Susan Manfull: 00:00:07

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 tics 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 Manfull. I am a social psychologist, the executive director of the Alex Manfull Fund and the mother of Alex Manfull who died at 26 [00:01:00] years old due to Pandas 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 seven of untangling pandas and pans recorded August 12th, 2024.

Susan Manfull: 00:01:27

In a field like medicine that seems as if it's [00:01:30] moving at a snail's pace, Dr. Ubi is making extraordinary advances in the UK. He would be the first to say, I'm sure that there is much more to learn in order to understand, recognize and treat pandas and pans and to make treatment available to a wider audience. But what he's doing right now will have a significant impact on this population and the pace that he's doing. It seems well rather breathless. [00:02:00] He is very busy and I am very grateful that he made himself available for this interview. I am very fortunate today to have with me Dr. Tim Ubhi, and we are going to talk about the fact that he has just launched the London Pans Clinic and Research Center just a couple of weeks ago. It's an incredible accomplishment and we [00:02:30] would like to hear all about it. But first of all, I would like to learn a bit about you and your career path to understand what led you to establish this clinic. So going back over 30 years ago, if my math is correct, what led you to pediatrics?

Dr. Tim Ubhi: 00:02:53

Thank you, Susan, for the lovely introduction. The history of pediatrics [00:03:00] in my life goes back to probably my medical school days when I saw pediatrics as a specialty that was broad in terms of the type of diseases that you encountered, but also dealt with illness from premature babies all the way through to adulthood and also included molecular aspects of disease and inherited disease, the [00:03:30] genetic type issues. So that was the thing that drew me into pediatrics tricks, but also from a very altruistic perspective, the fact that for me, treating a child can have such a big impact for such a long period of time, and it's something that appealed to me from a very early part of my medical training. And then I was fortunate enough to encounter [00:04:00] some really interesting individuals who had

made a big difference in medicine through the development of their own services, including a professor of hepatology called Monte Ky, who first introduced me to the idea of teaching and research and almost encouraged me to consider that as part of something that I might do for the rest of my career. [00:04:30] And then other workers who established new services in an environment where medicine was actually in certain aspects, particularly pediatrics, was actually lacking behind medicine in general. And these innovators, they excited me, they stimulated me. They made me want to follow in their path and to push the boundaries of medicine.

Susan Manfull: 00:04:56

In our earlier conversation, you had [00:05:00] talked a little bit about the role that your father might've played in planting seeds even earlier than medical school. Can you talk a little bit about that?

Dr. Tim Ubhi: 00:05:09

Sure. Yeah. I mean, my father was, I was born in Kenya and my heritage is Northern Indian, so Punjabi by origin. And we had two generations in Kenya. My grandparents on both my mother's side and my father's side moved to Kenya to work on the railways when Kenya was a British [00:05:30] colony. And so my father and mother were both born in Kenya and my father used to work in the Red Cross in Kenya, and he would frequently come back and tell the stories of what he had done while he was in the Red Cross. And I think that just laid a seed for my interest in medicine, medical practice, the science that is medicine and also the art that is medicine when you're doing things [00:06:00] that's just slightly differently to the norm. So I was probably about five years of age when I first said I wanted to be a doctor.

Susan Manfull: 00:06:08

Thankfully for us you kept that as your aspiration. You mentioned the Red Cross. Have you done any charity work abroad?

Dr. Tim Ubhi: 00:06:19

Yeah, so I set up a service called the Children's E Hospital in probably 2012, so quite a while back now. But [00:06:30] before that and also since that time doing charity work and also specifically doing disaster relief work is something that I really enjoy. So I was involved in helping with the tsunami when that hit Thailand back in boxing day 2003, I think it was. Now my memory might be failing, but I think it was 2003. And a couple of us went packed up bags, got some supplies, got [00:07:00] the local towns infused who then did some fundraising. And we got a plane and we went to Thailand and we went to help in the few days after the wave hit. And that was my first experience of disaster relief work. And one of the most amazing things about being in that environment was just meeting people from other parts of the world who were doing similar things, who just

wanted to help, who wanted to make a difference, [00:07:30] and who were willing to get their hands dirty irrespective of their professions.

00:07:34

They just packed their bags and they got on a plane and they went over to Thailand. And one of the most interesting chaps I met was a guy I met at the local petrol station. So I'd literally landed off the plane, I was filling up a higher car and he pulled up on a motorbike next to me and he had Swedish lumber plates and he and I got chatting [00:08:00] and I said, what did you do? Why did you come here? And he had no profession as such, but he said he just wanted to come and help. He got on his motorbike and he drove overland from Sweden to Thailand to come and help. That was just amazing. That was the nature of the people that we met there from all over the world. It was an absolutely stunning example of what humanity can do. [00:08:30] Absolutely stunning.

Susan Manfull: 00:08:31

That sounds like that must be very rewarding to be able to engage in that kind of work. So talking about the man from Sweden, you came from the UK and people came from all over the world to Thailand to help with the effects of the tsunami. So they went to a different frontier. And in many respects, your work now is a new frontier and people are coming from all sorts of different [00:09:00] disciplines and different parts of the world to conduct research, to do clinical work on this relatively new area called pans and pandas. So can you tell us a little bit about how you got started in working in this area?

Dr. Tim Ubhi: 00:09:23

Sure. Although I would challenge you, Susan, on whether this is actually as new as we think [00:09:30] It is. Very true. Yeah. I mean if you think about the history of conditions like rheumatic fever, very well established conditions, post-structural conditions, which cause neuropsychiatric change, which have been accepted for many years, the fact that we're actually having to battle for the recognition of this disease baffles me, absolutely baffles me because for 130 years [00:10:00] we've been accepting of these conditions. We've had the Ducky Jones criteria for acute rheumatic fever, we teach it in medical schools symptoms, career is accepted, movement disorders are accepted. So what happened? What happened on that journey over 130 years for us not to have the bandwidth in our brains to accept a post structure pub core [00:10:30] movement disorder with OCD and anxiety in children, it baffles me.

Susan Manfull: 00:10:36

I think it baffles everyone in this field. What is the answer to that question? Because you're absolutely right. Strep is a wildly bacteria that can damage the kidneys, can work its way into causing heart disease. Rheumatic fever as you mentioned, skin diseases, sydenham's chorea, [00:11:00] which is absolutely

accepted. What's the problem with accepting pandos and the broader category

Dr. Tim Ubhi: 00:11:10

Pans? Yeah, no, absolutely. So I think the problem is the establishment, but I think that over the last a hundred years, we have developed a range of conditions where there has been an inefficient interface [00:11:30] between psychiatry and conventional organic medicine in terms of standard physicians. And that battle between psychiatry and what I'm going to call organic medicine goes back to the times of Willie Osler and Tourette and Charcot when Willie Osler was questioning why children were being put into asylum when they had what he called treatable organic [00:12:00] condition, right? So this is a battle that's gone on. But what happened over the last a hundred years is that conditions such as Tourettes have become established and accepted as a disease process. And of course you will know that to get a diagnosis of Tourettes, you need a vocal tick and a motor tick for more than 12 months, and that's your diagnosis.

