Bartonella and PANS: What Clinicians and Families Need to Know Transcript

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Introduction to PANS, PANDAS, and the Podcast

We need a National Cancer Institute approach to neuropsychiatric disease and chronic infection that is central, funded. And we need to go back to where we were in the 60s and 70s, and say, we may have an epidemic and pandemic that's so important that we can't just have a few centers of excellence around the United States.

It's the only way we're going to address this problem, in my opinion, and in a way that might be meaningful for a parent who has a child now, or a parents who's gonna have a kid with PANS, PANDAS, you know, 10 years from now.

Welcome to Demystifying Pans and PANDAs, the podcast where we uncover the mysteries, breakthroughs and hope behind these life-altering conditions. I'm Dr.

Nancy O'Hara, a board-certified pediatrician, educator and advocate. With over three decades of experience helping children and families navigate the challenges of neurodevelopmental and neuropsychiatric conditions, especially PANS and PANDAS, these disorders can feel overwhelming.

But here we'll break down the science, explore transformative treatments, and share stories of resilience and recovery. If you've ever wondered what's possible for your child or how to find answers, This is the place to start.

Let's dive in. He's the co-founder of Galaxy Diagnostics and a recent coauthor on a wonderful book called A Blind Spot on Autism Rethinking What Could Be Driving the Autistic Pandemic.

And Ed has written hundreds of peer-reviewed publications. He is internationally recognized for his research in Bartonella, diagnosis, treatment. He's consulted widely on an array of infectious diseases, many leading veterinary diagnostics, therapeutics vaccine industry.

He's a veterinary internist and professor of medicine and infectious diseases, North Carolina State University's College of Veterinary Medicine and the co-director of Vector-Borne Disease Diagnostic Lab.

And his research at NC State university intercellular pathogens research lab has really produced significant research findings concerning the medical importance of Bartonella and other emerging infectious disease pathogens in not just animals, but also human health.

Ed Breitschwerdtu2019s Background and Bartonella Research

He's received numerous awards and this most recent book talks about what we all talk about in functional medicine, that infections and immune dysfunction may help us shift autism and other chronic illnesses as systemic, treatable medical conditions.

So Ed, I cannot thank you enough for being on the podcast and joining me today. Thank you, Nancy. It's certainly a pleasure to be here. And I'm at that stage in my life and career where I can look back and say it's been a pretty enjoyable ride most of the time.

Well, that's pretty good. If you can say most to the tie, but if you said all the type, I think you might be fudging it a little bit, absolutely. You know, we talk about Lyme, but so many of us, you and me included, know that that really is a misnomer or a miss-representation of what our children and adults are going through.

And even tick-borne disease is not complete enough. I've heard you talk many times about vector-born diseases. Why is that so important? great question to start with because one, I think it's important medically, scientifically, and when the lay public communicates and thinks about infections that we try to keep the organism separate.

And then we acknowledge that, unfortunately, patients can be infected with more than one infectious agent, and some of those can vector transmitted, some can viruses that we carry around our entire lives.

And I think the reason it's so important that keep them separated and then try to understand how they're interacting within an individual patient, is that's going to give us the best answers as we talk about individualized medicine.

Because clearly, if we look at the three Bs, which has been a major focus of our research for the last 10 years now, we see people that are infected with all three.

We see them infected two of three, and we seen them affected with only one. whether it's Babesi or Bartonella or Borrelia. And honestly, if you look at their medical history or their symptoms, which sometimes has spanned two years to 10 years, there's so much overlap that using symptomatology solely to try to sort this medical complexity out is impossible.

Yeah, absolutely. And for those who don't know, Lyme is classically Borrelia burgdorffii. As you said, the three Bs are Borrelia, Bartonella, and Babesia.

Bartonella, particularly, is one that we've known about as cat scratch disease, as trench fever for decades. Why do you think it's so under-recognized as a vector-borne disease?

So, as you indicated, we've known about both trench fever and cat scratch disease, initially described as Perinod's oculoglandular syndrome, well over a hundred years now.

I think the important thing for me in regard to Bartonella is just looking at the North American experience. And if it were not for the AIDS epidemic, we might still not know that a cat, dog, horse, or human on the North American continent was infected with a Bartonella.

And you mentioned cat scratch disease, which is a classical, important Bartonella infection caused by Bartonnella hensile. Why that is so important is the human literature goes back literally to at least the 19th He's in France and in the United States saying, oh, gee, there's an association between getting scratched by a cat, getting a fever, and getting big lymph nodes.

So it was recognized as an acute infection. And that is so true, I think, as we think about the complexity of infectious diseases. If you can associate a acute onset illness and a couple of typical symptoms like fever and lymphadenopathy.

You can put a disease diagnosis on that and you can call it cat scratch disease. But what our research has shown that has been disputed somewhat is a person can get cat scratched disease and then two years, three years after they've had immunological elimination of the Bartonella, they are still infected.

