Introduction to PANS and Holistic Care

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And many, many doctors don't like to leave their lane. They want to stay. They don't have a holistic approach to this. And you need a very holistic approach.

So you don't have a lot of docs out there that are willing to stick their necks out and move into the full arena. And that's what you really need to be successful in treating these patients.

This is Doctor Talks, real talk from real doctors on the issues that matter to you most. Hi, everybody. It's Dr. Nancy O'Hara. And I am absolutely thrilled to welcome our guest today, Dr.

Dennis Babulis. Dennis was an early pioneer and specialist in diagnosing and treating pans and pandas and autoimmune encephalitis. And he has treated thousands of patients with symptoms that were previously overlooked or misdiagnosed.

And like me, our mission is to raise awareness among physicians patients, parents to get proper diagnosis for these kids. So Dr. Babulis leads the Advanced Allergy, Immunology, and Asthma Center and is the founder and director of Superior Associates Infusion Center, both in Darien and got his doctor of medicine at New York Medical College and over 13 years as a board certified physician in allergy, asthma, immunology, and specializing really in neuroimmunology and treating PANS, PANDAS, and tick-borne infections.

So Dennis, thank you so much for being here. No, thank you. It's a pleasure being here. Now, you and I first met back in 2012 after you received some notoriety for diagnosing successfully and treating a child with a persistent sneezing tick.

Can you just tell everybody a little bit about that? Sure. So this was a young girl that had presented with incessant, incessant sneezing.

The Sneezing Tic Case and IVIG Response

I mean, thousands of sneezes an hour where she couldn't sleep, she couldn't She couldn't go to school. She couldn't do very much of anything. And she had pretty much gone throughout the country looking for an answer as to why she was sneezing.

She had seen many allergists. She had seen ENTs. She had seen neurologists. And everybody really was scratching their head as to what was going on. And when I saw her, she was pretty much in that condition, constantly sneezing.

And we did an initial workup and found that this was really not an allergy. It was in fact a motor tick where she had an autoimmune response that was directed against her brain, throwing off brain chemistry of a particular your transmittal, known as dopamine, that was keeping her sneezing.

It's a great example of what can so easily be misdiagnosed as an infectious or allergic But as you said, this was autoimmune, so continue. Completely autoimmune and misdiagnosed as an allergy.

And it was infection-induced. And it turned out to be due to Lyme disease. And we started treating her for Lyme. And then we also did some immune modulation therapy with IVIG.

So we gave her antibodies that cleaned up her own antibodies that were attacking her brain, thereby stopping the motor tick. and it really stopped after one infusion.

Wow, wow. And I want to talk about all of those things, but let's start with IVIG, if you don't mind, intravenous gamma globulin, because you are my go-to person for that and have successfully treated and recovered countless, countless children.

So describe a little bit more how it works and how often you see this one and done, where one infusion makes such a big difference. So we don't always treat with IVIG.

Usually the immune system doesn't one day wake up and say, I'm going to attack the brain of a child. It has to be driven to do so. And usually it's infections.

So we look to uncover the underlying infection. We treat the infection or infections because sometimes it's not a singular infection. It can be multiple infections.

And often the immune system rebalances after you do that. And a lot of the neuropsychiatric symptoms, which is resulting from the encephalitis, go away.

Yep. And that's during the course of the treatment. However, there are situations where the immune system doesn't readily rebalance. And that's when we have to use immune modulation therapy and we bring in IVIG.

Yeah. And go ahead. I was going to say, and when we do that, that rebalances the immune system. It cleans up the antibodies that are attacking the brain initially, and then it resets the immune system over time.

Now, one treatment doesn't usually do it.

How IVIG Works and When Itu2019s Needed

Occasionally it will, it did for this patient, but usually you need a few treatments to rebalance the immune system. Because the immune system tends to be stubborn after it's been deranged, if you will, by infections in the body.

So there will often be several treatments that are needed to do the job. And often when when kids come to see you or or me they've been misdiagnosed you know under treated and and just told that this disease doesn't exist so often they've been to see.

three, four, 13 different clinicians as this child did before they see you. So also the chronicity affects how many treatments they may need also or how long the treatment may need to continue, right?