00:12:26

There is no biological marker for Tourettes. There is no radiological [00:12:30] sign that we have to look for. It is about the constellation of those relatively simple symptoms together, gives you a diagnosis. And then let's think about autism. Let's think about the way that autism has evolved over the last a hundred years and how autism as a sort of overarching umbrella diagnosis actually does depend upon quite a lot of subjective assessments by the [00:13:00] physicians making the diagnosis. Yes, there are scoring systems available, but there is still a very high reliance on subjectivity within that diagnosis. And then probably my favorite one is functional neurological disorder, which was coined by a group of psychiatrists around about 2013 because the previous label that we used to use for that constellation of symptoms was very different and perhaps not palatable for [00:13:30] the world we live in currently. So what I mean by that is that a functional neurological disorder up until 2013 used to be called convergence disorder and then, sorry, conversion disorder.

00:13:43

And then prior to that it was called hysteria. And the catchall with functional neurological disorder is that you need to make sure that there are no other conditions that can account for that person, that child's symptoms before you give them that label. But of course [00:14:00] in practice that isn't what's happening. People are actually giving that label without, I think in some cases thorough exploration of possible organic causes. So we have a number of conditions that have been established, many of which have a psychiatric basis to their evolution, which actually have now become entrenched in our medical environment, which

overlap [00:14:30] with the symptoms that we see with children with pans pandas.

00:14:34

And that's where the problem arises because of that, because overlap. And that's where I think that the establishment struggles, and I can understand why they struggle. I mean you imagine if you are a leading professor in the world of disease X, right? And disease X happens to overlap with pans, PDAs, and all your research is based on [00:15:00] this condition that you spent your life researching. And that if that condition overlaps with pans PDAs, then the research group that you looked at, the population that you've been studying, part of that population may have been children with pans pandas, which would be a different disease profile, a different group of patients to your subject group. And that may have an impact on people's research. It may have an impact on [00:15:30] lots of things in medicine. But at the end of the day, we have a responsibility to ensure that if there is a disease process out there, which if we treat can make children better, we have to treat it, we have to investigate it, we have to research it, and we mustn't be afraid of the establishment.

Susan Manfull: 00:15:49

So it's that paradigm. It sounds like you're saying two things. There's that paradigm shift that is so slow in medicine and in this case [00:16:00] it's beginning to accept that for some disorders they may look very similar. Let's just take OCD for example. There's fully 30% of people who are labeled with obsessive compulsive disorder are not responsive to the gold standard treatment. Now, is it possible that those 30 plus percent actually have a different cause [00:16:30] for their very similar symptoms and that if it's seen through a different light, different cause therefore a different treatment, that they would be responsive. So it sounds like one of the things that you're saying is that it's difficult to accept that the way you've seen obsessive compulsive disorder for your entire career needs to be shifted. But it sounds like the other thing that you're saying is [00:17:00] that one of the objections to pandas and pans is the consolation of symptoms, maybe. Is that accurate? There's multiple things going on

Dr. Tim Ubhi: 00:17:16

Here. Yeah, absolutely. And I guess the statement that comes to mind that perhaps summarizes all this is that we only know what we know. [00:17:30] We only know what we know. And what that means is that let's say a child goes into hospital with a cough, they have an x-ray and that X-ray shows a patch of infection, that child would a diagnosis of pneumonia. That's what standard. The child will then get some antibiotics and hopefully in most [00:18:00] cases those antibiotics will provide some relief and they will get better, but sometimes they don't. And it's when they don't that we then investigate further. And by investigating further, one of the simple things that we do is that

we ask for a sputum sample or a cough swab and we will look at the organisms that are actually causing the infection. We'll put it on a plate [00:18:30] and we'll look at the sensitivity of those organisms, and then we will determine the right antibiotic for that patient specifically for that patient. So in other words, we start to investigate more intensely when there's a poor response to the traditional treatments that we give. And that process is exactly what we should be doing with cancer funders. If a child comes in with a TIC disorder or OCD and you employ standard [00:19:00] therapies and they don't work, you need to be inquisitive and you need to investigate harza.

Susan Manfull: 00:19:06

Excellent point. And I am thinking of your colleague, Dr. Janet Cunningham, who was part of a group who wrote a paper, I guess about two years ago, suggesting that these intractable cases of OCD need to be examined more closely. As we both just said, looking for different kinds of causes. And she's suggesting [00:19:30] maybe there is a subset of OCD cases which have an autoimmune basis. You need to be investigative physicians as well as researchers, as a physician. There's so much that you need to know, but you can never stop investigating and reading the latest research to understand the person who's sitting in front of you. [00:20:00] The other person that I'm thinking of in our conversation is Dr. Robin Warren, a pathologist whose name everyone may not know, but I know you know this story, that he's the one who suggested that it was a bacterium that was causing stomach ulcers, h pylori. And for years no one would believe him. They stuck to their views that this was stress [00:20:30] or alcohol or wild living that was causing the stomach ulcers until finally they did accept that in the majority of cases, this h pylori does play a significant, if not the role as the culprit. And it was hard, I'm sure to feel like he was swimming upstream. He said in an article that I read that [00:21:00] at times he felt that it was only his wife who believed him, but he kept at

Dr. Tim Ubhi: 00:21:08

Yeah, absolutely. And also you'll be aware of the story about

Semmelweiss.

Susan Manfull: 00:21:16

Have you heard Yes, yes. Tell the listeners.

Dr. Tim Ubhi: <u>00:21:22</u>

So Semmelweiss was an Austrian obstetrician and he was working [00:21:30] in Vienna, this is about a hundred years ago now. And he worked on a ward where the obstetricians were in charge, but across the corridor was another ward where the then equivalents of midwives were in charge of childbirth. And what he found was that when he was looking at the data of the number of deaths that were experienced was that the deaths on the obstetricians wards were much, much higher than they were on the [00:22:00] maternity wards. So on the wards run by the

midwives. So to cut a really long story short, he basically went to the leaders of the hospital, the primary physicians in the hospital, and he said to them, look, there must be something happening. So they tried to fob him off a bit and just, everything's fine, just go. But he didn't let it go. So he challenged them so much that eventually [00:22:30] they managed to do a bit of a walk around. And they hypothesized that the reason that there were more deaths on the obstetric led boards rather than the midwife led boards, was because of the size of the windows. Oh, I

Susan Manfull: 00:22:45 Don't know this part.

