P5P - Nancy O'Hara #3 - 09.17.17.mp3

Welcome to the next episode of P5 Protocols with Dr. Nancy O'Hara, who fortunately is based in Wilton, Connecticut, right near my home. She is a traditionally trained pediatric doctor who is also the child of two doctors; but her approach is anything but traditional. She started her career as a teacher before attending The University of Pennsylvania Medical School. Of note, she currently is treating two of my sons who have chronic Lyme. As I recently started in the last few transcripts, I ***bold and italicize background information*** and I **bold and underline treatment related information**. Dr. O'Hara was so clear thinking and methodical that most of the transcript is marked up. In other words, for those who are listening, this is a very dense interview. The focus is on pediatric neurological disorders from ADHD to Lyme Disease symptoms to Autism. I do not think you will find a more scientifically, evidence-based doctor in the world. And, as those who are listening to this and past podcasts will notice a common theme as Dr. O'Hara pivoted from the pure traditional medical world to looking for every edge she could get to help her patients. Her mentors are some of the best medical doctors and researchers in the world, but she has long reached an age and stage where she is materially contributing and perhaps teaching her mentors a few things. Ever curious, I think you will enjoy listening to Dr. O'Hara lay out an approach and framework for treating children with various neurological disorders. Remember that at the end of this transcript are links to resources. It is long… So let's get started

[00:00:01] [DE] So I am sitting here for the next edition of P5 protocols with Dr. Nancy O'Hara from the Center of Integrative Health in Wilton Connecticut. I first met Dr. O'Hara back early mid-winter when the first of my two boys who had had some health issues that had gone undiagnosed for very long periods of time, and she was the first one to figure it out. Now granted we had spent several years on a wait list because she is popular and we've found since for a good reason. But I will let Dr. O'Hara in one second, talk about her areas of specialty and background but we are here because to our knowledge, my boys both wound up with Lyme disease and she was the first one to figure it out, and give us a treatment protocol which we're still in the middle of and it's a long-term thing, but seems to be working quite well. it was time especially in the state of Connecticut to be after things like Lyme and other disorders that seemed to be very prevalent in this area. So with that Dr. O'hara I want to thank you for taking the time for being here.

[00:01:20] [NO] Thanks for inviting me.

[00:01:22] [DE] And Fred is lying here on the floor hopefully if we hear anyone barking. Fred is an awesome dog that is always here and always calm and with Fred asleep - we are not going to give him a mike - But I would love it if you would give me your background. We share the same Alma Mater although I did not go to med school but if you could kind of go back and give your background and be good.

[00:01:48] Sure. I first come from a very traditional medical family. Both of my parents are family practitioners. I went to undergrad at Bryn Mawr, and then went on to medical school at University of Pennsylvania, and got a master's in public health at University of Pittsburgh. I started my career before medical school as a teacher of children with autism. And I realized I was a lousy teacher. So that's why I took the easier road and went to medical school, and I mean that honestly for all the teachers out there. And but in my private practice after a fellowship in General Pediatrics I had a lot of children with autism and as such I was seeing a lot of families in a lot of distress. Had one little boy in particular that just struck me. ***He was a little boy at age 4, who had no speech, was autistic but also had a tremendous amount of allergies, asthma, eczema and was on that typical toddler white diet. And I had tried for a couple of years to get his mom to get him on a healthier diet really for his asthma and allergies but she couldn't choose a full time working mom really couldn't do it. This particular time when he was four they went away on vacation and he got a viral illness. Called our office. The nurse said "take him off all dairy because it's making the diarrhea worse". She took him off dairy and he started talking. She***

called me and she said I'm spending time with him I've taken time off of work.

[00:03:26] I'm working with him full time and he started talking and I said keep doing what you're doing. No question. ***Came back, put him back on milk because he got over his illness. He stopped talking. She called me. I said well it's the flight it's the transition it's the this and that that we always said. Thankfully she didn't believe me and she took him off milk again. He started talking. She did this cycle three or four times and then found Sid Baker, who is my mentor, and she came back to me and she said you got look at this. And I thought diet affecting autism, this is crazy. There's no way. But at the time I was going through five years of infertility and had been very disillusioned by what the medical community still had to offer me. So I thought well I'll go to sit as a patient. And that changed my life. And so I went from being a typical pediatrician partner in a very thriving practice to starting my own integrative practice about 20 years ago.***

[00:04:32] [DE] And so, and you went to Penn medicine.

[00:04:34] [NO] Correct.

[00:04:35] [DE] And so and then you got your masters.

[00:04:38] [NO] Correct, during residency, chief residency and fellowship.

[00:04:43] [DE] Wow OK. And then you go to Sid as a patient and that's a little over 20 years ago. Yeah. And then what. What did he do either for you or what did you just kind of the parameters because I know you're so close to him, because that's how I went back to him after 20 years ago thinking he was out of practice.

[00:05:02] [NO] Sid and I are very close and it's nice that I can teach him a few things these days not just the reverse. **Sid did what I do now with patients, which was look at all of me and look at the things that I needed to get more of that I wasn't getting and looked at the things I needed to get rid of that I had too much of.** So one was I had too much yeast, I was overloaded with yeast and needed to get rid of that. I also wasn't getting the amount of minerals partly because I was pretty constipated. Didn't realize that going a couple of times a week wasn't good enough. And so he helped me to **detoxify in several different ways, treated my yeast. I also did a couple of what some people might call alt therapies or alternative therapies, like cranio sacral and acupuncture. And within a few months of doing all of that, I was pregnant for the first time.**

[00:06:06] [DE] I love that. I actually saw a woman years ago, Mind-Body, back in 97. Actually I was told about that person by someone I met [00:06:17] at Jeff's Bland's conference, which that year was in Aspen in 97. And because I had gut problems and she said oh you know you have to meet Niravi Payne. Niravi was this phenomenal therapist, her specialty was fertility. And she had several books out. She just passed away a few years ago. She was well in her 80s but, Kenny Loggins, I think he dedicated a CD to her, the original one which we used for our kids. But you know it's there's, there's that mind-body stress thing. And then there's all that [***physical***.]

Can you can talk about the different, maybe talk about **your protocols, and how you treat patients**. And you know we came in, we filled out a **very extended questionnaire**. We went over, **had blood work** and other things done and maybe talk about maybe we'll about the spectrum of from - I use that term loosely - on from autism to everything else that you see in your practice and you specialize them.

