

Susan Manfull: [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 ticks and restricted eating behaviors, and a whole host of other symptoms following a strep or other bacterial or viral infection. I have 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 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: [01:18](#) This is episode 10 of untangling pandas and pans recorded December 6th, 2024

Susan Manfull: [01:26](#) Epidemiology. It's the study of the distribution and determinants of disease in populations. In its simplest sense, the word itself comes from three Greek words, epi meaning on or upon demos, meaning people and logos, meaning the study of, so literally epidemiology means the study of what is upon people with the ultimate goal of preventing and controlling disease. Epidemiology is the cornerstone of public health. In early December, I joined Dr. Juliette Madan for lunch with her colleagues at Dartmouth-Hitchcock Medical Center home of the Neuro Immune Psychiatric Disorders Clinic in Lebanon, New Hampshire. Afterwards, we huddled at the end of a long table in that quintessentially Ivy League room and surrounded by walls lined with dark wood shelves filled with books from floor to the ceiling. We proceeded to talk about pandas and the broader category of pans. How prevalent is pans and why is it so important to know, and yet why is it so hard to determine? Dr. Madan co-founder of the internationally known clinic, along with Dr. Richard Morse is an epidemiologist who studies things like that. She plays many roles in the emerging field of immuno psychiatry, including her work as a psychiatrist and pediatrician. She's a graduate of Brown University School of Medicine, completed a fellowship in neonatal perinatal medicine at Tufts University and holds a master's degree in clinical and translational research. Also from Tufts, I hasten to remind listeners that our conversation was recorded before the American Academy of Pediatrics. The a p released their preliminary clinical report on pans on December 16th.

[03:30](#) Okay, let's get started. Today I'm very fortunate to be up at Dartmouth visiting the Neuro Immune Psychiatric Disorder Program, and I have with me the co-founder of this program, Dr.

Juliet Madan. And there's many things that I could talk to Dr. Madan about. She wears three different hats and more, but three huge hats in psychiatry and pediatrics and in epidemiology, and we will focus on the latter in this conversation and come back at another time to talk about some of her other work. So Dr. Madan, I am wondering if we can just start out with the basics. What is epidemiology?

Dr. Juliette Ma...: [04:17](#)

Thanks so much, Susan. So epidemiology is the study of human health in a large scale way, and so epidemiologic investigations help us to study the distribution of disease and some of the determinants of disease. So for instance, in our program, we're interested in understanding the incidents, which is the rate of occurrence of new cases of a immune psychiatric condition or the prevalence of a condition. So new cases and old established cases measured within a specific timeframe of a condition of interest. And so in our program that would be immune psychiatric conditions. That type of investigation helps us understand the scope of a problem so that we can further our investigations and work in advocacy and policy to affect change for large scale patient populations. The other piece of what we spend quite a lot of time doing in epidemiology is evaluating risk factors. So when we do large scale studies on a population level, we're able to look into specific variables, specific risk factors that help us understand if a certain population is at higher risk of developing a condition of interest. Some of those variables might be family history, environmental exposures, diet, sleep, and other factors that may play into a risk factor for a disease process. All of that, again, we are always hoping to translate that into better understanding underlying mechanisms of disease and translating that into policy for health across populations and of course to affect change with novel interventions.

Susan Manfull: [06:12](#)

Wow, you make this subject sound particularly interesting. I'm wondering, one of the questions that we get quite a bit in our symposia for example, is race. Are you able to tap into the distribution across racial and ethnic groups with epidemiology?

Dr. Juliette Ma...: [06:34](#)

Absolutely. That's a big important piece of the puzzle. And when we do large scale studies in human health in the United States and with our international partners, there are several specific variables in human health that are extremely important and race is one of them. Sex and gender is one. And other aspects with respect to access to care, socioeconomic factors, educational factors, these are all very important when we think about health on a large scale.

Susan Manfull: [07:05](#)

Well, you anticipate in my question about the socioeconomic status of those who are being diagnosed or not being diagnosed as having pandas and pans. I think that whole issue of access to

medicine, medicine within pandas and pans and medicine in general is undoubtedly affected by one's socioeconomic status. It's very difficult to navigate the medical system as we all know. I think we're all wondering what role that factor may play and would that give us some ideas about how we could make changes there so we don't see these inequities treatment access?