Totally, totally. If these infections are detected early, they go away faster. If they tend to fester in the body and they penetrate the tissues, then they become more resistant to treatment.

requiring additional treatments such as IVIG. Right. Now, is all IVIG created equal? Meaning, do you feel that some forms of it are better tolerated, more effective?

So, there are various brands out there. They're generally interchangeable, but there are certain patients that will tolerate one over the other. So there are cases where we have to switch brands, but generally they are interchangeable.

But the purification process differs from company to company. They use different detergents and that can affect tolerability. How about, how do you feel about the way that the product, because it is a blood product, is tested to make it safe?

You know, we hear people talking about viruses within the IVIG, etc. Can you speak to that a little bit? Sure. Sure. So IVIG has been out for decades, well over 50 years.

It's been a life-saving immune modality for many patients. And I often cite my father when people ask me this, because my father's been on IVIG for 17 years now.

Yeah, that was fascinating when you told me that. Yeah, yeah. He's 103. And he's been on IVH since 85. And it's been keeping him going. So I'm a big supporter.

But in terms of safety, it is 100% safe. It is a product that is pooled, that is from many donors. However, it is purified, it is acid precipitated and crystallized.

So you get rid of all infectious agents, viruses, even sub viral particles are denatured. And people sometimes ask me about the mRNA vaccine, can any spike proteins be in there?

No, those are all acid precipitated out. And then what you get is just pure antibodies. Great. And I think that's very important for people to understand because we get those questions a lot.

You see it in the chat rooms online. And I think it is important to hear that this is really a safe intervention. Now efficacy, one of the things you and I talk about a lot and certainly as in all the literature is the difference between treating a child for immunodeficiency and the dosing that is used for that and treating a child for autoimmune disease, autoimmune encephalitis and the dosage for that.

Could you speak to that for a minute? Clearly, the application is totally different and the dosing, as you mentioned, Nancy, is different. When we treat patients with immune deficiencies, the dose is much smaller.

It's roughly a quarter or a third the dose that is needed for older immune disorders. Because when you're treating a patient that is immune deficient, all you are seeking to do is really to reconstitute the immune system.

That is to bring it up to a higher level. So you want the IgG, which is the main antibody that we infuse with IVIG, to go from a lower level to a higher level, because going from a lower to a higher will now confer better immunity and keep people from getting recurrent infections, usually spinal pulmonary infections.

With autoimmune disorders, the dose must be much higher, three, four times the dose of the one we use for immune deficiencies. And that is because we want to achieve immune modulation.

We want to rebalance the immune system. We wanna overwhelm the bad antibodies that are being produced by the immune system that are attacking the brain.

IVIG Safety, Dosing, and Delivery Methods

We wanna clean them up initially, and then over time, we wanna reset the immune system. We wanna knock out the factory that's making these bad antibodies that are attacking the brain.

Yep, yep. And how do you deal with a child that has known and significant immune deficiency, as well as autoimmune disease, PANS, PANDAS, when you're considering IVIG?

Right. So that's a mistake that a lot of people make and certainly immunologists that do not understand the autoimmune encephalitis and it kind of goes over the, it goes right over their heads.

So in this situation, the mistake that often is made is that the patient is diagnosed as an immune deficiency patient and the autoimmune encephalitis is ignored.

So they are treated with low dose immune globulin that actually makes more antibodies that will exacerbate the encephalitis. Yeah. Yeah. They get worse.

They get worse. And we've had several patients like that. Yeah. Yeah. And I think that's very important for people to understand. And, and the IVIG, when a child comes to your clinic, you know, is over two days because number

one, you're giving high dose in most children, you know, depending on their size, it's based on weight, but over two days and also with appropriate amounts of fluids so that they're not getting the side effects.

This is not something to be rushed, right? Is there something more you want to say about that? Yes, exactly. It has to be infused slowly, particularly the high dose infusions, the ones for autoimmune encephalitis, because the infusion is not just water, it's water with antibodies.

And these antibodies, when they go into the brain, they can cause increased pressure. and the increased pressure can result in severe migraines. And sometimes a lot of patients develop very bad migraines after the infusion if A, the IVIG is infused too quickly, and B, if they're not hydrated well, they haven't been hydrated or they have not received hydration before the infusion.