[00:07:27] Well first of all **I started my practice with children with neuro developmental problems autism and other neuro developmental issues. And I think those children are**

canaries. I grew up in West Virginia and we used to send canaries into the coal mines. And if the Canaries died that meant the mine was too toxic.

[00:07:47] So I think our children with autism are those canaries. **We were all exposed to all of these problems. But those children are the beacon that show us which way we all need to go in looking at our innards, so to speak. So one of the things Sid taught me was if you listen they will come and I think that is something that is often lost in medicine. We don't listen. Our greatest teachers are our patients and if we just listen we would learn a tremendous amount. The other piece of that is the the root derivation of doctor is teacher.** So I think it has to go the other way. That our role as doctors is to be teachers. **So much of what doctors in general do is that prescription pad medicine and do this because I tell you to because I know best**. If we would spend more time teaching. This is why, this is how, this is what may help you or your child. I think there might be not only a much better relationship but also a much better understanding of some of the good and bad that may come from the treatment. So why I have a **30 page questionnaire? Is it helps me to get a flavor before I walk in the room of what a child may be going through, and my practice is entirely pediatric based.** I'm a pediatrician by training so I don't see adults mainly because I don't like them - but that's OK - So I have the parent or parents fill out this questionnaire to give me a sense.

[00:09:34] But it also gives them a sense of things that they may not have thought about. **There are several pages of just signs and symptoms. You know when my child has autism, why am I thinking about how they're pooping, or why am I thinking about whether they have hot or cold intolerance, or how they're sleeping, or where or you know what relaxes them more or works them up or whatever.**

[00:09:57] But all of that helps them to see **those things as part of the whole package**. And then I **can take that information together with a physical exam that I do that day and some very tailored laboratory testing to sort of come up with a differential diagnosis.** Now no matter what the child comes in with and you ask what are the children I see. ***Well, in addition to autism and neuro developmental problems, I see children with PANS and PANDAS which is pediatric autoimmune neuropsychiatric disorder associated with strep.*** And then in 2012 [00:10:39] Sue Suido and all, coined the term PANS, which is Pediatric Acute Onset Neuropsychiatric Syndrome. So and then, children with Lyme certainly and other tick borne illnesses and then children with other neuro developmental problems because as I said, autism are those canaries there at one end of the spectrum. But in that spectrum is also all the kids with ADHD and learning differences and sensory processing or auditory processing. And also children with mental health problems, anxiety, depression, OCD and they're all on that same spectrum where **we have to look at what's going on particularly in their immune systems. Is there inflammation? Is there auto immune disease where the immune system is attacking self? Is there immune deficiency where things are depleted or is it the whole spectrum and it's just disregulated. We have to look at their metabolic systems. You know, are there mitochondria, the energy cells of the body, working the way they should. Are there detoxification systems working the way they should. We have to look at their gastrointestinal systems.**

[00:11:55] I mean you know we **talk about the gut as the second brain. I actually think it's the first brain and everything begins and ends there. So we have to look at how all of those systems may be impacting the child and ending that child up with that label, because that's all autism and learning differences and all that is, it's a label for the symptoms they have, given what may be going on internally.**

[00:12:23] [DE] Is that certain diagnoses or clinical diagnoses? And there, this looks like this, because of these symptoms. But you know what I wrote was, before seeing a new doctor, say do

this typically they do this because I know best and really when you when I first had this when I was diagnosed with colitis and I kept pushing this doctor, I said I think it's a bacterial infection. This is in 87. And and he said: "how do you know? And I said well because I have high school biology and common sense. And he said, well, I don't have any proof. And I went "ah". And so it really is, it's not that I know best, it's that I don't know any better.

[00:13:14] And that's why, in my in my search for meeting with people like yourself and really more for my children or for anyone else that I care about and being able to refer, is that you know, I don't know about a doctor but I know as a patient I want to get every edge I can get. And that's what that that's serious.

[00:13:36] So what I would like is maybe into **go into a little more details. You know you listed all the things that you look at but, in terms of creating a little more of a linear path, so people understand that these things don't happen overnight**. You know putting aside a couple of years it takes to get an appointment, someone comes in, you have them fill out a questioning before the first appointment, they send it in, then you review it. You come in, you meet with them and do you typically have bloodwork ordered ahead of time or OK. Saw you meet with them, you together digest what they filled out, and you then order the blood work, and then I actually remember that we were waiting for the results. So you get the results and then you come in, and you come up with the first course of treatment.

[00:14:36] [ON] Well let me step back one moment because, **a group of doctors that I work with, we often get together and have think tanks.** That's where we think during the day and get tanked at night. You know, **it's actually a group of clinicians and researchers that get together to try to figure out what are the best ways to treat our most severely affected kids and many years ago, one of the doctors asked "What are your most important biomarkers" and what he was asking was "what are the most important lab tests that you think are important to get on a child with autism" and my top 10 are history and physical exam. I use lab tests to prove or sometimes disprove because I'm not always right. But to prove what I think is happening from the history and physical exam. And so yes, I don't get the testing before a patient comes in because these are children I'm seeing and to have them do a blood test, and then do a blood test again, can often be, not only daunting and anxiety provoking but very difficult, with little veins and little arms and all of that kind of stuff. And also many of my children have tremendous anxiety over something like that. So I want to make sure we're getting exactly the right tests for that child because it's not a protocol of tests that I get on every child. There are some I'll get on everybody but it's very set up by and decided by the history and physical exam. So, that by far is the most important part. Then even before I get the test results back, which often can take four to six weeks, we will start at least four or five different things in that first month, that just based on history and physical exam, I think are the biggest hits. And why I do that, why that's important, is because, I do have a lot of families that come here and are very skeptical, either because they've seen 15 other practitioners first and nothing's worked, or because they're new to integrative medicine and they are looking at it with a very scant eye, or because they are afraid of trying something different than what their pediatrician or their parents are saying is the right thing to do, or because there's a difference of opinion between the parents. So I try to find at least that one thing if not three or four things that will make the most and the quickest difference for that child and do that before I even have any test results.**

[00:17:21] [DE] And curious, in most cases, are there 3 or 4, of the 4 or 5 things, that are common almost every time.

