. Sometimes they don't, and then the doctor gets it and lets 'em know. But, um, [00:47:00] and you know, if it's Cigna, Cigna actually sends out a text message that tells people they've been denied, which is like super friendly <laugh>. Uh, so like, like, hey, guess what? No care. So, um, so you don't need it to start an appeal actually, like we, we don't require it because people often know they've been denied one way or another. They may not have the letter. Sometimes what happens is that the insurer just doesn't respond to the prior authorization request. We've seen this as well where there's like literally no response. We saw this with me with [00:47:30] Meritain, who's an Aetna, um, an Aetna company, but they, it took them like months to not respond to a prior auth.

00:47:38 And we appealed it because we just took it as a de facto denial. So long story short, you don't need it. You start it, you basically say like, I've been denied for whichever reason, and it's either not medically necessary. They want to move my care from, you know, getting it in an office where it's safe to like, you know, some infusion center that they own with like crappy nursing ratios, [00:48:00] um, not covered out of network, all of the things. So we allow someone to select, but for pans, pandas, it's typically one reason. It's medically necessary and formulary exception. So we just presuppose that and then we ask a lot of questions and this will take someone like a good, I'm gonna say 40 minutes to kind of tell, you know, the

software@getclaimable.com. What happened to them? So like, tell me about your son or daughter mm-hmm <affirmative>.

00:48:27 Tell me when they were diagnosed, tell me if it was [00:48:30] pans or pandas, tell me what you thought, you know, the cause was, was it Lyme disease, COVID Strep, et cetera. Um, and then we asked 'em if they've tried IVIG before and what else they've tried. And you are fine at these parents. Like they've tried everything and they know what they took. They know what they took, they know when they took it. They know how long they took it for, because they were keeping notes because it's been such a battle to get diagnosed to begin with mm-hmm <affirmative>. They have every scrap of paper because they need [00:49:00] it. And so they input all of that, that all goes into the story. Uh, and then they tell us like about, you know, their, their child and they say, you know, you know, Anna, Johnny, whoever, uh, was a brilliant child who was academically excelling or straight a student, loved riding horses, um, you know, predominantly accelerated child.

00:49:21 All of the things now lost independence. And we like, make it really easy for people to select from options, you know, can't feed themselves, can't shower, [00:49:30] um, lost social relationships, can't attend school, and then people tell us about that. Like, you know, now needs to be on like a special learning plan. Um, the one I hear frequently is Absconds in the night, or, um, which is really dangerous or, um, tries to get out of a moving car on the way to school. Mm-hmm. I've heard that a lot as well. Um, like you, you kind of see this kind of commonality. So we're able to make it easy for people to select options and then tell us a little bit [00:50:00] about it. And then we also then go into like the, the experience of the parents. So like, did your marriage fall apart? Did, did one of you lose your job?

00:50:09 Did you lose your house? Did you know? So we, we kind of have options that they can select and they tell us about that. All of that gets kind of summarized by the AI into a narrative. And then that gets blended with the clinical evidence. So like the MeMed studies, the, the Franco Past Act studies, um, [00:50:30] and you know, a a host of other studies that we've kind of curated. And then, uh, we also add in state laws because there's I think 12 states, I wanna say mm-hmm <affirmative>. Thereabouts who passed laws 12 for coverage of IVIG. Um, so depending on, we, we cite it anyway, but depending on your plan type, we'll say like, this, this state has this law or whatever. And then federal protections which come under the Affordable Care Act. And there's also something that your listeners should

know about the Mental Health Parity [00:51:00] and Equity Act, M-P-H-E-A, which is under affordable care, which means if you make care available for physical care, you must have commensurate standards for, uh, for mental health.

