

0:04

Good evening, afternoon, everyone.

0:08

Thank you for joining our webinar this evening. We're from the foundation for peripheral neuropathy. And we're tuning into something new that we haven't tried before, but I'm sure will be informative for everyone. We're doing our patient roundtable webinar.

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The webinar tonight is and brought to us by a sponsorship by Live on Labs. There does vitamins and supplements, and we're grateful for their support.

0:39

I'll introduce myself. My name is Nancy ..., I'm the director of Development and marketing for the Foundation for Peripheral neuropathy. Pleased to be here and to join our panel. I got my colleagues, Lindsay Colbert and Tanya's event here as well, helping to make sure this all goes smoothly.

1:00

Before we begin, I'm going to give a little bit of housekeeping.

1:04

First of all, hopefully you're hearing me and hearing us, if you have trouble with the audio on your computer, you can dial in by phone. There's a dial in instructions on your e-mail.

1:16

We are recording this webinar so that you can listen to the broadcast at another time or share it later on.

1:26

And we're also going to be taking questions and, and, and Providing answers later in the at the end of our discussion with our roundtable I'm going to tell everyone here that we could keep a general all that none of us are doctors.

1:47

We can't give any specific, um, and directions are specific diagnoses.

1:57

We're just sharing our stories and, and hopefully that will, you'll find that useful as people who've try things and find what works for them, and that's what we're trying to get to tonight.

2:10

I'd like to now introduce our panelists, and I'm going to turn my, \*\*\*\*\* my camera on, and hopefully, everybody else will, as well.

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We've got three people or four people joining us this evening. I've got Jeff Cooper, who is coming from with us from Connecticut.

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I've got Linda patio who's from Calgary, who is joining us from Virginia. And hopefully we'll get Michael great who's joining from from South Carolina, North Carolina.

2:47

And there it is.

2:48

Perfect, Thank you, everyone, for joining us Evening. The format for tonight is we've come up with some questions that I'm going to pose and hopefully get some answers and responses from our four panelists.

3:04

At the end of the, uh, the event will have questions and answers and give our audience some time to a chance to ask you all some questions and I'll be posting them to you as well.

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So for the first question, just to get started, tell me your story. Why, what what brought you here? And what's your connection to peripheral neuropathy? And if I can start with Jeff this because he's first on my screen, that would be great.

3:40

OK.

3:41

So, I was diagnosed with peripheral neuropathy this last August.

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So, mine is a new story, and I'm new to this, so, I'm learning a lot when I was diagnosed with it, and I did a little research, actually became depressed.

4:01

But then I found on Facebook group, called Peripheral neuropathy, Success Stories and Michael Ryan, who's on the line founded the Facebook group.

4:11

And Michael and that group helped me a lot, and actually helped me to get over that depression.

4:18

And the other thing that helped me to get over that was, I learned to become active, to take control, and that was doing research, And also, a big decision was, I decided to be positive, and I learned that from the, from Michael, right, and from the the Facebook group that I mentioned, that when you have peripheral neuropathy, attitude to your attitude is, is crucial.

4:52

So, that's my story.

4:54

Very good, thank you, Jeff. I think you answered a couple of the questions that will come later, but I'm sure we'll explore that. That's terrific.

5:01

Well, since Jeff mentioned, Michael, I'll pass this the baton over to Michael to give a little introduction for himself. Yeah, well, thanks for having me. It's good to be here and talking to everyone that I can't see, but I wish I could.

5:16

So, I guess my story started about seven years ago.

5:20

I started getting twitching and my calf muscles, and it just about unraveled me because I didn't know what was going on and I went to my internal medicine doctor and suggested that I might need to see a neurologist. And he told me I was depressed that this was all depression and I said, No, it's not.

5:39

And finally I had to leave him as a doctor and I found my way to another primary care doctor who sent me to neurologist, did the EMG and nerve conduction studies. And yes, I had peripheral neuropathy. So that was my store. I went to the Mayo Clinic for a second opinion.

