

250618_DrShiling_Recording

Dr. Shilian

Yes, so you have some dust mite allergy. This is a good handout to read. What you want to do is, dust mites are everywhere, they're microscopic. Regardless of how much you clean, they're everywhere. They feed off of our dead skin, and you're allergic to their body parts. So we need to kill them. The best way to kill them is to wash everything that could be washed on your bedding in a hottest setting every two weeks. And then to get rid of the body parts, they stay behind in your pillow and mattress. So you want to get some encasing for your pillow and mattress. So you could call this company or any other company that's where they have good products and get an encasing for your pillow and mattress.

Me

I've got covered on that already. And now the only thing I think I might need to do is my down comforter, maybe. Wash it over to us. Yeah, get that, get a casing for that. But question about that. I guess it said I was allergic to one of two types of dust mites. Is that a thing?

Dr. Shilian

Yeah. So, but they're common here.

Me

They're common here. Okay. Got it. It was like European versus American. I don't know.

Dr. Shilian

There is cross reactivity regardless.

Me

All right. Good to know. So, I think I've always kind of known that a little bit. If I don't, you know, wash my sheets or whatever for like, you know, a few weeks, it gets stuffy a little bit. Yes. But nothing ever really bad.

Dr. Shilian

You have significant markers for mast cells.

Me

Yes. Yes. Okay. So, let's get into it. I'd love to hear what this is because I can't make sense of it.

Dr. Shilian

Yes. So, I advise you against reading things online because they can just take you on a wrong path.

Me

I didn't, I just figured I'd talk with you first. Yes. Yeah.

Dr. Shilian

So, you, so what happens is everybody has mast cells. They're basically a type of your immune cell and they're present in every tissue in the body except for the brain. But even the meninges have it, the lining of the brain. They have a receptor called the IgE receptor. The receptor itself is called the IgE and this is a mast cell. Mast cells contain histamine. Under normal circumstances, the histamines don't get released unless there is an allergic reaction or there is a some form of an infection.

Me

I have no idea that's how histamine gets released in your body.

Dr. Shilian

Yeah. Okay. So, under normal circumstances, unless you have environmental allergies, food allergy, or some infection, histamines don't get released. In your case, your body is spontaneously triggering this receptor. This is a very simplified version. Okay. There's a lot more going on.

Me

I'm sure. Yeah.

Dr. Shilian

So, your body triggers this receptor and causes spontaneous release of histamine. And that's where the term mast cell disorder comes from. So, there are, there's mast cell activation syndrome, which you don't meet the criteria for that, but you're on the spectrum. You have mast cell disorder. So, your plasma histamine is significantly high. So, you see it's 9.4. Normal is less than 1.8. Your, uh, PGD2 is high, where the 260.

Me

What's the PGD2?

Dr. Shilian

It's a breakdown of histamine. Okay. So, histamine, as I said, histamine is a tissue, mast cell is a tissue cell. It doesn't hang out in the blood for long. Hmm. So, that's why we, so, we normally check for the byproducts of histamine that comes in the urine, or in the blood. But in your case, even your plasma histamine is significantly high, which is unusual usually because mast cells usually don't hang out enough time in the blood for the levels of histamine to be elevated. But in your case, it is very high.

Me

Mm-hmm.

Dr. Shilian

So, that's significantly high markers. Then the next thing is, uh, we did a little bit of, so you have recurrent infections, so we did some immune workup for you. So, the numbers

are okay. These are, these are decent good numbers to have. So, immunoglobulin A, G, and M are normal. So, in immunology, we look at numbers, we look at function. So, that's one, not one number here. Right. You have, what we call the MBL deficiency. So, you have an immune deficiency. So, this is part of your, so, we have a, we have two immune, two parts of the immune system. That is, the innate immune system, and then the adaptive immune system. The innate immune system is, uh, less sophisticated. It tags, uh, normally tags stuff that, that don't seem like their self, and they try to destroy them. And the MBL actually is used for that, in that process of tagging and destroying, uh, bad guys. That's part of your initial immune system, and that's why you may be getting, you get sick a lot.

Me

Yeah, this, I will admit this was something I did, uh, look up, but of course, I want to come to you. Does that, does it have to do with, uh, bacteria specifically, or like?

Dr. Shilian

Mostly bacteria.

Me

I do get a lot of bacterial infections. Um, in fact, last year, you can see this, I mean, this was just the skin thing. It goes beyond that, but this is just an example. I had a skin infection, it was bacterial, would not go away on its own. Like, it, I had to get it removed because it wouldn't go away with antibiotics or anything. And then, every year or so, I get, uh, bacterial tonsillitis that only goes away with antibiotics.