[00:17:30] ***If a child hasn't tried dietary changes, changing and removing something that they eat a lot of or crave, is usually the biggest hit. The first child I saw in this practice, was a child that joined me from my previous pediatric practice and he was a young boy with***

ADHD. And we were about to put him on a stimulant medication for his symptoms. And they join me in the practice and I finally took a diet history and although he had a very good diet he was eating at least nine bananas a day. And the parents thought they were doing great. You know it's a fruit. It's not. What's wrong with bananas. And I said take out the bananas, just take out the bananas 100 percent for the next two weeks and let me know. And they came back two weeks later and the teachers were raving about whatever medication I had chosen to use because his ADHD symptoms were so much better. He was so much a clear thinker, he was so much more organized. And all we had done was remove bananas. So kids crave that which they're most sensitive to.

Or if I kind [of would] like in the example of the first child I gave when I met Sid, you know he was eating a ton of milk, in all different forms. Milk ice cream, yogurt, cheese and so just removing that, made the biggest difference for him. So that's number one. Number two, **if a child comes in with OCD, anxiety, severe self-injurious behaviors, aggression, influencing the glutathione pathway is one of the most important things and glutathione is a molecule within all of our bodies. That you'll hear a lot about in the next 10 years, with regard to cardiovascular disease, cancer but it's also true in all of us. It's that which we all need to detoxify our system. So in it's good form, glutathione sticks to and gets out of the system the toxins, the chemicals, the allergens, the germs even that we may have too much of**. What Jill James, Dick Deith and others in research found, is that **our children with autism have a 71-72 percent decrease in good glutathione and instead have oxidized or bad gluthatione***.* So they are, I'm just playing the percentages. So especially in those children - ***children with autism or PANS or PANDAS, that have anxiety, trichotillomania, which is pulling their hair out, OCD, etc.*** Then I'll try something like **N-Acetyl-Cysteine (NAC) that [2.3] raises gluthatione** and that can be a big hitter. So those two things. **Third would be in a child that comes in without language or without much language. I will often try methyl B-12, because in research again and in our practice about 60 percent of children will improve their communication, at least nonverbally if not verbally, just with methyl B-12.** So I feel very confident, you know, given a set of symptoms, given a history, in using one of those things and getting a good hit and then I know I got him so to speak, to be able to say OK, now we're going to do something more difficult.

[00:21:06] **In addition to removing milk, now we're going to remove all the gluten, or now we're going to go on a yeast free diet, or now we're going to add this medication or whatever it may be**.

[00:21:16] [DE] OK, so maybe, to me, this is a, you know, it's a path like anything that's not a straight line. Correct. How. Of your. **How impactful are parents in the equation**?

[00:21:35] [NO] I often say that **I am the co-captain of their ship. Because they are on the frontlines**, they are dealing with whatever it is every day and for me to come in and assume that I can take over is just wrong, because without them instituting whatever I'm recommending, it won't happen. So, **one of the ways it's very impactful is especially if the parents are on the same page**. And that's one of the reasons **I strongly recommend and almost require that both parents are here**, at the first visit, because I think I have been able at least 75 percent of the time, if not 90 percent of the time, to get the foot dragging parent into the conversation and getting them on board initially. And that's very, very important because, and in fact we now have a preliminary questionnaire that **one of the main things we're looking for is how much resistance will you get at home to changing diet, to adding supplements, to making lifestyle changes. And if they have a lot of resistance. You know, I say, I may not be the right person for you, because I don't want them as I often say, to take out a second mortgage on me, and then them not to be able to even institute what I recommend,** because somebody else at home - their primary caregiver for instance - if mom works - you know that's there won't do it. They need to work on those things before I can make a difference.

[00:23:18] [DE] And and so start with someone, let's start simpler so, and maybe this is totally different but you know, Lyme, ADHD, lower colon in the broader spectrum of illnesses. What is the length of process? You know how often do people check in or do you think is optimal? Not them checking in because some people would check in every week if they could but, you know what do you think the time needed and the check-ins and alterations. What does that process look like and how how long is it, you know what's that range of time and maybe a broad range but what is that range of time until you think you may.

[00:24:00] [NO] So **the initial consultation usually takes at least two hours and up to four hours, depending on the complexity of the child and of the family. Then the next visit is usually four to six weeks later. And that's partly because getting test results is partly a chance to get them started on a few things**. Read about a few things I may recommend etc. then the next visit after that. I use the first two visits to decide whether it's six weeks later or three months later but usually no sooner than that and definitely no longer than that. And then I think after that it really depends on how things are going. How many things a family can assimilate. How many problems I think they'll have as to how frequently. So once a month to once every three months is is the range. And you know if a child's having a lot of problems in those first couple of visits they have, what we call **herxheimer reactions or die-off reactions where they have an initial negative reaction to the treatment I'm using for Lyme, or yeast, or some other type of infection, then I may have to have more frequent appointments to walk them through that**, because otherwise, and I say this to people all the time, **don't give up if there's a negative, email me and that e-mail conversation maybe once a week, once every other week, especially initially**. And I think that's **very important to be available because especially with doing integrative interventions**.

[00:25:46] **Many of our traditional colleagues will not understand it and there's a great quote, that I will butcher now, but it's you know "if we don't understand something, if we don't appreciate it, we'll poo-poo it and pretend like it doesn't exist".**

[00:26:02] And so part of what I need to do is **help the parents to understand OK your child negative reaction, that worsening of the anxiety, is actually a good thing**. That's that bad good or good bad. However you want to phrase it, that that means that we're on the right track.

[00:26:21] [DE] That diagnostic and the treatment is part of the diagnosis. Right.

[00:26:25] [NO] That's our N of one. Yes. That clinical trial that helps us to know. But a lot of parents, when they get a negative reaction, they just want to stop whatever it is, and get rid of that negative. And if they did that and they're not seeing you again for three months, you've lost three months of care. So I first have to **explain how negative reactions are a good diagnostic tool**. And we may need to step back but we need to proceed with that path. To help your child to get better.

[00:27:03] [DE] And on, so let's kind of jump over to the more serious cases, kids in the spectrum all the way from low to high in the spectrum of autism. What is the length of that process? I mean I'm sure it varies tremendously. I mean like I said to people before I have a friend who had M.S. and went off gluten and the M.S. was gone and there are other people who go off gluten with M.S. and it doesn't have any impact whatsoever. So everyone's different. So what is that range and how do you analyze and approach, and how long can that take, so people, sometimes it's just a long process. I'm just curious because I know you've had a lot of success so.