Right. Now, one of the things that you and I agree on and that we've talked about is the differences between coming to your clinic and getting IVIG there, doing it at home, sub-Q immunoglobulins.

Could you speak to that to our listeners and viewers? Sure, sure. So when you're dealing with an immune deficiency, you have the choice of whether receiving subcutaneous immune lobulin or IV.

It will do the same thing. It will reconstitute the immune system. And it's just a matter of choice for the patient. Do they want the IV once a month or they want the subcutaneous once a week?

I believe we also have some monthly subcutaneous products out there, but it's just a matter of choice. It doesn't matter. However, when you're treating autoimmune encephalitis, then the choice becomes critical because you need to rebalance the immune system.

You need the high dose IVIG to be given together and not slowly over time. So the subcutaneous version really doesn't work very well for these kids who have the encephalitis.

It has to be given high dose. And even if you take high dose and you divide it over the course of weekly infusions, that also is not satisfactory. It has to be given monthly at the prescribed dose.

Great. And I also think, in my opinion at least, it's very important to do this safely. Although this is a very safe and effective intervention, sometimes there can be effects that we need to be monitoring.

And I've sent several patients to you who previously had been doing home IVIG because of the significant side effects they had seen and really needing it to be monitored.

Go ahead. Yeah, yeah, the high dose particularly needs to be monitored closely because again of the volume, the infusion rates have to be hydration status.

And we've had lots of bad side effects that occurred at home. Yeah, yeah. So I think, you know, it is safe, but it needs to be well monitored. Absolutely.

Now, one of the things both of us have seen again and again and again, and I know you're in the thick of it, is the lack of insurance coverage for IVIG.

Can you talk about that a little bit more? Because I know that's a real sticky wicket for a lot of our families. It is, it is. So, insurance companies don't generally cover for autoimmune encephalitis.

They will cover the immune deficiency diagnosis. So if a patient has a concomitant or comorbid condition of immune deficiency, we can treat them on that basis alone.

And if they happen to have the autoimmune encephalitis, that will help that as well. As long as, again, we get the dose correctly. Right. Also, there are patients often that will have concomitant peripheral neuropathies that will also are deemed worthy of IVIG.

So when that exists, we often will treat that and we will by default also cover the autoimmune encephalitis. So we're not yet at the point where insurance industry is recognizing this fully for this particular diagnosis.

Right, right. And do you have any comment on the most recent AAP report that came out and how that affected you in getting this prescribed, how it affected insurance companies, how it's affected families?

Um, hasn't really affected us much. Okay. Really? We, we, I mean, there are states, for example, Massachusetts that have now passed laws that, uh, that require insurance companies to pay for IVIG.

But I haven't seen that much in practice yet. Yeah. I think one of the problems was there were a few states that took the proposals off when the AAP statement came out because it certainly wasn't strong enough.

It certainly wasn't up to date in the reporting of the research, especially since 2017, that we know is there proving that this disease really exists.

I mean, you and I know it, we live it every day. Why do you think it's so controversial? First of all, that's a multi-part question. In a huge can of words, take what you like and leave the rest.

Right. I don't think it's controversial. I think it's a very complex entity. And I think that this is an entity that requires expertise in many disciplines of medicine, immunology, infectious diseases, neurology, psychiatry.

And many, many doctors don't like to leave their lane. They want to stay. They don't have a holistic approach to this. And you need a very holistic approach.

So you don't have a lot of docs out there that are willing to stick their necks out and move into the full arena. And that's what you really need to be successful in treating these patients.

We've had so many patients together and we understand that, but other doctors don't.

Insurance Barriers and Why PANS Is Misunderstood

Yeah, so that's one problem. The second problem is that psychiatry today is still, so psychiatrists still are still, they're still trained on a symptom-based model, right?

So you go into psychiatrists with anxiety, OCD, mood swings, and you come out with the same diagnosis with a drug that's trying just to control the symptoms.

They don't look at the immunology, they don't look at the infectious disease component that could be complicating the clinical symptoms or the neuropsychiatric symptoms.

So it really goes over their head. And very few psychiatrists, as we know, have really the ability to venture on to these other disciplines. And then finally, there's a push or an aversion from the insurance industry to pay for this for obvious reasons.

