0:03

Hi everyone. Welcome to our foundation for Peripheral neuropathy's webinar on Living Well with Peripheral neuropathy.

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Today we're going to be doing a question and answer format with our very own doctor Shanna Patterson And thank you again for joining us today.

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My name is Lindsey Colburn. I am the Executive Director here at the foundation for peripheral neuropathy and I will be moderating today's session.

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Before we officially get started, I just wanted to remind everyone that we are recording this presentation.

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We will be uploading it to our website, as we do with most of our future programs like this.

0:43

So you'll be able to gain access to it shortly after, probably about tomorrow or so.

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We ask that all questions be submitted through the questions box.

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If you have any questions that you'd like to ask, please feel free to do so. We'll try our best to get to as many as we can during this one hour session.

1:04

And just reminding everyone to try to keep your questions as general as possible. We're not going to answer any specific medical questions for you personally, whereas we prefer general questions that can benefit the entire group.

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And, lastly, if you're having audio problems, which by now you'll have known, if you can't hear me, I hope you are at least reading the slide. There is another option to use your phone to dial in to hear the audio for this presentation.

1:35

That information can be found in the e-mail that you use to click to login to this webinar.

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But, again, at any times, if you're having any issues, feel free to type in the questions box or the chat box, and we'd be more than happy to help you throughout the throughout the webinar.

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And, finally, I am pleased to introduce our own, doctor Shanna Patterson.

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She is the Foundation's Edge Patient Education Advisor. Hi, Shana, she just joined us. She's also the assistant professor of neurology at Mount Sinai West in New York.

2:06

And we're so pleased that we can welcome her for yet another session where we can ask her all the questions that you guys are asking us.

2:14

So again, Shanda, thank you so much, Lindsay, Thank you so much, and thank you to the Foundation for hosting these wonderful and informative events.

2:23

Great, well, let's go ahead and get started. As I said, we have about 58 minutes or so remaining, and we have a robust agenda there already, plenty of questions coming in and as I said, we'll try to get to as many as we can.

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But I thought it would actually be a good idea to start with helping some of our new patients And what would you suggest to new patients? What should they do first after they just been diagnosed with peripheral neuropathy?

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That's a great question.

2:52

Well, I think, you know, I think that being kind of proactive, there's a lot of questions that come to mind, especially with any new diagnosis, but including peripheral neuropathy.

3:03

one thing I always recommend is, make a list.

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If you can make a list of your questions that you have so that when you are with the provider, for those that precious visit time that you're able to kind of at least have your questions at hand and hopefully get them answered.

3:19

And I think also asking a provider and getting familiar with in-between your visits. What is the best way to communicate with them? Do they have an online portal that you could submit follow up questions through, or questions you may not have had time to address?

3:34

Or is there another mechanism, Do they have, for example, a nurse practitioner or a fellow who you can work with, which can be very helpful and a great resource?

3:43

I think that, um, a couple of the big two main questions, and sometimes, you know, there are different answers, but I think that many patients have and that you want to find out is one What is causing the neuropathy?

3:57

And that is not always known, but sometimes it can be known, and two, what are the things that you can do to help you feel better and live your life? Your day-to-day life, kind of in the best way possible, without pain, without problems with mobility, and so forth.

4:15

Great.

4:17

Some of our new patients have asked us if there's any correlation between cognitive health and peripheral neuropathy so ultimately it is our brain affected by neuropathy?

4:31

That's a. that's also a great question.

4:33

As we know, the nervous system as a whole does encompass the brain and the spinal cord and the peripheral nerves which are the nerves impacted in peripheral neuropathy.

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And what we, you know, what we think about peripheral neuropathy and it strictly speaking is really only the peripheral nerves that are impacted directly by the disease itself, not the brain or the spinal cord which is known as the central nervous system.

5:02

However, that being said, especially for patients who are experiencing pain chronically. We know, for example, that pain itself can have impacts on cognition, on the ability to sleep well. Things can be on mood and and these things really, you know, it's a source of chronic stress, if you will, and can have a lot of sort of brain, brain, impactor or brain symptom impact.

5:29

But the peripheral neuropathy itself, the disease itself does not impact the brain.

5:35

That's good to hear.

5:37

So when you had kind of talked about the two approaches, or the two things to do for a newly diagnosed patients, you had mentioned symptom management ultimately, right? So, we're trying to live our best life.

5:50

So, what type of what type of drugs or alternative medicines are out there in general that you might suggest a newly diagnosed patient ask about. Or does it kind of depends on if your symptom is a balance issue or a pain issue?

6:08

Of course, Lindsey that's a great question, so it really matters what your symptom is. And, in general, we think of sometimes two categories of symptoms. one could be things that you experience newly, that are, like, shouldn't be there, that weren't there normally like pain, or trouble with balance. And then, sometimes there's symptoms that were something that used to be there is taken away. And that might be something like numbness.

6:37

And there are certain types of symptoms that we have medications to help with, such as pain, or discomfort, or painful tingling. Sometimes it can feel really different to different people, or even sometimes muscle cramps related painful cramps related to neuropathy.

6:55

Some of these medications can help with those as well, we don't unfortunately have a pill that makes numbness go away, and we don't have a medication that makes balance improved.

7:08

That being said, there are things that we can do to help balance. For example, like physical therapy.

7:14

What I like to say to patients is, when we're talking about a concern related to drop it the imbalance, because which usually comes to be for some patients if you don't have the sensitivity, the normal sensitivity on the bottoms of your feet, it's hard for your feet to sort of tell your brain, if you will, what the ground is doing underneath you. Is there a slope?

7:35

Is it a little slippery? Is there kind of a curve to this, cobblestone, that sort of thing. And it can be harder for your brain to help the rest of your body adjust, to keep your balance?

7:46

And also, walking around in the dark can become really tricky, because we normally would rely on that feeling's under the feelings under our feet to help us kind of maintain our posture and keep our balance.

7:57

But I say to patients, physical therapy isn't going to potentially, um, fix the nerves, if you will, and make the sensitivity on your feet come back.

8:06

But what it can definitely do is help you really optimize all of the other parts of your body, and the other kind of responses that you might have to these situations, to help make your experience as best as it can possibly be. And I think a lot of patients learn new tricks and approaches, or things to avoid, that help keep them safe and more comfortable in terms of the balance issue.