00:51:16 So that compels 'em to do so, and all of us gets zipped together. It usually ends up like a, you know, five to eight page document. And then on the back of that is the PAN'S Research Consortium letter, and then a whole bunch of references, [00:51:30] which is a huge pain in the butt for the insurer to have to pass through and actually go get them and read them if they're gonna go do that. Uh, and we also include something called a claim file request. And that is, I think, really important. So this, we got this idea from Maya Miller and Charles Hornstein and Co at ProPublica who did this great piece of research about requesting your claim file. And this came from another article they did about this chap called Christopher McNorton, [00:52:00] who was this young guy who had ulcerative colitis and got into a huge fight with United Health, um, over his care. And they started, you know, they went to some external experts, but because one of the experts was favorable, and I could be misremembering this, so I'll just add allegedly to every time I mention an insurer, but they, they, uh, they went and solicited another expert who con, who concurred with their opinion to deny, and then all of that came out in a lawsuit plus with his claim file. So [00:52:30] we request a claim file if they choose to deny, because it costs the insurer money to go get it.

00:52:35 Mm.

00:52:36 And so the, the idea is like, listen guys, you're gonna pay for this both ways. You're either gonna approve of care, in which case you pay, and it's also going to, it's gonna cost you to like physically hold and receive an appeal in the mail. Cost 'em like 800 bucks. It's a lot of money. Every time we send one, it costs 'em money. And then if they deny it, it's also gonna cost them money. It's gonna cost them more money. So the goal is to say to these guys, your business practices are not [00:53:00] acceptable in 2024. You need to modernize and if you wanna start using ai, make sure your policies are up to date <laugh>. So, so that's what we do.

Susan Manfull: 00:53:10 Mm-hmm <affirmative>.

Warris Bokhari: 00:53:11 And it might have been a lot <laugh>,

Susan Manfull: 00:53:13 <laugh>. Well, it, it certainly sounds very thorough. Uh, do you have any, how many of these have you done for Pandas pans patients so far?

Warris Bokhari: 00:53:23 I, I do, you know, couldn't even you mm-hmm <affirmative>. Um, there, there are a lot of fa there are a lot of families who've started [00:53:30] but not submitted. I've probably been involved in like five-ish in individually where I've like pulled them out of a pile and tried to work with individual families. I know my, my co-founders have done the same mm-hmm <affirmative>. Where they've gotten support requests and they've, they've dived in. Maybe we've done 10, I don't know, but like, I honestly don't know

Susan Manfull: 00:53:46 Mm-hmm

Warris Bokhari: 00:53:46 <affirmative>. To be, to be honest. But like, there are a lot of families who came in, there's something like 200 plus families signed up and then there were some families who said, oh, well we don't know if we need IVIG yet, but we'll keep this in mind [00:54:00] in case we get denied. And they just signed up because they were curious

Susan Manfull: 00:54:03 Mm-hmm <affirmative>.

Warris Bokhari: 00:54:03 And they wanted to know what it would, would involve. That's great. Like, you know, not every family, it turns out needs IVIG for their child. Like it's a, some, some people might improve with other therapies, don't know. That's actually not for us to determine. What we're trying to say is if Mark passed an ACT decides that one of his patients needs IVIG, that they get IVIG without the hurdle of having to deal with insurance denials for six months

Susan Manfull: 00:54:29 Mm-hmm <affirmative>.

Warris Bokhari: 00:54:29 That, that's [00:54:30] our goal. We're not trying to prescribe it and we're not trying to increase the prescription rate. We're, we're trying to make sure that if it is prescribed, that a family gets it.

Susan Manfull: 00:54:39 Well, that is the key. If the doctor, after working with this patient determines that IVIG is needed, then, um, that's really in my very humble opinion, should be what's top in making the decision. Um, well you've had lots of other successes in other areas. Mm-hmm <affirmative>. Though, in rheumatology, [00:55:00] and I think I read someplace that, um, you have

sought approval and been successful for as much as, as many as 60 different types of treatments in other areas.