5:56

one thing that was really important to me was to find people who could understand and as I got on and started looking for support groups, they were all pretty much dreadful. It was all depressing stuff that I was reading. So on a whim I decided to start peripheral neuropathy, success stories.

6:16

I want it to give it a positive name, we keep the group positive. It's working when we started the group about 2.5 years ago, and we have almost 20,000 members in over 100 countries.

6:26

So, it's, um, it's been very helpful for me for support, and thank you, Jeff, for letting me know that it's helped you, and hopefully, we're helping a lot of other people as well. So, that's my story one day at a time.

6:42

We just get through one day at a time.

6:45

Terrific, Michael, and I'm going to pass to Linda who is heading another support group from our neighbors up north and Linda, maybe you can give a little bit of background.

6:56

Sure, thanks, Nancy.

6:58

Yeah, so, I have what's called hereditary peripheral neuropathy or short co marie tooth disease is the original name, but, as it implies, it's genetic.

7:09

So, I got it from my dad who suffered his whole life, because, of course, it's genetic. We're born with it.

7:17

But he didn't know what it was. So he had the shooting pains. He had restless like really bad.

7:23

He has the numbing and everything.

7:26

And he just didn't know until 77 when he was finally diagnosed my neurologist. And I just happened to be there, and the neurologist said, well, why don't you hop up on the table, and we'll do a couple of quick tests.

7:41

So he did that, and he said, Yeah, you should book an appointment with me, mm, OK, So that's how I kinda got diagnosed. But, boy, it sure explained a whole lot of things when that finally happened. Like, I was clumsy all my life, I would follow a lot.

7:56

I had shooting pains everywhere.

7:59

Like from my lips to my feet, I would get shooting pains and why you couldn't wear a good shoe, like buy shoes, stuff like that. It just explained so many things.

8:08

When I learned, and that was only about 5 or 6 years ago, I started searching around as we all have.

8:15

And I came across the Calgary Neuropathy Association, so I just happened to be fortunate.

8:20

It's the only one in Canada, so the fact that I live in Calgary was just lucky for me, and before I knew it, I was volunteering. and learning more and more and learning ways to help myself.

8:32

Great, thank you.

8:33

And last, but not Least, Diva, who's also another wonderful volunteer with the many of the support groups. And for the foundation for peripheral neuropathy.

8:49

And Diva I was, so I technically just like Linda have had PN all my life. I was always clumsy you can never hold the basketball when it was passed to me and would always just drop And but nothing really was significant enough. Or like you know, enough of an issue until I fell off a horse in 20 17 and then I started developing symptoms in the summer.

9:17

Like right after the summer of 2019 and then my diagnosis process went through to 20 20 and I was diagnosed with small fiber neuropathy, autonomic neuropathy.

9:32

And it explained pretty much everything and explained low blood pressure and explained clumsiness. So I ended up like seeing a lot of specialist. And I basically got the diagnosis right after graduating from college. I had to unlearn the whole college lifestyle of like sleeping for the week and actually start taking care of myself and sleeping and exercising and all of that.

9:59

So doing all of that has really helped.

10:01

And then also I've started, like Nancy said, volunteering with groups like the Foundation and the peripheral neuropathy support network switches in DC, Virginia, but also help support groups across the country.

10:15

And then, I've also been writing about my experiences, which I would say is the thing that has helped me the most, because I always like expressing myself through writing, and it has really helped me kind of work through it.

10:30

Yeah, thank you. You're all of you have, I have given answers to my questions, but we'll explore a little bit more. But thank you for sharing your stories. The next question, we're going to drill down a little bit more on some of the things you've already talked about.

10:47

Is has, that, if we can take the next question, is what is how have you changed your lifestyle? Have you changed either, your exercise, routine supplements, what have you found in changing your lifestyle that has helped? Probably your mind as well as your body?

11:12

Maybe we can start, Michael, do you want to start, and then we can pass the baton sir?

11:18

I think the biggest thing for me is prior to peripheral neuropathy. I was traveling. The world was gone, and doing so much stuff, and I really kind of have to back off a little bit.