8:30

In terms of pain, there's a lot of different medications that we can use to treat pain.

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Many of them, interestingly, were initially developed for other types of conditions.

8:41

Sometimes, other conditions in neurology that deal with the nerves, such as seizures, for example, and sometimes conditions related more to mental health or psychiatry, such as depression.

8:53

And, interestingly, because a lot of these medications, we're designed to impact and help nerve function.

9:00

And these other ways, we actually found, when we study them beyond that, that they help nerves, that nerve pain as well. And the effect they have on nerves can help nerve related pain.

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So, it can be confusing sometimes to patients, because a lot of these medications treat more than one thing, but that's really the underlying reason.

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And what I also say is, there are a lot of choices. And so, it's always important to work with your doctor, to figure out what the best medication may be for you.

9:27

We, of course, want void medication side effects if you're taking multiple medications.

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And, though, there may be studies that show that, oh, this can help people with neuropathy and neuropathy related pain.

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You are only, you know, only you know your body, and what works best for you, or the person as an individual.

9:47

You really have to work together with your provider to find which medication helps you, and of course, without causing any side effects that are problematic.

9:58

No, and it's interesting because obviously, one's journey with peripheral neuropathy will change over the course of months, years, decades, and I think we started this session talking about some of the newly diagnosed, you know, what should they do?

10:14

The new patients, but then when we go to the patients who have been suffering from this condition for a little bit longer, what should they do. I mean, should they continue doing periodic exams with their neurologists? But what should they expect from these types of appointments?

10:28

Is it more just a check in to see if they're doing, what they should be doing, or try new things?

10:36

Or I guess, the expectations for, for, for someone who's had this condition for a little bit longer and how they should manage and not get burnt out ultimately?

10:47

Sure.

10:48

That's a great question.

10:49

I think just looking, you know, I think there's a variety of approaches, and this is where, I think, something called shared decision making really comes into play.

10:58

And when we think of shared decision making in medicine, it means that patient, and the provider, or the physician, are really partnering as a team to help determine what's the best approach.

11:09

What I like to do is I usually tend to think of kind of three different main options for patients who we've kind of gone through that in this initial phase of figuring out the diagnosis, and if we can, what's causing the neuropathy, initiating medication if we need to, for pain management, and physical therapy, if it's needed. And, we usually think about three different options.

11:29

one could be, some patients really need regular follow-up. Maybe there's some things that still aren't going well. Maybe they're worried if their condition is stable or not. Maybe we're still really adjusting a lot of those medications to try to find the best fit. For those patients, we'll make sure that we have kind of regularly scheduled follow-up, and the time interval really just depends on what's happening. It could be every three months, or every six months.

11:53

Then there are some patients who are really doing well, we've kind of come to a good spot, and we might decide, but they still want regular follow up because we need medication refills.

12:06

And though we can do medication refills through the electronic medical record system or on the phone.

12:12

It's always important, I think, if you're seeing a provider who's prescribing a medication to see them, I would say, at least once a year. So they can go through and make sure that it's still appropriate for you to continue the medication. And it may not be. In some cases, we can remove a medication after a period of time.

12:28

The pain may change or diminish, and so I do think, at minimum, that's important, especially when medications are being prescribed. And then of course, just doing a basic exam to make sure everything's stable.

12:40

And then there's some patients who are doing really well, they don't have any medications that we're prescribing.

12:45

And I may with them sometimes decide to have them just reach out to me if and when they feel like they need more support or if they have any concerns.

12:55

No, that's fantastic.

12:57

So, are our patients, our constituents? They're always interested in what's new? What kind of breakthroughs are happening today or in recent months, or maybe on the horizon? Could you maybe speak to that?

13:11

I know that's a very loaded question, but kind of shifting away from that to it's kind of see, well, yeah, what what else? What else has changed? What can we be hopeful for?

13:23

Sure. That's a great question.

13:25

Well, one thing.

13:25

I would say as a lead into that is that neuropathy of course each patient who has neuropathy has their own specific type of neuropathy, But as a whole neuropathy like many other conditions in medicine is a big umbrella term and can refer to?

13:45

A whole spectrum of really different types of neuropathy and so because of that I I think that in some ways it would be a big challenge and I don't want to say never but I feel like it would be the ultimate almost like Finding one treatment that cures all cancers.

14:01

I feel like finding one treatment that cures all neuropathy is, is very tricky, so but what we do see is that we do see a lot of targeted research in neurological diseases.

14:15

Looking at pushing the envelope really in terms of certain types of disease pathophysiology that may lend itself to new really robust treatments.

14:27

So that may include there's nothing really in the immediate, coming out sort of this year with respect to neuropathy but I can say with respect to certain other conditions, we're seeing even some advances.

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For example, in Alzheimer's, you know, where people are learning about what are some of the underlying molecular mechanisms that might play into Alzheimer's and coming up with new infusion treatments for that.

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These may not be universally effective, and there's still a long way to go. But if you look back in years past, this is a huge step forward and I think is only the beginning of what we will have to offer in the future.

15:01

Similarly, genetic diseases, diseases with genetic underpinnings.

15:07

We are learning a lot about there's a lot of patients that we're seeing where we run genetic panels on them, and they may have certain genetic predispositions to neuropathy.

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Just the ability to test for this where we we really weren't able to now we have, there's like saliva tests that people can take at home, which make it a lot easier, and I do think that we're starting to see across a number of genetic conditions, including neurology, although not specific yet, to neuropathy, different types of gene therapy oriented type of treatments.

15:40

And this is, this, is, these are things that, again, even a decade or two decades ago sounded no, so futuristic, and now it's exciting to start to see these things, really, The research kind of coming through, and it may not all be related to neuropathy right now, but I do think that some of these advances that are happening across maddison or other neurological conditions will lead to meaningful advances with respect to neuropathy in the future.

16:08

No, That's great.

16:10

There has been a lot of talk about some advances with respect to stem cells, and specifically, peripheral neuropathy.

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We've heard in the past from you, and some of our other experts that stem cells still have not been proven to be effective for neuropathy, is that still the case? Has there been any movement on that?