Warris Bokhari: 00:55:13 It's, it's more than that now. I don't even know what the number is. I'm sorry. I should have prepared. We, we've added <laugh>, we've added a few more. It, I I it it's more of a net now. I think it's closer to 80, but I could be wrong. But, um, we're, we're constantly adding things like I think like Otezla and [00:55:30] AKA and something else is being added this week, I think, because we've, we've got to add them. And then there's also like additional treatments for gout that we just added, like, like Krystexxa, which gets, um, denied a lot. Uh, and I have done all of the research for Prolia for Osteoporosis, which gets denied a ton. And it's the only therapy that actually improves bone density in women. So you, they'll put you on a bisphosphonate [00:56:00] and that might stop you from losing, but it doesn't actually help you improve your bone density. So, you know, it's kind of interesting. So I, the weirdest thing about this, and Mark you'll appreciate this, is that it's so hard to keep current <laugh>, but I swear I'm doing more reading now than I've ever done at any other point in my career. Like, I'm constantly in journals all the time, which is, it's completely, it's kind of, it's kind of great. I don't feel like I've lost too many steps, but it's kind of, you know, for that, for that, from the nerd aspect, I'm really quite [00:56:30] delight to do this.

Susan Manfull: 00:56:31 <laugh>. Um, well on the subject of treatments, what about rituximab?

Warris Bokhari: 00:56:35 Um, we could, we could add it. We, I mean, if, if Mark, if you're willing to send us data on it, add it.

Dr. Mark Paster...: 00:56:43 Um, no, I, I think it's the victim of the same small study kind of experience that you alluded to.

Warris Bokhari: 00:56:48 Mm-hmm <affirmative>.

Dr. Mark Paster...: 00:56:49 Um, it, it's a harder cell for two reasons, uh, maybe three reasons. One is it doesn't work quickly.

Warris Bokhari: 00:56:58 Mm-hmm <affirmative>.

Dr. Mark Paster...: 00:56:59 It shuts down [00:57:00] antibody production, but the existing antibody pool is slow to turn over. And they, the general statement is, don't expect to see any benefit for three months.

Warris Bokhari: 00:57:09 Right.

Dr. Mark Paster...: 00:57:10 So for a child in crisis that sounds like, don't expect to see any benefit for three eternities, because every day is so stressful. Uh, the second is that it's about three times the cost of IVIG, believe it or not. Mm-hmm <affirmative>. So it's a major commitment, and in fact, it's worth putting in an appeal letter that if you don't appeal this, the kid's gonna decline and we're gonna [00:57:30] come back and need rituximab, which is gonna cost you three times as much. Right. Um, the third though is that it's remarkably effective at what it does, it, it ablates B cells antibody producing cells from the circulation. When we do, uh, flow cytometry looking for circulating B cells after administering rituximab, it's always zero for a whole year.

Susan Manfull: 00:57:53 Wow.

Dr. Mark Paster...: 00:57:53 In the pre covid era, I didn't think too much about it. Um, but there have been anecdotal cases of [00:58:00] children who, or adults who have been B-cell depleted and got covid and had a bad sort of course. So I'm a little bit, um, more cautious, uh, than using other agents. I have colleagues who treat a lot of multiple sclerosis and other neurological disorders with rituximab, and they think I'm the biggest chicken in the world. I've been told to my face, you know, I'm, someone else has said to me, I'm treating a hundred patients with rituximab, and not one has gotten sick with covid. Like, [00:58:30] what are you, what are you waiting for? Basically? And so, isn't

Warris Bokhari: 00:58:33 This though, isn't this though the difference between like a guideline and a protocol, right? Like physician, physician autonomy and judgment and your acumen basically draws the line at where, at, at how you practice medicine?

Dr. Mark Paster...: 00:58:48 Right. No, I, I think, you know, the rituximab therapy, per se, is regimented. I mean, it's a standard, you know, you give for, for pendas, you give a dose and you give another dose two weeks later, and then you're done for a year. When it's [00:59:00] used to treat lymphomas, it's given on a more regular continuing basis. Although since I don't see any evidence of return of B cells for a year, I'm not sure you need such frequent treatment, but it's, that's how it's given. Um, but the decision to give it Morris is right. You just decide you're up against a wall because IVIG has really not been helpful and the child, uh, is, is really struggling. Um, so I've, I've used it some and, and I, I haven't had that eureka response [00:59:30] that thrills me. So with IVIG kids, and so I basically offer it when I have nothing else to offer. So it's the, my denomin, my personal denominator is small, but

maybe if I were practicing in a different environment, it might be higher.