They did not eliminate that organism and now they're being seen at Duke for seizures. which is one of our published cases many years ago with Chris Woods at Duke.

Yeah. And I highly recommend, in the show notes, many of Ed's, probably all of them, articles are there and so many fascinating and important research.

But you mentioned the neuropsychiatric symptoms, the seizures.

Why Vector-Borne Disease Matters

First, with Bartonella, how common is Bartronella in neuropsychiatric issues? Well, you're asking my opinion, so this is only my… Yes, absolutely your opinion.

Based on your years of research and knowledge. Well I'm pretty well convinced at this point in time that Bartonella is a very important and very major contributor to a spectrum of human neurological diseases.

And I base that on the fact that we've A paper that we published last year in the Journal of Central Nervous System Disease, which was a case report for a child in Canada, was of critical importance to me because that child was scratched on the face in Cananda in middle of the winter by a feral cat.

That's important because we know the prevalence of Bartonella in feral cats is extremely high. We know that cats can carry that bacteria around in their blood for three to five years because, we've cultured cats over that period of time and demonstrated persistent bacteremia.

We also believe, based on laboratory studies primarily, that cats have to have fleas on them to be able to transmit Bartonella hensilei to a human. And it's because when a flea takes a blood meal, it amplifies the Bartonnella in the intestinal tract and actually deposits infected Bartonella henselei onto the skin where it grooms and contaminates the nails for at least 15 days in laboratory study.

The reason this occurring in the winter up there, I'm really surprised that a feral cat in Canada that time of the year could have any fleas and therefore, but we are sure when that scratch occurred and we're also sure, when my lab tested brain biopsies from this child, he was eight years old, so six years later, that we used two culture media.

We did more PCR testing than we would tend to do on any samples we've gotten into the lab because these samples were so valuable. And both samples, we were able to amplify Bartonella hensile from the brain biopsy.

So what that story or that clinical case says to me is that Clearly, the cat was the source of infection. The infection persisted. It actually caused disease on the same side of the brain that the cats scratched the boy.

And the reason brain biopsy was done was not so we could do Bartonella testing. That was insisted by the parents. but because they thought the child had Rasmussen's encephalitis, which is a unilateral cerebral en cephalitis.

That's just one example, but it tells us that this bacteria can persist for a long time. Decades ago, we used microglial cells from cats cat brains that we cultured in our laboratory.

We infected them with Bartonella hensile. we kept them in culture for six weeks and used genomycin, which will kill all the extracellular bacteria, but genomysin won't penetrate cells, so it doesn't kill the intraceller bacteria.

So we washed these cells. Lice the cells and we grew Bartonella on a blood auger plate. So for our audience, that's important, obviously, because the microglia is the professional macrophage within the central nervous system.

We have known for a long time that Bartonella can induce persistent infection within most important cell in the brain that controls infections. So I'll kind of stop there, but I think it causes a spectrum of neurologic disease, certainly including PANS.

Yes, absolutely. And clinically, we see that. I mean, in our children, and our practice, you know, the numbers are at least 40, 41 percent, just in little practice of children that have the clinical diagnosis of PANS or autoimmune encephalitis of the basal ganglia and have documented Bartonella.

That's not even to mention all the ones that maybe were missed because we didn't do correct testing or the testing on that particular day was negative.

And we'll get to all of that because I think it's so important. But I thinks that the other piece that you were saying is, and I read that article, it is amazing, is that even though we talk about vector-borne diseases and fleas being one of the vectors, not just ticks, in this particular case, maybe not fleas either.

And I think there's such a spectrum of how this particular disease can get transmitted that it's so important.

Bartonella and Neuropsychiatric Symptoms

So what makes Bartonella so uniquely capable of causing these chronic, relapsing, acute neuropsychiatric

symptoms compared to other infections? So it took me a long time as a veterinary internist trying to study and understand vector-borne diseases to come to the conclusion that many of, even our tick transmitted infections, if we talk about Ehrlichia, Anaplasma, Babesia.

The goal of those organisms is to evade the immune system. They really do not want to, it's like a veterinary example, is you really don't want a hitted elephant in the back end.

You just are going to aggravate him and he's going turn around and do something you don t want him to do. These organisms are smart enough to not aggravated the immune system.

They're smart enough to not burn down the house they live in. And on an evolutionary basis, they have been around for millions of years, co-evolving with animals, including us, and with the vectors that transmit them.

So all they want to do is get back to the skin and get picked up by another flea, another tick, or another sand fly. As you pointed out very early, I'm so glad that you did it.

We all need to think more and more about vector transmission and the vectors an individual can be exposed to. A lot of the evidence becomes circumstantial based on cases, but right now we've reported rat mite transmission of Bartonella hensilei to both dogs and humans.