16:30

Sure, That's a great question.

16:31

So, I think, like many things, there's a lot of research that's happening, We do not yet have, in terms of the real, kind of, scientific, overarching community, we don't have anything that's reached, patient care.

16:44

So, there's nothing that, though there is a lot of research that's happening in the lab, there's nothing that's reached the level where we would refer patients for this, and then, so, I would caution.

16:56

Because I do know that occasionally people will find center, or maybe in a different country, or something, who will take their, you know, take their money and, and offer them, promise them some sort of treatment. So I would argue, I would caution against that.

17:13

Certainly, not to say that stem cells aren't exciting and hold a lot of promise.

17:18

But at this point, we do not have anything that's really then proven scientifically to help patients, that's proven enough, where we are referring patients for that treatment.

17:30

And on a similar note, stanton's, is there any connection between stanton's and peripheral neuropathy?

17:37

Stettin question is so fascinating, and I think for a variety of reasons.

17:42

one, because so many people take statins. And so it's a common Medicate. It's a relatively common medication that people take. And so it's not unusual to find patients who have neuropathy and also take a statin.

17:54

Historically, this has been, you know, we know that statins in some individuals can cause certain nerve or muscle side effects and going back now, almost 20 years there has been this body of literature in the scientific medical literature describing an association between statins and neuropathy.

18:14

And what's also interesting is that over the years, new Stanton's have come out.

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And some of them are thought to be to have less, sort of to have more benign, if you will, side effect profiles, than some of the other students. So I think there's a variety of different things, And there's also certain, there's also recognition now that there may be a hereditary predisposition for some individuals to have more adverse side effects to statins. So that's something that can be tested for.

18:41

But some of the more recent and sort of meta literature, which means that when people look at aggregates of studies, and collections of data, that have been coming out now for years, to be honest with you.

18:53

That it's a little bit less black and white, than it ought to be, 20 years ago.

18:59

And, and I think we still need more information, But I part of me wonders if maybe, know, I think we're, so I think it boils down to really an analysis for each patient with their provider. Know, which data are they taking? What was the relationship of the timing of the statin, with the neuropathy? If there's a severe reaction, maybe there's a role for testing, you know, for doing some genetic testing or rethinking things.

19:25

I've definitely had some patients where we've looked at, they have an neuropathy, we may not know what it's from, or maybe we have a few ideas what it might be from.

19:36

They take a stat and we think, well, could the statin be playing a role?

19:40

Sometimes we'll reach out to the referring to the provider, whether it's a cardiologist or someone else who's prescribing it and say, you know, could we do a trial of being off the stat and for six months or something to see if anything improves? Right? And that, and, to be honest with you, sometimes the answer is yes, sometimes it may make a difference, but oftentimes, it may not, OK.

20:02

And then the other thing is, sometimes the other provider will say, Well, you know, we don't know if this is causing the neuropathy, we know the latest literature calls into question really whether or not in compared to what was a, you know, the initial kind of literature 20 years ago. Present it. Now. We think there may not be as strong of an association.

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But what we do know is that the stat and is really important for your heart, and really important to help prevent cardiovascular events or cerebro back.

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And so we weigh that.

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And there's some pain, They, we don't know that. I think the discussion is transitioning to where it's more of a gray question, mark, than it was 20 years ago.

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And we always have to weigh the benefits with each individual patient.

20:46

Fantastic. No, that's good to know. There's been a lot of questions, and it seems like like a lot of other things, things, things are different. Right, things change on a, on an annual basis, sometimes even quicker. So, it's good to know kind of where we are currently, and maybe next year, if we're still doing these sessions, will have a different answer, But that's good to know.

21:09

So, what kind of medications do you most often prescribe for neuropathy?

21:12

That's also been a very common question, whether whether it's for pain. I mean, Right?

21:18

Gabba penton like a lot of names kind of come to mind for me, but as as a practicing physician when you see patients, which ones do you most typically kind of glom onto for patients? that's a great question. Thank you so much for asking that.

21:36

I think first, you know, taking the whole patient into consideration and the severity of their symptoms.

21:42

So, for example, some patients, baby, just to give kind of a few examples, some patients might say, I really don't want to take oral medications, for whatever reason.

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And so we try to look at other top, but, you know, other topical sort of options which are out there, and if you have all over your whole body, that's tricky. But, especially, for many people who have pain, mostly, in their feet, we can think about that because there's kind of one targeted area.

22:10

If it's something that's mostly like cramping pain, there are different types of topical, magnesium, creams and lotions. You can even buy them kind of over the counter or online. Some people feel like they really help.

22:22

And so that's one option and there are different kinds of numbing patches if you will. Again, this is for helping pain, burning pain discomfort.

22:32

Those can be like light achim patches or other things that have kind of a numbing effect and can be beneficial again if people have pain mostly on their feet.

22:41

Again, some of these things may not be as practical if your pain is throughout the whole day when it's hard to have something like a lotion or a patch on under your shoes.

22:51

But it, again, depends. For patients who are open to taking a pill, which may be or trying it at least all of this I say, is trial and error. Nothing set in stone. And I always encourage patients if it's not working for you, where it's not.

23:06

If it's causing bad side effects, let me know. And we'll make adjustments from there.

23:10

Trying something does not is not a commitment. It's just a trial.

23:14

But for people who have pain predominantly at night, there are a number of these neuropathic pain medications, which also happen to have a side effect because of the way they work on nerves, of sometimes kind of dampening down nerve activity. And sometimes helping people sleep.

23:29

Because of their effect on brain cells, Gabba Penton is one of those medications.

23:33

And so for people who have a lot of pain at night or feel like the pain is interrupting their sleep, I try that medication simply because it often is well tolerated and may have kind of a, if you will, a dual effect of helping the pain and helping them sleep.

23:48

And for patients who have pain, maybe throughout the day, gabapentin can still be a good choice but dose throughout the day.

23:55

And for people who have side effects, where it makes them too sleepy, there are a number of agents which can help with nerve pain that do not have a side effect of making making people. Groggy do Locks a teen or the brand name is Ben. Balter, is one that I tend to think about. There's one that's kind of an older generation of the same mechanism, drug called ... vaccine, or effects, or those we can actually look at, those can be dosed in the daytime. They tend to not have side effects of making people groggy.