[00:27:49] [NO] Right. I think **the minimum is three months, the maximum can be many years and it's dependent upon how many different pathways and systems are involved in the disease. So if I see a history and a physical exam in some initial lab testing that has one abnormality such as a gluten sensitivity, or a milk sensitivity in that first example, that child**

can be better almost instantaneously. I mean three months to get all the antibodies out of the system etc.. But if that child also has yeast overgrowth, and mineral deficiencies, and thyroid dysfunctionm and mitochondrial dysfunction, then, the more systems that are affected, the longer it will take to improve all of those different areas. And then it's sometimes especially in children that I see at older ages, who have had problems for many many years, or who have multiple problems, with one abnormality in detoxification on top of another, one abnormality in the gut on top of another, then it may take several years to get to the bottom of it, and really help them to be better.

[00:29:12] [DE] And on, so on yeast, which I know keeps coming up everywhere now it seems to be. I know when I was at Penn last year that's the hottest area of research over there.

[00:29:25] [NO] They didn't believe in it when I was there but.

[00:29:27] [DE] This was the head of IBD at [00:29:30] ... [0.2] who said now, for all auto immune they're all following the same path. Can you talk a little bit about that incidence, and how often you're seeing it in your practice, and how the two steps of treating it which I think you know one less invasive, one more drug oriented.

[00:29:46] [NO] So I think that you know I sort of have a bent toward yeast because you know, my mentor, Sid Baker, was taught by Dr. Crooke, and Dr. Leo Galland, and Dr. Jeffrey Bland and so I have always looked for it. **And so when you're looking for it you may find it a little bit more than if you don't really believe in it. So I would say at least 60 percent of the children that come in here have some problem with yeast. And I can see that by their behavior.** I often say to families any behavior that you see a drunk do, may be a yeasty behavior. **So you can have belligerent drunks. You can have brain fog drunks.** You can have silly inappropriate drunks. Any of those can be a yeasty behavior. Then I look at their exam. You know it was also in their history: **have they had thrush out of the infant period. Have they had ringworm. Have they had yeast diaper rash. Out of the diaper wearing period of time. Have they had a lot of athlete's foot.** You know so I get that in the history and then on the physical exam looking for all of those. I'll do a woods lamp exam which is an exam with a special light that can show up yeast on the skin and in all of those I may find it.

[00:31:13] **YEAST**: And then I will look for it in testing. Now one thing about yeast is and why I think many traditional doctors don't believe in it or believe in finding it, is we tend to look for germs in a culture like a stool culture. **Well often yeast can't be found that way, for two reasons. One sometimes it's an abnormal way that you're reacting to a normal level of yeast. So you just can't process the normal levels of yeast we all have in our systems. And the second is, yeast especially if it's there for a long time, our bodies want to sequester it. So it may well be in a biofilm matrix, sort of hidden away in a mucous layer. So, hard to find on culture and also hard to treat. So I often will use a urine test looking at the metabolites of yeast like arabinitol to see if there is yeast overgrowth. And I again won't use one of those but look at if they have one of any of those then yeast is present. So history physical exam or that kind of lab test and then I'll treat it depending on the severity and how quickly a family might need or want to get that yeast treated. And that child's ability to handle that quicker fix. So Diflucan [or an antifungal medication if I am sure it is yeast and I want to see that quick and of one clinical trial I will use a medication like a systemic antifungal to treat that child and have a long discussion about that die off, that negative before the positive. And often I will see that in that child, then I will move from that to what I call a biofilm protocol which is using a combination of enzymes and usually herbal remedies to continue to treat and kill that yeast because I often use the analogy of yeast and other germs in the gut being the enemy army.**

[00:33:29] And so initially we may have to bring in our heavy artillery to sort of deplete the enemy

troops but we can't just do that and then leave. We have to follow that up with some sentries that are out there and continuing to treat. And that's the herbs. But the third piece of that and what a lot of families have trouble with especially in today's **SAD diet, the standard American diet is feeding the yeast. So if we're trying to kill the enemy and yet we're sending in you know food to them all the time, they're going to be a lot harder to kill. We have to stop feeding the enemy. So we have to take out the complex carbohydrates, the sugars, the deserts, the grandma treats in order to really kill that. And the more a family is willing to get on board and do all three of those facets, the faster we can get rid of it**.

[00:34:34] [DE] How, you know it's funny because before we started recording I was saying my voice has been raspy, and as the last year and a half I've been infinitely lower carb. I still cycle because I don't want to wind up in that there's not enough carbs to feed the good bacteria and I'd love to starve the bad bacteria. Any sense of how to talk about striking that balance?

[00:34:59] [NO] I think **in children especially they need to have some carbohydrates for growth. And I think if we remove them 100 percent for longer than nine months, we're doing them a huge disservice. And even in the short term, there has to be some amount of carbohydrates from some vegetables and a modicum of fruits if other complex carbs grains etc. are taken out. So I usually cycle where I'm very strict for about three months. Little bit less strict for the next six months. And as long as I am killing the germs otherwise with either anti-microbial prescriptive agents or herbal agents, then I will allow some amount of grains in, in a cycling way, meaning that I'm also very conscious of when they're eating their proteins, when they're eating their oils and all other foods that they may have develop sensitivities to, you know, whether it be lectins or salicylates or phenols or etc. because of the disruption the gut has gone through**. **In many of these sensitivities our kids have, are because of the underlying inflammation from the germs or from an inflammatory condition with the gut, that once that's taken care of they won't have those other sensitivities in the future**.

[00:36:38] [DE] Do you break down kids in the **high histamine, low histamine**? Is that part of the way you look at it as well?

[00:36:43] [NO] I do look at that. Absolutely. **I think most of the kids initially, almost all of the kids I see, have some amount of inflammation. And so most of them will have sensitivities to that. I look at it more later, when I've gotten the bulk of their inflammation better. And yet they're still having problems then I will focus in on it**. Let's look at the high versus low histamine, let's look at the high versus low oxalates, those sort of things later, if they're not showing significant symptoms of that early on.

[00:37:22] [DE] And you mention lectins before, because that's become a big thing for me, and I had cycled pretty much off them since February of 16 and then this past winter I was running a lot in the winter and all of a sudden my ankles started bothering me. But it was never swollen. I was never hurt and I was cheating a lot. Little things. Few French fries here. They're little but small quantities but little things. And I found myself with food sensitivities again I don't know how much of is just low carb or how maybe if I just took lectins out all the time that I then became more sensitive when I reintroduced them. And you know I'd love to understand that because I think that pattern I'm seeing with other people I know, and maybe just talk a little bit about how you recognize those patterns.