Dr. Shilian

So you have immune deficiency, and it's, it's pretty, uh, it is, uh, moderate to significant, uh, deficiency. So because your numbers are not close to 200, you have, you have less than 52, so it's pretty low. So you had a higher risk, and what, what should we do about that? So let me go on to the next phase. So this is for strep pneumo. Yeah. This is the most common, uh, bug in the environment that could cause skin issues, but a lot of times upper respiratory. Do you get a lot of upper respiratory too? Infections? Or is it hard to beat? I mean, the tonsil itself could be caused by this. Yeah. So it's usually related to tonsils when it's doing, you know. Yeah. So you don't have adequate protection against this strep pneumo.

Me

That's what, okay. Because yeah, there's no reference or anything.

Dr. Shilian

Yeah. So, uh, I'm recommending a pneumonia vaccine for you. The one you got as a child, but you wouldn't be due under normal circumstances until age 60, but in your case you need it. Especially because of the MDL deficiency also. You want to boost this up.

Me

What, um, what, uh, is it like an overall, you look at the numbers overall, there's specific parts of the numbers that...

Dr. Shilian

what we want is numbers that are 5 to 10 to 15 all over. Oh, okay. Yeah. Got it. Well, at least most of them. Okay. But that's not the case with here. Okay. Got it. It's not horrible, but it's not for you. I would want it to be higher. All right. But overall, you're not a very allergic person. Uh, cockroach allergy is not really relevant here.

Me

No. Yeah. That's, I mean, I wasn't really surprised. Again, I am surprised with, I don't understand dogs and stuff like that. Cats and dogs, how I have problems with them.

Dr. Shilian

You have problems with them. So what happens is they attract dust mite.

Me

Yeah. Yeah.

Dr. Shilian

So you may be allergic to the dust mite itself that they're carrying and they're, they're bringing in with you. So because they're, yeah, you have Pets?

Me

No, I used to live with the dog and I, but you know, it was a little weird because I think that apartment actually had problems with venting the dryer, I think it actually spit dust back into the apartment and I had breathing issues.

Dr. Shilian

There you go.

Me

And it must have been that.

Dr. Shilian

Yeah. Most likely

Me

Huh...

Dr. Shilian

So, uh, when you have an infection, it needs to be very aggressively treated. And if that doesn't work, you may need to be on a low dose antibiotic every day of your life to protect you from infections. To protect you from, God forbid, life-threatening infections. And then this is, this would be our, the vaccination would be our first step to try to protect you from infections too.

Me

Okay.

Dr. Shilian

So you have a, you have an immune deficiency and you need to, you need to have immunology eyes on you. So a clinical immunologist needs to follow you forever.

Me

Okay. Uh, is this, uh, do you take, well, I guess if I'm going to have someone watching me, we're going to test a lot. Um, but is there like over time tests, is there any chance that any of this could be, I don't know, off or anything? One thing I do want to say that they marked wrong. I was not fasting.

Dr. Shilian

You didn't have to be fasting for this.

Me

Oh, I know. I just, they marked that I was fasting.

Dr. Shilian

Okay. That's their job. Because some of the testing the doctors want to know, they, that's what they ask everybody. So they ask everybody, uh, they may or may not mark a problem. But that would be, not really relevant to the...

Me

Question for you. Um, this is something else I read online, but of course I'm going to ask you for the real deal. It's food with histamine. Is that, is that a thing food that-

Dr. Shilian

you noticed some food trigger you?

Me

No, I just, I know that, uh, every day, I, well, I don't know, I have like balsamic vinegar for lunch. I have like, you know, leftovers, things like that. I sometimes drink alcohol. Like it's, I don't notice anything triggers me.

Dr. Shilian

Histamine, uh, alcohol will lower your threshold for reactions. Okay. So you just have to be cautious and see, especially older, older wine.

Me

Yeah. Yeah. Right. Like wine. Yeah. Yeah. I, I never,

Dr. Shilian

Some patients are very sensitive and when they have alcohol, they tend to have a reaction to some, to something.

Me

I mean, I, it's hard to tell because I've always felt like alcohol's affected me worse than others. But you know, it's always hard to tell some people.

Dr. Shilian

It could be because of the histamine.

Me

Yeah. Okay. It could be. Wine, I know. I mean, it gives everyone headaches, but definitely it's very much up in my sinuses and stuffy and, uh, all of that. Uh, okay. So,

Dr. Shilian

this is the plan. Yeah. Uh, you're gonna get vaccinated. And I can tell you where to go to get the vaccine if they don't have the vaccine in your local pharmacy. Uh, we have a, you know, pharmacy in the area that could order that for you. It's a very specific vaccine that I want you to have because we want to trace the markers. So there are other pneumonia vaccines that, that, that have come on board, but those will not have the good traces to, to, to check. So I want you to get this vaccine, the pneumonia, the pneumonia vaccine. I'll give you the order to get the vaccine. And four weeks after that, you do blood work. And then two weeks after that, I'll see you. So I'll see you in six weeks.