Insurance companies do not want to open up the can of worms where they're going to have to pay for an expensive treatment like IVIG for pandas or other things like that.

And I think another piece of that is just a couple of pieces from the pediatric standpoint is number one, there's such a push about the negatives of antibiotics on our gut, et cetera.

And when we talk about a disease that may need to be treated with antibiotics, there's some pushback on that. Absolutely. I think the other thing is often we treat with antibiotics a child may come in with a cold, but they also have a strep throat, but they have the ear infection or the sinus infection so they get treated with antibiotics without doing a strep culture.

And then weeks later, they present with these neuropsychiatric symptoms, ticks, OCD, anxiety, and there's no documented strep in their history or no recognition that that infection, whether it be viral, mycoplasma, strep, has any bearing on this abrupt onset of neuropsychiatric symptoms.

Yeah, correct. And that's a fallacy out there, right? Because a lot of kids will be taken to the pediatrician, they'll do a throat culture or rapid or overnight, it'll be negative and they'll be dismissed as not having strep, which is really the farthest thing from the truth, because you don't always identify strep by a culture alone.

And often you have to do blood work, which really the pediatricians don't do. You need to look for biomarkers for these group-based strep infections. And even then, it's not 100%, because it's about 30% of these kids that will still not show biomarkers on blood work.

So this remains a clinical diagnosis. Absolutely. And it really, you need astute clinicians to see these kids and to make the diagnosis. And the laboratory is supporting for us.

It doesn't define the entity. Right, right. And speaking of complex disorders, as well as disorders that are really a clinical diagnosis, at least when it comes to conventional labs, I wanted to talk a little bit about tick-borne infections and PANS-PANDAS.

Can you give me and give our listeners and viewers your thoughts on that? Sure. Sure. So, autoimmune encephalitis is not germ specific, right? So, it is not caused by one germ.

It can be caused by many germs. The prototypical infection is group A strep, which causes the entity that everybody now has heard of known as pandas, but it could be caused by other infections.

And other notable infections are vector-borne infections or tick-borne infections. And there's a plethora of these, the most commonly known being Lyme disease, but there are other infections, there are other gram-negative infections such as Bartonella we discussed, such as Ehrlichia and Eplasma.

There are malarial known parasites known as Babesia. And these collectively can derange the immune system and cause an encephalitis picture indistinguishable from PANDAS.

Yeah, and I think it's very important that everybody understands, and I've said it repeatedly on this podcast, that this is an immune disease, an autoimmune disease, not an infectious disease.

So your child may have evidence of multiple infections. It may be harder to treat, but that doesn't mean anything more than if they present with one infection.

It's the dysregulation of the immune system that's the underlying pathology, correct? That's correct. And I said, as we discussed earlier, the immune system just doesn't wake up one morning and say, oh, I'm going to start attacking this child's brain to cause pandas.

It is driven to do so by infection or infections, plural. And when we look at these patients, it is really incumbent upon us as physicians to identify these infections.

and to treat them, because that's really the beginning of the trip to recovery, or the road to recovery. Now, you and I are in the Northeast, and so we're seeing a lot of tick-borne infections.

Over 40% of our ticks are carrying Borrelia, Babesia, and Bartonella now. How does your treatment, how does that affect your treatment of children? Your testing, your moving toward IVIG, anything within what you do?

Well, I always try to identify all the infections that are causing the problem. And one of the main problems that I find in patients that come through my doors is that they have not been fully evaluated.

So one infectious agent may be identified, let's say the strep, but they've missed the beryllium, the line.

Tick-Borne Infections as Triggers

Or they may have identified the line, but they've missed other co-infections. And when you do that, you're not very effective in treating the patient.

So you get into a situation where a patient develops or has chronic symptoms that really don't go away. or they go away a little bit, but not completely.

And you're going back and forth with symptoms that improve, symptoms that come back. And these infections often will become exacerbated when the patient comes in contact with other germs in the community, like community-acquired infections.

If someone has Lyme, for example, and they develop strep, their symptoms are going to flare. Right. Their Lyme symptoms as well as their neuropsychiatric symptoms.

