

250822_DrShiling

Me

updates I've been I got my Pneumovax like you asked for. I mean that's really it on your end off topic but I saw specialis, I might have vascular thoracic outlet syndrome figure that out I got a lot of questions just about the MCAS and Mannen binding lectin deficiency

Dr. Shilian

MBL yeah yeah but

Me

the first before any of that I got my blood drawn a week ago I didn't get the results yet were you able to get the results

Dr. Shilian

not not back yet yeah we could send it to you and I could give you you know send us a message when you see it on your portal okay sounds good yeah I'm surprised the results are good or something else needs to be done or not just send a message on our portal on our website on the contact us page you go on my website there's a contact us page just send a message there or send an email and hey I just saw dr. showman last week he told me to follow up with you regarding my result usually comes to me just in case okay okay okay yeah I can see it's not normal if it's not normal usually it doesn't trigger us to reach out to patients so but if it's good it usually sits there in my inbox okay yeah I can see yeah I'll see you know okay yeah I can see yeah I'll see the results on quest when it comes in if it's abnormal just send a message and just say yeah I'll take a look at it and let you know hey you're good get the vaccine work or just say I got the vaccine the lab results were sent yeah they just resulted see what the doctor wants me to do okay and then I can reply to you or someone can reply to you

Me

okay okay

Dr. Shilian

yeah thank you so you're on uh... Duloxetine 20mg, vitamin D vitamin B12 okay and then magnesium okay very good

Me

yep

Dr. Shilian

excellent what's your question for me

Me

uh... let's see uh... let's start with uh... let's start with the mast cell stuff again so uh... can you explain to me what the criteria is for MCAS and if it's important that we determine what sort of...

Dr. Shilian

you need to have an elevated triptase

Me

triptase and I don't have that

Dr. Shilian

yes

Me

right so but I'm... you said I'm in some sort of spectrum of mast cell dysfunction mast cell disorder yes

Dr. Shilian

because of your biomarkers are elevated

Me

so there's no specific it's just mast cell disorder general

Dr. Shilian

yes

Me

okay

Dr. Shilian

yes

Me

got it

Dr. Shilian

as a matter of fact people have chronic hives have you met... do you have anybody... usually every family has someone with hives

Me

no I don't

Dr. Shilian

good good family

Me

yeah

Dr. Shilian

usually every family does people just get random hives those people have mast cell

disorder they're on the spectrum

Me

yes yeah yeah yes

Dr. Shilian

yes because their immune system is causing the uh... in a way acting like an autoimmune limited to the skin causes the release of histamine spontaneously and that people... those people go around having hives it's... it's... it's very common

Me

okay yeah I have a...

Dr. Shilian

most people are also on the same spectrum as you are you're just a little bit more advanced than they are but you don't reach the definitive diagnosis of a syndrome that we know that would cause a lot more symptoms or... yeah that's very telling because in your case because it's not overwhelming it's not severe it may not explain your symptoms

Me

right yeah right uh... okay so I took the allegra like you uh... prescribed last time I took it at the high dose I did for two weeks uh... like you said

Dr. Shilian

two at... two in the morning and two at night?

Me

yes uh... it was like the... I can't remember the precise dose but it was the all day

Dr. Shilian

very good

Me

um...

Dr. Shilian

any improvement?

Me

uh... I think I saw some minor improvements

Dr. Shilian

okay

Me

um... uh... I also at the same time took precautions that you mentioned about my dust allergy

Dr. Shilian

yes

Me

and so that might be helping a little bit too

Dr. Shilian

good

Me

uh... so my question was uh... you know I stopped taking that since uh... is... to treat this as something that I continue to take is it something else that...

Dr. Shilian

you... within two weeks if... if it does... so that's... that's one way we know if my cell is actually in the background causing your symptoms or attributing a great deal to your symptoms is to see your response to that high dose so if you were on it for two weeks how much improvement did you say? did you see?

Me

I didn't... I didn't have any crashes is the biggest thing I'd say like you know um... fatigue crashes or anything like that uh... uh... trying to remember

Dr. Shilian

if you're a hundred is where you want to be and zero is where you... where you were at the time when you started it... before you started it

Me

hundreds where I want to be zero is where I was probably like uh... uh... I don't know somewhere 30 or 40 it was probably close to 30 it wasn't that significant I just noticed I didn't have any major crashes like major fatigue crashes or anything like that

Dr. Shilian

that's... that's not bad

Me

it's not bad it's definitely not bad yeah... it was a normal day... every time I would take it I would get pretty... I don't know... not like dizzy but this weird feeling I'd take a high dose and I'd get really...