Me

Uh, so again, I, so I go to New York. Uh, actually I, I shortened the trip a little bit. I leave 29th, um, or this 27th of this month, excuse me. Uh, does it have to be four weeks exactly for the blood?

Dr. Shilian

No, no, at least four weeks. It could be five weeks. It could be 10 weeks. But at least four weeks.

Me

So we can get it. We can get it now and I could get blood tests done. When I get back.

Dr. Shilian

Yeah.

Me

Okay. And then, um, so based off the symptoms and stuff that I talked about, I mean, do you think this low immunity, I mean, can that cause general fatigue and weakness and...

Dr. Shilian

Yeah. Yeah.

Me

It kind of popped up. I mean, I never got immunity tests done, but all the symptoms popped up over the course of a month. I mean, does immunity change quickly?

Dr. Shilian

Um, it can, uh, it's sort of, you probably, the, the MBL will probably stay with you, but the numbers may wax and wane a little bit. So it may go to a hundred and come back to 50, go to 30, but it's not something that normally fixes itself, unless there was a lab or something, which it doesn't make sense. It's most likely what you...

Me

you're, is there some sort of like resource or something I can read up on? Anything related to this that you would recommend?

Dr. Shilian

MBL deficiency? Yeah. I could give you something to read on.

Me

Yeah. Just sort of things that I can understand better. I mean, anything that, yeah, MBL and I guess the histamine stuff we can.

Dr. Shilian

I want you to be on a higher dose of antihistamine until the next time. Do you have, you still have recurrent symptoms, right? Like you talked about some sinus headaches.

Me

Oh yeah. Um, it's actually gone down.

Dr. Shilian

So you don't have symptoms on a, on a regular basis?

Me

So it was, it was, here's what's interesting. I had it consistently, it was like every Tuesday from January to like March or April. It was a few weeks before I think our first appointment when I first mentioned, right? So I thought I was going to be in crashes and I actually, I, I was waiting to do the 24 hour urine histamine collection because I was waiting for a crash, which didn't exactly come. So, um, I did it just the other day just to get it done. And so we're just waiting on those results, but I wasn't in like a particular crash, but yeah, I haven't had, again, not since earlier this year did I really have the, the crash with my, uh, like sinuses and all that, but that was very consistent when it was happening. I don't really know what changed.

Dr. Shilian

Okay. So I think again, things could also wax and wane. So if you don't have symptoms, I don't really need to start you on any regimen right now, but if things, uh, show up and you have symptoms, then we could, I could give you some medication.

Me

Yeah. I mean, the only thing again, is just the consistent, um, the muscle aches, you know, the, just the general fatigue and the exercise intolerance, which, uh, again, you know, I don't know how those relate to immunity issues. I mean, these are certainly things that we want to keep an eye on, but, and you know, manage, but, uh, that's still mostly what I'm trying to figure out. It's, you know, my inability to exercise properly.

Dr. Shilian

So what you could do is go on a course of, uh, a high dose on the [anti]histamine and see if that helps you. And that tells you if that's causing, uh, it's, uh, whether or not this is, uh,

actually playing a role in your, uh, in your symptoms.

Me

It's a little like empirical testing kind of thing.

Dr. Shilian

Yeah. Yeah. Yeah.

Me

And what's, uh, uh, what's, what's a high dose [anti]histamine? Is that like prescription?

Dr. Shilian

Uh, no, it could get over the counter.

Me

Okay.

Dr. Shilian

Um, I'll have you get Allegra, uh, fexofenadine, and, uh, take two in the morning and two at night for two weeks and see if that does anything for you. Uh, it could be because of your ME, um, ME/CFS, uh, but, uh, and if that's the case, then it's very easy after two weeks of being on this high dose [anti]histamine, you know, if there's any difference [unintelligible]

Me

Okay.

Dr. Shilian

So what you want to do is pick up Allegra, Allegra over the counter, and it's 180 milligram and it's going to tell you it's one per 24 hours, but it could safely take two in the morning and two at night for two weeks.

Me

Got it. Okay. Got it all recorded.

Dr. Shilian

Uh, there is, I want you to look up, uh, immunodeficiency foundation, immune deficiency foundation, IDF, immune deficiency foundation. Let's see if they have anything for MBL support.

Me

Okay. Uh, okay. As far as immune deficiencies go, I mean, um, I know there's people who have really bad immune systems who have to be very careful about going out and just things like that. I mean, how does this fall in terms of like all the different immunodeficiencies that are out there? I don't really know much about it.

Dr. Shilian

Uh, so there is, you could read about it a little bit. There is immunodeficiencyuk.org and

actually there is one about Ellie's story. You could actually take a picture of it.

Me

Okay.

Dr. Shilian

That may be another source of support for you.