24:25

And, in fact, they were initially designed, as those were initially designed for depression.

24:32

So, occasionally, people will report to me, Oh, I'm using this, and I didn't really realize it, but, you know, I think this is, you know, I've been feeling kind of stressed or maybe a little depressed because of this.

24:43

And I'm noticing that I'm feeling a little bit different in that way. Yes, that's not why I'm prescribing it. I'm not a mental health provider. I don't know, diagnose or treat depression.

24:53

But, again, trying to see if you're treating a patient with the medication, What is the best fit?

24:58

What might help accomplish more than one thing, if possible, for that patient?

25:03

No, that's great.

25:05

And for those patients who are trying not to take medications specifically for nighttime relief, it. Obviously, you know, neuropathy seems to worsen at night maybe it's our brain playing tricks on us, because we have nothing else to do and keep us busy, and we're just kind of sitting around or line line down, trying to fall asleep. And we have some patients that just say, you know, I don't want to take medications, but I still need to sleep and I still need to have my neuropathy symptoms lessons so that I can sleep.

25:37

So, how do you respond to those patients? No, That's great.

25:41

That's a great question. So first to say, it is very common for people to feel like the interrupt these worsening worsening in at night, it does not worsen at night.

25:50

But we think that there may be, like, you were mentioning, some kind of, combination of factors where, we're not distracted by other sensations on our feet because we're not walking around and so forth.

26:02

Our minds might be quieting down, so we're kind of more attuned to any other discomfort. That's happening. That's kind of becomes, right? No background kind of comes to the forefront.

26:11

So things that people can do, it's, it's, this is becomes really individualistic, and it is a trial and error.

26:18

There's no one size fits all, but I have found a number of things that sometimes help.

26:23

one, for some patients, they find that the temperature of their, or around their feet can make a big difference.

26:30

Usually, the pattern tends to be, for these patients, that warm, When it's warm, when their feet are warm, it tends to feel better when it's cold, or their feet are cold. It tends to feel worse.

26:42

Patients will say, I want to be, you know, in the middle of the winter here in New York, where I can get cold.

26:46

They'll say, Oh, I went on vacation to Florida or whatever, and I didn't feel my neuropathy the whole time. Now, maybe it's just being on vacation, but maybe it's also kind of being, excuse me.

26:57

Do you leave your problems at home while you take a vacation? So then all neuropathy: patients should just always be on vacation.

27:04

I wish vacation every night. That's right?

27:08

The warmth we've noticed, sometimes can help, so some people notice if they wear, like warm socks, or use it, like a hot water bottle, Something, obviously, that's safe and it's not going to burn you.

27:20

Um, or be a fire hazard, but sometimes people notice that.

27:24

Sometimes people notice, kind of, maybe before they get into bed if they soak their feet and then, you know, warm water maybe with some epsom salts or something like that.

27:33

And then that that can help or do some stretches or, you know, massage, that that can also be beneficial.

27:40

And again, not taking medication in the middle of the night.

27:44

You know, there can be some of these topical lotions that are more natural, if you will.

27:50

And sometimes having those kind of at the bedside and trying them, you know, can be another option.

27:56

Sometimes, people notice, not just the war, but occasionally, people will tell me, they noticed that, just having, like, the sensation of something holding on to their likes, like, not a massage but like kind of putting a little bit of light pressure like a compression stocking almost fields.

28:13

And so, that's also great.

28:15

So, they, kind of where those at night because it's just, maybe it's having that little other tactile input or something about it kind of pushes the pain, you know, sensations away.

28:27

What about diet? Right? So does diet or one's nutrition? I mean, that's also another kind of non prescription non drug consumption option for many of our patients that we speak with.

28:39

Could you maybe comment on that as a general kind of just direct correlation between diet and neuropathy?

28:45

And then similarly, if you have any thoughts on what the best diet might be in, in general, for someone that has neuropathy or just in general?

28:55

Sure.

28:56

So I think, unfortunately, we do not have, for somebody who already has neuropathy, we do not have, like, a one size fits all. This is your neuropathy diet, and it will make you better.

29:07

That being said, there are four different types of neuropathy: is potentially a dietary component, and I will go through a few examples, and these do not apply to everyone for sure, but just to kind of provide some ideas.

29:21

So, for example, for some patients who might have celiac disease, which is like a immune driven, immune driven gluten, sensitivity or kind of allergy, if you will, where you attack your intestine.

29:34

Those patients can sometimes have neuropathy.

29:37

classically, we think of them as having a lot of GI symptoms, but occasionally they don't, and so can be their diagnosis can sometimes come to the forefront because of some nour neurological symptoms, including neuropathy.

29:51

These patients, we don't know in these patients, if it is from the celiac disease itself, which responds to a gluten free diet or if in some patients, it might be from vitamin deficiencies because they can't absorb vitamines, well if they have a lot of gut inflammation.

30:08

So, it's, it can be, there's, there has been some debate about that.

30:11

But nonetheless, if you, if you think you might have celiac disease and you have neuropathy being screened for that is important and treating that, which would be a gluten free diet, would be important.

30:22

For patients who have different vitamin deficiencies, whether it's vitamin B, 12, vitamin B one, or vitamin B six, deficiency, have all been linked as possible causes for peripheral neuropathy.

30:35

Because at least in the sort of classic, I think Western diet, we have a lot of enriched grain products, cereals, milk's, that have these vitamins added. It's usually very common to find people who are deficient in these. But we do see it sometimes. It does come up sometimes. People who may be sometimes leading really healthy diets, but might be really restrictive in some ways.

31:01

Sometimes we can be surprised and identify certain vitamin deficiencies, patients who may have had a history of bariatric surgery, which can sometimes impact vitamin absorption, sometimes could be more at risk. They can be more at risk for having vitamin deficiencies.

31:17

Obviously, the big one, I would be remiss if I were not to mention sugar and diabetes eating, dessert, or candy or whatever is not directly linked to neuropathy, but having diabetes certainly is the most common cause of neuropathy.

31:35

And so, for patients who have diabetes really kind of working, which it may not always be controllable through diet, as we know sometimes, diabetes is hereditary or it and you can have a healthy diet and still be diabetic.