The French have reported pigeon mite, so essentially Bartonella quintana, the trench fever agent, transmitted where a person's up in an attic cleaning out areas where there were a lot of pigeons and pigeon waste.

Again, you also alluded to the fact that, With cat scratch disease, there's examples of people that seemingly had classical cat-scratch disease from a rose thorn or from Bob wire tear in their skin and transmission.

Again, a lot of that was published before we knew that Bartonella Hensile caused cat scratched disease. But transmission is much more complex. Ant bite transmission has been reported in Australia.

It's been recorded in the United States. And so we're not just talking about ticks. We're just not talking fleas. we are talking a lot of different vectors.

I have made the statement it lectures because I figure if I'm wrong somebody is going to come up and say you're crazy. that as far as I can tell, Bartonella is likely transmitted by a broader spectrum of vectors than any other vector-borne organism we know about.

And if that is true, that makes it a much greater threat than an organism that's only transmitted one tick species or one or two tick and can't be transmitted anything else.

Yeah. And I talk to parents about this all the time because they're often so confused. They say, well, my child was never bitten by a tick. I've never taken a tic off.

Well, first of all, in the Northeast, where my practice is, that's impossible. These tics are the size of poppy seeds sometimes and can still transmit.

But as you're saying so eloquently, there are so many different vectors and many more that probably we don't even know about yet as the prevalence of this disease continues to grow.

So when you think about it, Ed, what do you thing about as red flag symptoms that clinicians or parents should look for that suggest that Bartonella may be part of their pan's symptoms?

I think the certainly confusion initially, sleep disturbances are very, very important and are right up at the top of every publication we've done, regardless of the age group, that we can document Bartonella infection in the blood by molecular mechanisms.

Hallucinations are not frequent, but they've certainly been in some of the children that we've tested that would have been the pan's age group. Nightmares and alterations in dreams, having scary dreams including some children who have actually reported that they thought a cat was chasing them in their dream, which is just a little weird.

You know, for me studying Bartonella and cat scratch disease history and everything. I mean, I think so often And it's variable depending on the age and how the Bartonella was transmitted.

I'm guessing that many of the PANS cases reflect a fairly recent transmission of bacteria. at a time where the immune system is capable of responding fairly strongly, but not capable eliminating the organism.

I think it's very important that everyone understand that we've gone from thinking that veterinarians, veterinary technicians, wildlife biologists, people that have a lot of animal contact, a little exposure to vectors were the at-risk group, My thinking now is you'd probably have to work pretty hard to get through life without being exposed to and infected with a Bartonella.

With that said, most people clear this infection. In many instances, it probably never gets further than the scratch on the skin, and that's the end of the story.

Right. So why, I have so many things to say after all of that, but let me just lead on that one. Why do you know or does anyone know why some people are more susceptible?

I mean, certainly other infections that are suppressing the immune system would make you more skeptical, But are there any genetic, genomic or other factors that make one person more suspectable?

Do we know that yet? I think what we know is that if you're severely immunocompromised, so if we go back to how did we figure out Bartonella exists on the North American continent, it was because of the AIDS epidemic.

So prior to 1990, Veterinarians didn't know cats had Bartonella hensile, Bartonella chlorigiae, and a number of Bartonnella's that cats can have that fleas can transmit.

And because of the AIDS epidemic, we figured out, gee, have Bartoneslla here. Then we've figured we had two or three species of bartonellas on the North American continent.

Skin Lesions, Rage, and Diagnostic Clues

We're now in excess of 60 species. That's all happened since 1990. And the unfortunate part for me as a veterinarian, which I've certainly said in other lectures or podcasts, is that I'm responsible for all the animals that on an evolutionary basis have become the reservoirs for these Spartanella species.

And then I keep trying to explain to people, don't blame the animal, you can blame to vector or you could blame bacteria, but don' blame animal. It's not the anima's fault.

So yeah, I think. Back to your question. Yeah, I think, you know, one of my questions was also about the symptoms. And I just wanted to bring up a couple of others that you mentioned, the nightmares and all of that.

In little children, we may well just see that as anxiety. or even as rage. One of the symptoms we see a lot is anger and rage and agitation. And it may be because they're not understanding the nightmares, the hallucinations that they are having, feeling they were being chased by cats, however small or big.

That would be, although I'm a dog person, I am not a big cat person. So that would a nightmare for me. But anyway, and sort of that unrelenting, almost daily flair with so much of pans and pandas, we see a relapsing and remitting course.

When Bartonella is part of it, it's almost like they're always confused, as you said, or agitated in some way. So I think those are really important. Do you see the classic Bartonella stretch marks as a necessary ingredient or as we

do?

Yeah, we're lucky if we see it, but there is a lot of Bartronella when we don't see that. Absolutely. I think, Nancy, you're familiar with the stretch mark story as am I.