Exactly. Yeah. That's right. And what about how you treat them? The antibiotics, et cetera. And the timing, if you feel a child needs IVIG. I know a lot of families that I've referred to you are like, I wanna get the IVIG today.

And we're like, no, whoa, we have to look at all these infections and start to treat those before we move right into IVIG. Correct, especially with tick-borne infections?

100% answer you can't put the cart before the horse right you can't you know the the analogy I like to use is I said if you have a car you're driving a car at 100 miles an hour you have the foot in the accelerator right you want to stop the car right the first thing you do is you take your foot off the accelerator then you slam on the brakes.

If you slam on the brakes and the accelerator is still down, the car is not stopping, right? These infections are the accelerator. IVIG is the brakes to the immune system.

So you want to first address the infections. And then you look to see if the patient needs IVIG because when you remove the infections, often the immune system will rebalance on its own.

Right. Right. Absolutely. And You're usually using antibiotics in treating the tick-borne infections, correct? Yes. And often that's not one antibiotic.

Can you speak to that a little bit? Yes. So these infections, by the time they come to my office, The infections have been in the body for a long time.

They've been in the tissues for a long time, and these are tissue-based infections. These are not infections that are just floating in the blood for antibiotics to come in and clear them.

They fester in the tissues. They're parasitic infections, most of these, and they need often more than one antibiotic to do the job. And depending on which infection we're talking about, we need sometimes two, three antibiotics.

If we have parasitic infections, we need anti-malarials to be added to the regimen to clear the infections. And often the patients will also require some herbal treatments that is in your domain to complete the job.

Sometimes patients cannot tolerate antibiotics. Sometimes they'll do herbals before doing antibiotics. So we have to look at these patients and see what's best for them.

Yeah. Yeah. And in my experience, it's a marriage and no one size fits all for everybody. You know, we've shared patients where, you know, the herbs have not done the trick at all and they need the antibiotics.

We've also had those where the antibiotics were causing more havoc and they needed to add the herbals. And I think going back to this is a complex and immune mediated disease.

So we have to be treating everything that may be in the child's way of getting better. For his best interest, depending on their immune system and their body and their body chemistry.

Right, absolutely. Because it will impact differently to different treatment modalities. Yeah, and looking at that, looking at their nutrients, looking at their diet, looking at their gut, you know, and using appropriate probiotics and gut healing techniques at the same time that we're treating the underlying infections.

Exactly. Yeah, now one non-bacterial infection that's been in our laps for the last few years is COVID. Can you talk a little bit about COVID and pandas as well as long COVID and pandas?

Sure, so COVID, so COVID is a virus that we all know came novel to this country and caused immune responses that we had not seen before. Hematologic, neurologic, neurologic, cardiac.

Thankfully, most of these patients recovered and did not have any long lasting sequelae to the infections. However, there has been the notion of long COVID that we've all heard about in the news and even patients that family members and friends that we know.

My experience with long COVID has been the following. When I've evaluated patients for long COVID, I've often found that they have underlying tick-borne infections.

Absolutely. Yeah. And the reason for that is because most patients who have chronic tick-borne infections, whether we're talking about Lyme or Bartonella or any of these infections, the immune system has the uncanny ability to contain these infections for long periods of time.

with a positive symptoms. And it really goes under the radar. It goes under radar in the patient and the patient's family. It goes under the radar with respect to the primary care doctors.

And so there are patients that walk around with these infections with a positive symptoms. Now COVID comes along and infects that same individual. And when that happens, the immune system's attention of containing these infections is diverted.

Long COVID, Viral Reactivation, and Testing

So it goes from containment to fighting COVID. And when that happens, these infections now start to become symptomatic in the body. And that's what leads to a lot of these long COVID symptoms.

And I found when these are detected and treated, the long COVID symptoms resolve. And I think in a lot of our long COVID clinics and in many of our practices, those tick-borne infections may be missed.

And can you speak again, going back a little bit to the tick-borne infections about using conventional labs to diagnose Borrelia, Bartonella, Babesia and others?

Sure, sure. So the conventional laboratories like Quest, LabCorp, all the hospital laboratories, they have machinery that falls short of being able to detect these accurately.