Dr. Juliette Ma...: [07:48](#)

That's a big question. Big question with a really important area of focus for all of us in epidemiology, you might see that a lot of the work that we do at Dartmouth is really focused on that question. Specifically at Dartmouth, we're asking questions related to rural healthcare and the socioeconomic disparities within rural populations in the United States, and that's true with some of our partners in our international work as well. I think epidemiology is one of the most important ways we can access some of those questions. And we do that by doing large scale population based investigations. And the way that we do that in our programs at Dartmouth, specifically in our program called echo, which is an environmental children's health outcomes program, it's nationwide, is that we have a very large scale birth cohort study here at Dartmouth studying pregnant people and their children, and we're focused in on things like the microbiome in development and neuropsychiatric outcomes in that population. But then we partner with other cohorts across the country, and those are cohorts that are on Native American reservations in the southwest populations on Puerto Rico and in San Francisco there's a cohort in Idaho and other rural populations in the us. So with a collaboration of that size and scope of 50,000 children across the United States, we're able to ask those questions in a much more meaningful way that might not be able to be accessed or answered in a smaller scale.

Susan Manfull: [09:28](#)

How long have you been collecting that data?

Dr. Juliette Ma...: [09:31](#)

So our birth cohort here at Dartmouth was started by Dr. Margaret Karagas, who's the chair of epidemiology and my partner in work on the birth cohort study that was started by Dr. Karagas in 2009. And then our cohort was asked to join the national NIH funded ECHO program in 2016. So we're going on the seventh or eighth year now with a national cohort, which has been extremely exciting, very meaningful work coming out of that cohort and very focused in on socioeconomic disparities and how we can address that in healthcare.

Susan Manfull: [10:07](#)

Interesting. Tell me what drew you to epidemiology?

Dr. Juliette Ma...: [10:14](#)

I was walking in the hallway at the hospital and got invited by Dr. Karagas. She had heard about my work, so I came to research through neonatology and was really focused and excited about breast milk and diet and its impact on human health and

preterm infants and infants generally sort of a very important gold standard in terms of developing health patterns for a lifetime. And I started a cohort in the intensive care nursery for babies. These looking at the infant microbiome, then started another cohort in cystic fibrosis studying the gut microbiome and the respiratory microbiome in relationship to health outcomes in cystic fibrosis. Dr. Karagas had heard about my work and was interested to see if we could build together a really healthy large scale cohort of infants and their parents and siblings to try to understand the microbiome in all comers in a birth cohort study. And we've been partnering since about 2011 and it's been really fascinating to learn and work with her and our very large team in epidemiology at Dartmouth.

Susan Manfull: [11:25](#) Wow. And were you a pediatrician at that point and also a psychiatrist?

Dr. Juliette Ma...: [11:31](#) Yeah, I started my training in pediatrics and trained in neonatology after that and worked in the NICU for about 10 years and then added in psychiatric training after that because a lot of my research in the gut microbiome and in epidemiology was really focused in on neuroimmunology and neuropsychiatry and cognitive outcomes in children in relationship to environmental exposures and relationship to the microbiome. So I added training a little bit further along in my career.

Susan Manfull: [12:02](#) So where can we go with the data that epidemiologist collect or maybe a better way of asking the question is, who's interested in this? Where can you use it?

Dr. Juliette Ma...: [12:19](#) That's a great question. So epidemiology I think answers some of the really foundational questions that we would see in chapter one of most of our textbooks, right? How often does this particular disease process impact our patient population? How often should a pediatrician be thinking about this condition in her day-to-day operations in her clinic? And so that I think is one really important piece of the puzzle. Is this a common condition that really requires more training for our physicians or does it require more research dollars on the part of the NIH and foundations? So it gets at some of the numbers, the incidents I talked about before. What is the rate of occurrence of these cases or the prevalence? How prevalent is it across populations in our country or nation or internationally I guess would be important too. The other piece of the puzzle is only in epidemiology, especially if conditions are not as common.