When I first would attend Lyme disease meetings and lecture on Bartonella, I would have physicians come up and say, "I see these children that have stretch marks and we test them and they have Bartonella." I thought, The stretch marks have nothing to do with the Bartonella.

And then as time went on, you know, we would get samples of both the stretch mark or the blood. I believe that those stretchmarks were associated with Bartonella.

We did one study that's entitled Bartanella Associated Cutaneous Lesions in Patients with Neuropsychiatric Illnesses. The importance of that paper is that we work with a dermatologist, and it wasn't just a human dermatologists, obviously, it was just stretch marks.

There was kind of a spectrum of skin lesions that people reported. Certainly the strea-like lesion or Bartonella cutaneous tracts, I think, are the most common skin manifestation.

And as you said, most people do not develop that manifestation, unfortunately, because the Lyme erythema migrans, if you have that, it's fairly prototypical and it would help us say Bartonella testing is definitely indicated.

But yeah, the skin lesions component is really important. The other thing that you just commented on is our initial studies with veterinarians, that questionnaire we have is fairly extensive on animal contact and all the different things.

Unfortunately, what we didn't separate out was anxiety and rage. So it was kind of like anxiety in rage and there's a study that we did with Duke infectious diseases in which Chris Woods and his fellow actually went to a international veterinary meeting that occurs each year in Orlando collected blood from people who knew they were going to be tested for Bartonella because that was all done under IRB approval, obviously.

And the reason I mentioned that study is what they could put a p-value on was those veterinarians that were bacteremic, not just had antibodies to Bartonella, had checked the box on anxiety and rage.

And so exactly what you said, and I know Dr. Bransfield and other people feel that perhaps amongst the three Bs, if there's rage, not just anxiety, that Bartonella may be more of a consideration in regard to a differential diagnosis.

Absolutely. And I agree with Bob, Dr. Bransfield. You know, that's what we see clinically also. typical stretch marks of stress or growth, you know, that sort of thing.

And I've seen them on the knee, I have seen on them the forehead, on back of the neck. You need to be looking for them. As you said, the paper that you talk about the cutaneous manifestations with neuropsychiatric symptoms is so important because that's exactly what we see.

We've tested them dermatologically taking a biopsy as well as bacterimically. And it definitely coincides with the symptoms they're having. Yeah. And the lesions respond to treatment for Bartonella.

They will resolve. If the infection is eliminated, they don't come back. Right, right. And we do see, I want to remind parents of this though, often as we start to treat, those stretch marks, just like the behaviors, can flare.

It can be like part of the Herxheimer reaction.

Why Bartonella Is Missed in Standard Testing

They look like they're getting worse before they get better, and we certainly see that. So for you certainly, Ed, and

definitely for me, Bartonella is such a big part of PANS.

Can you explain at all or in your opinion why it is so misunderstood, not diagnosed, or not even accepted? When you look at the CDC, it doesn't cause problems.

Why do you, in you opinion, why is that? The team that I work with on a research basis here, and Dr. Ricardo Maggi in particular, that we've worked together for 23 years, Ricardo is a molecular microbiologist.

We've constantly prayed for a tipping point for Bartonella. where it would be acknowledged as being an important pathogen worthy of study and worthy funding.

To an extent, I think we have either reached that tipping point or are approaching it just based on the publications and based the fact that physicians are now using the term Bartonellosis and rather than just focusing solely on cat scratch disease, which has been historically very important because there is the atypical cat-scratch disease.

Meaning the patient had maybe the classical signs, but then went on to have many non-classical symptoms. Not the fever, not the lymphadenopathy. I think my It is so hard to change paradigms in medicine and that doesn't, whether it's human medicine or veterinary medicine, you know, there was a publication that basically after the Bartonella associated cutaneous lesions has said, these have nothing to do with Bartonella and they're just stretch marks and this is ridiculous.

So it is easier to reject. something than it is to say, is there any basis in fact here and let's look into this situation. As far as I know, NIH has not funded one clinically relevant Bartonella study in the history of the National Institute of Health.

So, you know it's very hard. And that goes back to the question you asked me about, what do I think about Bartinella in neuropsychiatric disease or neurologic disease?

And I made it very clear that what I was going to say was my opinion, because if our National Institutes of health is not funding any research in an area, where we think an organism is important in neuropsychiatric disease, my opinion isn't really worth too much.

Well, in this podcast and in my world, it's worth the world. Thank you, Nancy. I mean that seriously. And as you know, Dr. Wells, Doctor Ingalls and I are currently doing research with the company, the lab that you co-founded, Galaxy, looking at how PANs clinically correlates with both an established questionnaire and with the testing that Galaxy does.

And one of the things I wanted to say is how much I appreciate the integrity, the external validation testing, and the clinical improvements and laboratory improvements that the Galaxy continues to do to try to better understand not just Bartonella, but all three of the big three B's, Borrelia, Babesia and Bartonella.