[00:38:09] [NO] Right. Well first of all one of the things that's very important to me whenever a child or family comes back for their follow up is we ask them for an update and we're asking them for an **update on their symptoms but also an update on their sleep, their stools, and their diet.** And so **I need to know what changes**. Oh ***we're not quite 100 percent on what you told us to be. We've added this back in and then they've also told me that the child's***

complaining of ankle pain every day. And the pediatrician says it's just growing pains. But I look at it and they've added legumes back in, that they thought were OK. Well OK, those two symptoms may well go together. Let's take those out again. E-mail me in two weeks and let me know if that symptoms gotten better and that's how I know I'm not going to do another food allergy profile or look at any other testing. We're just going to look at whether those symptoms get better with the change in diet or if they got worse because you changed it the other way. And that can be lectins certainly. Especially in our children that are on specific carbohydrates diets or our children on GAPS diet, the GAPS is Gut And Psychology Syndrome Diet, very similar diets, very few of my kids are on the body ecology diet. It's just very hard to do in children. But if they're on any of those diets they may be overdoing it with other foods that may be causing a new problem.

[00:39:47] So for instance ***oxalate, which are very high in almonds***, a lot of the specific carbohydrate diet is not based. So you're making carbohydrates out of not flour and you're having almond milk rather than your regular milk. Well ***you may now develop problems with oxalate***. So it's it is something that we have to tweak and that's why having frequent reinforcement, working with dieticians as I do, I have a wonderful dietitian here in the office who helps me look at the details that I may miss. One little caveat. I give you. How we met. I had a young boy who I was sure the gluten free diet was going to make a difference for him. Absolutely 100 percent positive. And the family was 100 percent with it for three months and not a change in behavior whatsoever. And you know I was still a little bit new into the integrative world and a little bit more in my traditional hat of "I've got to be right". And so I asked Vicki to look at the diet - the dietician I work with - and ***it was the gum that was being used as a reinforcer in OT that had gluten in it that was making the difference. And once we took that gum out, within a week it was a new kid.*** And so being that detail oriented and looking at the diet and knowing exactly what a child is taking can be really important to be able to make that difference.

[00:41:29] [DE] So a little selfishly **on Lyme**, I'm just you know I mean you can I guess you'd probably be retracing some of what we've done but what is your approach to that because that just seems to be everywhere.

[00:41:46] [NO] Well I'm not of the camp that Lyme causes autism or autism is Lyme. I think there are overlapping circles sort of in that Venn diagram. So there are some children that have both, the same with PANS and even PANDAS. You know Lyme can be a part of that. But whenever a child comes in with neurologic symptoms, whether it be anxiety, a tic disorder, OCD, or even in the severe end of the spectrum autism, then I look for something else in the history or the physical exam that makes me think of Lyme, besides just living in this area of the country where it's most prevalent. **So I will look at history of joint problems or sleep problems or rashes and not just the typical Lyme rash that bull's eye rash but stretch marks without changes in weight, or look for any of those other little symptoms**. And if I have anything else then I will follow that up with good testing. One of the things **I often do is culture for Lyme**. If a child has not been on any herbs or antibiotics in the previous six weeks, because often that will capture children that have otherwise been missed on typical testing. **I will usually as long as family finances allow, do some of the more specialty testing which are the gold standards for testing for Lyme. And if not, then I will do some of the more extended western blots from traditional labs where I may capture more of the bands of Lyme than in a typical minimal Western blot**. And I'll use my own take on that test not what the lab says as to whether I would diagnose the Lyme for for instance.

[00:43:58] An **IGM Western Blot, meaning a child has acute Lyme**. ***From a traditional lab, they have to have three bands for it to be called Lyme. If they have one or two of the most significant ones, I may well call it Lyme and treat it as such. Again, in my end of one looking what happens when I treat. Well that child that had absolutely no joint symptoms, now all of a sudden has joint symptoms when I started to treat. We're on the right track because***

that's part of that Herxheimer reaction, they'll get worse before they get better. To give you an example, ***I had a young woman, 17, come in and she had called me. I knew her prior to this and she had called me and said I have flu like symptoms. I'm just feeling really under the weather, it's not going away, I don't know what else is going on. I asked her all the other symptoms, she had nothing and say come in and see me. By the time she got here from the time she left home she had developed a rash that she hadn't had. So I didn't need to do any testing to start treating her. When I started treating her with one antibiotic, her symptoms were so severe she had to go to the hospital to get I.V. pain medicine to treat the pain, the joint and bone pain she was having just with 12 hours of antibiotics. That kid there was no question whatsoever that Lyme was the diagnosis.***

[00:45:34] ***We then went on to find that she had not only Lyme but she had several co-infections other tick borne diseases that can go along with the traditional borrelia burgdorferi. So that's probably why her symptoms were so severe because she ended up having six co-infections in addition to the Lyme. And you know with each thing we added She had another Herxheimer reaction, another worsening before she got better and still three months later, every time we add something because we have to add things slowly to let her get over the negative, she gets a negative before it turns positive. And that's probably one of the reasons this type of medicine doesn't work for everybody because you have to stick through the negatives to get to the positives. And some people don't have the wherewithal to do that. The guts to do it. And unfortunately some of us and maybe even sometimes me, but I tend to talk a lot so I end up getting it all in, don't reinforce to the families that these negatives can happen. And so when they do, they think "oh, that doctor didn't know what they were talking about because I got worse rather than better". And then you know that goes back to that doctor his teacher and that's part of what we have to teach as we treat.***

[00:47:20] [DE] And in the way you practice, you mentioned antibiotics but so do you typically use antibiotics only if you see a Lyme or similar infection at the beginning. And are they less effective over time or how do you see that?