[13:19](#) So epidemiology allows us to have the power that we need statistically to look into rare risk factors. So examples would be specific environmental toxicants that are only happening in a certain part of the country. We can answer questions about the

impact on health of those types of exposures using epidemiologic investigations. The other piece of the puzzle that EPI is more able to answer is those risk factor questions I brought up before. So on a large scale we can look at a multitude of different variables because we have significant power because the numbers of people in our studies are, we're talking hundreds and thousands and sometimes hundreds of thousands or millions of people in our investigation. So we get to do the first pass to say that this particular exposure is related to this particular outcome. Looking back in time, it was epidemiologist who proved that smoking was associated with lung cancer. And so it takes large scale investigations to really definitively show that these particular exposures are related to health outcomes. And that means that we can change policy and change our practice in the clinic

Susan Manfull: [14:34](#) Because it's hard to argue with the numbers that show that there is a relationship between smoking and lung cancer. Exactly. So are organizations businesses like let's say pharmaceutical companies, are they interested in epidemiological data? I think you sort of touched on this when you mentioned rare diseases, but are they one of the groups who would be interested in epidemiological information?

Dr. Juliette Ma...: [15:06](#) They would be interested in epi research for sure. Certainly when we think about different disease processes and their impact on human health, something that is rare but has a very substantial impact would be a very important focus for investigative drug studies for sure. There are a lot of stakeholders. That's usually the phrase that we use when we're doing large scale studies. Who are the patients, the community members, the investigators, the drug discovery people who has a stake in the information that we're gathering. And there are a lot of stakeholders when it comes to epi research.

Susan Manfull: [15:50](#) So focusing on the pandas pans world, there are a lot of stakeholders there who would really like to know what the incidents is of pandas and pans, and are there differences, as we said in race and socioeconomic statuses across the country. And you mentioned gender and age, we really need that data. We need that data to show the major funding sources like NIH, that there are a lot of people who are being affected by this in terms of direct effect as a patient and the burden of the disease, the cost of the disease, how schools are affected, how hospitals are affected and so on. Why don't we have that data and everybody will agree. I think that there are no real valid numbers about how many people have pandas and pants. Am I correct first in that first assumption?

Dr. Juliette Ma...: [17:00](#) There's been attempts to get at that number. There's been four papers or a couple more than that I think in the pipeline right now trying to make an estimate of what the incidents might be in certain academic institutions and the populations that they serve. And the numbers are pretty varied in terms of the data that's been published to date. I think the question you asked was why do we not have that number? I think one reason putting my clinical hat on is that there are not a large number of coordinated research-based clinical programs. I'll speak for the United States. That's where I work. So currently there are really a handful of coordinated programs that are able to or are working on the process of understanding the incidents and the prevalence of immune psychiatric conditions and specifically pans and pandas is even more focused and even more focused question. So I would say that the programs are growing and that the opportunities to do these research projects are growing and certainly our team and others across the US are working on these questions as we speak.

Susan Manfull: [18:26](#) What about the diagnostic codes? I'm thinking about what the challenges are in carrying out this kind of research. So you mentioned that there are just a handful of large scale academic hospitals that can do that kind of research. What are some of the other challenges in doing this research?

Dr. Juliette Ma...: [18:49](#) I think the primary challenge is that it's a relatively novel set of diagnostic considerations. There is not. So the American Association of Pediatrics and the American Association of Child and Adolescent Psychiatry both recognize and train their trainees in immune psychiatric conditions, specifically pandas. There are other specialties where this type of coordinated multidisciplinary lens on specific presentations and conditions are not recognized or they're not trained in that type of work. And those examples of that would be the American Association of Pediatric Neurology is one.

[19:36](#) So some of it I would think very clearly is related to education and related to recognition. The second piece you had alluded to the fact of diagnostic codes. So when we're doing large scale epidemiologic work here at Dartmouth, the Dartmouth Institute is an internationally renowned group that works very diligently on very large scale database type investigations, leveraging things like ICD nine codes, which we use in medical practice for billing and for diagnostic clarification. And there are not really clear diagnostic codes for everything that we evaluate and treat under the umbrella of immune psychiatry. And that I think is another piece of the puzzle with respect to capturing the numbers when we're trying to understand how many people have the condition we're discussing.