Dr. Shilian

wired up a little bit?

Me

a little bit yeah...

Dr. Shilian

yeah... cause sometimes it does that especially on those higher tendencies...

Me

okay...

Dr. Shilian

you're just very sensitive...

Me

yeah...

Dr. Shilian

what about taking one... just one twice a day would that give you that sensation too or no?

Me

I don't know...

Dr. Shilian

try that...

Me

try it... okay... now is that something...

Dr. Shilian

one morning one at night...

Me

one morning one at night... is there a certain time period I should only do it for?

Dr. Shilian

no...

Me

okay... can I build a tolerance that would be a problem?

Dr. Shilian

in three months... but you switch to Zyrtec or Zizol...

Me

so you just keep switching around...

Dr. Shilian

yeah... and then three months after that... you could go back on... like... temporarily tolerance...

Me

sure...

Dr. Shilian

you can definitely get back on it...

Me

great... okay... and none of those different... allergy medications have different sort of effects?

Dr. Shilian

not... not... bad side effects... no...

Me

I mean... in terms of actually helping the Mast Cell...

Dr. Shilian

you do the same thing...

Me

they do the same thing... okay... great...

Dr. Shilian

exactly...

Me

okay... so then for me... just with I have... with... what I have... regular allergy medication... is... the best way to handle it...

Dr. Shilian

no... that was just the beginning...

Me

just the beginning... okay...

Dr. Shilian

yeah... okay...

Me

yeah... so what do you think?

Dr. Shilian

I think 30% in two weeks... it's good...

Me

yeah... yeah... yeah...

Dr. Shilian

with what you've been through...

Me

yeah... I think I'll take 30%... I'll take it... and I'm interested to see...

Dr. Shilian

and then you were doing Pepsit as well... with it or no?

Me

Pepsit...

Dr. Shilian

you were just doing the Allegra...

Me

just the Allegra...

Dr. Shilian

have you ever taken Pepsit?

Me

no...

Dr. Shilian

amazing... so you may actually go up to 50%... or 60%... with Pepsit...

Me

remind me what Pepsit is?

Dr. Shilian

Pepsit is a histamine 2 receptor...

Me

okay...

Dr. Shilian

good... so we have... we have another layer that's hopefully gonna get together with Allegra... maybe give you better improvement...

Me

okay... Pepsit is over the counter...

Dr. Shilian

yes...

Me

okay...

Dr. Shilian

I can prescribe it for you... sometimes they color... Allegra too... I can... I can send that in...

Me

that would be great... I mean it's expensive... I've got it on my... my flexible spending account... but it's still expensive...

Dr. Shilian

you can get it from... Costco...

Me

Costco? oh... that's... you know... that's a great idea...

Dr. Shilian

yeah... I'll show you which one to get...

Me

I was just there last night...

Dr. Shilian

get your phone out... and tell you which one to get...

Me

okay...

Dr. Shilian

um...

Me

you want to tell me what it is? or...

Dr. Shilian

uh... yeah... so you look for... ALER... A-L-L-E-R... F-E-X... ALLERFEX...

Me

easy... okay... ALLERFEX... now that's Allegra... and... that's Costco brand... or is that...

Dr. Shilian

uh... Costco brand... yeah...

Me

okay...

Dr. Shilian

you could even get a... on... Walmart... Walmart...

Me

so it's a Costco brand... oh... okay...

Dr. Shilian

it's cheap too... but yeah... you could... that's a Costco brand... uh... Costco brand... yeah... okay... uh... you could even get it... on... Walmart... Walmart... so it's a Costco brand...

Me

oh... okay...

Dr. Shilian

it's cheap too... but yeah... you could... that's a Costco brand...

Me

okay...

Dr. Shilian

and then look for... uh... Pepsid...

Me

Pepsid... alright... so I will be... then... uh... maybe I'll... maybe I'll try the Allegra first... just in the single dose... and then I'll add Pepsid... later on... once I get a feel for... how the Allegra is working... on that... single dose... twice a day...