So that is their sensitivity is low. So to have a good screening test, you need a high sensitivity. You need a sensitivity in the 90s. In other words, you can't miss people who have the disease because you're going to not be able to make the right diagnosis and treatment for your patient.

So you need a test that has a high sensitivity. These laboratories do not. In fact, the sensitivity can fall into the 50s, making it a flip of the coin whether or not you're able to pick up a tick-borne infection or not.

And they've really never, these laboratories, they've never looked back and tried to revamp the way they detect these infections. I mean, we're looking probably 45 years now, at least since the late 70s, early 80s.

They've never revamped the way they do their diagnostic testing. And so they fall short of being able to give us an accurate diagnosis. And as a result, there have been other proprietary laboratories that come into existence that have higher accuracy, that give a high sensitivity and specificity that gives us the right diagnosis.

And with them, we don't miss infected patients. And you and I agree that although we don't want to burden these families with more expenses, that making the right diagnosis with an accurate, externally validated specialty laboratory is vital.

Is vital. We can't really do our work properly otherwise. We can't make the right diagnosis. We can't find the germs, the germs that are causing the problem.

And how can we cure the patient then? Right. Exactly. And just a note, the testing that you're talking about from the 70s and 80s, the two-tier testing that most clinicians do from our conventional labs was only meant for surveillance.

It wasn't even meant for diagnosis. That's correct. And so we're misusing that test in saying that a child doesn't have Borrelia. And then why I keep switching us to tick-borne and vector-borne.

You know, Borrelia burgdorffii, what we know as Lyme disease, is only one of many, many species of Borrelia, let alone that's not even thinking about the Bartonella babesia and other what we've come to term as co-infections.

Yeah, we're still in the dark ages in general medicine when we're referring to tick-borne infections. People still think of Lyme as one germ that can be easily eradicated by two weeks of doxycycline.

Right. And that's why we have a whole society or a true pandemic, if you will, of tick-borne infectious agents that are that are causing a severe illness in our society.

Absolutely. And I absolutely agree with you that a lot of those that are coming in with long COVID actually have tick-borne infections, but I also have seen reactivation of other infections like EBV, CMV.

Are you measuring those also? And are you measuring COVID antibodies or cytokine panels or anything like that when you're presented with these children?

Yeah, so you're 100% correct. They do also activate a lot of the large DNA viruses like CMV, like Epstein-Barr, like herpes zoster. They have the ability to do that because these viruses, in fact, are viruses that never leave our bodies.

When we first contract them, they're never cleared. They remain dormant in our nervous system. And then when other infections come into existence, they are reactivated.

And when they're reactivated, they can cause additional autoimmune sequelae to an already existing encephalitis. So yes, that we always check for those.

And I also always check for spike protein to see the level of that. Although it's difficult to assess that because a lot of people now walk around with very high titers from the vaccinations, from having had COVID and the spike protein is usually quite high in many patients.

So it's difficult to, to evaluate that as a biomarker that can help us. Now in your practice, are you doing anything specifically differently to treat those children, antivirals, detoxifiers, you know, anything that you're doing?

I'll carefully consider antivirals, but I often look for real evidence that there has been a change in the immune response. Because a lot of times when you look at antibody levels, let's say to Epstein-Barr, which is the most common virus that we look at for reactivation, a lot of patients have higher levels anyway.

And I try to look at the delta of the difference between before and after to see if there's been an reactivation. Because often, patients are just making oodles of antibodies just because their immune system is in that mode.

They may have just recently had Epstein-Barr, and therefore the immune system does not get settled down. or there are patients that can make lots of antibodies after Epstein-Barr for years before it starts settling down.

So it's very difficult to sort out. Right, right. And I think that goes also for checking for a multitude of viruses, that we're all exposed to them, we're going to develop antibodies.

Yes. And we may keep persistent antibodies for a very, very long time, and it has nothing to do with the neuropsychiatric symptoms at hand necessarily.

It's more about getting that clinical history. Yeah, every time he gets a cold sore, he gets these neuropsychiatric symptoms. Well, then we got to say herpes may be one of the triggers, right?

Yes. Again, it goes back to the notion that this is not a germ-specific immune response.

Allergies, Immunotherapy, and Other Treatments

It's a collaborative effort between multiple infections, viral, bacterial, that in the right genetic setting would lead to autoimmune encephalitis. Absolutely.