Warris Bokhari: 00:59:43 What about plasmapheresis? That's one that comes

Dr. Mark Paster...: 00:59:45 No, no. So plasmapheresis the third, like major immunological intervention. Yeah. Um, the problem is, it's, it's very difficult to find a venue to plasmapheresis children. Especially. It requires placement either of a surgically [01:00:00] placed central line

Warris Bokhari: 01:00:01 Mm-hmm

Dr. Mark Paster...: 01:00:02 <affirmative>. Like an equivalent of a dialysis catheter, or else having two large bore peripheral IVs put in into your arms. And you're hooked up to a machine, uh, in a sort of crucified way, um, for six hours every other day for three days, or four, three sessions or four sessions. The problem is that to immobilize a pan's child for six hours,

Warris Bokhari: 01:00:23 Almost impossible.

Dr. Mark Paster...: 01:00:24 Exactly.

01:00:26 Very challenging. My hospital from the get go told me they would not [01:00:30] plasma free pan's children, period, like end of discussion. I must say. The person who told me that has since retired or moved on, and, uh, I haven't been quick to go back because for years I would send, uh, patients down to Beth Latimer in Washington DC mm-hmm <affirmative>. Who probably had the biggest plasmapheresis practice in the country, and she's not doing it now. And I think she had some sort of issue with Georgetown University, and I don't know the details, but I know that she's not presently performing plasmapheresis. [01:01:00] So it, it's, it's a theoretical option that's not really been employed very much. And I think that's been true across the country because when we have our occasional, uh, group phone calls, there's always a question where does somebody else plasmasphere or kids? And everyone says, you know, I don't know. I know they're there, there, there may be a few scattered practices. I think teenagers have a better possible tolerance of the process. I think a grade schooler is a really, it's a big [01:01:30] ask to, uh,

Warris Bokhari: 01:01:31 Huge, huge, huge. And those central lines are no joke.

01:01:35 Right.

Susan Manfull: 01:01:36 Well, recently, a couple of people have gone to Mexico for the plasmapheresis,

01:01:42 Dr. Omar Morales, I think. Um, but you're right. It's in, it, it, it definitely is not available widely in this country. So let me just change subjects a little bit for you 'cause we're, we're about at the end. Um, [01:02:00] uh, Dr. Bokari we spoke about two weeks ago, and it was right after our conversation, the, um, horrible event. Uh, the, uh, the murder of the United Healthcare CEO Brian Thompson occurred. And, uh, uh, we all know now that it unleashed a, a, a flood of anger [01:02:30] and, and hate against insurance companies. And I, um, wanna make it clear that no one condones. I I certainly don't, I don't think anyone on this zoom condones

Warris Bokhari: 01:02:42 The,

Susan Manfull: 01:02:42 The personal attacks at, at Robert Thompson or Brian Thompson, um, the really vulgar, uh, comments that were made. But just looking at the, the, the hate and the anger that was unleashed, I'm, I'm wondering, um, [01:03:00] if that or how surprising that was to either of you.

Warris Bokhari: 01:03:06 It's so, you know, to your point, um, you know, I don't condone attacking individual executives, um, or people in general, and certainly not murder. That's like, it's, or the

Susan Manfull: 01:03:19 Comments

Warris Bokhari: 01:03:19 That occurred. Yeah. It's quite, it's quite something. I mean, it's, it's also like not surprising, um, either like the, the, you know, these, [01:03:30] these executives are often guarded, like very heavily by security. They flanked by exec, uh, by security. It certainly was the case on Anthem, um, that the CEO was heavily guarded. Uh, you couldn't even really get onto the executive floor unless you had a reason to be there. Um, so I mean, that's, that's, you know, been true. I think on, I think what hasn't, what people haven't really thought about is why do they need guarding? And the reason why they need guarding is because the business [01:04:00] practices at scale become discriminatory to like one in five people, one in three. If you're really sick and you're a high health user, your odds are being denied are way higher. So, you know, this, this has led to like severe economic and hardship for, you know, many families across the country and people whose, you know, health has been impacted and lives have been, you know, lives have been badly, badly affected.