And I think it's so important that this research continues on all levels, clinically and in the lab. But why do you think, and I I you mention this a little bit, you know, we know that Bartonella is a stealth infection.

Maybe you can talk about that a bit more. Um, but and also induces immune deficiency as well as is more difficult to find and treat if there already is immune deficiency.

Are those all the reasons why standard blood tests and antibody testing so often fail to detect Bartonella? Yes, they are all part of the reason. So when our Bartonella research started in and around 1992-1993, shortly after Bartronella was discovered, because a rickettsiologist, so my lab had been studying ricketsias, Ehrlichia, Rocky Mountain spotted fever, anaplasma.

So just a different group of organisms, all tick transmitted and all infecting dogs and humans. Russ Rignory at CDC at that point presented data saying, we found the organism that actually causes cat scratch disease.

And he said that because for almost a hundred years, virus has been suspected as the cause, rickettsia had been suspect as a cause. A organism found by the Armed Forces Institute of Pathology called aethypia fetus was thought to be the cost.

And lo and behold, finally Russ gets up in front of us at a meeting and says, we found the real cause of cat scratch disease. and since I'm a veterinarian and I take care of cats, I thought, well, We ought to know something about since it's cat scratched disease, what's it doing in cats?

Back to your question, I had been on a PhD student's thesis committee and we had done experimental infections with Borrelia burgdorferi, the cause of Lyme disease in dogs, to try to understand that.

And the mistake we made, and a lot of other researchers had made was we grew the Borrellia burgdorfari up and the laboratory and we injected them in the dogs and then we followed the dog.

And for nine months they wagged their tail and didn't do a thing. That's not very good for a PhD student. And what I learned from that, not being a microbiologist, is that if you have a vector transmission and you really want to understand what the organism does, you had to transmit it by a factor like a tick, which Cornell then went on and did in dog studies and other people did with other animal studies.

Why that was so important was when As a result of that experience, when we decided we were going to infect cats with Bartonella, I got a cat that had caused cat scratch disease in a son and in the father, and it made the Father really sick and he was hospitalized.

The son had classical cat-scratch disease with fever and lymph adopathy. He missed a day of school and then was fine. But then another cat, that caused neuroretinitis in a lady being seen by UNC ophthalmology.

And so we did our studies by blood transfusion. Why that's important was other labs were growing Bartonella up on a plate. characterizing the inoculum, putting them in cats, and within weeks there was no Bartonella.

New Species, Transmission Routes, and Pregnancy Risk

Our cats remained infected for nine months before I contacted Bayer in Germany and said, I've got all these cats. I infected them with blood transfusion.

And I expected them to behave like the ones everybody else is saying cleared the infection and they're still infected. So what we also published in those early papers is Bartonella is in the blood, out of the, blood in blood.

So for my research study, we've insisted on a triple draw, meaning a person has to submit three samples collected in seven days. And we published it in The Journal of Clinical Microbiology years ago that by doing a Triple Draw, you will increase your ability to detect DNA of the organisms.

Obviously, this is costly, it's complicated, and it is complicated for the patient or the parents that are trying to get these three samples pulled within a week and then stored and shipped to a lab.

But the reality goes back to what you were saying earlier is this bacteria hides so well, it's not always in the blood. I think it likes to be in tissues and that's a really important thing we're learning about the treatment component of Bartonella is getting rid of it in blood is probably not hard.

Getting rid in all the tissues in which it can infect is the much more difficult part of you know, medical management, whether I'm treating a cat or a dog or you're treating the human.

Yeah. Just a couple of points on that. Clinically, I have a young man in our practice who has continued knee pain, swelling, effusions. The effusion didn't grow.

The tissue, the skin tissue grew Bartonella after years of treatment. And in addition to that, in the study that I just

referred to, that Dr. Wells, Dr Engels and I are doing with Galaxy, we have a few children that we've been able to do triple draws on.

It's hard in kids. Sure, absolutely. To get kids to one blood draw. I understand that. But in ones we done triple draw, often we found one day we see the Bartonella, the other two, there's nothing.

And so here you have these parents, you know, they've got the symptoms, They've Got the stretch marks. They got to rage. they got The neuropsychiatric sleep symptoms and all of that.

and yet they do the blood test and it's totally negative and they're like, well, I guess it is not Bartonella. My point is, it may still be Bartonnella.

Yeah, we've honestly, when Ricardo joined me 22 years ago, he came from a company in Italy right after he had done a post-doc. And, you know, He's just a great guy to work with.

We've gotten along pretty well to working together this long. He says, what do you really want me to do Ed? And I said, Ricardo, I'm a clinician. I am going to bring you a blood sample from cat or a dog, and I want you to tell me whether it has Spartanella in it.

and i want to be right 98% of the time. 22 years later, we cannot do that. And it's exactly what you just said. I think on a research basis, I thinks my lab can do it better than anybody in the world, because we've worked very hard on it.