31:49

But if it is something that's linked to diets, certainly working on a low glycemic diet is what we call it with certain types of carbohydrates. And avoiding refined sugars is important.

32:01

Anecdotally, I've had some patients who swear they feel much better on a lot of these diets that are out now like these anti-inflammatory diets or different things that they try.

32:11

All fruits and vegetables and no glutenin things and they feel better.

32:15

I, there is no scientific kind of evidence that we have to say, this is the prescribed one size fits all diet for you.

32:24

I think there is a lot of interesting research that we know about with the microbiome and the impact of our diet on our physiology and inflammation and systemic inflammation.

32:35

And how wouldn't it make sense? If some of these things also impact neuropathy, it would, but we just don't have any research to prove that connection.

32:43

So I think I don't have any universal sort of recommendation to make.

32:47

We always, as part of the initial screen, ideally would like to screen for any dietary deficiencies or for diabetes, any person who might have diabetes and not know it, and then beyond that, it's really kind of partnering with patients.

33:01

You know, encouraging of course a healthy lifestyle, Um, excess excessive alcohol can also lead to neuropathy, but honestly it's usually in in Dramatic excess not kind of having a glass of wine with dinner sort of thing, right? And How how long should someone give a new diet a try before they rule it out? When you know where if people want to say, Oh, I'm going to try this out see if it helps my neuropathy symptoms.

33:31

How long like six weeks? eight weeks.

33:33

I mean, that's typically what, I've kind of read it, but I'm not a doctor. So, what do you think?

33:40

Now, I would agree, that's, that I would agree with that.

33:43

And I think even in cases where we've seen patients who have a really strongly identified cause further neuropathy, whether it's a vitamin deficiency or a medication toxicity.

33:54

And we want to let time go by to allow for meaningful change that you could perceive with the neuropathy. We do want to wait. I think, you know, a couple of months or So.

34:04

The reason being, even if, let's say, there's some things circulating in your blood, that's too low or too high and we're correcting it.

34:11

It takes time for that to have an effect on the nerves and that doesn't happen overnight.

34:17

And so I think it has to be something that's sustained that has an impact on the nerves and allows the nerves to undergo physiologic response to the new diet, or whatever it is. And so I think it can be hard, because it is, you know, does involve some waiting if you're really dedicated to it.

34:35

But I would say, if you're going to try to see whether, no, this definitely didn't work for me, you would want to give it a couple of months to know for sure.

34:45

And speaking of waiting, this has been a common complaints of patients who are trying to see any type of specialist, but specifically in neurologists and that specializes in neuropathy. Sometimes it takes upwards of a year to get into see a neurologist.

35:02

And what if a patient just can't even wait until tomorrow, because they really are suffering?

35:08

They need answers, They're not living their best life, and they need to see someone right now, How do you what, what do you tell them? I mean? Do you go are you desperate and you go somewhere else? I mean or you wait for the right person? I mean, how, how do Pete, how should, how should a patient navigate when they're really desperate for answers, but they can't get in until 20 23?

35:32

So, first of all, that's, it's horrible, But, I think, you know, one thing we know is that there is a national, at least, shortage of neurologists.

35:44

Unfortunately, and that the wait times are long, and there's all kinds of interesting initiatives that are underway to actually encourage more medical students to go into neurology.

35:56

And to try to, you know, there's a lot of things. Kind of big, high, high level things that are in place to try to correct this, because it is recognized, that we have a shortage of all neurologists in the United States, currently.

36:09

So, a few ideas, you know, that I would have.

36:11

First of all, if you are in excruciating pain, if you're just like really suffering, go to the emergency room or go to your urgent care, because, in some cases, maybe especially, you know, with urgent care, you know, because the emergency room may be kind of a harder place. And we may not want you to be there and sort of waiting.

36:29

You will probably be triaged behind people with a lot of different issues. You might be waiting for a longtime.

36:34

Urgent cares can sometimes be a little bit easier in that way, but sometimes providers can at least give you know, they know about gabapentin.

36:41

Oftentimes, if you're in a lot of pain, they know about certain basic things that might actually be valuable to help get you some relief.

36:50

It may not be the neurological workup that you need, but that might be kind of an emergency moment and a response that I would advocate for if you're suffering that much, If you have a primary care doctor, you know, hopefully also that they can partner with you similarly.

37:04

So I would certainly speak to them and ask them, Knowing what you know now from this webinar's saying, I've heard about this and this. I'm having pain. I'm waiting to get my appointment. Can we try this?

37:15

The other thing I would say, if you're working with a specific office or institution, depending on where you live, and to get the appointment, is that, oftentimes, if you call, depending on where you are, or if you call, you call, kind of one group of people who are scheduling appointments, and can tell you when the next available is.

37:35

There oftentimes, may be.

37:36

if you look at the website, other avenues where you can call the department or call somebody else or send an e-mail, you can usually find contacts online to say, Hi, I'd been waiting, but I really need to, you know, know, is there a cancelation list? I need to kind of get?

37:53

Or, there may be like a patient relations branch, especially for big academic medical centers, that patients, you know, oftentimes, will reach out to, And then it may not be the first thing you see on their website, when you're calling to make the appointment.

38:06

But oftentimes, they do exist, and they can help get patients in sooner, whenever possible.

38:11

And the last thing I would mention is, depending on what state you are in, if there's a state you're in, and there may be a lot of neurologist in a couple hours away or something, and it's hard for you to get to them.

38:23

Frequently, you might not want to rule them out.

38:25

Because, especially since the pandemic, one of the only upsides is that in medicine in many areas, it's pushed a lot of people to be more comfortable doing tele neurology or telemedicine, right? Yeah.

38:38

And that those licenses tend to be really state based.

38:44

And so, what I say to some patients who are in New York, many patients, they live, you know, let's say upstate far away, but they want to come to see us in the city, what we might say.

38:56

Of course, for your initial full workup and so forth, we do really need to see you in person so we can examine you properly, and maybe do different tests in person.

39:05

But beyond that, there are some patients I work with, who live several hours away, where we'll say, We're going to do some routine follow ups, or, if you're having an urgent concern, we're going to do video visits.

39:16

And it works really well.