- Susan Manfull: [20:31](#) So you talk about immune psychiatry and then within that falls, pandas and pans, correct?
- Dr. Juliette Ma...: [20:41](#) Yep.
- Susan Manfull: [20:42](#) Is it more challenging to look at immune disorders than it is for pandas and pans who have a much broader group with the immune psychiatric disorders?
- Dr. Juliette Ma...: [20:54](#) We definitely have a much broader group with immune psychiatric disorders, which is our goal eventually to have a very broad group of conditions that would be under the umbrella of what we evaluate and treat and study.
- [21:07](#) I think the application is going to be vast in my career, I hope, but I think of pans and pandas as a very concrete, measurable and identifiable condition. That is an excellent example of a immune psychiatric condition is a post-infectious neuro immune psychiatric condition. I like to teach my trainees that it is a canary in the coal mine for a much broader group of applications for these conditions. There are examples of other conditions that do have appropriate coding, but whether or not there's training in all of the various subspecialties involved in what we're discussing today, I think that's not where it needs to be, and that's where we're hoping to move in the future. So examples of that would be there are codes and diagnoses for post covid anxiety, for instance. So I think the pandemic provided an opportunity for us to reignite the conversation about the importance of respiratory viruses in the immune dysregulation post-infectious immune dysregulation leading to changes in brain and behavior. And so the post covid sequelae in children and teenagers and adults really opened the door for broader discussions and a multitude of very important research endeavors that would be considered under the umbrella of immune psychiatry for sure.
- Susan Manfull: [22:41](#) So with immune psychiatry, you mentioned the long covid anxiety, and that makes me wonder, is it possible to break down immune psychiatric disorders or pandas and pans in terms of their primary symptoms and get a sense of those in an epidemiological sense? Would it make any sense to track those, just the symptoms rather than the diagnostic category?
- Dr. Juliette Ma...: [23:24](#) I think that that's one way that I would describe psychiatry more generally is that I think psychiatry as a discipline coming to psychiatry as a medical doctor and an intensive care doctor in particular, what you are describing is how I would describe psychiatry, that there is a group of symptoms that we will elicit from a patient or their family and then use that description to decide how many of those symptoms meet the criteria for what we would consider a diagnosis. It really is a descriptive process,

and I will sometimes share with families and patients that the importance of identifying a diagnosis and psychiatry is so that we can provide opportunities for treatments that we have studied that show evidence, and so that we can talk amongst treatment teams about our general understanding of what's happening. However, the diagnosis in and of itself is based on descriptors.

[24:34](#)

It's based on a description of an internal process that we can't access from outside. So these are important questions I think very important questions, and I think you may be getting at the question of coming from immune psychiatry is I think the most important question there rather than specific diagnostic categories, unless we're doing a randomized control trial where it's critical when we're in clinic with patients, the world's a little bit of a different place and we're much more interested in understanding how to answer. The first question is this presentation that you are coming to me with, is it stemming from an underlying organic cause? And I think once we start with that question, the description of the symptoms of concern allow us to tailor some of our treatments, but I think the first question is the most important. So that is how we practice and we've taken to stepping back and just saying, this is an immune psychiatric condition. The only reason we give it a name like depression is I know with evidence what might help if we talk about Ellen's study, that's a good example of when you're looking for a symptom cluster that we would call PANS or PANDAS. If the person collecting the data didn't know what to ask, we can't find it. So it's a good example of the limitations of trying to do classic epidemiologic research on a new disease.

Susan Manfull:

[26:11](#)

Juliet, I'm wondering if you can talk a little bit about what people in the PANDAS community generally speak of as the Red Book issue and why epidemiological information would be so valuable in changing the perspective of the authors that write that book.

Dr. Juliette Ma...:

[26:31](#)

Yeah. Well, it's another example of a guideline, A published guideline of published guidelines from different professional organizations like ACAP and a P like I before. The Red Book is another important resource. And if we are training people in pediatrics and a P is telling them, and there are board questions for those pediatricians about PANDAS, but the red book, which is also one of their important reference guides, does not include the same information. It's confusing and I would say not evidence-based, certainly based on the evidence that's available currently in the literature. And I think as physicians and physician scientists and epidemiologists, we need to realize that we're learning every day. And as a researcher, that is the whole premise of doing research. I'm out there trying to learn something new and we need to incorporate that new knowledge

into our reference guides so that we can train the next group of professionals who are going to be providing evaluation and treatment for all of our patients.