But we got a long way to go to have the test that has the absolute sensitivity to be able to say that a patient does or does not have Bartonella. After 22 year, s I wish I wasn't saying that, but honesty is the best policy.

Yeah. And that's in what we would consider a specialty lab. We're in research, but parents who cannot afford the specialty testing that may be slightly better with conventional standard blood testing.

I mean, I've been in practice for 30 years. I've never seen a positive Bartonella from a standard conventional lab and I have, like I said, 40% of my kids with PANS have Bartonella.

Right. Galaxy is able to do now, which we developed here at NC State, thanks to the Cohen Foundation in New York, because the Coen Foundation bought us a piece of equipment that was about a half a million dollars to an academic institution, and that's a lot larger than the research budget for equipment for the entire college that comes open every year.

And so it allowed Ricardo, there's two parts of that. One, it increased our sensitivity of saying Bartonella DNA, yes or no, just due to the advancement in technology.

And then the one advantage we have in veterinary medicine is the reservoir host, whether it's a cat, a dog, or rat, bat, whatever, they maintain higher levels of the bacteria in their blood.

than does the incidental host, which is us in this instance. And so, we were able, with Babesia, Borrelia and Bartonella, to get isolates from all different types of animals, and all types, of Bartronella Babesea and Borrelia species.

and that was through collaborators in Europe and the United States. So if you look at those validation studies with digital PCR, it's not just that they'll detect one species.

Generally, we've designed them to try to detect as many or most or all species in some instances. I think the technology improvement has helped us Clearly, the enrichment culture helps us, and doing triple draw helps.

But trying to commercialize that into something that is CLIA approved can be done consistently as you well know in the laboratory every day. And a doctor will actually order the test and an insurance company or a patient could

actually pay for the tests.

All those things are extreme complications that when we started Galaxy, I was somewhere between stupid and naive. I'm a little smarter now. Well, and as you said, there are 60 species of Bartonella and we are only testing at most for two in most conventional labs.

That's true. And so we're missing multiple species. In addition, we were only checking the serology, the immunoblot. We're not checking culture, DNA, other ways that Galaxy and other labs can measure it.

Absolutely, and I kind of want to interject this example because it's my computer and it is the last 48 to 72 hours and a 70-year-old lady in California who was walking her dog one evening just before dark and had something strike her ear.

She felt like when she went up to reach it, it was fuzzy. And she actually got rabies prophylaxis because she strongly believed she had seen bats on her walk and she believed it as a bat.

Bartonella maotinensis was, so this is a Bartonella species and it's a good example because it was found in a human in the United States when they went in and took his heart valve out.

So one of the things Bartonnella causes that nobody debates is culture negative endocarditis. It's culture negative because Bartonella's are so hard to grow.

Treatment Challenges and Clinical Recovery

And in most instances, if you send the sample to the microbiology lab at the Mayo Clinic or anyplace else, and they do standard microbiological testing, it's going to be negative.

In this instance, he had culture-negative endocarditis. They went in, they put a new valve in. Using DNA techniques, They said, gee, this valve is chock full of Bartonella DNA, but there's no match genetically in GenBank, meaning this is some new Bartonella.

We knew about that from the publication that was generated by the Mayo Clinic and the group over in France that work with them. For about five or six years, we didn't know what the vector was and we did know with the reservoir was.

So now we've got a person that's developed a Bartonnella classical infection, endocarditis. Well, it's a bat that transmits it. So, and there's been a more recent study on bat-transmitted Bartonella from the University of Washington Infectious Disease Group, where they included another two patients, as I recall, with Bartonella meiotensis.

And unfortunately, there wasn't a lot of clinical data associated with what their risk factors were or what have you. But it's just an example of, you know, we worry about bats and rabies.

Should we be worried about the bats in Bartonnella? Right. Well, we should now. So is that what this 70-year-old woman has, or do you not know yet? We don't know.

She just contacted me literally two days ago. You know, I sent her the original paper published in Emerging Infectious Disease by CDC on Bartonella meiotensis, and we'll see where things go from there.

Wow, wow. So we should be testing for and possibly treating preventatively for when we have a bat bite or a suspected batbite. We should treating for Bartonella in addition to rabies.

Well, I would not say that. I will say at this point in time, hopefully most Bartonella transmissions are, regardless of whether it's a cat scratch, which is far more common than a bat strike, are going to be self-limiting.

We've got so much to learn about this genus of bacteria to make good public health recommendations based on an exposure. Right, right. And as you said, many people do not get sick with this.

Absolutely. You learn so much in the AIDS epidemic because those were immunocompromised people for other reasons. As our children, I think, we often hear that a child with pandas then gets Bartonella.