11:29

So I had to find other ways to to occupy my time and be happy. And I did develop a lot of new hobbies which I can talk about in a little bit, but I did I've tried every single supplement probably known to man.

11:44

I've tried a lot of different things including hypnosis I've tried acupuncture, upfront and medical massage, um, you name it, and I've tried it.

11:54

Um, as far as the exercise, I do try to walk, I can walk 3 or 4 miles at a time.

12:00

I've got to push myself. I've also got some arthritis on my feet. So it's hard. But I do push myself further.

12:07

I've tried Reflexology assist.

12:09

I don't think I've left anything on the table, The biggest thing that's helped me swimming.

12:15

So we built a swimming pool in our backyard. and I swear, I spend every spare minute out of that poll and in the spring and summer, I'm in the water, either in the hot tub or in the pool. And it really want. There's something about water. This is therapeutic.

12:30

So that's really what's helped me, I would say the most.

12:33

Yeah, Terrific. Thank you. David, do you want to address what's helped you, and what changes you've made that have been useful?

12:44

Sure, um, so for like no further. So I went to college for five years, and for all those five years, I was eating dining hall food, basically. So, I immediately, like kind of switched to home cooked food. My doctor told me to eliminate refined sugar, which was really sad, but I did. And I also went vegan and gluten free.

13:11

So, now I'm pretty strict with myself But it has really helped because my autonomic neuropathy also impacts my digestion.

13:19

So, it has helped, like, Yeah, just, like, reduce the pain in general by a lot and then, as soon as my diet kind of stabilized. And that led to a lot of changes. I started kind of building up in the exercise realm, my building has yoga classes. twice a week, I started going, I started going on, like, hour long walks every day that I don't go to yoga.

13:47

So now I can walk like Fast, actually like the time that it says you'll get there on Google Maps. I can actually get there in that time and you know I thought I had a tumor on my forearm and freaked out and it turns out it was just the first time I've ever had a forearm muscle.

14:09

Now that the exercise aspect of it has really helped me, and in terms of supplements.

14:14

I just I was very lucky to get a doctor who kind of helps me stay on top of it. So every six months, we get my levels checked, or, if I'm feeling fatigued, we get my levels checked before. And if there's anything that's not exactly where it should be, I will like alter my supplements to fit that. And the main thing for me has like, being on top of my health, like just treating it. Like I would a class, and just like studying up on everything and making sure that all my graphs like, look the way they're supposed to look.

14:52

And just through the process, I ended up losing about about £80.

15:04

That's terrific. Yeah. Linda, can you can you add to what these folks have been talking? I think Dave and I are very similar. I definitely have a problem with sugar and carbs if I, if I do eat them especially late at night.

15:24

Then my feet will be burning and I won't be able to get to sleep, right?

15:27

I've cut out all kinds of like alcohol artificial sweeteners, caffeine.

15:33

I've discovered I'm also sensitive with gluten and dairy.

15:37

So if you're sensitive to anything, cutting it out as is a big thing to do, I've increased the good fats.

15:45

Because my neuropathy is my lawn sheath based.

15:51

That's where the problem is, and the way I understand it is that eating that good fats will help.

15:57

I'm not sure how much it would help, but, so I use like olive oils and grape seed oils and stuff like Omegas.

16:05

I take supplements with Omegas Like Michael, I do swimming anything that's impact.

16:13

I don't do anymore, pretty much, so, I tried to do something every day, Swimming, do a lot of biking in the summer, I go to the gym, I have a wide membership.

16:25

Sometimes I'll just do an online yoga class with a group that I belong to.

16:30

And weights.

16:34

Weights, and bands.

16:36

What I'm trying to focus in and one thing that I do, that I I don't know if a lot of people do. I think I'm strange this way.

16:44

Over the years from my chiropractor, my Physiotherapist Athletic therapists, all kinds of people, I've gotten exercises that I can do, and what I try to do is just fit them in the bits, that's what I call it.

16:58

So if I'm standing in line at the grocery store, I'll do some calf raises or do some stretches or whatever. You know, I same with pumping gas or if like if I'm standing there doing wasting what feels like wasting time I will try and stretch something or move a muscle.