	01:04:24	So like, this has been considered like the price of doing business in America for a very long time. [01:04:30] And it's been this kind of like deep pain that's like woven within into the kind of fabric of American life. And everybody's been living with it. And then, you know, Brian, Brian Thompson gets, gets murdered in New York City and suddenly it just erupts. And sure, there's a lot of, there's a lot of hate and vitriol, and that separate that out is like not particularly useful to engage with mm-hmm <affirmative>. But like, let's look at the stories which are coming out here and they're horrifying.
Susan Manfull:	01:04:54	Mm-hmm <affirmative>.
Warris Bokhari:	01:04:55	You know, the, the actual, the, the actual like denial stories that people are sharing, they're absolutely [01:05:00] horrifying to me. They're no surprise. And, you know, I, I look at this as akin to talking about gun violence after a school shooting and talking about, um, you know, gun reform and gun safety and all, all of those kinds of issues. It comes up every single time. And then the gun lobby will say, it's too soon. We, you know, we shouldn't talk about this right now. Okay, this has happened. You know, un unfortunately this has happened. But [01:05:30] I think we should have this conversation about what needs to change in healthcare. I think we should be actually listening to these families. The, the United Health's response, United Health Group, which is the parent company of United Healthcare, is run by Andrew Witty.
Susan Manfull:	01:05:44	Mm-hmm <affirmative>.
Warris Bokhari:	01:05:45	He said that it's noise that, you know, we shouldn't listen to the negative comments in media. It's all noise. These, this is not noise. This is families actually expressing their deep, deep frustration with the service and the product you sell. Um, it, it's a [01:06:00] really good opportunity on some level to listen to them, to actually figure out what's wrong and make it less bad. But I truly think this is existential for the health insurance industry because they've got a really big problem. If they start acknowledging that they've made mistakes, there's gonna be a tidal wave of like quite righteous lawsuits that, uh, you know, for all sorts of things, which I imagine would just come out of a woodwork. So the, so there, there's a interesting, it's an interesting moment, but for the first time, like their business model looks [01:06:30] really, really vulnerable. And I'd love to see it change

Dr. Mark Paster...: 01:06:33 You. Of course. The only thing that surprised me was it turned out that, uh, the perpetrator was not, uh, enrolled in a, in a, in a united healthcare product at the time. And apparently, if ever, I'm not sure about that, but he just selected this individual and this company, uh, clearly it's a big, big company and, and highly visible one, but I was shocked it [01:07:00] speaks more to the level of violence in America mm-hmm. Than, than to anything else. But, um, you know, the anger that it exposed is just dramatic. I, I, I lived right near a little bicycle path in town, and there was graffiti denied deferred delay or something like that, uh, right off mm-hmm <affirmative>. The, the casings of the bullets, the squirrel down the wall of one of the buildings. Uh, it's just, whoa, this is like two blocks from my house. So I, I know that, [01:07:30] uh, it's gotta be pretty widespread.

Susan Manfull: 01:07:32 Mm-hmm <affirmative>. So it may be difficult to navigate the, um, navigate through the, the vitriol, the, the, the language that's been used. But I agree it is important to hear the stories of the families and try to make some constructive changes. Well, one way and, um, uh, um, [01:08:00] Dr. Kora, you had said this before this incident happened, that this is a really constructive way to change the system.

Warris Bokhari: 01:08:07 Yeah.

Susan Manfull: 01:08:07 That I think you spoke, uh, and you sort of alluded to it earlier in this conversation, that you'd really like to dismantle the current, uh, medical landscape in, in terms of health insurance, and that a program like this could well do it when they finally realize that it's not financially worth it [01:08:30] to deny every claim, and then to have to go through the appeal process each time. It's not, it's not financially viable.