Dr. Tim Ubhi: 00:22:47

It was something to do with the size of the windows. And so they said, we can change the windows. Well, semis didn't want to like this case. So he said, let me just try some things. He said, [00:23:00] let's just swap the wards over so that the midwives are in this ward with the big windows and we'll go to the other ward and see if there's a difference. So they did that experiment. And of course the death rate, the mortality rate followed the obstetricians. So then this really did push the establishments nose out of joins because they were trying to find an explanation for this. And nobody really wanted this to be a problem because they were quite happy with [00:23:30] playing their games in the afternoon and having their cups of tea and so on. But some advice looked at this and eventually he realized that actually the working pattern for the obstetricians was different to the midwives in the mornings, the obstetricians did autopsies.

00:23:49

So they would go and they would cut cadavers, they would learn about the body. I try to understand why mothers had died and they would have their hands within the cadavers. So [00:24:00] he hypothesized that there was a particle, which he termed the cric particle that was taken from the room where the autopsy was taking place to the areas where the children were born. Of course, now we know that that cric particle was streptococcus, and by employing chlorine water washing, he reduced the death rates to a level equivalent to that that was [00:24:30] seen with the midwives. But the very sad part of the story is that he was still not accepted by the establishment. And I went to see a play about this six months ago. It was on in London. I dunno if you ever get the chance, if anyone gets a chance to see this plane, it is just called. It's absolutely brilliant. But it just shows how ignorant the establishment was at that time. And he ended up in a mental institution [00:25:00] and he ended up dying in that institution. And that's because he never gave up fighting and would not accept that there wasn't substance to hysteria, that there was some sort of particle, which as it turned out, happened to be a bacterium or streptococcus.

Susan Manfull: 00:25:19

Wow. I did not know what became of him. I did not know that he died, never knowing that people [00:25:30] eventually came around to accepting his view. I see you and your colleagues in a very similar role in that. I think years from now, we'll look back and we'll say it's so clear that infection plays a role. Common infections trigger the immune system to go awry, which leads to [00:26:00] autoantibodies eventually crossing the blood brain barrier and affecting areas of the brain in this case, mostly the basal ganglia leading to these various symptoms that we see primarily psychiatric, but also a full range of symptoms that we see that these are clearly related to infection and the immune system. And I think that we'll all be scratching our heads. [00:26:30] Why didn't more people in medicine understand this? Do you see a time when that might be the case?

Dr. Tim Ubhi: 00:26:42

I think with the pace of research that's taking place at the moment with the incredible work with people like Jenny FranFrankovich and the Stanford team with the incredible work of people like Russell Dale in Australia, [00:27:00] and the passion for trying to untangle this disorder from people across the globe, including Italy and in the UK, I don't think this is far off. I think that we will get there very, very soon. And I think that the reason that we want to get there is because nearly all of us are primarily pediatric doctors, children's doctors, [00:27:30] and we have a moral duty to ensure that the children that are suffering with this condition get the right treatment. So that's a moral and professional obligation that we have. That obligation started when we took the Hippocratic Oath and we have to see this through. And I genuinely think as every month goes by and we see more and more research [00:28:00] papers being published and we see the energy within the world of pandas and there is incredible energy that we will absolutely get there, including Susan, people like yourself who've with personal experience and the tragedy of what been through which cannot be underestimated, but how you have converted that tragedy into such positivity is absolutely amazing.

00:28:28 Absolutely amazing.

Susan Manfull: 00:28:30 [00:28:30] Thank you for those kind words. And I do feel that

there is a great team of advocates here in the United States, in the UK, Europe, and around the world who I hope are the wind beneath the wings of physicians like you and researchers across the world. So we can hasten this [00:29:00] change and see more money put into conducting research and more acceptance such

that we see more doctors.

Dr. Tim Ubhi: 00:29:11 Because

Susan Manfull: 00:29:11

I think in the UK, just like in the United States, there's definitely a shortage of physicians who are knowledgeable in this area. Before we move on to the next topic, I want to ask you about something else that I think is important that happened in the UK. [00:29:30] Dr. Belinda Lennox, a well-known psychiatrist in Oxford last year, was interviewed in The Guardian, and she demanded essentially that a paradigm shift take place in psychiatry and that psychiatrists and all colleagues in other disciplines recognize the role of infection and [00:30:00] the immune system. She was referring to schizophrenia and other psychotic disorders. But the same can be said, of course for pandas and pans. Do you think that her voice has led to some change in the UK and around the world?

Dr. Tim Ubhi: 00:30:22

Yeah, no, absolutely. And I think it was incredibly brave of her to stand up [00:30:30] and advocate the need for that mindset shift in psychiatry in the world of psychiatry, because it's very easy just to sit back and to just accept the status quo. That's the path of least resistance. The people that make a difference are the people that stand up and say, we're going to have to do something different here. And the reason she did that was because she [00:31:00] could see the evidence of it. She's a scientist and she's a scientist and she's a doctor, and she can see that actually there is something happening here that does require us to change the way that we approach these disorders. And if you look at the front of many of the psychiatric journals now, there is a lot of work on autoimmune diseases within psychiatry. So people have realized that [00:31:30] there's a big role for autoimmune disease processes to actually contribute to psychiatric phenomena, which we have been a little bit slow to pick up.

00:31:44

And of course, the step from accepting a psychiatric condition such as schizophrenia with an autoimmune basis potentially to then accepting a condition such as plunders where you have a [00:32:00] molecular mimicry phenomena and autoimmune encephalitis is not such a big step. It's perhaps a baby step actually. So Professor Lennox's comments, her voice in the world of psychiatry and beyond has made a huge impact and will continue to make a huge impact. And we need more people like [00:32:30] her who are going to be brave and just stand up and say, we need to start looking at things differently.

Susan Manfull: 00:32:37

Absolutely. And to your point, we also need more research. It is just a very baby step to move forward and to accept the role of infection in the immune system. But it could be hastened if we had more research. I

Dr. Tim Ubhi: 00:32:57

Think research will certainly help with [00:33:00] creating those guidelines that everybody seems to be craving for to standardize

treatment, but we must be careful about that. So guidelines are exactly what they say on the tip. They are guidelines. So every patient is different. This is a really important message, particularly for young doctors, young health professionals. [00:33:30] Medicine is a science, absolutely, but it's also an art. And the nature of the art form becomes more expressive as time goes on and you get more experience. A great example of this was last year when I was at the American Association of Child Psychiatry, the annual meeting in, [00:34:00] what was it last year?