[00:47:37] [NO] Correct. So **if I think it's an acute illness I will almost always use antibiotics because I know I can help them more quickly in that way and avoid the more chronic Lyme. Otherwise if it's already in it's chronic phase, usually the children have multiple germs, not just Lyme or even the Lyme co-infections but they also have yeast and viruses and other bacteria. And then I will usually use an herbal protocol because it will get more of the plethora of germs the child is dealing with. And also many of the herbals are very good anti-inflammatories. So where I can get multiple germs with one group of herbs rather than one germ with multiple antibiotics,** I'll do that. So it's a judgment call and it's also what I think the child will take. You know, my own son for instance, hopefully is not listening to this podcast, but ***my own son for instance who is away at school would not take 20 different herbs and liquids to boot. So he went on pills of antibiotics. And so you have to know where that family is too and where that child is as to what they can digest and what they can take.***

[00:49:18] [DE] I know, it's doing the herbal protocol in our house. It's, my boys are pretty good about it. But every once in a while it is a giant pain. And when one went off to camp and we sent him with the herbs and I had to walk in and hand to the nurse, they were fantastic. And they mixed all the things. But it's not, it can't be for everyone in terms, just logistically, purely logistically speaking. How do you see your practice evolving in terms of the test, the things you're seeing being presented to you and how do you see it evolving. Let's take a step back. How has it evolved the last 10 years and do you see it evolving faster based on the new tests coming? What are the new options or things that you're hearing about?

[00:50:18] [NO] Well I think first of all ***I'm always learning. Whether it be through the think***

tanks I mentioned, or the other groups that I'm involved with Medical Academy of Pediatrics Special Needs, the new pediatric arm of FIM, the Institute for Functional Medicine or even some of the parent groups like TACA. As I said I learn a lot from parents where ***my practice has evolved in the last 10 years is, it's gone from mainly just autism where 80 percent of my practice was autism to now probably only 30 percent is autism and the rest is other autoimmune neuro-developmental or chronic illnesses, whether it be Lyme patients, PANDAS, severe allergies, inflammatory bowel disease***. Because I think more and more people are looking outside of traditional medicine to help their children. And ***because of what I went through with my own son, I have developed a particular expertise in PANS and PANDAS***. And I think ***the research in that area is also helping my work in children with autism, because autism like those diseases like Lyme, are auto immune diseases, where the immune dysregulation is affecting the brain. And I think that's where the research is going, where we're learning more and more about how that immune system is really impacting our neurologic system. Probably how all mental and neurologic disorders are immune disorders and inflammation. And the more testing we can have to show that rather than just suppose, it will help us to reach more and more people, and help us to use not only medications and supplements, but also diet to treat that inflammation and bring it down and help these kids to get better.***

[00:52:41] [DE] So a little bit more on diet, because it's one thing to say get rid of the whites and the starches and control yeast but do you make recommendations on keeping organic in the house. Or you know because of pesticides etc. Can you talk a little bit about that?

[00:52:59] [NO] So I look at all of that and also have been part of a group called the ***Neurologic Health Foundation, which is about how to prevent neurodevelopmental diseases before mom even gets pregnant***. So we are there speaking very strongly about ***staying as organic as possible. At least the dirty dozen and the clean 15 and looking it at for instance ewg.org which is the Environmental Working Group***. And you can find this information there or the neurologic health foundation you can find this information there, **avoiding GMOs, avoiding pesticide laden foods especially those in the dirty dozen. And increasing your anti-inflammatory foods which is really a diet that increases natural proteins and good vegetables, highly colored vegetables and fruits as well as good oils. And I think that's something that we push a lot, you know particularly in our pregnant moms or soon to be pregnant moms, is really getting good oils in, oils that have a long shelf life or are very light so you're extra virgin organic olive oils, your macadamia nut oils, your coconut oils, being much better than some of your canola oils et cetera.** So **really educating the moms very early on in how to do that, and then getting them early breastfeeding because that's a big big promoter of good immunity vaginal deliveries. With the increase in C-sections and the decrease in breastfeeding we've seen a big increase in auto immune diseases and then getting them to start our kids on good first food. What's the typical first food for babies. Rice, rice cereal, we're starting kids on carbs. If instead their first food we're avocados and we were pushing vegetables and proteins in that first few months that we start foods our babies would be much healthier, than if we're doing carbs and fruits first**.

[00:55:26] [DE] No more applesauce to start..

[00:55:28] [NO] Right. Especially that with arsenic and a lot of applesauce and rice has arsenic in it.

[00:55:37] [DE] So I've probably, when I was macrobiotic probably had enough rice to last a lifetime.

[00:55:43] [NO] So take your selenium anyway.

[00:55:46] [DE] I do. And I take NAC and vitamin C and all the precursors to glutathione. So, what other protocol, what are the areas of how you practice. Is there anything that we haven't touched on that you think is important.

[00:56:03] [NO] **MITOCHONDRIA:** Well, we didn't really talk about the mitochondria much and that is a big one. You know when you talk about mitochondrial disease, that's very different from mitochondrial dysfunction. So ***mitochondrial disease probably only 4 to maybe 7 percent of children with autism have that but dysfunction, it's more like at least 70 percent maybe up to 80 some percent, and mitochondrial dysfunction***. I always liken it to an engine that's not working as well. So think about your car engine. It can either be sputtering and a lot of stops and starts or it can be revving and warranted at a stoplight. Either one of those can be mitochondrial dysfunction. ***So the mitochondria are the energy parts of each of our cell and it's in every cell of our of our bodies. So basically any problem can be a mitochondrial dysfunction. We think particularly of kids with constipation, with low tone, with speech delays, with regression after anesthesia, or an illness as mitochondrial dysfunction***. But that is something we look at with any of those things in the history or physical exam, we look at mitochondrial dysfunction. And that is something we're pretty quick to treat. And one of the interventions that I may add in that first month is something like **CoQ10 in a child that has mitochondrial dysfunction because CoQ10 in its very best form. And and let me back up a little bit. Brand is very important. They, not all supplements are created equal**. And to say go and get the over-the-counter CoQ1 versus the high quality CoQ10 that the mitochondrial disease doctors use is like night and day.