And a quick question, I don't think I've ever asked you, Dennis, is what about allergies? I mean, you're an immunologist, you're an amazing neuroimmunologist, but you're also an allergist.

Do you ever see allergies as the only trigger for PANS, or is that something that comes as a result? So that's very interesting. So So any pro-inflammatory event in the body will result in exacerbation of encephalitis, again, in the genetically predisposed patient.

Generally, what we see is patients who have already existing encephalitis will exacerbate during seasons of allergies, of allergic rhinitis. For example, if a patient is highly sensitized to pollen allergy, we're going to see a flare in the neuropsychiatric symptoms in the spring.

Right. That can happen in the fall. Rarely in the winter. Mostly the pollen season is the season where we see flares in children with pandas and autoimmune encephalitis.

And with those children with allergies, are you finding sublingual or other immunotherapy helpful in decreasing their neuropsychiatric symptoms? Yes, it does help.

However, one has to be careful because these kids, you can't treat them the same as children with allergic rhinitis who don't have the encephalitis because you have to be very ginger with the initial dosing of the sublingual or the subcutaneous immunotherapy.

You have to go many dilutions below often. because otherwise you can trigger a neuropsychiatric event if you don't do that. Right. And we've seen that with other treatments also.

You know, one of my mottos is always start low and increase slowly to try to avoid those Herxheimer or other negative reactions that may come in these exquisitely sensitive kits.

That's right. They do have very sensitive nervous systems and in the context of atopy or allergies, one feeds into the other. Yeah. Yeah. And any other effective treatments besides the ones we've talked about, you know, treating the immune system, treating the underlying infection, treating the allergies if they're there.

Any other treatments you wanted to mention? Well, I mean, first line, I think we covered pretty much everything first line. There are other immune modalities that come into play for stubborn cases of autoimmune encephalitis, such as plasma exchange, such as biological, such as rituximab.

These are not first or not second. They may be third, fourth line. And sometimes we have to bring these in, in cases

where we're not getting the response that we need from A, treating the infection, B, using IVIG, C, looking at family members because also sometimes exposure to family members can affect the immune system.

So you want to make sure you look at that as well. That's overlooked a lot of times. Absolutely. I remember a kid we had in common who dad traveled a lot.

And every time dad came home, the child would get worse. And I spent months trying to help the family in therapy, trying to help figure out what the dynamic was.

And there were, you know, therapeutic things that were helpful, but When you found out that dad had strep, and I think mycoplasma actually, and treated him, the child stopped flaring every time he came home.

It made a world of a difference, yeah. And that's overlooked so often. And a lot of families are a little reluctant to look at themselves And how can I be affecting my child?

But when you have an immune system that is off balance, off kilter, if you will, it can happen very easily. And also, I've also had the experience of having dogs and pets sometimes.

I was just going to ask you that. Right. I remember I had a case of a little boy that was flaring and we've done everything right. He was on antibiotics, we checked the family.

And then finally, he was very close to his dog. And I said to the family, I said, why don't you have the dog checked, take him to the vet and just swab his throat, right?

And they took him and, lo and behold, the dog had strep. We treated the dog. I didn't treat the dog, of course, the veterinarian did. And everything went away.

And it was remarkable. It was remarkable. And I didn't believe it because I asked the mother, I said, can you please send me a copy of that culture? And sure enough, she sends me the culture.

There it was in black and white. Wow. It's just another sign that we really are detectives, that we really have to keep digging. And my mentor was Dr.

Sydney Baker. And his mentor always said to him, Sydney, have we done enough for this child? And you are one of those clinicians, Dennis, that keeps asking that question if a child's not getting better.

And that's one of the reasons I love working with you. So thank you for that. We have to do, right? We're here. to go to the nth degree, right? The nth degree to figure out what's going on with these patients and these kids.

Because if we don't do that, we really, we've failed in our mission as physicians, as scientists. And that's very important. No, I so appreciate that.

One quick question. I know we both agree, effective treatments, you know, antimicrobials first, if that's not doing it, IVIG. than possibly moving on to plasmapheresis or as you mentioned, Rituximab.