Susan Manfull: 00:34:01 New York

Dr. Tim Ubhi: 00:34:03 In New York. Yeah, that's right. Thank you for that. And I was

due to have a meeting. We were due to have a lecture with Jenny Frankovich and Chris Pittinger and Juliette Madan as well. So the four of us on this panel, and just before the lecture, I was sat outside and I sat next to a psychiatrist who had the very big list of badges [00:34:30] on his jacket, one of which said distinguished member. And he started to talk to me about what I was presenting. And I mentioned Pans pandas, and he asked me a bit about that, and he didn't really understand what I was talking about, but when I said that one of the main symptoms was obsessive compulsive behaviors, and I talked a little bit about how we managed der, and he'd be going to the ACAP meeting for, well since the late sixties, [00:35:00] so a long, long time. And he said, oh, he said, OCD. And children said, that's interesting. He said, he said, because whenever I get a child with a sudden onset OCD, I give them two weeks of antibiotics. And in a lot of these patients, they get better. And so he hadn't got anything in the way of research, but through his medical practice over many decades, he'd realized that [00:35:30] there was a group of patients children with OCD sudden onset that if you gave them antibiotics, they got better for two weeks. And I actually took that conversation into the lecture and it went down very well. And that for me is about the art of medicine, using your experience to make patients better.

Susan Manfull: 00:35:53 You have to be a good observer and listen to your patient and

[00:36:00] observe what's working. So tell me about your first experience with a patient that turned out to have pans or pandas.

Was it a pandas patient?

Dr. Tim Ubhi: Yeah, it was classical pandas. It was post streptococcal. I'd read

about pandas when I was a junior. I'd read about post streptococcal [00:36:30] changes in children, and I had a patient in front of me with sudden onset tics and OCD. I'd gone through all the absolutely everything that I could possibly think of in terms of investigations like MRIs and egs, all of which were completely normal. And then I did an as o test, and it was very

high. It was 800. And I just thought, this is post streptococcal. And then I remembered panda. So I gave him some antibiotics [00:37:00] and he got better. He was my very first patient. And then thereafter, not long after, probably within six months, I got a phone call from somebody from the UK Pans Pandas charity asking if I treated patients with pandas. And I said, well, I have treated them, but I'm not a world expert. And that was it. The next day the flood gates had opened and there were hundreds and hundreds of patients that were waiting for treatment, [00:37:30] but I didn't know about.

Susan Manfull: <u>00:37:32</u> Wow. Wow. So you were really thrust into pandas and pans.

Well, I guess, well, shortly after that patient, you opened the E

Children's Hospital. Can you tell us about

Dr. Tim Ubhi: 00:37:55 That? It's called the Children's E Hospital.

Susan Manfull: 00:37:58 Oh, sorry. Oh, I'm sorry. [00:38:00] No, that's

Dr. Tim Ubhi: <u>00:38:01</u> Fine. It's fine actually, it's interesting. A lot of people get that

wrong around. I think it's because if it was an adult service, you would call it the E hospital, wouldn't we? Yeah, no, the Children's E Hospital, the idea behind the Children's E Hospital originally was to try and deliver care to children in a more safe and efficient way. And I say in that order, safe first and then efficient to make sure that we can [00:38:30] get children treated quickly and promptly. And the reason that actually started was because one day I was in clinic and it was a general pediatric clinic and a mother came in with three children, a double buggy, and the child that she brought for the review appointment had asthma. So a really simple pediatric condition though. And I said, how was your day? And she just launched into me. She said, it's terrible. She said, it's [00:39:00] taken me an hour to drive here. It's taken me half an hour to park and it's going to

appointment.

00:39:10 And I realized actually she had a point, she had a really big point

take me an hour to get back. And this was for a 10 minute

because why didn't we use technology? Why weren't we using telephone consultations or video? Now this is back in 2012, right? This is that we set up the children's hospital. So this was way before covid, but the [00:39:30] technology was present there, and that was with Skype initially, if anybody remembers Skype, they seem to appeared now. But we set up the world's first online child health service. And that was originally for general pediatric problems. But then my half changed and because of the encounter of Pans Pandas, and then I very quickly [00:40:00] started to develop the service around Pans Pandas, and that became the predominant disease that we now treat.

Susan Manfull: 00:40:07 So did you see them exclusively online? Were there any

Dr. Tim Ubhi: 00:40:15 Initially, yes. Initially it was purely online with, and also then

trying to develop a model of care that was going to be safe and

effective,

<u>00:40:26</u> That challenge. So there were patients that I needed to see

[00:40:30] face-to-face as well. So I started to develop that part. But this was unknown territory. This was going into an area which nobody had done before and trying to do it in a safe Safeway. And so I eventually had a virtual service plus a face-toface service and the two integrated, and that face-to-face service was in the north of England [00:41:00] initially. And then over time. I realized that I needed to be London based because of the fact that people could commute into London so much easier. And that's how we came to start a service in London, which I think we did about five or six years ago when we were renting out a room and it was having to carry all of our equipment every day that we wanted to run a clinic, we would come with three suitcases of equipment. [00:41:30] And it wasn't the easiest, easiest, but it delivered a service that was necessary. And then now two weeks ago, we opened the London Pans Clinic and we've got everything we need here. We've got the equipment, we've got the space, we've got the time, and we're able to deliver

a much more, much more efficient service.

Susan Manfull: 00:41:54 So tell us a little bit more about that. It's incredibly exciting to

hear this.

Dr. Tim Ubhi: 00:41:59 I had [00:42:00] the option of continuing with my national health

service work manager's work or to actually take a bit of a risk and do what I love doing. And working with children with PAMs pandas is so rewarding because we make those children better and we make them better relatively quickly with relatively simple treatments in the vast majority. [00:42:30] We're not taking away the fact that there are complex patients out there that require a little bit more in the way of work, but we work hard on those patients and we work together and we work collaboratively. I mean, prior to this call, I'm not allowed to say who I was talking to, but every two weeks I now have a phone call with a physician in the US and we have an hour where we chat about our patients and we share information and we share experiences [00:43:00] and we help each other to treat our

patients better.

<u>00:43:05</u> So where we've got a transatlantic relationship already with the

London PANS Clinic, and if there was somebody, for example, in Australia or Singapore or anywhere that I felt would be helpful in making our patients better anywhere in the world, the beauty of the Children's E-Hospital is that we can bring that in.