Susan Manfull: [27:47](#)

Do you think if we provided incidents data to those who write the red book, that they would be more inclined to change some of their guidelines? I would hope so. Just another reason why this is so important. Alright. Well, we frequently see the number of one in 200 stated as what does the incidence rate of pandas or maybe pandas and pans. I'm not, I see in some places they say this is of pandas and other people write that this is of pans and I assume include pandas. Can you talk about that figure?

Dr. Juliette Ma...: [28:36](#)

That figure is from the pandas network. There's no research study that would be cited by that particular number. So when we think about citing an incident of one in let's say 160 right now for children in the United States with autism spectrum disorders, that comes from epidemiologic investigations and publications. And so the one in 200 was an estimate, right? And it's very reasonable for new conditions that are being described and organized and research is ongoing and clinics are building, it's reasonable to craft an estimate based on a local community or based on the community around an academic institution. But that particular number is not based on published research. So there has been work done by several investigators working in this space, and the numbers are between one and 800 that has been published by Dr. Murphy and Dr. Gore's group published one in 46,000 for the incidents of pans and pandas.

[29:44](#)

There's a couple of studies with numbers in between including a study that I was part of and did research with Dr. Ellen Wald from the University of Wisconsin. She's the chair of pediatrics there and an infectious disease specialist. So she isn't an interest in strep and what it might do to brain and behavior. And so we worked together to do a three center study to try to do a retrospective evaluation of young people who presented to pediatrics in their primary care setting for some of the symptoms of concern that are part of the criteria for pandas or for pans to try to look at the charts specifically to determine whether or not they might have met criteria even if they were not diagnosed. And so we looked at a very large group of young children, a total number of about 95,000 children actually, whose charts we pulled and looked at and tried to understand if their symptoms looking back in time might've met the criteria for a immune psychiatric condition, specifically pans.

[30:53](#)

And that the tricky part about doing this type of study is that we realized we really can't do it looking back in time. And that was my takeaway from trying to do that work and it was really important work to do. We established some really exciting

collaborations that I'm excited to tell you about actually. And it was great to train a lot of really new investigators on that project. And what we learned was that in the absence of every primary care pediatrician in those three academic centers knowing and treating PANS and PANDAS, that we would not be able to make these diagnosis retrospectively by looking at the chart. And the reason for that is that some of the critical information required to make the diagnosis of PANDAS, for instance, is not typically asked. And so for instance, it's very common for children to present to their pediatricians with new onset anxiety, but taking the time in a general pediatrics visit to establish what kind of anxiety is that?

[31:59](#)

Is it separation anxiety? Is it obsessions and compulsions? And might it meet the criteria for OCD that typically doesn't happen in a general pediatrics office. So that was one piece of the puzzle that was missing. And it's also pretty unusual to ask the question of did this anxiety come on overnight? Was this a really abrupt onset of symptoms, which is part of the criteria for this condition, this group of conditions, especially when we're looking at it from a research angle when we're trying to be very specific to the criteria. So that was also a piece of the puzzle that was very commonly not present and not a piece of the puzzle. I would say also it's uncommon right now for most pediatricians to test their patients for strep if they come in with acute onset eating restriction or new ticks or new OCD. And so some of it is hard to ask if the initial questions were not evaluated when the patient initially presented. So the range in that study of possible cases was as high as one in 266. And the range of actual cases that we identified as actually having all of the criteria for PANS or PANDAS was one in 11,000 approximately. And I would say on the clinical side, when we speak with our partners at Stanford and we talk to our partners in Arizona and in Wisconsin, we would very much say on the clinical side, the incidence is much higher than one in 11,000.

Susan Manfull:

[33:34](#)

So I thought that that paper did an excellent job identifying what the limitations of the study were, most of which you've already identified. But ironically, those are some of the same challenges that we have in this community. And about how do you educate physicians and anybody else who may be making these diagnoses, how do you teach them which questions to ask to get at that information and more generally speaking, just make them aware of PANDAS and PANS, which is still an ongoing issue. Yeah. Can you dive into some of the details that emerged in Dr. Walt's study with her team, including you?