Me

Okay. Yeah. That's great.

Dr. Shilian

It's, uh, really when it comes to immunodeficiency, uh, is you, uh, I guide you through the process. You don't have to educate yourself. Uh, you do it to, to be at ease and feel comfortable with the condition.

Me

Of course. Yeah.

Dr. Shilian

Uh, but when it comes to symptoms, you, you need to have, uh, just be in touch with me. As soon as you have an infection, you need to start an antibiotic. So, and, um, you need to be treated more aggressively. That the, uh, the emergency doctors and your primary doctors may shy away from. So your, your, your, your infections need to be aggressively treated for a longer period of time. With a higher dose of antibiotics. So we can suppress it and help you. Because if you end up doing the same dose antibiotic that you got in the past, then you end up having an issue again. Things, uh, not, not recovering.

Me

Okay.

Dr. Shilian

So, uh, printing out the form for you for the vaccine. And you get the lab books done in four weeks. And I'll see you in six weeks. And you let me know if anything comes up.

Me

Yeah, I'll, um, I'll get, I'll get them done as soon as I get back, which might be a little bit longer than four weeks. And then I'll see you in two weeks after.

Dr. Shilian

Okay. So. [Doing physical test]

Me

A little bit of earwax. Yeah, that makes sense. That tracks. I can't hear so well.

Dr. Shilian

D-E-B-R-O-X, Debrox can help you. Eardrop over the counter. Tongue Out... Check your nose, a little bit swelling but you have room to breathe.

Me

Yeah, definitely. I guess this is a bridge you can cross when we get there but for antibiotics I mean will that wreck my, my microbiome or anything, I have to go really hard on it.

Dr. Shilian

No, no. The thing is we put people with immune deficiency, [gesturing with hands] so this is normal, we're people without immune deficiency and this is people with MBL. So same dose of medication antibiotic for these people, so the higher dose antibiotic for you would be the same dose of [unintelligible] and the same dose of people for...

Me

Because my body doesn't... Oh, because it doesn't have the...

Dr. Shilian

The machinery. Yeah.

Me

Yeah. Okay.

Dr. Shilian

And god forbid that happens, then we'll deal with that. Okay. If we need to put you on a probiotic and... We'll do the repair workup that's necessary.

Me

And I should continue to try and raise my vitamin D because it's always been low, I should still try and supplement with that?

Dr. Shilian

Yeah.

Me

That'll help? Okay.

Dr. Shilian

Yeah, yeah.

Me

All right.

Dr. Shilian

Let me get your lab work and your requisition. Any questions for me?

Me

I think that's it for now. I'm sure I'll have more in the future.

Dr. Shilian

Any... Yeah, yeah, yeah. Just reach out anytime.

Me

Okay. Thanks.

Dr. Shilian

All right. One more thing for you before you leave.

Me

Oh, and this, uh... So moving forward with this, I just have to check in with like CVS or something, see if they have it and then they don't.

Dr. Shilian

Then I'll give you... I'll give you a pharmacy information before you go. Okay. I could just go right to...

Me

You want, we can. Yeah. I guess it's whatever is easier, right? I'll call up CVS first and I'll check out your recommendation if that doesn't work. Okay. Okay. I guess it's whatever is easier, right? I'll call up CVS first and I'll check out your recommendation if that doesn't work. Okay. They must have checked... Well, I guess... As a kid, they must have checked my immune function after I had pneumonia on it.

Dr. Shilian

It's hard to say. And nobody has ever checked you for MBL. Nobody was looking. Have you ever seen a clinical immunologist before?

Me

I've seen an allergist, but no one that's like...

Dr. Shilian

Most of them are not trained in immunology.

Me

Yeah. Not... That's a distinction. I mean, the... Allergists... Are focusing on allergies, not just the immune system. It's...

Dr. Shilian

Yeah. 90% of allergists are not trained in immunology.

Me

Yeah. That's why I see you have this... You have immunology in the title, so...

Dr. Shilian

Yes. Yeah. Yeah. I mean, all of us do. All the allergists do. Right. So, the problem is the training because there aren't... It's still very rare. So, not a lot of people... So, during training, they don't get exposure to the experience of handling the immune deficiency. I was blessed to be trained by... By the authorities in the field. Managed a few thousand patients with immunodeficiency, so... I was blessed to have that training. Yeah. I'll be right back. Give me a card. There it is. So, that's your blood work. I already sent that to Quest,

and the other one I gave you was for your vaccine. Great. Okay. And then, one more thing. Come with me. I'll give you the... Okay. If your pharmacy doesn't have it, This gentleman can give you the Pneumovax 23

Me

All right. Well, thank you, doctor.

Dr. Shilian

Great to see you.

Me

I'll see you again soon.

Dr. Shilian

Have a safe trip.

Me

Thank you.