Dr. Shilian

I think that's a good idea...

Me

okay...

Dr. Shilian

uh... which pharmacy?

Me

CVS... uh... Ventura... in Sherman Oaks...

Dr. Shilian

yeah... that's a good... uh... okay... got it...

Me

great... awesome... sounds great...

Dr. Shilian

so I'm sending... uh... famotidine... which is Pepsid... uh... Pepsid... you have to pay attention to the dosage...

Me

okay...

Dr. Shilian

so I'm sending you... these to the pharmacy... so take a picture of these...

Me

okay...

Dr. Shilian

so... uh... uh... so that's Pepsi...

Me

okay...

Dr. Shilian

if they give it to you... great... take it twice a day... if you have to get it over the counter... the over the counter one comes in 20mg tablet... so take two in the morning and two at

night...

Me

okay...

Dr. Shilian

yeah... so... this is uh... so Pepcid is usually used for stomach... because most of the cells that it... uh... most of the receptors that blocks are on the... GI tract... but it's uh... it's uh... it's anti-histamine on the last...

Me

okay...

Dr. Shilian

it has a systemic effect with anti-histamine also... I'm not giving [unintelligible]...

Me

sure... you say Pepcid and it sounds like Pepto-Bisball on that... it makes me think about it...

Dr. Shilian

yeah... and it does... Pepcid is used for people who have heartburn... but I'm not using it for that...

Me

okay... um... um... alright... then uh... then questions for the MBL deficiency... um... so the deficiency... let me just confirm... so it's MBL and... specific auto... or specific antibiotic...

Dr. Shilian

Specific Antibiotic Deficiency ... is hopefully temporary...

Me

okay...

Dr. Shilian

hopefully it gets fixed... based on the... profile that I see in your immune system... hopefully that gets... corrected by the vaccine...

Me

got it... okay...

Dr. Shilian

that's uh... temporary...

Me

okay... and um... so you mentioned... I need to contact you if I'm sick... is that only when... it's like... lasting... like it won't go away...

Dr. Shilian

no... any time I get to... no... I'm happy to... yeah... I'm happy to treat your infection...

Me

okay...

Dr. Shilian

so even if I think it's... I mean I'm not gonna know if it's a virus or bacterial... but I should call you anytime... with my... with my immune deficient patients... we usually accommodate them... uh... to save them a trip to the urgent care... or [unintelligible]... or so on... so...

Me

okay...

Dr. Shilian

just tell them... come and we'll see you in between patients... if I'm in the office...

Me

oh... okay... okay... great... alright... so I will call you...

Dr. Shilian

if I'm not... if I'm not in the office... uh... uh... we could do telemedicine... we could do telemedicine... I think telemedicine is going away... uh... but... uh... if I'm in the office... I'm happy to see you...

Me

okay... uh... great... perfect...

Dr. Shilian

yeah...

Me

and then... uh... so I'm assuming then if... you know... if I'm filling out... medical forms or whatever... I just have to disclose that I have an immunodeficiency...

Dr. Shilian

uh... it's... uh... from a legal standpoint?

Me

no... I just mean like... um... if I'm at a doctor's office... should I say specifically what I have... or just say immunodeficiency or something... like if they're asked about past... you know... conditions or whatever...

Dr. Shilian

People like you go through life without devastating infections...

Me

yeah...

Dr. Shilian

so there's some people who get really sick from it... there's some people who just go really fine... so you're just missing... the... the component that goes in your blood... that's... and helps with tagging... bad guys...

Me

yeah... no... we've seen that... we've seen that... we've seen that... my... times where I get bacterial infections... they will not go away unless I take antibiotics...

Dr. Shilian

okay...

Me

so... um... so I... my question is...

Dr. Shilian

you could... but... don't go... get yourself into... a whole... uh... I don't want it to... for this to negatively impact you...

Me

uh... look... I'm not thinking about it that much...

Dr. Shilian

okay...

Me

I'll tell you...

Dr. Shilian

yeah... you could write... MBL deficiency...

Me

I'm not... yeah... I'm not really thinking about it that much... yeah... I just want to make sure I know... what you recommend... um... okay... and then...

Dr. Shilian

you may require longer course of antibiotics... and stronger doses...

Me

yeah...

Dr. Shilian

that's why I offer to treat your infections... because other doctors may shy away from that...