Dr. Juliette Ma...:

[34:22](#)

Yeah. So that was a study at three different centers in Wisconsin and Dartmouth and in Arkansas. And we found in the absolutely confirmed cases, looking back in time that the mean age of onset

of these symptoms was six years old. So it was a very young group that were identified in these three centers. In fact, the center in Arkansas had zero cases. So we were really interested in maybe some geographic variability and whether or not that's actually true biologically or if that's something that is more related to education and sort of dissemination of information about this particular condition, a little more than half of those patients were male, and most of them had commercial health insurance, which speaks to some of the questions about socioeconomic disparities in terms of understanding and accessing subspecialty care when we're looking prospectively at the next study that we'll be doing. That is the next step of the work that we're describing right now. We had almost half of them had a definitive relationship with group A strep. So almost half of the cases that were identified retrospectively had documented strep infection, either with throat culture or with blood work.

- Susan Manfull: [35:36](#) Were you able to see what diagnoses, if any, those children had at the University of Arkansas? Were they the diagnoses that are typically given to individuals in which pandas and pans are not recognized? For example, a conduct disorder or just a basic anxiety disorder in those children?
- Dr. Juliette Ma...: [36:01](#) No, sorry, I don't have that information.
- Susan Manfull: [36:05](#) Okay. It is curious though.
- Dr. Juliette Ma...: [36:08](#) Yeah.
- Susan Manfull: [36:09](#) Yeah. Okay. That didn't seem right.
- Dr. Juliette Ma...: [36:12](#) Yeah, but there was a big difference between Wisconsin and Dartmouth in terms of the incidents.
- Susan Manfull: [36:21](#) So the years for which you collected that data were 2017 to 2019. I wonder how different that may be now having gone through covid, and I think there is a much greater awareness on the part of physicians. It's not a hundred percent by any means, but if we were to do that now, do you think find greater numbers of those diagnosed with pandas and pans or those that you could recognize as having the symptoms of pans and pandas?
- Dr. Juliette Ma...: [36:55](#) A hundred percent. I think the numbers would be higher, definitely at Dartmouth. And I think part of it is the covid paradigm shift in understanding the relationship between infection and neuropsychiatric conditions and also the education piece. So where there are centers that are robust in doing education and patient care evaluation, those patients are

diagnosed with PANDAS in our clinic and they go back to their primary care doctor who says, oh, that's what that is, and understands now the symptom profile that they might identify or recognize the next time that patient comes through. And we see that trend every day that our primary care partners who are really important partners in clinical care are then sending us more patients for evaluation for the possibility of pans when they've recently had strep or another infection or just an abrupt onset of change and symptoms that might meet the criteria.

[37:49](#)

And certainly we're shifting gears now with that initial study that we published. Dr. Wald and I have been really excited to move forward with a prospective study. So the findings from that retrospective study really were, it's really hard to do this backwards in time because of the limitations I just described. And so we are so excited to have funding to do this study prospectively. And so we'll be doing a two center study now using the same really important high level data analysis where we pull data every day from our primary care clinics to identify any children and adolescents who come into primary care for any anxiety disorders, specifically OCD and eating restriction or ticks. And those kids will have the opportunity to have evaluation in the Immune Psychiatric Disorders clinic at both institutions. They'll have strep evaluation and very robust strep typing for species specific and strain specific differences in strep if it's present.

[38:56](#)

And then doing clear diagnostic analysis using validated surveys and psychiatric and neurologic evaluation and rheumatologic evaluation if it's indicated, and then follow those patients over a year. And so we'll be looking at early capture of disease onset, what does it look like? We'll understand what the denominator is of that group. So of the children who come to primary care with a new onset psychiatric condition, what is the number of that group that actually has a neuropsychiatric condition like pans or pandas? And then what is the larger end? So the larger denominator is sort of all comers to primary care. So we'll get a sense of coming up with a number of an incidence in that timeframe for the study, and we'll be following sort of the natural history of the condition with standard protocol based treatments over that timeframe. So we're really excited to be able to do that in collaboration with Dr. Wald.

Susan Manfull: [39:55](#)

So the longitudinal part of that is particularly exciting.

Dr. Juliette Ma...: [39:59](#)

Yeah, I'm really excited.

Susan Manfull: [40:00](#)

So in order to make this successful, I assume that there will be a great effort to educate the primary care physicians?