Warris Bokhari: 01:08:40 Oh, you know, I, yes. I mean, I, I reflect back on the time in 2008 when I was working in the emergency room in London, and it was full of bankers who had like either attempted to overdose or, you know, self harm because their belief system had been broken about how the economy, how the economy [01:09:00] worked. Right. Suddenly all the whole subprime thing blew up.

Susan Manfull: 01:09:03 Mm-hmm

Warris Bokhari: 01:09:03 <affirmative>. And, um, their entire belief system changed. I, if you actually wanna change healthcare, it's not about replacing an individual executive, you actually have to remove a belief system. And the belief system is that you can make money this way. So, but if you change the belief system, if you prove it out,

that actually it is uneconomical for you to proceed down this path of denying lots and lots of care, because companies like mine will spring [01:09:30] up to make it painful for insurance on, on the economics. Wall Street will react to that really quickly, and we're already seeing it. Anthem got down, uh, Elance got downgraded I think yesterday, uh, which was interesting. Um, CVS last year removed, oh, sorry, it wasn't even last year. It was like two months ago, removed Karen Lynch, um, who was their CEO and replaced her with David Joiner, who's, you know, in principle worse because he actually lied to Congress, um, allegedly.

01:10:00 [01:10:00] Uh, so you know that, so you know, the Wall Street, you know, watchers are paying attention when these companies stop performing, they'll make changes. And right now there's been, you know, discussion about separating out the PBMs, the pharmacy benefits managers from the insurance arms, and the insurers are running scared. I I was on a call last night with something like, you know, 60 pharmacists at like 8:00 PM last night because there was a bill that got squashed, [01:10:30] and they were all pretty disappointed about that. The truth be told, these insurers are terrified that if the PM business goes away, they go outta business, they're absolutely terrified. There's a lot of chat, there's a lot of chatter internally at these insurers that like, they're afraid to spend money. Um, because if, if the, if a money printer, you know, disappears, they've done such a bad job at actually running the insurance arm of their business, they go outta business.

01:10:56 Hmm.

01:10:56 Um, so the, their model today does not work. It is [01:11:00] propped up by, you know, a system that makes drugs very expensive and, and inaccessible and drives independent provider practices out of business.

Susan Manfull: 01:11:09 Mm.

Warris Bokhari: 01:11:10 So the, the, it's already a bad model. It's a bad business. And, you know, we, it, the reason why we perpetuate it is because it's been very profitable for a select group of individuals.

Susan Manfull: 01:11:21 Mm-hmm <affirmative>.

Warris Bokhari: 01:11:22 Change that goes away.

Susan Manfull: 01:11:25 Well, we'll be watching. And then in the last couple of weeks, the, well, in [01:11:30] the last few days, the other major event that took place, and, uh, certainly we don't have time to talk about it at length, but any comments on what role? The 37 page document that was just released by the American Academy at Pediatrics might play in, um, insurance appeals. And I, I hasten to add, I realize that this is a, I think they used the word maybe preliminary, um, it's not their final document, [01:12:00] but, um, it was great that they acknowledged the pandas or the pans. I think that's the,

Dr. Mark Paster...: 01:12:06 I think that's the main thing you can say is a take home lesson, because along the details they were skeptical at every turn.

Susan Manfull: 01:12:15 Mm-hmm

01:12:15 <affirmative>. Yeah.