Me

sure... okay... great... so I'll contact you anytime I get sick... um... yeah... and then... um... last... question... just related to... sort of allergies in general... so I've started taking steps to try and reduce dust... in my apartment... as you recommended... um... are there any

types of allergies that can just affect... say... the sinuses... versus... you know... bring... hives and things like that... where...

Dr. Shilian

it's more of a susceptibility in... in... in individuals...

Me

okay...

Dr. Shilian

so some people get more... lung infections... some people get more sinus issues... some people get... yeah... yeah... it's not necessarily that... grass allergy only does this... or... or... dust bite only does that...

Me

so my question more is... on an... allergy test... eh... are there certain... things that would show on the skin test... that maybe you get... like... sinus allergies for... I only ask because... I'm still... I'm still trying to figure out... um... you know... the dog allergy stuff... and... and what not... I know what we were talking about... it's based on... perhaps dust... and... and... it could be... it very well could be... uh... but... I... I've talked to people who are also allergic to... the dust... and... they have no problem with dogs... and... it's just... it's... it's very odd... you know... I'm trying to figure it out... and... so that's why I was asking about... the sinus thing... because when I'm around the dog... I can... tell...

Dr. Shilian

you know... your... sinuses...

Me

right here... it... hanging right in there... yeah...

Dr. Shilian

we did the skin testing for you... and we also did the blood test...

Me

yeah... both... I'll tell you... all my skin tests... all my blood tests... never said I'm allergic to the dogs...

Dr. Shilian

you have a... type 2, 3, or 4 reaction to the dogs... so... what we test in the world of allergy... worldwide... we are... very good at checking for... type 1 allergy... IgE... meaning an allergy... but... there are 4 types of allergies... so... you could have type 2, 3, and 4 allergies to the dog...

Me

okay... so that's just what's not...

Dr. Shilian

that's probably what you're experiencing... that's probably what you're experiencing...

Me

I do... I do... I do... because... I mean... I definitely feel it...

Dr. Shilian

you feel it... so you may have... uh... one of those reactions... okay...

Me

alright... so that's just... it's just things that aren't tested for... okay... well I appreciate the explanation... because I think I've been sort of told that before... but not to the...

Dr. Shilian

of course... yeah... yeah... yeah... yeah... you are entitled to have... more than just... type... one type of allergy... you could have type 2, 3, 4...

Me

got it... uh... okay... alright... alright... alright then... um... oh and also... um... I had another doctor recommend... trying... uh... Quercetin for... uh... for potential ME/CFS you know I don't know if that's...

Dr. Shilian

Quercetin?

Me

Quercetin, yeah.

Dr. Shilian

It's like Allegra but it's more of a...

Me

Yeah I was gonna to ask you for like you know for mast cell stuff-

Dr. Shilian

You could take that. It's pretty safe. It's basically like Allegra but it's just more like organic. That's a safe one. You could take it with Allegra but change only one thing at a time. You're good at that.

Me

For sure absolutely.

Dr. Shilian

Very good. Okay. So now that we have some data with you we will continue to do investigation as necessary but now that we have some information about you the next phase is to just get you feeling better. So that would be our shift. They're gonna shift to more treatment focused, symptomatic treatment focused for you to just get your symptoms under control. So start this regimen of the Allergra twice a day. Hopefully that would be less of a side effect with the benefits. Pepcid and stay on it until I see you maybe in two to three weeks.

Me

Two to three weeks.

Dr. Shilian

And then we will can adjust course and use some medication to just get focused on your symptoms.

Me

Okay.

Dr. Shilian

(Doing a lung exam) Take a deep breath... Fantastic

Me

Okay. Great

Dr. Shilian

Great to see you

Me

Great to see you too. So again two to three weeks. You want to do a little longer for more testing. You know so I can test a little longer of these medications.

Dr. Shilian

Because you're doing the Quercetin too.

Me

Yeah.

Dr. Shilian

Yeah. As soon as you have given the regimen I gave you a good full two weeks. So if you're giving it if you want to do the corsetine first you can do that.

Me

Okay.

Dr. Shilian

Yeah. So once you have given me the um once you have given me uh given two weeks worth of trial to this regimen let me see you.

Me

Great. Okay. Sounds good.

Dr. Shilian

Great to see you. Have a good weekend.

Me

You too.