- Dr. Juliette Ma...: [40:12](#) Yes, and we're really excited to partner with Dr. Tanski who's in charge of our academic pediatric group on the outpatient side. And she's a very important investigator in her own right on the epi side in preventative health. And so Dr. Tanski is going to be working on the study with us, and we'll be doing education for all of our primary care teams to talk about what are we looking for and please refer your patients. And so that in and of itself, I think will be increased in the number of children who have evaluation and proper treatment if it's indicated. Really excited.
- Susan Manfull: [40:47](#) That is very exciting. And the age range of the children that you will be working with?
- Dr. Juliette Ma...: [40:55](#) This group is going to be up to the age of 17, so three to 17.
- Susan Manfull: [41:00](#) I see. So that may change the age of onset. I think you had, was it six, age six in the earlier study? So we might expect that that may change. Okay. Well, this is very exciting. And when are you starting this?
- Dr. Juliette Ma...: [41:22](#) We've already started all the planning. It takes a lot of work to get it up and running. So we're meeting every week with the Wisconsin team, which has been really rewarding and exciting. So we're already in the planning stage, and we'll be starting it very soon, probably right after the holidays.
- Susan Manfull: [41:39](#) Wow. Well, anything else you want to add about the upcoming study?
- Dr. Juliette Ma...: [41:45](#) Nope, I'm excited. I think we'll probably have some results within about 18 months, I would imagine.
- Susan Manfull: [41:51](#) Oh, great. Yeah, that's great. So just to wrap up here, do you think it would make a difference if there was a category for immune psychiatric disorders or maybe a more specific one for pans in the diagnostic and statistical manual?
- Dr. Juliette Ma...: [42:12](#) I do. I think it's important to have clarity and to have diagnostic categories. I think that allows our trainees and all of our practitioners to understand that this is another condition that requires specific type of evaluation and treatment, that it's different. I think OCD is something that we see often in our clinic under the auspices of immune psychiatric conditions, and it's a good example of conditions that we need to better understand the underpinnings. My hope is that as we work towards including more of these immune psychiatric conditions as more clear examples of what we're talking about when we're talking about the interplay between infection and the immune system and autoimmunity and neuropsychiatric outcomes, that

our whole field is going to be able to provide more comprehensive care to all of our patients.

Susan Manfull: [43:13](#) What is your vision for the future as far as diagnosing these individuals and getting appropriate treatment?

Dr. Juliette Ma...: [43:22](#) Yeah, I feel very strongly that we've been so privileged at Dartmouth to have the opportunity to have these conversations across multiple disciplines and multiple areas of focus. Our administration has been extremely supportive beyond my wildest dreams, and to have your support, Susan and your foundation, it's really just been such a privilege, to be honest, to be able to have these conversations and even to be asked the question of what is our vision about how best to serve this population? I feel like we are on the cutting edge of something that is so incredibly important to be able to ask the question in a really different way. And so instead of saying, this is a neurologic condition has been rolled out, therefore I need this patient to go and see a psychiatrist. I have really hope and dreams and practically speaking, we're living this every day in our clinic that we start very differently, start the conversation that we start the conversation with, assuming that every patient that we see who has change in their brain and behavior, has an underlying organic etiology for their presentation and that workup that we do currently is incomplete and that we need new research.

[44:43](#) We need epidemiologic research. We need translational and basic science research, and we need to partner with all of our physicians who are working in this space to really do the best job that we can as quickly as we can to clarify what is that signal that helps us understand that this person has an underlying immune component to the changes in their behavior because the treatments are different. And to be able to offer patients life-changing effective treatment that changes their life trajectory is beyond my wildest dreams. And that is where we're trying to be in this interdisciplinary space.

Susan Manfull: [45:26](#) And you're clearly moving forward. You're doing amazing things here at Dartmouth, and in particular at the Immune Psychiatric Disorder Program. I commend you and your co-founder, Richard Morse, and everybody else who is part of your team, just really incredibly exciting work that you're doing, and I think it will change the landscape of medicine. Thank you very much for chatting with me today, Dr. Madan. It was incredibly interesting, and I look forward to talking to you again about your microbiome work.

Dr. Juliette Ma...: [46:06](#) Thank you so much.

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William Manfull: [46:07](#) This concludes episode 10 of untangling pandas and pans. Thank you for listening. For more information about pandas and pans and the Alex Manfull Fund, please visit the alexmanfullfund.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.