[00:58:00] So you, **it's better to invest in the high quality, may cost a little bit more money but it'll get you a lot more bang for your buck**. So anyway those are all things we do. And when you talk about how things are evolving. There's excellent research from [00:58:16] Bob Naviaux at UC San Diego looking at the metabolomics and the mitochondrial dysfunction of many of our kids. And one of the things that he talks about and has shown that many of our children particularly ***with autism have, is a persistent cell danger response*** and that's going back to that army. ***When you or I get exposed to a virus or a chemical, we put our cells, our mitochondria put out a cell danger response and that's where we set out cytokines and mitokines kinds those army sentries to fight that virus, or get rid of that chemical, and when that virus is treated or their chemical exposure goes away the centuries, the cytokines and mitokines retreat. But what he's shown through good research is that in children with autism, those cytokines are persistent.*** They don't retreat and these are persistent cell danger response. And so what does that mean. ***Well think again about the enemy example. If you always feel like you're at war and you're sentries are always out there. You're always in a state of hype heightened alert. So you get that hyper alert look that deer in the headlights look which many of our children with autism have. What else do you do if you're at war. Well you close down your borders, you close down your cell to cell communication, you socially withdraw, you have speech delays or dyspraxia or apraxia***.

[00:59:53] And ***in each of those symptoms of autism we see, can be well explained by a persistent cell danger response, and he's shown in mice models that antipurinergic therapy, a therapy that flips that switch and makes that turns off that persistence cell danger response, can also turn off the symptoms of autism. And this is in a mouse model that's 30 years equivalent to a 30 year old with autism. It's in a mouse model equivalent to a genetic example of autism and an environmental model of autism. So that is going to be a big game changer as the research in children changes and develops***. But **right now, we can look at those mitochondria, we can look at that dysfunction in our kids, and treat it effectively and make a big difference**.

[01:00:59] [DE] Is there a drug that does that, that's safe for human, that's considered safe for

humans?

[01:01:03] [No] Right now, we have some supplements that help, but the drug that Bob Naviaux is researching, and you can find all this information on our web site and certainly on his web site, is called Suriman, which is a drug in logarhythmically lower dosages, has been used to treat autism. But what it's used for in greater dosages is African sleeping sickness. So only about three to four thousand dosages a year. And he looked at 4000 different medications and herbs before he found this one that may well flip the switch. Now the studies in children is very preliminary. Five got, five Suriman got placebo, but the difference is both metabolically in the testing as well as in what those children showed, were drastically different. So the next phase of research will be coming soon and we'll know even more, and hopefully after that it will then become available to our children with mitochondrial dysfunction and autism.

[01:02:19] [DE] And is that then, and that drug is out there, has been out there a long time for other purposes.

[01:02:24] [NO] Right. But it's not available for a physician to write a prescription for now.

[01:02:30] [DE] OK. You know, it's amazing to me how many drugs were developed 30/50 years ago that are being repurposed. I would argue certainly as for in terms of return on investment, the amount of money we spend every year overall in drug development, there's been a very low return for decades.

[01:02:48] [NO] But it brings up another excellent point which is, ***we can use other diseases as models to how a drug, or an herb, or a supplement may help our children. So I do this with mitochondrial dysfunction. We use our mitochondrial disease. Children help us to know how to help other children not as affected on the spectrum but people with Alzheimer's have a lot of things in common with our children with autism, people with Parkinson's, people with M.S. and all other autoimmune diseases. So drugs that may have helped those people with those diseases may also well help our children in off label usage. And most of the drugs we use in autism are off label usages. You know the only ones that are that are on label use are anti-psychotics.***

[01:03:54] [DE] Couple of little things about in terms the way you practice them. And we talked about but I just want to kind of summarize it, is that you know, you may test and you may test in a lab or you may test your physical test but how often do you kind of shift and then I don't mean this change course. But based on the feedback based on what's happening, you think one thing's going to happen, there's a humility, I think comes with time, which you've already alluded to. But how often do you find yourself shifting based on feedback. I mean, it's pretty much, there's some change every time people check in. Or is it, how often do you say to people no [change needed,] we nailed it.

[01:04:38] [NO] **Yeah. It's a great question and there's almost always a shift and a learning and a evolving. Now some of that may be. Look I thought you had yeast over growth. You absolutely do. But now I found you also have clostridium overgrowth or you also have bad bacteria. So it's layers and many of the children I take care of, you know people use the analogy of an onion, and we're peeling back the layers of the onion. That just makes me cry. I think of it more like gifts. And so I.. in a gift that may be wrapped in nine layers of wrapping paper. And so I look at it more of, OK we've got that layer of wrapping paper off. Now we see the next layer. And we got to get to that. So it's not so much a shift to a whole different gift. It's just that evolves as you unwrap. What was much more prominent to the more subtle defects that you may not have noticed or that that may not have been as prominent as you unwrap that gift.** But keep in mind to all the parents and teachers and practitioners that that ***child wherever they are is a gift. And part of helping that child to get***

better is to see them as a gift at every stage rather than just something that needs to be fixed, because that I think as traditional physicians we often anoint our patients with what we prescribe, and this will get you fixed or better. But **if instead we empower the child and the family to get better, the long reaching and long term positive effects can be much greater. Because that, there's so much that can be said about the power of positive thinking and the power of healing in. In wanting to join into that relationship**. A kid I had not too long ago probably seen 15, 20 physicians and she came in with a puss on her face that you know the parents were sure she wasn't going to get over and I was never going to do anything to help her. And just listening and hearing that she didn't want to tell me the specifics of what her headaches felt like and she just said they are horrible pounding every moment of the day, and anything else you ask me is just irrelevant. Listening to that and hearing that and saying OK I'm not going to ask her any more of that, helped her to allow me to then say, OK, I've got these three things. This is all I wanted to try for the next month while we're waiting for the tests to come back. Whether it was that what I prescribed actually helped or that what she said to me at the end of the two hours which was you're the first doctor I've ever met that I've liked. Which one of those doesn't really matter. When she came back a month later, it was the first time she had ever felt better in six years. And so that that interaction may have been as important as the B-12 or NAC or diet change that I gave her.

[01:08:20] [DE] Well, you also listened and I remember when I was still in college and one of my old fraternity brothers friends came, who was older, came back to visit and he was interviewing now, from the business side and he said, the best interviews are where the person interviewing you does all the talking. So it's great cause you actually listened. So I know we're coming to a close time wise. And so I do want to just talk about your **success rates and how you measure outcomes and where you are in that**. Because what I've found with my own gut issues over the years was there was no expectation of an outcome. That's just management. And I don't believe you function that way.