We've got the structure [00:43:30] to bring people in from all over the world to work effectively together in the same way that we did that work with the patients in the disaster relief zones in Greece with the Syrian refugees, where we provide an expert online opinions from people who are specialists in their field, but who are elsewhere in the world who couldn't be there, but who could advise the local doctors on what to do. And I do [00:44:00] believe that in the future, the Children's e Hospital will be able to provide something very special, got the right framework. We've got the experience and we've been doing it for a while now, and our audit process shows that what we're doing is really good. We're getting 90% of our patients show a really significant good response to treatment. So

Susan Manfull: <u>00:44:21</u> 90%?

00:44:44

Dr. Tim Ubhi: Yeah, 90%, that was our last audio. So 90% of our patients show

a good, very good or excellent response [00:44:30] to treatment. And by good, I mean at least 50% symptom improvement.

Susan Manfull: 00:44:35 Alright, you're going to keep the children's E hospital running as

well as having the London Penns clinic, correct? Yes. Great.

And you've just made a whole slew of important points I think. I mean, one is that you made clear that this is a treatable disorder if it's identified early and treated properly. This is [00:45:00] largely a treatable disorder. However, there are complex cases that don't respond initially to the current treatment protocols, which is why it's important to make sure that there is collaboration. And you talked about that as well. This is an emerging field in terms of how best to treat these cases. While the concept of infection and the role of the immune system is [00:45:30] not new to those people who have been paying attention, the best treatment protocols are still being researched. And to your earlier point, this is medicine is a science, but it is also an art. And those two I think are intertwined. Hopefully the art part can play a role in determining what research to conduct [00:46:00] and the research part can contribute to the art of treating as well. Can you tell us about the patients that you see

standard pounds pound as patient, but it's sub onset and these

and will be seen at the London Pans Clinic?

Dr. Tim Ubhi:

Yeah, we see children, and that's the first thing to say. And we have been seeing children [00:46:30] with parents pandas. So children who present with tics OCD behaviors, but also children who come with some unusual neurological phenomena. So children that have been given a label of autism, for example, but they're very young and they suddenly become mute or demonstrate some significant behavioral dysregulation. And it's a sub [00:47:00] that kind of what you would normally see in the

kids are young. And so that's one end of the spectrum. And then of course we have the other end where you have the older child or young adults who again has a sudden onset of neuropsychiatric phenomena and it's about whether or not you investigate those, which we do. And usually we find a problem and we treat that problem and we make them better.

00:47:30

[00:47:30] And it's almost as simple as that. Actually, Susan. It's just being inquisitive enough to explore and not say, oh, that child is clearly got a behavioral problem, or whatever other diagnosis you want to throw at them just from observation. You have to find evidence. And I suppose what was the biggest challenge is that we have to, because of the environment that we were working in and because of the potential risks of [00:48:00] treating a, what is felt to be a new emerging condition is that we have to provide objective evidence of what it is that's wrong. So we cannot treat blindly. We have to explore, we have to investigate. Now for me, that's good medicine. That's about making sure you've got the right data behind you before you start on an empirical pathway. The problem for us is that this service is a private service and there are people [00:48:30] within the UK who cannot afford that private service. So how do we take that knowledge that we've got and put it back into the public services like the National Health Service? So what we're planning on doing is teaching and training doctors like we've already offered to train up a doctor in the northeast of England to start a NHS based service, and we will continue to do that. So it's about spreading the word, spreading [00:49:00] the knowledge and encouraging people to learn. But the people that we are willing to train need to come forward and say we want to be trained.

Susan Manfull: 00:49:10 That's great.

Dr. Tim Ubhi: 00:49:12 Yeah,

Susan Manfull: 00:49:12 That's super. When will that start?

Dr. Tim Ubhi: 00:49:17

Well, we're ready to go. We are ready to go. And in two weeks we've been open for two weeks now I've got my feet under the table. I've got two people that are helping me [00:49:30] with the research. They're working hard next door and the ring way through all the data. We've got a lot of data that we need to unpack and show from a UK perspective what it is that we're doing here and how beneficial it is. And of course, using new innovative techniques to measure patient illness, which as a scientist at heart, that makes me [00:50:00] very excited because data is fabulous when it can support what you're doing clinically.

Susan Manfull: 00:50:08 So one of those devices you have been working on, you and your

colleagues is something that measures the size of the dilation of the pupil. Can you talk a little bit about what the role of that may

be?

Dr. Tim Ubhi: 00:50:28 Yeah, [00:50:30] actually this is about parents saying to us

repeatedly. And anybody that's in the world of pans, pans will know this, that their children have got, when they're in the flare, they'll have big dilated pupils. So then you put on your inquisitive hat and you go, but why? So every time I asked that question and I said to doctors who like neurologists or [00:51:00] even psychiatrists, they'd say to me, well, this is just a flight fight response. This is because this child is anxious. But when I was examining these children, there was something unusual about the papillary response. It wasn't just that the pupils were dilated, it was the fact that the response was unusual. There was a constriction and then a lag, and then there was [00:51:30] a redating dilation of the pupil. So it just looked different to me. And it was also accompanied by other features, which I would

put under the general umbrella of dysautonomia.

<u>00:51:45</u> So when we get things like the pots phenomena, the heart rate

dysregulation that you see, so I thought the only way that we're going to work this out is by looking, is by putting it into a [00:52:00] process where we actually start to measure these patients with a device, which we've now got, and we're at the early stages of the research, but we're looking not just the pupil size, but also at the speed at which the pupil constricts the end dilation, the way it dilates and a few other little bits and pieces, which give us about 10 different measurements [00:52:30] from a single light pulse into the pupil, into the eye, which again is us trying to put the science behind what we're doing to understand why these patients are behaving in this way. And then can we use that to predict that when they start to go into a flare or can we at the very least use it as evidence that this is an organic

process [00:53:00] rather than a psychiatric process.

Susan Manfull: 00:53:04 So will you be able to collect longitudinal data?

Dr. Tim Ubhi: 00:53:09 That's what we're trying to do.

Susan Manfull: 00:53:11 And the normal pupil will constrict in bright light and dilate in

dark light. The normal pupil may respond, may dilate in emotional experiences such as seeing a loved [00:53:30] one. But these, in the case of pandas and pans, the pupil dilation, it's unclear and you want to investigate under what circumstances this dilation is well, that it occurs and that it's inconsistent. It's unclear what it's responding to, neurological perhaps [00:54:00] most likely, but maybe an autonomic nervous system response.