So Strep sets the stage. causes the autoimmune encephalitis of the basal ganglia, and whether Bartonella be in the background or Bartronella comes in afterwards, then that dysregulated immune system is more susceptible.

Yeah. It's an area that deserves some real research, that interaction between Strep and Bartinella. And as you alluded to, who's there first? Is the Bartnella there Yeah.

Yeah, and what about pregnancy transmission? So it's a neglected area for all vector-borne infectious diseases. And I would start with that statement.

Certainly, we know from Zika virus that a mosquito transmitted virus can definitely cause an epidemic of transmission amongst fetuses. And if we go back to Bartonella, there's not been much research.

And we published a case report, again, that I think is very important because it was a mother who had classical cat scratch disease. Years later, she gets married.

She has extreme problems getting pregnant, which has also been something that we've seen with some of the young veterinarians that have tested who wanted to have babies, and we were testing them generally for other reasons, including neuropsychiatric symptoms that they had developed.

What ends up happening is through in vitro fertilization, the mother gets pregnant. She has twins. Unfortunately, one of the twins has a congenital cardiac defect and dies at nine days of age.

And the Mother sends me an email 10 years later. The remaining twin, the son, has had medical problems the entire time, including learning disabilities and other things.

The mothers had chronic cognition problems, memory problems and headaches. And what is so important in that is we were able to work with the pathologists in New York and get the tissues from the child that died and blood from mother, father, and son.

little girl that died, the mother and the son were infected with two Bartonella, Bartonella vinsonii burcoli and Bartonnella henslae. We were able to sequence that from samples from all three of them down to the strain type and genotype for Vinsonia burculi.

So that can't occur by chance alone. And the children were born by cesarean section, so we called it perinatal transmission, but I think it's pretty obvious that she was infected in utero.

We could only get in Sonya Iberkolfi out of the husband. The stories are complicated. If it weren't for the techniques that we kept trying to develop and make more sensitive, the stories wouldn't exist.

So we really need to know how often Bartonella is transmitted, you know, child. Yeah, and so often in mainstream medicine, these case reports, case studies are dismissed.

They're not double-blinded, randomized, controlled studies. But I think the stories, not just the clinical story, but the laboratory story is so important for our learning and for understanding.

And we have to put more meat into those because they're real, they are life. Go ahead. Well, I agree. 150%, if you can have an additional 50%. I usually don't think about this or relate it, but a good friend and colleague and I started the Journal of Veterinary Internal Medicine.

It was actually started in a bar over wine one night. And is now one of the most prestigious internal medicine journals in the veterinary side. And I think I bring it up in as much as I've always argued for the importance of case reports, because science often starts with a clinician who makes an observation that is absolutely unique and it has the guts and because publishing things is not easy to put it out there, have it reviewed by his colleagues and ultimately be other people can read it.

And then all of a sudden, somebody else finds five or six cases of the same thing, and that becomes a cohort study or a case series. After that, finally, you can start getting some hypothesis-driven research to try to understand naturally occurring disease.

It just brings up one other thing that I don't think I've ever said in a podcast, but Barbara Haggerty, who was my research associate for 29 years, and we worked in a BSL3 lab together with Rickettsia rickettsii and these other organisms.

I finally walked in one day and said, Barb, I don't want to ever do another experimental infection in my life. And I want a study natural disease. We're going to study natural disease and we may be successful or we might not.

And so, you know, I think studying natural diseases exactly what you said. It's studying what's happening in patients, be they a cat, dog or human, and trying to understand what we're missing.

Right. And I take it back one step beyond the clinician to the parent, to patient. Absolutely. As a clinician, we have to listen. We have be curious. You have listen to symptoms, the signs, and the whole history back to how the baby was born, all the things that may have gone on.

It's in that listening that I find that we can then say, wait, I heard that story before. that patient tested positive for whatever, let's think about it in this kid.

And I think that as clinicians, we need to say that and as parents that are listening today, you know, make sure you're thinking about those things and find a clinician that will listen.

Yeah, and you know and I know that that's a tremendous problem in human medicine is having the time that a pediatrician or internist or general practitioner can actually listen to the patient.

I still spend a third of my year in our specialty hospital seeing referral internal medicine cases, which are cats and dogs. I still train veterinary students, interns and residents, and particularly my residents.

Okay, you got a history, did a physical exam, now run all this lab work, done ultrasounds, EKGs, but you don't have a clue what's wrong with the animal.

The Need for Centralized Funding and Research

What are you going to do now? Go back and get the history. Yeah. That's what I tell him. Go back and get the history. Right. The history of little kids is about the same as the story of the dogs.

You know, that dog's not going to really tell you. They may show you, but they're not to speak the words unless we're watching a movie like Good Boy or something like that.

But anyway. Yep, I hear you. And one last thing, Ed, before we close up is, in your opinion, can these infections be treated? Why are they so difficult to treat?