17:18

Super fun, Yep. And Jeff, what what what about you? What, what do you do? What can you add?

17:26

Well, what I do is I do a half hour of cardio and strength training every morning and then I would say that I eat healthy diets.

17:36

I'm just changing over from a healthy diet to a Mediterranean diet, which my doctor tells me is healthy.

17:43

But he wants me to go on so I'm just starting that.

17:47

Terrific.

17:47

Yeah, I think if I can sum up what everybody has said is, First, It helps, but to toss it over whatever you do.

17:58

Talk to your doctor to get in, in stages, and, and keep track and notice what, what helps you, and we then recommend to love food, to see what helps and what doesn't, thank you, to the next question, I think we'll say so.

18:20

They, what, what, I think you, I've answered some of these already, What do you, I think was what has, what's helped you the most in managing your proof?

18:36

Oh, we're going back a question there we go, when, when you have P N, what do you tell people about your peripheral neuropathy?

18:48

How do you tell people about it?

18:50

Um, can I go, we'll start with Diva.

18:58

So basically, I've had to tell a lot of my friends about this and my friends, because we're all like in our early twenties. No one has heard about this. No one knows even remotely.

19:12

That nerve issues could be a thing that affects someone, our age.

19:18

So I've come up with a bunch of analogies that help. Like it feels like I'm wearing leggings when I'm not, or it feels like I'm wearing gloves when. I'm like trying to touch my fingers together.

19:32

When I'm not so that helps me communicate that like I'm numb, but I can still feel like it's like there's a layer that's in the way.

19:43

Apart from that, what I tell people is just that this headset limitations on me, I'm very clear about here is what my limitations are, Here's what I can and can't do, and no, like, try to get my friends to work within those, and the best way that I've found to get around it is, I'm already kind of like the planner of my friend group. So, if I can continue to be the planner, I can just plan stuff that is within my limits.

20:17



So that has worked out really well, and apart from that, just, what I tell people is that, like, my, my system is sensitive, like something that might give someone else, like a sugar rush or just like a mild stomach, upset might.

20:35

Like, give me a stomach upset that lasts three days or just might give me stabbing pain that blast like hours instead of just like making me a little bit uncomfortable. So it's like kind of an elevated like reactivity to things that are bad for me.

20:53

So, that's why I need to be more careful now, if it's like, a special occasion, like, I passed a macaron place that had a flavor that I really wanted to try. I ate one single Mac or on, and I let myself have that. And then, you know, I prepared myself for, OK, this might hurt a little.

21:14

But, if I decided it's worth it, then I'll give myself that one macro. Balancing, that's great. So, Michael, what about you, do you find that you need to explain to the people around you?

21:30

Well, I do one thing that I didn't say as mine neuropathy as idiopathic they don't know what caused that.

21:35

They never tested me for small fiber or, Um, yeah, so I don't think I've got small fiber, I don't have the burning Or the thing that people talk about, I've got to pain that shoots down my legs into my feet. So as far as server sensitivity, I'm not really sensitive to that. Sugar is inflammatory and people should probably moderate for sugar intake.

22:00

I eat sugar, I love dark chocolate. Dark chocolate a lot and I don't see any reaction from my body to that.

22:08

But as far as what I tell people, neuropathic Pain is not something that can be really described.

22:14

You can't put it in the words of people have an experience, nerve pain. You can try all day long to explain what it feels like.

22:22

But people just can't understand what it feels like, you know, sure, you can say it burns and tangles.

22:28

But as far as my large fiber neuropathy, it just as painful and I can't really say too much more than that, but I do try to stay.

22:40

Does the, that's the biggest thing for me is seeing distracted, staying amongst as many people as I can, really helps me.

22:48

So those are the ways that I kinda get beyond it, not thinking about it.

22:52

I tell people that, but it's probably hard not to really focus on it.

22:56

But with that said, wide open book, and I'm really happy to get people more educated.

23:03

Because I do think we need to build awareness. I think with 30 to 40 million people in this country with peripheral neuropathy.

23:10

The awareness is very, very low. And we need to build it.