Dr. Tim Ubhi:	00:54:08	So what we're hypothesizing here is that what we see as a result of the heart rate instability, the pots phenomena and also the pupilary dilatation in these children is due to the basal ganglia abnormalities that we see in children with transplants. We think that's the root [00:54:30] cause. Now these are going to be very complex pathways, but the logical scientific way to approach this is to measure it and collect the data and then to see whether or not there's linkage that helps you to demonstrate that your hypothesis is either correct or incorrect.
Susan Manfull:	00:54:56	And right now we don't have a biomarker for pandas or [00:55:00] pans. Perhaps the role of the pupil dilation may cast some light, but I doubt that it's going to be a biomarker per se. But it may be something that indicates an abnormality that Right.
Dr. Tim Ubhi:	00:55:20	Well, I think what it'll do is that if we can show that it's relevant, it gives us another tool to measure with. Okay. Yeah.
Susan Manfull:	00:55:29	Alright.
Dr. Tim Ubhi:	00:55:30	[00:55:30] So in the same way that we use sidebox and the Yale Tick scoring systems, this will be converting the physical presentation of the children into numbers so that we can then quantify the disease process and follow it. And that way then if we give them treatment, we can look at the treatment responses.
Susan Manfull:	00:55:56	So to sum up, you are [00:56:00] treating children as well as it sounds like adolescents and young adults in the PANS Clinic. Is that correct?
Dr. Tim Ubhi:	00:56:08	Well, actually we've just launched the adult service. So now last week we have started to accept adult patients and we're going to have to see how it goes because we've not put an age cap on that service yet. But we've got to remember [00:56:30] that if people have had hands panda symptoms for many years, part of what happens to 'em in terms of the psychiatric presentations become entrenched and those can be more difficult to unpick and resolve. But I felt that there was a need for an adult service because I had a patient only three months ago who I saw her for the first [00:57:00] time, she was 23, and I agreed to see her because her mother pleaded with me. She was having somewhere in the region of a hundred to 200 seizure-like activities a day.
	00:57:15	And she was being cared for college, well, what we call college, but some sort of an educational establishment with three to one care, which meant that she was so severe that she had to [00:57:30] have three adults looking after her all the time to make sure that she was safe three to one care. And she came in and I did my investigations. I found that I had some problems in her physiology. It wasn't just post strep, there were other things

that were going on, but the point of doing the blood test is that you fine tune what's going on in terms of the physiology. We gave her two weeks of treatment and for the first time in many [00:58:00] years, and when I say many years, I'm talking about over 10 years, she was seizure free for over three months. So going from a hundred seizures a day to being completely seizure free for over three months. And then she only had one seizure and then was seizure free again.

00:58:21

So what then happened was that she ended up buying the coffees for her carers every day because [00:58:30] they had no role. They were paid for, but she didn't need them and she didn't do any, she'd not done any exams, no GCSEs, no A levels because she basically couldn't have done them with her level of sickness. And so she got better. And then she said to me, she said, I want to get to university, I want to do forensic science. And it [00:59:00] was just amazing. And I just thought, wow. And my mother said to me, you have to treat adults because if you hadn't treated her, where would she be? And she's absolutely right. So we have to find a way to treat the adults as well.

Susan Manfull: 00:59:17

Of course, you would not be surprised to know that. I completely agree with that. In the case of our daughter, she did not surface with any symptoms until she was 19 [00:59:30] years old. So after about of strep on top of mono so it can surface for the first time in young adulthood. And had it been identified, had it not been seen as a pediatric disorder entirely, exclusively, had she been diagnosed, I think that she would still be here with [01:00:00] us today. So I applaud your efforts to take on young adults. Do they need a referral or can they come to you directly?

Dr. Tim Ubhi: 01:00:10

No, they can come to us directly. Actually, they can just book online through the e hospital website. Yeah, I would say 95% of our patients do that. They come directly to us. There are support groups out there where people will talk about their experiences. And I [01:00:30] guess that we're getting some quite positive feedback. I don't know because I'm not allowed on those support groups because they are for parents and patients. But I think that they must be positive because we are busy. But Susan, it's a privilege to do this. It's such a privilege to do this job because it's why I went into medicine. It's, it's why at five years of age I wanted to be a doctor. [01:01:00] It just fits with my DNA.

Susan Manfull: 01:01:03

I'm so glad that you're doing that. And I know that that's a view shared by everyone I've spoken with in the UK, and you're offering some services that I think are desperately needed but not always offered in a clinic such as offering support services for parents and family. What led you to do that?

Dr. Tim Ubhi: 01:01:29

So [01:01:30] I would say that nearly all of our patients, so the parents of the children with PAMs Pandas suffer with PTSD as a result of what they see, the illness that they see the child going through. And that PTSD is variable in terms of the severity depending on how long and how severe the child has been and how long the child's had symptoms for. So I used to say, make sure you try and get some counseling to try and get some [01:02:00] support with this. But of course, if a counselor hasn't even heard of plan planners, they will not know what they're dealing with. And then we had a mother of a child who, we've got two mothers of children who have been treated for pandas and they won't mind saying this because I know that they put this out on their social medias as a statement, explain who they are and what their background is.

01:02:29

Raj Bassi [01:02:30] who has a child with pans and she sets up a CBT service for us. So that's cognitive behavioral therapy that helps give children the tools with how to manage their problems in the future, which I think is very useful for particularly the slightly older children. And then Lucy McDonald, who is similarly, has personal experience of Pounds pounders who then trained to become a counselor [01:03:00] and we now offer that service through the hospital website as well. And I think it's something that's incredibly needed for parents who have gone through this very difficult process of having a child who's changed overnight. And parents will say to me, thank you for giving me my child back. And that just that phrase, thank you for giving me my child back [01:03:30] is powerful. What they've been through needs support, and they need to be able to bear the cupboards of all the skeletons that are there and take a big breath in and start their lives again knowing that this is a treatable disease and their kids are going to be okay.

Susan Manfull: 01:03:52

Absolutely. According to research out of Stanford in which the caregiver burden index is [01:04:00] administered to families, the scores are higher than those who are caring for Alzheimer's patients at times during the course of pandas and pans. It's a very trying disorder for one to have and for one to be responsible for caring for those individuals. So at your clinic, [01:04:30] recognizing that this is a multi-system disorder, you mentioned you have a cognitive behavioral therapist, you have a staff member who will work with parents. Are there any other staff members from different disciplines that you have now or you plan to have?