Warris Bokhari: 01:12:17 I, it, it concerns me greatly. Uh, I read through it yesterday, and I think they lay out a path for making it incredibly difficult to diagnose someone with panto pans to begin with. Right. By [01:12:30] codifying it the way they, they they do. Um, there are certain exclusions of even testing for strep under certain conditions, which they're just gonna make it really difficult for someone to even get the initial diagnosis. And then they propose, like effectively no intervention. Mm-hmm

Susan Manfull: 01:12:45 <affirmative>. So

Warris Bokhari: 01:12:46 There I get, it's a position statement. My concern is, is that it will be taken as being, you know, the guidelines and, uh, from the American Academy of Pediatrics, [01:13:00] it is not signed by individual authors. So it's attributable to the board of EAPI wrote the president yesterday. Um, it is missing key studies, uh, and it lays out a very precarious path for these parents and for physicians who be managing this condition. They said they spoke to experts, they didn't say which experts. There's no published list. Uh, and it certainly, you know, was very few members of the PANS Research Consortium, and I'm not even sure what they were asked. It's unclear.

Susan Manfull: 01:13:26 Mark, any thoughts?

Dr. Mark Paster...: 01:13:28 Well, I, I only know that, uh, Ellen Wald, [01:13:30] who is the chief of pediatrics at the University of Wisconsin, and, uh, someone who is now quite committed to pans and pandas care and research was on a committee and said she was simply

outvoted for a number of the recommendations that were listed about testing and about other things. She didn't go into details of who the other members were. But, um, you know, my, my philosophy has always been that older academics who probably haven't seen kids with strep throat and certainly [01:14:00] haven't seen kids with post-infectious complications in a, in, you know, 20 years are not the best people to be commenting on the problems at hand in the current era. You know, I start every talk of mine with the fact that theoretically there are over 5,000 unique streptococcal isolates,

01:14:18 And we know that some strains are genic and some strains are nephrogenic. And, um, not all strep is the same. And we're in this era where we rely [01:14:30] on rapid strep testing. We have no culture data. We have no serological characterization of strep isolates. Um, and so the notion of collecting strep and banking them and having them as a substrate for characterization and research, you know, has been left vacant. Um, and it's frustrating to me because I think there might be great lessons in saying, well, we found a pandis genetic kind of strain. Um, if there's a genic strain and we know that, uh, <inaudible> chorea is a direct [01:15:00] complication of that immunological event, there must be overlap with other strains that are producing pans or pandis. So my long-term hope is that sometime we'll collect strains. Um, but you're right, it's frustrating, but at least they acknowledge the problem exists. Mm-hmm <affirmative>. Which is a step forward.

Susan Manfull: 01:15:15 Mm-hmm <affirmative>. That is a step forward. Well, uh, when they, uh, come out with the final product, I'd love to have you back and talk a little bit more about it. Thank you both very much for the work that each of you are doing and [01:15:30] also for appearing here with me on this podcast.

Dr. Mark Paster...: 01:15:34 And I just wanna say to ours, I will definitely reach out to you for the next, anytime that I need. Okay.

Warris Bokhari: 01:15:39 Anytime.

Susan Manfull: 01:15:40 And to those people who are listening, I, how did they reach you or what is the web address?

Warris Bokhari: 01:15:45 It's get claimable.com. Um, and generally people find me by harassing me on LinkedIn and Twitter or whatever. I mean, I'm very responsive. Like if, if genuinely, if there's a family you needs help, I will like, try and figure out a [01:16:00] way of helping you. Um, so the goal is to just try and get as many

		people onto therapy as possible and start building up this precedent library so then we can start helping more and more families at scale. So happy to help, and thank you for having, thank you for having me.
Susan Manfull:	01:16:16	Great. And we'll, we'll keep, uh, keep making people more and more aware of what you're doing. All right. You both very, very much.
Dr. Mark Paster...:	01:16:23	Good night. It's great to see you both.
Susan Manfull:	01:16:24	Thank you.
Warris Bokhari:	01:16:25	Happy holidays. Thank
Susan Manfull:	01:16:26	You. I see you too. Bye. You guys,
William Manfull:	01:16:30	[01:16:30] This concludes episode nine of Untangling Pens and Pens. Thank you for listening. For more information about pandas and Pans and the Alex Manful Fund, please visit the alex manful fund.org. [01:17:00] The content in this podcast is not a substitute for professional medical advice, diagnosis, or treatment. Always seek the advice of your physician or other qualified healthcare provider with any questions you may have regarding a medical condition.