Can they be cured? Or is remission a more realistic goal? In your One line I draw is I'm a veterinary internist and I don't treat humans and. I do not consult on treatments with humans.

So when the questions come up, I just refer them elsewhere. But I think the case report that we published on the boy with pans literally changed the direction of our research because that before that, we were looking at

Bartonella and endocarditis, myocardiitis rheumatologic presentations.

And that case, because the boy was homicidal, suicidal, Because the family had paid a half a million dollars or the insurance companies had in medical fees before a nurse saw strea-like lesions and suggested to the doctor that the Boy be tested for Bartonella.

He was also treated for a month of doxycycline before we got involved when the father contacted us. And after a months of Doxycycline, he was still positive for Bartonella.

We've also reported a veterinarian that was treated six months with Doxxycline who was having seizures and status epilepticus and other really serious seizure-type manifestations that failed six-months of DOXY.

Since you're asking about treatment, you know, DoxiCyclone may clear Bartronella, the immune system was going to do it in the first place, but my bias is you cannot float a cat, dog, horse, or veterinarian in enough doxycycline to eliminate Bartonella if it's been a well-established infection.

So treatment is complicated and I do think treatment can be absolutely successful. I think we need the studies that are highly structured and controlled with the diagnostic testing that is state-of-the-art to help physicians follow these treatments to ultimately determine that we have truly eliminated Bartonella.

And yeah, so yes, that boy went, you know, I probably have 150 emails related to that single case report. And he went from all these neuropsychiatric symptoms, which were well detailed by his parents and are in graphs in that publication.

to being treated by several physicians that consulted on that particular case. And I think what's amazing is, you know, the emails I would get from his father is he's doing so well, he is dating again, He's back in his fencing again.

He actually has a job. he has now been admitted to The Ohio State University. As well as I know he graduated last year in pre-med. Wow. Wow, yeah. And there are hundreds, if not thousands, of those kind of stories.

But it's not easy. As you said, it is not just doxycycline. It's often more than one antibiotic that is needed. Now we're seeing resistance, for example, to azithromycin and chlorythromysin together with another antibiotic may be better.

Go ahead. You want to say something before? I do, Nancy. We need, and I think again, as a result of the Cohen Foundation and being on some key opinion leader panels with very distinguished scientists and physicians, we need a national cancer institute approach to neuropsychiatric disease and chronic infection that is central, funded, We need to go back to where we were in the 60s and 70s, and say, we may have an epidemic and pandemic that is so important that we can't just have a few centers of excellence around the United States.

That's the only way we're going to address this problem, in my opinion, and in a way that might be meaningful for a parent who has a child now or a parents who's gonna have a job with pens, pandas, 10 years from now.

Closing Thoughts and Hope for Families

Absolutely, because not just Bartonella, but many of these infections, it's not about just the infection. It's about the effect on the immune system, the crossing of the blood-brain barrier, and therefore the autoimmune encephalitis or the inflammation in the brain.

And all of that is so important. Ed, I cannot thank you enough for all your years of research. your generosity of spirit and your continued work in this field.

We couldn't do what we do without you. And I have to say, if anybody's ever listened to my lectures, more of your articles are in many of my lecture than almost anybody else.

So I so appreciate everything you do. Thanks, Nancy. And again, I just want to credit the team I work with and the

folks that have funded us, which has really been foundations and donations to allow us to do the work we've done.

So, thank you very much. No, Thank you. Any last words of wisdom or hope you want leave our families or practitioners with? Well, I think the whole concept of chronic infection, inflammation, autoimmunity is now gaining some momentum across a number of fields.

And the technologies that we have continue to get better. Who work in this area know the limitations, so we're not going to stop with the technology development, with engineers and the others that can make the testing even more sensitive.

So I think it's a very, very hopeful time. And I think a lot of people are coming to the conclusion that we don't understand what these chronic infections are doing in the context of a person's lifetime exposure and duration of infection and relapsing diseases over that time.

So I'm very hopeful that were very close to a point that won't be so solid where we're only looking at Lyme disease or we are only look at Bartonella.

that we're going to figure out that, we are a very complex microbial system and that periodically some organism comes along and upsets that microbio system.

Yeah. Well, here's to hope. And thank you, Ed. For those of you looking for more information, the information on Galaxy, et cetera, will be in the show notes.

Thank you again for joining us and we'll see you next time on Demystifying Pan's Pandas. That's it for today's episode of Demystifying Pan's Pandas. I hope you're walking away with insights, tools, and hope to help you and your child on this journey.

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And if you have a moment, leaving a review helps us reach even more families who deserve answers. Also, for more information, training, and community, check out our website, drohara.com and join our annual membership.

And remember, every step forward, no matter how small, brings us closer to healing and understanding. Until next time, be present, Be hopeful, And we look forward to seeing you next on Demystifying Pan's Pandas.