Dr. Tim Ubhi: 01:04:52

So we've got neurophysiology. So we have a neurophysiology tech who's helping us with EMG, so electromyographic [01:05:00] analysis to quantify movement disorders. And I'm also doing some work with EEG to see whether or not we can find an e EEG system that allows us to measure electrical deeper

in the brain. That's one of the things that we'd like to do. Again, to quantify the disease process. We also have very close links within this area with neurologists [01:05:30] and immunologists and psychiatrists. So we interact with those to try and deliver that multidisciplinary team approach that can be invaluable for these patients because we normally aim to get our patients in the region of 80 to 90% better somewhere in that region with our first couple of courses of treatment. But once you get beyond that to optimize treatment, we quite often need to bring in either neurology [01:06:00] or more commonly psychiatry to just help stabilize things even better, to give the best outcome that we can in with the tools that we currently have available. Bearing in mind that new tools are being developed all the time with new medicines and so on. We have to keep our eye on that to try and control things. So yeah, that MDT approach with disease optimization is the way that we work.

Susan Manfull: 01:06:25

So a patient comes in your office and you diagnose them [01:06:30] as having pandos, what generally speaking of course, we recognize that each individual may present differently, but in general they will have the cardinal symptoms of OCD, perhaps tics, perhaps an eating disorder,

Dr. Tim Ubhi: 01:06:52

Anxiety, ais

Susan Manfull: <u>01:06:57</u>

Misophonia. So a range of symptoms. [01:07:00] How will you treat them in general at your clinic right now? How are you treating them?

Dr. Tim Ubhi: 01:07:06

So we place a lot of emphasis on investigation first before we treat. So we don't support that treat blindly type process. Part of that is because I think that PLS is actually multifactorial and it's about you want to try and identify all the bits that might be stimulating the immune system to try and [01:07:30] make that child better. But I've seen the majority of patients a course of antibiotics, usually two weeks of full course, full treatment dose antibiotics, and then sometimes with a tail of four weeks at low dose is usually my go-to for a patient who's just got group A strep. And there's a clear history and the biological markers are in keeping with that. Some patients we'll use anti-inflammatories on [01:08:00] nonsteroidals like ibuprofen or naproxen. Some patients be given steroid pulse to. And then hot off the press is that we are hoping to very shortly launch a international IVIG service, which is not going to be within the UK, but will be elsewhere where patients can potentially be treated with IVIG if we need to [01:08:30] in a way that's cost effective. But everybody

Susan Manfull: 01:08:33 Not in the UK though?

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Dr. Tim Ubhi:	<u>01:08:36</u>	Not in the UK, we can't do it over here because we haven't got IVIG.
Susan Manfull:	01:08:41	Ah, okay. And would you include any other immune modulating sorts of treatments like rituximab or plasmapheresis?
Dr. Tim Ubhi:	01:08:54	Yeah, as the experience grows with those agents within this population, [01:09:00] we're probably going to be reliant on people like Jenny to get that data together to show the benefit of those treatments. And of course Jenny's background in rheumatology is ideal for that actually. So if we approach pans pans as almost like a rheumatoid inflammatory disorder of the brain and we can use these agents effectively, then if once we've got that evidence, then we can start to utilize it. But [01:09:30] for those bits, we need the scientific evidence behind them.
Susan Manfull:	01:09:35	So this is a problem in the United States as well, or let's call it a challenge in the United States as well, that there are not enough doctors and the treatment can be quite expensive and to navigate the system in the United States is quite [01:10:00] expensive. So therefore often we see that the patients who end up getting the treatment are those with families who are savvy enough to navigate the system and have the money to pay for the treatment. How do you see us moving forward where it's more equitable?
Dr. Tim Ubhi:	01:10:24	So I think in the UK it's going to be about training doctors. So [01:10:30] we plan to have within, I hope within the next six months, as long as I've got enough time and space to do this, and I'm hoping that the admin support which is increased now within the hospital will help me do other things. And part of that other thing will be to run some training packages to help teach other doctors how to treat these patients. [01:11:00] And I think that'll be the key to being able to provide equitable care in the UK. It may not be the solution for other countries, but of course if we can get to the point where we have either national guidelines or international guidelines and online teaching packages, which we're currently building the framework [01:11:30] for on the background of the hospital, the E hospital also has what we call a virtual medical school component. So there'll be an ability there for us to provide teaching for registered users. They can just log on, get the teaching packages, and away you go. So that's where E hospital will really come into its own as a way of almost spreading the word very quickly and do that kind of mass education program [01:12:00] that we might need to really bring people up to speed quickly. And then I'll be out of the job.
Susan Manfull:	01:12:09	Well, if your job comes to an end for that reason, let's just do some wine tasting in the south of France or something like that. What would be better? So just one more question on that. And because some patients [01:12:30] don't respond to the initial

approach of antibiotics and NSAIDs and steroids, how do you foresee IVIG being introduced more fully to the UK in the future?

Dr. Tim Ubhi: 01:12:51

I'm not sure. And I'm not sure whether or not I'd want it to be either, right. So I think that there is an absolute reason for giving it in [01:13:00] an acute setting with a patient with new onset, very severe neuropsychiatric symptoms. And when I say nuance, I'm probably talking within a couple of years. So not over the last couple of weeks, but relatively new. But remember what happens with IVIG? IVIG mops up your antibodies. So when you have your standard antibody care for the response to say [01:13:30] strep, you start with zero antibodies, you go up to a level of about 800, and you come down to a level of about 200. And although that's not necessarily the antibody, it's the proxy for what's going on, the antibody response is similar across different diseases and different pathogens.

01:13:51

And the point of that is that your body has immunity. You have to have immunity. That's why we vaccinate. So you're never going [01:14:00] to have zero antibodies. And if you give IVIG and you try and get rid of all the antibodies, eventually they will come back, but there'll be less of them than there were at the beginning in the acute phase. But an antibody curve will decay anyway. And the point of that is that even with patients that we treat successfully, I always say that there will be some residual symptoms because there are residual antibodies. And if you think about Chris pitcher's work and [01:14:30] the inactivation of the cholinergic neuros with antibodies from patients with pandas that are in their plasma, that fits very well with what we can anticipate as the treatment response and what's left over. So in the UK, I think we've learned to live without IVIG, and we must remember that IVIG is a blood product, so it is a composite blood product. Now [01:15:00] without making people too worried, we have had conditions in the past where blood product transmission resulted in a number of infections that were then transmitted and we can only screen for what we know. And my worry is that if we use it too liberally that we may end up making a different problem for ourselves.

Susan Manfull: 01:15:24

Okay. Well, I think that that underscores the [01:15:30] necessity for much more research on the effectiveness of IVIG and alternatives to those immune modulating kinds of treatments. Okay. So Dr. Ubhi, working in the field of pandas pans, you must feel like you're at the very beginning of a new field in many ways. Dr. Sweeter published her first paper in 1998, [01:16:00] wasn't really that long ago that this concept was put forward. Have you had this experience in your earlier life at all in working with new fields? Have you had this experience in other areas of medicine?