39:18

And I think for some patients, if they say, you know, I can make time once a year, or whatever it is to drive for a day trip, to see, you know, this provider, and then work with them in between.

39:32

On video visits from home, like that can be a lot more doable. And it might expand the number of options that you're considering for what neurologist to see.

39:42

That's interesting, and, you know, I couldn't help, but hear and echo the concerns that there, there are seemingly fewer and fewer neurologists. So, do you have any thoughts as to why that's happening? Is it is it that covert pandemic related?

39:56

Is it no less medical students going into this field or this specialty?

40:04

On behalf of all the neurologist's, Shana, could you comment on that? I know it's interesting. Actually, I would say, there's a physician shortage.

40:11

It's not just, OK, neurology, but there's, you know, primary care doctors. I'm sure many people have experienced trouble getting in with their primary care when you're like, Isn't that the point? I'd like to be able to get in.

40:25

But it can be, like, months, or something. So it's kind of this dream moment.

40:28

I think that, you know, I don't have certainly all of the answers.

40:32

I think that, No, I, but I do think that things will improve and that, you know, as long as the medical societies and other governmental agencies and people they thought about, you know, that popular.

40:43

I mean, something as basic as the population of the United States has grown, but when we have increased the number of medical schools and enough time, no more. And so it becomes harder if you will, to get into medical school. You can have a lot of qualified applicants but this number of spots is not increasing proportionate to the population.

41:02

So, even that, of course, you're going to experience shortages.

41:06

You know, it's, it's kind of this interesting phenomenon.

41:09

We did see like I think with many every probably profession that the pandemic shifted certain people who, maybe we're thinking of retiring and then they decided to retire, mean things like that.

41:22

But I think that was a small kind of issue relative to the big picture that we've been seeing happening for much longer.

41:30

So, it's not an overnight fix.

41:33

But, I think that, over the long term, the real kind of, solutions are going to be things like, opening up medical schools, having different, you know, expanding the number of residency slots in neurology, which is how you train neurologist's, creating more slots, and so forth.

41:48

Uh, things like that, I think, are going to be the long term. It's going to take time.

41:52

I know that for some practices in the short-term things that people are looking at, unclear things like, what if we have a nurse practitioner working with us?

42:00

So maybe they can help see certain follow up patients to allow us to get more new patients in sooner, you know, so we kind of expand our team, Right?

42:10

And, and help to get in more new patients faster. I think there's a lot of practices are looking at that as well recently.

42:18

It's, it's a complicated question, it's very interesting, There's actually a body of literature on all of this, and I think hopefully we'll see some really sensible solutions that you know, will come to fruition.

42:29

I know it's already being worked on, but hopefully we'll start to see the benefits of that, because this is, No, it's it.

42:35

Nobody thinks that this is the way that patients should have their experience of their health, is, you know, being told, Oh, I can see you and months.

42:45

Yes, yes, no.

42:49

And I know, I know many of our patients, if they can't see their, their neurologists, or maybe they don't yet have one, they see their primary care physician which no is better than nothing, of course, but do you have comments on that?

43:04

I mean do you think as a patient who has peripheral neuropathy, do you need need a neurologist? Is that, is that, like, the current recommendation that? The neurologist's is your doctor for neuropathy, just like, an endocrinologist? Is your doctor for diabetes?

43:22

Sure, So, I think, I would say it is, ideally, at least to have, an appointment, would be the ideal.

43:29

But, I think that, just from a practical perspective, let's say, for example, I think it depends also on who your primary care doctor is. I've seen some patients, primary care, doctors, who are, who do are excellent.

43:42

And maybe there is, you know, a clear cut cause. Maybe it's diabetes, for example.

43:48

They check some basic other blood levels of thyroid hormone, B 12 levels, different things that are other common issues to make sure there's nothing else going on.

43:57

Start gathering to help the patient with their pain, like there's really, they've really taken care of a lot of things, you know, to help the patient. I think.

44:04

I think it does depend, sort of on, on what the nature of the cases, who the primary care doctor is.

44:13

For patients, of course, who have no aggressive forms of neuropathy or refractory types of neuropathy where they can't find relief or they're having trouble moving around or walking, or, you know, progressive weakness.

44:26

That may suggest that there is.

44:28

for example, like an autoimmune driven type of neuropathy that requires IVIG. Other complicated type of treatment, not just pain, treatment or physical therapy, and that I would say usually almost always requires a neurologist. So.

44:42

No, I think it does depend.

44:43

If you feel like you're in great hands that your condition is stable, that your symptoms are really well maintained, that your primary doctor has been partnering with you on all of this, I don't think it's like an emergency. I think it might be nice, you know, at some point. And I've definitely seen some patients who say, I've had this big workup. I've been on this, but I just wanna make sure we're like, Not missing anything, right? I think that's totally fine.

45:05

But the people who I would say really urgently should, you know, see a neurologist as if nothing is really helping you, your condition is getting worse.

45:16

You're, you have weakness and it's, and it's progressive or significant weakness things, I think nobody knows what's happening to you, and it's really kind of severe. I think all of those would be conditions. You know, instances where I would always say you need to see a neurologist.

45:32

Understood, OK.

45:35

So, let's pivot a little bit to Alternative medicine therapies for neuropathy, are there any that come to mind right off the bat for patients to ask their personal care providers about, or specifically try.

45:54

one of the things I think that's interesting is so many of these things are off, you know, they don't require prescription, and so not a commonly patients will come to me and say, look at this. This is great, and they, you know, a friend told me about it, and I'm delighted, and it's like, wonderful. I'm like, OK, great.

46:11

So I think that you know There's it's kind of an interesting dynamic because patients can try a lot of these things on their own My Overarching philosophy is usually that as long as it's helping you as long as we've kind of taken a look at it together to make sure that there's nothing about it. That would be a surprise that could be an interaction with one of your other Medications. Or might hurt you.

46:31

And then also you know I would never want patients to be Looped into something that is going to cause them financial hardship.

46:39

I think all of those things are are, then those are my main criteria. Then I think, you know, beyond that, I think it's fine.

46:44

We have very few kind of randomized clinical gold standard trials for a lot of these different naturopathic approaches. And I'm not sure if we ever will.