Are there any cases that you skip over and go directly to either of the latter two? No, because you first want to identify cryptic infections. So hidden infections are very important.

If you do not do that, you will not succeed in treating the patient and curing them. And if you go directly to the immune modulation modalities and the patient is still infected, either A, they won't work, B, they'll work temporarily.

And then when you stop, the patient's going to revert back to where it was before. And I have tons of patients like that that have come back to me. They've had IVIG, they've had plasma exchange.

It says, we've done well, but it didn't last. And it didn't last because the infections were not first addressed. Right.

Right. As always, Dennis, it's a stepwise approach.

It's doing things in the correct way, in the correct order, to really get a lasting improvement in these kids. We need to practice good medicine. And when patients come, a lot of times the families, they've heard of IVIG, they've heard of plasma exchange, they've heard of this and that, and they want, I want this for my child, I want that.

But they need to be educated, because it has to be in the right order. And often, as I said, if the infections come first, treating underlying infections, and often you don't even need to go to those other more complicated modalities when you treat the underlying infections.

And if you do, of course, they're there for us. They're there at our disposal because we're going to, at the end of the day, treat the patient the best of our ability.

But we want to do it in the right context, in the right order, so we cure the patient, not just temporarily relieve their symptoms.

Family, Pets, and the Team Approach

Right, and there is no quick fix. Yes, there will be the children that we catch early that one IVIG may help them or one antibiotic, but in general, this is a marathon.

And we need to remind our families of that, that they can get better, but don't skip steps one through nine thinking that you have to have 10 today. Exactly.

Because it won't work. It won't work. It won't work. And I've seen it over the years. It just does not work. You have to be methodic. You have to be, as you said, a detective who will unravel these infections to go after them meticulously.

You have to be meticulous here. You can't be sloppy because you miss something. A little germ that you think may not be there is there. And then that just throws everything off.

Yeah, and we have to educate, you know, our families, other clinicians, because, you know, as you and I have talked about, doctor is teacher. Yes. And we need to take on that role too.

I've often sent to families when they come, I said, look, I'm not here just to treat your child, right, or if it's an adult for you, I'm also here to educate you, because I said, part of my job is to make you understand what I'm doing for you.

That's part of my job. Right? And you as the patient or as the family of the patient needs to be educated on what's going on and why, as your doctor, I'm doing why I'm doing what I'm doing for you.

Right. Right. And it's a community. It's a mutual understanding between the family and the doctor. It's us listening to them and them listening to us and working together.

And also this is a collaborative effort, right? This is not, and what I've lived over the years is this is not really, it's not a one man show, right?

You can't be one doc that can expect to treat all these kids by yourself, right? It's a team effort. This is too large and too complicated for any one doctor to manage.

And when people don't understand that, that's when they fail and they falter. takes a village. And a lack of ego too, because you do have to defer sometimes.

You do need the psychiatrist, the therapist, the general pediatrician, certainly you, to really help these kids get better, plus the family and the kid.

We got to get that kid on board. Absolutely. There are a lot of moving parts within the disease entity, the syndrome, and you need many, many, many minds to come together to get to the finish line.

Yeah. Well, thank you for giving us yours, Dennis. Now, I know you're incredibly busy, but how would people find you if they needed to reach you? We're on the internet.

Maybe just Google my name. Uh, uh, also advanced allergy, menology, and asthma is our practice. But most of the time when people find us, they just find them, find us through my name.

Yeah. Well, I'm glad I found you. And any last words of, of wisdom or hope for the families out there? Yes. Uh, we, we, we, I want. that we want to make sure that awareness continues to build and grow.

We want every clinician out there, every doctor, social worker, pediatrician to know this entity, to recognize it. And even though they may not have expertise in this, we wanna make sure that these children are directed to the right doctors.

to identify these infections and treat their condition successfully. Because otherwise they get bounced around and nothing gets done. And the level of frustration that we see in families is overwhelming.

And I'm sure you see the same thing. So we want to make sure that we get people and children to the right place. Well, thanks for being one of those right places and thanks for all you do for the children and their families and for our practice.

I so appreciate it. Thank you. It's a pleasure working with you. Yeah, you too. Happy having you on your podcast. Yeah. Thank you for being here and see you again soon.

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