Dr. Tim Ubhi: <u>01:16:21</u>

So going back to what I did when I was a junior, and my first experience of research [01:16:30] and development, one of the areas that I was involved in prior to going into pediatric oncology, so pediatric oncology, I did for several years with a particular interest in a disease process called Ewing Charcotma. And of course, with pediatric oncology, when you're looking at diseases like Ewing Charcotma or other tumors and cancers within children, you are dealing with conditions which quite often are [01:17:00] about defects at the genetic level of DNA or antibodies interacting with receptors. And of course there's a lot of overlap with that and with what happens in pans. Funders, certainly in my opinion. But prior to going into that field, one of some of the earliest research that I carried out was with a substance, which then was relatively new called botulinum toxin. So this, now, we all know [01:17:30] about Botox now because it's probably the most common uses for cosmetic purposes for people who want to rejuvenate themselves.

01:17:39

But in the mid to late 1990s, I started using Botox along with two other researchers, one called Ted Unis and the other one was bi B to both who have unfortunately passed a few years ago. But the three of us worked on this project [01:18:00] where we wondered whether or not we could harness the potential of oline and toxin to relax muscles in a way that might help children cerebral palsy to walk properly. Because in cerebral palsy, what you are seeing is overactivity of muscles and we call that spasticity and that overactivity of muscles results in them walking on their toes, walking in a way where their legs crisscross and they [01:18:30] walk in a very inefficient way and in some cases can't walk at all. So we wanted to utilize or look to see whether or not we could utilize the substance which had previously been used in twitching of the eye by an ophthalmologist to help control the light twitch.

01:18:49

And we call that blood flow spasm and see if we can use it for these children. So we undertook a pilot study where we treated six children [01:19:00] initially with very small doses of botch line toxin. And that pilot study was positive and there were a couple of other researchers around the world looking at doing the same thing. So we were looking at the data that was coming out of these other centers, and we felt that the only way to prove that this substance was going to work was by doing a randomized control study. [01:19:30] Now, bot line toxin at that time was being marketed or being presented in the press as the most toxic substance known to man. So where a spoonful of this substance could kill the whole world, that was the way that it was being presented in the everyday press. So of course, we had to tread very, very carefully and we were on the boundaries of some very significant innovation. [01:20:00] So we first of all made sure that it was going to be safe, and we controlled the dosages and

we did a lot of work on the pilot study. And then we embarked on a single center randomized control trial, which actually showed very significant improvements in walking pattern for these children with cerebral palsy.

Susan Manfull: 01:20:21 Remarkable.

Dr. Tim Ubhi: 01:20:21 And I presented that data at the 2000 meeting of the Royal

College of Pediatrics [01:20:30] and Child Health where there were two or 3000 people in the audience. And I was a junior adoption at the time. So it was quite scary, the word IQ, to be put in front of these people. And after I presented my data and I was taking questions, the first person to come up and ask a question came up and said, remember, this is in front of a couple of thousand people. And he said, I cannot [01:21:00] believe that you got ethical approval to inject children with this poison.

Susan Manfull: 01:21:04 Oh my gosh.

Dr. Tim Ubhi: 01:21:06 So that was the first question. And so I had to bat that, and I

think I batted it back really well. And my argument was that in order to make children better, that we had to prove that what we were doing was right. And the only way to prove it was to do trials and particularly randomized controlled trials where you take away the placebo effect so you know that it makes a difference. [01:21:30] And actually, as a result of that presentation, we then Botox got the license for use in Children's Cell palsy, and we with that research work that we did in the UK, and we went on to establish the very first NHS clinic called

Bot Lung Tox in children with cerebral palsy. I

Susan Manfull: 01:21:49 Did not know this,

Dr. Tim Ubhi: 01:21:52 And then I was awarded the Michael Blake Prize by the Royal

College of Pediatrics and Child Health for my work in that

[01:22:00] field.

Susan Manfull: 01:22:00 Wow. So you've seen this rodeo before. You know what it's like

to be in front of thousands of people and have a person question what it is that you're doing. So you're perfect to be in the field of pandas pans. That's really interesting. And you also have some experience in doing something very innovative and needing to provide the data that's compelling enough [01:22:30] to change minds. So we've been talking about your clinic for the most part, but I just want to remind listeners that it is called the London Pans Clinic and Research Center. So we talked a little bit about the research that you're doing, and I think that you're going to be talking about some of your research, some of your ideas at upcoming [01:23:00] conferences. Can you talk a little bit about what you're going to be doing? I know several places where

		you're going to be in the next few months. Can you tell our listeners?
Dr. Tim Ubhi:	01:23:11	Yeah. So I think we're in Rome at the beginning of October
Susan Manfull:	01:23:15	In Rome. Okay.
Dr. Tim Ubhi:	01:23:17	That's with the pounds pound Italia group. And there I'll be talking about the pans pandas and the evolution of it as a disease, but also the evolution of it as a disorder [01:23:30] within patients over time and how it changes over time. Then we will be in Seattle at the American Association of Child and Adolescent Psychiatry in mid to late October. I think it's mid October, around about the 20th. And we're going to be presenting some data from our clinical data from treatment response and the different types of symptoms that we see based on the UK population, which should be quite interesting. [01:24:00] And then we are presenting in Canada next year in the spring. So that's planned so far.
Susan Manfull:	01:24:10	Well, and we're hoping that you will be at our conference in early November. We have to talk a bit more about exactly what we envision you doing there, but we're hopeful that you will come there as you did two years ago. So thank you, Dr. [01:24:30] Ubi for spending some time with me today. I know that you must be incredibly busy having just started the clinic, and I'm very grateful for you taking the time. You are doing really wonderful things, and I hope you feel good about that.
Dr. Tim Ubhi:	01:24:49	I love it. Sometimes I sort of say that PANS PANDAS found me, rather than me finding pans pandas. That's great love. That's [01:25:00] how it feels. It feels like it just kind of came to me, and yeah, I love it. Absolutely love it.
Susan Manfull:	01:25:09	Well, again, we love you for being in the pans Pandas arena.
Dr. Tim Ubhi:	01:25:14	Thank you. Okay.
William Manfull:	01:25:16	This concludes episode seven of Untangling Pandas and Pans. Thank you for listening. For more [01:25:30] information about pandas and pans and the Alex Manful Fund, please visit the alex manful fund.org. 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.