[01:09:14] [NO] **RESULTS**: ***No, so I think first of all we tell people very early on if we don't think we can help. For instance in the children with autism, there are a percentage, this is a genetic disease. And in in in my perspective autism genetics loads the gun, but environment pulls the trigger. So for 90 percent of the kids there are environmental triggers that we can impact. But for 10 percent there really aren't. And it's just a genetic illness, and if through history and physical exam and test results in those first three months and trialing some of the big interventions I see absolutely nothing, I will say to the family don't take out a second mortgage on me and use your money to invest in therapy and things like that***. And if there's anything you want to try that I think is safe because it helped your neighbor or you read about it. I will try it with you and I will give you the percentages that I think it may help your child but ***that's about 10 percent of the kids that we really don't have any impact on***. There maybe ***another 10 percent that we don't and maybe 10 to 20 percent that we don't have an impact on because they don't follow up either we didn't do a good enough job telling them about telling them about the bad good and they gave up or they have too many obstacles within their home or financially or the child and they don't return after even the first couple of visits***. So, and we have these numbers we've looked at it, because of the **think tank and the Autism Research Group** that we've been involved in, we've been asked to look at this repeatedly, so **we've looked at our actual percentages. We've reported on them**. So **about 20 percent no change**, I think **10 percent of that are genetic** and **10 percent of that are are giving up for whatever reason**. I think there are **30 percent of those kids that recover 100 percent. They may be a little bit quirky but they recover**. There are **30 percent that moderately improve over top of what therapy could do**. So that they're not just much more available to therapy but **they've made leaps and bounds gains but they're still on the spectrum**. And then about **20 percent that have mild improvements and those are kids that are just more available for therapy. We've treated their constipation, we've gotten them healthier. We've gotten them more alert but really not any more changes than that**. And

that's just in the autism population. Now in the **PANS and PANDAS population, that depends more on how quickly we see them and how many germs are involved. But of those kids, we'll get at least 60 percent better and maybe up to 70 percent. And that really depends on the type of germ that's involved and how quickly they get in to see me, which is why we're trying to decrease the length of our waiting list and bringing on more practitioners** etc.. In the **Lyme population, that's very similar to the PANS and PANDAS, in depending on how many germs are involved, how many of the co-infections, how long the child has had it and that's often hard to to delineate whether it was gestational or not. But again that can well be in that 60 to 70 percent grouping**.

[01:13:13] [DE] And how much of this **before puberty**, you know the difference, does that have a significant impact?

[01:13:21] I would say as a pediatrician, ***most of the children I see are either around puberty or younger. The children that are older. The percentages do go down. But the large majority of kids we're seeing are less than 13 / 14. So those numbers are mainly based on that group. But I've had 17 year olds, that are have one word utterances and are stuck in their homes all day with huge sensory overload and we've added an intervention and they go to Disney World and they're talking in reciprocal phrases with their family. So it does happen. The percentages are just lower.***

[01:14:07] [DE] And what about on the other ***ADHD and other things***, I assume it's probably even higher if they fall through.

[01:14:14] [NO] Right. Correct. But the problem there is the follow through ***because well I can take this stimulant medication. And that's one pill and I feel better, versus changing my diet and taking these 10 supplements and then I feel better. I'm 14. Which one am I going to do. You know. So that's where some of the falloff may get greater and we don't see as much an improvement in what we do because the kid is not on board***.

[01:14:46] [DE] Well thank you, what I'm what I'm going to do before we post this is when we do the show notes, we'll list a lot of the different entities that you are a part of or that you recommend and then send that back to you maybe to edit. And I know some of them are up on your web site as well and we'll get a complete list for everyone because I want this audience here is and what we're gearing for is not just patients, but practitioners that are either open minded or in smaller markets who aren't as exposed that we hope to get this out to. And you know I hope there is more to talk about in the future and I really appreciate your time. And and so from my personal experience has been wonderful, and I would love to find a way to make your knowledge increasingly available to those that aren't there yet. One thing on these success rates. What is the variation of your success rates versus what you see generally in standard of care? I did forget to ask that one question. Without without criticizing the numbers that you see published by the government or that you see elsewhere. I'm not asking you to criticize your fellow peers but you're obviously doing this because you think it’s better.

[01:16:16] [NO] I think in children with autism often the families are left with a diagnosis and no hope and no help. And so especially in the children with moderate to severe autism, I think those families are given there's zero percent chance of recovery. And our percentages go whether you're on the mild and the moderate or the severe end, if we can find those metabolic immune gastrointestinal problems and correct them. So I think that that that's where I reach out the greatest. Same with PANS, PANDAS and Lyme. You know I think a lot of my more traditional colleagues don't want to even think it exists. So don't treat it with the necessary antibiotics or herbs that would help that kid to get better. So they're not seeing 60 to 70 percent improvement because they're not using those. So my hope would be they look at something like this and then go to the web site for New England PANS or for ILads for Lyme or whatever and find another way

to look at these children and help them to get better.

[01:17:40] [DE] Wonderful. Thank you very much for your time.

[01:17:43] [NO] Thank you for yours. Appreciate you doing this.

[01:17:45] [DE] Fred thanks for keeping us company, he barely moved. It's a good thing. And thank you.

[01:17:53] [NO] Thanks.

People Mentioned

Dr. Nancy O'Hara
http://www.ihealthnow.org/ - her clinic in Wilton, CT
https://www.youtube.com/watch?v=IJe9ZqEmumw - Autism Presentation
https://www.youtube.com/watch?v=Sd5dQvg5454 - PANDAS presentation

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Dr. Susan Swedo
https://www.nimh.nih.gov/labs-at-nimh/principal-investigators/susan-swedo.shtml
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https://www.youtube.com/watch?v=8EaG9dktM28 - PANDAS presentation

Jill James
https://healingautismandadhd.wordpress.com/tag/dr-jill-james-phd/

Dr. Pamela Crooke
https://www.socialthinking.com/Speaker%20Details?name=Pamela%20Crooke

Dr. Robert Naviaux
http://profiles.ucsd.edu/robert.naviaux
https://health.ucsd.edu/news/topics/suramin-autism/Pages/default.aspx

Dick Deith, PhD

Links

Suramin and Autism

https://health.ucsd.edu/news/topics/suramin-autism/Pages/default.aspx

Center for Integrative Health
http://www.ihealthnow.org/

Medical Academy of Pediatric Special Needs
https://www.medmaps.org/

The Institute for Functional Medicine
https://www.ifm.org/

Neurological Health Foundation
https://neurologicalhealth.org/

New England PANS / PANDAS association
http://www.nepans.org/

International Lyme and Associated Disease Society
http://www.ilads.org/