46:55

Because I think as we've discussed, a lot of the real research and grants for research are so focused on things like, you know, the other immune system mechanisms or molecular treatments are understanding the genetics and develop in developing gene based therapies.

47:11

That, I'm not sure if anyone's going to really go back and start pushing for financial support for research on certain supplements.

47:18

The tapping said, Like I mentioned, some people find that these topical creams really help.

47:23

I don't have, I'm not advocating for any specific brand but if you just type in like neuropathy, magnesium cream you'll see a lot of different things, some patients have found a brand that they really like. There's, no, I'm not like hiding one, I don't have any secrets, but I've had, I've had some patients tell me that they help.

47:40

Um, I think that some patients find even, you know, some people find that like different vitamins Help them. Sometimes, people like taking Tumeric or B vitamins, Alpha ...

47:53

acid, different things that that, you know, for vitamins, to be honest with you, the person kind of official position is that if you're not deficient, if your levels are really normal, then you shouldn't really need more buy extra extra super doses of vitamins to help your body do what it should do with normal vitamin levels. Right? If the level, for some people, is borderline low, but still just on the edge of normal, we do think that for some of those patients, maybe their bodies need a little bit of a higher level. And that makes sense.

48:23

The other, a lot of the other supplements that I mentioned, are kind of these anti-inflammatory type of supplements, and so, and for some of them, there have been, like, with Alpha Le ...

48:33

acid, some small research and studies out there that have shown a possible benefit. Again. I say to patients go ahead and certainly try.

48:42

The other big thing that people often ask about and worry and wonder about is medicinal cannabis and some patients who use canvas recreationally or otherwise will say, Oh, I've found that this really helps me. Some people say it really doesn't help them.

48:57

There's literature going both ways. It definitely doesn't rebuild nerves. But some people feel like it helps them with pain.

49:04

I've seen a really mixed, mixed bag. Like some people find it very helpful.

49:09

Some people don't, but it is out there, um, things like acupuncture. Also, some people find helpful in terms of pain or massage. And some people don't, but I always say, you know, if you're going somewhere that's reputable, that you make sure that, you know, person is licensed and so forth.

49:27

I think trying anything if someone is interested. I always, you know, would not discourage it.

49:32

as long as, and to your point with, with respect to reputable, I think we, here at the foundation for peripheral neuropathy and a lot of our patients. We've seen so many ads suggesting that we can cure your neuropathy if you come here, whether that is a clinic or a specific doctor or a various therapy.

49:54

Um, I mean, other than commenting on the obvious, do you have anything, anything else to say about that?

50:02

Yeah, no, it's interesting. You know, it is interesting, I think.

50:05

So, I, you know, for, for example, acupuncture, the literature with acupuncture is that there is interesting medical literature that shows a benefit of acupuncture for pain. For some people, it's not a permanent fix. It's, it is kind of like maybe a massage which maybe most people have experienced where for people who like massages.

50:25

Maybe you feel like, oh my aches and pains are better but it's not like it's better for a year, might be better for awhile. And people have found and there's been research into why that says that acupuncture might have kind of a similar phenomenon that it helps people.

50:40

And, but it's not a permanent fix. So I think if anyone is, is selling you a cure, I would be wary. There is if you are kind of strategic in, how you Google things, or look things up on the Internet.

50:53

There is a lot of kind of information that sometimes I think Google is linked more recently with medical kind of literature. So sometimes you'll get that coming up also.

51:02

Not just anecdotal or or or kind of proprietary information, and that can sometimes be a good check.

51:10

But again, kind of making sure you're looking at the source, is it kind of like a medical sources that are published, medical paper, or is it like somebody's company, whether, you know, trying to sell use, but that can be kinda good.

51:22

Check in the moment, if you're just wanting to look at something.

51:25

Yeah, you know, It just did, It makes me angry, because I think there was a lot of kind of false advertising out there, and they're getting away with it. I feel like, you know, if you're like me, you're aligned to that degree, and you still, and you actually have this business open. Like, it just, it, it makes me angry for our patients.

51:45

And for everyone that, no, has tried something that they kinda were duped into. But but we're, we're trying our best to keep that type of information disseminated and clear, and we always encourage whenever anyone thinks that they might have seen something to send it over our way. And we can kind of say, oh, yes, you know, we have heard that that's been helpful to some patients Or, you know, this totally looks like a little bit of snake oil, so yeah.

52:15

That's it, but it's it's hard to decipher sometimes and when a patient is so hopeful and as desperate, you know, try everything and anything but it gets, it gets, it gets scary.

52:28

Yeah, um, we have a few more minutes for a couple more questions.

52:34

So, peripheral neuropathy isn't always progressive.

52:40

No, it's not great, You know, some of, I think, that for some patients and it can start, it can, you know, obviously, there's a beginning. And there's some type of a trajectory, but for many patients, it can stay about the same.

52:54

And one of the things we've seen is that, for some patients, where, if you've gone on for a number of years and it's been kind of about the same, it's not uncommon to have kind of waxing and waning like fluctuations where things seem to go up and go down. Sometimes it's with stress or the seasons or your shoes or whatever.

53:13

That's very common, and sometimes patients will say, Oh, it feels worse and then we see each other the next week, they're like, oh, now it's kinda back to where it always was and when we look at the bigger picture, we oftentimes will see it's about the same, there are certain types of neuropathy.

53:26

Some of the autoimmune neuropathy is the right, some of the hereditary neuropathy. Some of them can be progressive or significantly progressive.

53:34

Neuropathy and poorly controlled diabetes can be, you know, significant right.

53:38

There are things that certainly can be progressive, but in many ..., for many patients, it's not.

53:45

Now, that's great.

53:46

But then when you talk about damage to the actual nerve, is that, can that ever be recovered?

53:55

That's also a great question.

53:56

So I think, and the answer is, is somewhat, is sometimes not all the time.

54:03

We do know, for example, with small fiber neuropathy, which are this small diameter, microscopic nerve fibers diet. The condition involves only sensory symptoms and is diagnosed with the skin biopsy.

54:15

And that, there have been studies, looking at patients who had high blood sugar levels who developed this. It was felt to be related to it.

54:22

They corrected the diet. And then this was part of a study So it was very, very controlled. And then they did the skin biopsy later and they confirmed, oh, the nerves regenerated in response to that.

54:33

You know, so I think nerves can regenerate, small diameter nerve fibers are much smaller.

54:39

And kind of a simpler structure, if you will. So it's probably easier for them to regenerate compared to some of the large diameter nerve fibers involved in peripheral neuropathy.

54:49

If it's a mild neuropathy that's had a recent onset and and the cause that's identified.

54:56

Or maybe sometimes it's a cause it's not identified. Maybe it was a virus or a toxin or something that we don't recognize that comes and goes through your system.

55:03

Um, and that then interrupt it gets better, sometimes that happens.

55:08

But in general for patients where it's been going on for a long time where there has been which we can identify either on exam or through EMG, some significant nerve damage if you will, it is it is not likely that that will reverse.

55:23

We are looking to do everything we can to help in those cases prevent any progression and we're happy if we can get some improvement, whatever that may be.

55:32

But for those cases, we aren't, we don't see a reversal, OK.

55:39

And does that extend into kovac related peripheral neuropathy or vaccine for co bid?

55:50

Because a lot of, again, a lot of patients are coming up to us saying that they are now experiencing pain and have been diagnosed with neuropathy or neuropathic symptoms either due to the actual virus itself, getting cobin or due to the vaccines or boosters that they received.

56:09

So in the last remaining minutes, could you maybe take a couple of minutes to just comment on that and how that might look with respect to right reversal or progression or just general, That's that's impossible kind of statement.

56:25

Sure.

56:26

So first, I will say, just as a preamble that we have seen, and especially New York, we've seen such so many covert patients locally, that we've been able to see, know, a lot of patients with a different types of symptoms following coven, or following the vaccines.

56:46

And what I can say is that, is that overall, you know, we always recommend this neurologist's, that people get the vaccine, unless they've had some known, really significant adverse reaction to the vaccine.

57:01

But we do not, because because it is so rare, the reactions to the vaccines that are severe are so rare, that we do not recommend that people not get the vaccines.

57:11

And I, myself, has have had three doses, and at any rate, the but so let me break it down maybe in a few different directions in the last couple of minutes with respect to the vaccines.

57:22

We we have not seen, we do see some neurological symptoms for some patients after they get the vaccines.

57:30

The vast majority of those are transient, um, there are rare cases of things, where that it can lead, that we've seen what we presume to be like an immune response in some patients, related to the reaction against the vaccine, which, interestingly, has been known for a long time, as a rare reaction to other vaccines.

57:55

I think that the attention to some of these things with covert is that we've never had such a big population, getting so much of one virus, becoming sick, or getting vaccinated for the first time with the same vaccine every in our lifetime, in our generation in several generations.

58:11

So, it creates a lot of attention about it, but actually in truth, some of these neurological complications that are rare that we've seen against the covert vaccine.

58:20

We've actually seen with other vaccines in the past.

58:25

These are things that many people have had, you know, in terms of being vaccinated before.

58:30

There's no way to predict for, you know, that we know of right now to predict who will have a reaction, you know, that's rare against the vaccine.

58:38

But again, what I can say is that for patients who have preexisting neurological conditions including autoimmune neurological conditions, we do recommend they get it.

58:48

For patients, many patients, after they get the vaccines, they might have side effects, where you feel kind of crummy for a few days.

58:55

And that's really a it's annoying but it's kind of an exciting symptom that your body is like doing what it's supposed to do and immune response.

59:03

And if you have anything else going on with your body already, it's not. It's not unusual for it to make those things feel worse for a few days.

59:11

So if you have neuropathy and then you are exhausted and you feel achy and you feel crummy, your neuropathy may feel worse. But the vaccine, we do not expect it to be making somebody's preexisting. Neuropathy worse.

59:25

Coven The virus itself, with respect to neuropathy.

59:29

And there's a lot of different long haul symptoms and things in neurological brain related effects that we hear about, And I'm going to leave that out of this discussion just to try to stay focused.

59:42

There are certain things like guillain barre syndrome, which is an autoimmune acute neuropathy.

59:47

That's by the driven by the immune system that we have seen rarely in response to two coven and rarely in Response to the vaccine. The interesting thing to mention is that we have seen this also rarely with other viruses and other vaccines.

1:00:04

So it's almost as if for peripheral neuropathy, we're seeing all of these different subtypes of phenomenon.

1:00:10

But it's not something that's, it's new, because we are seeing so many people in the population experiencing this at once, or within a short period.

1:00:19

But what's interesting, and there's been some, I think, data now that's been kind of collected in grand rounds and so forth.

1:00:25

They've been given when people step back and look at viruses and look at the way our immune systems react to viruses or even vaccines, a lot of what we're seeing now is, what we've seen before is just it's kind of on a different scale all at once. Right at the treatments as neurologists now that we've been recognizing these patterns, I think we're getting very good at helping people when these things.

1:00:49

And what I can say that for many patients with Cobo related neuropathy symptoms, Or post vaccine related neuropathy symptoms that many of them get better With time and for people who have these unusual kind of autoimmune reactions that are like guillain barre syndrome or others.

1:01:09

Now, you know, that, especially now, I mean, this is not two years ago, but especially now that we have an idea of what we're dealing with, we're, I think, good at recognizing the patterns, looking for these things when people have these symptoms. And we have treatments.

1:01:25

Well, that, I mean, that's encouraging. And it seems like the more and more data we collect, the more we know.

1:01:31

But it hasn't really contradicted what we thought we knew about a year ago, with respect to covert in general new vaccines. So, that's great, and I wish we could stay on longer, I do. We have so many other questions that we weren't able to address, but at this time, we do need to close the session.

1:01:50

It has been fantastic. Thank you so much again, Shana. And, thank you to everyone who joined today's session. I hope you enjoyed it. There's going to be a survey at the end of here, feel free to share your comments and feedback as always, both positive and otherwise. We hope to see you again in the near future, both all of you watching, and also you, Shanna, thank you so much your, your, your your real gem for us.

1:02:17

So thank you so much Lindsay, Thank you so much, thank you to the Foundation, and thank you to everyone who was able to join today. I really hope that this has been helpful.

1:02:27

Yes. All right, well, thank you, everyone. Have a good rest of your day, and thank you again.

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