23:13

So I do like sharing my story and getting people more where we just need to keep building awareness, right? Linda, what about you? Do you feel that you have to explain to the people around you and how do you do that?

23:29

Well, there are some people it's just not worth my energy to try and explain it too.

23:36

So, I'm sorry I just don't try and explain it to them.

23:42

And there's other people that you try but you can almost tell on their faces that they just can't relate.

23:48

So I do try and explain a lot of the time that, you know, it's not just about the nerve pain sometimes. And for some people it comes with feelings of isolation. It comes with loss of function.

24:02

Some people aren't able to work anymore until there's all kinds of problems with that, but actually, like Michael, I try and talk about awareness. You know, I tell people this. Right. The fact that there's one in fifteen, that's the number I sort of go with.

24:17

I think it kind of floats depending on where you look that have this condition.

24:24

Watch, people haven't even heard the word before and it's very frustrating for folks like us knowing that it's so prevalent, you know, diabetes in Canada. Anyway is one in sixteen.

24:34

Heart disease is 1 and 12.

24:36

Lupus is one and a thousand and people have heard of those, but they haven't heard of neuropathy, or CMT like what I have.

24:44

So I think Where the value is for me to add is two, try and raise the awareness as well. The more people know about it, the more attention that will get. So that's what I do.

24:57

Great Jennifer, what about you? How do you explain your peripheral neuropathy to the people around you?

25:03

And, you know, if you have limitations or not, how do you how do you make people understand?

25:10

Well, I'm in the beginning of my journey and where I am right now is I don't want to be defined by peripheral neuropathy.

25:21

So, what I've chosen to do is, I say as little as possible, and I only bring it up when I need to bring it up.

25:28

So, that's helping me with my attitude.

25:33

So, I try to live a, you know, my life and thinking about other things.

25:38

Yeah, terrific. All right.

25:39

I'm gonna kinda go through the next two questions together where I said, what's helped you manage the most, and what are the top three tips? I'm going to just say that you all have been talking about how you're managing for follow up with the all along. What would you give your top three tips to somebody to say what's helped you the most, of what are, what are your three biggest issues, and what's helped you the most? And maybe this time I'll start with Linda, because I haven't had the opportunity to start with Linda and the question yet.

26:14

OK.

26:17

So sugar and carbs goes, I try and cut down as much as possible.

26:21

Hands down, it is what makes the biggest difference for me, and with the burning and keeping me up at night.

26:30

The next one, I would say, is meditation.

26:35

I try to meditate every day.

26:38

I'm not always that successful, but, you know, the studies that I've looked at, it can help pain relief by as much as 30%. Because it, it helps grow the brain, right? So, for me, me, meditation. I know emotionally, I can handle things better.

26:54

And I can, if I'm having a shooting pain, for example, I can focus in on it, do the deep breathing, and I can actually make it go away. It took me awhile to get there.

27:05

But I can actually do that now.

27:07

And then, when I do have too many curves at night, which I, like, I do for, you know, not that often, but sometimes, I know that I've learned that if I take, like a topical that has Camphor.

27:23

And and Menthol in it. And you could use anything because PayPal rub there's all kinds of cinnamon oil or peppermint oil.

27:32

But I put that on my feet and that will quite often make it so that the burning goes away.

27:40

And for me, I need my sleep, if I don't get eight hours, I don't function very well the next day.

27:46

And if it, that's still doesn't work, I put a fan along so that the fan is blowing on my feet and that sort of doubles the help that it gives.

27:56

So, yeah, those are my three.

27:58

Good, good answers. Jeff, what about you?

28:02

Well, the first one is to be positive. So I think about what I can do, not what I can't do.

28:09

I think about what I have, what I know what I don't have, that kind of thing.

28:14

The second one is to be involved in support groups, like the peripheral neuropathy, the success stories.

28:21

And the third thing is to be self educated on peripheral neuropathy.

28:27

And two, is to be your own self advocate, which is crucial.

28:34

I think.

28:36

Yeah, yeah, and Diva, what about for you?

28:40

How do you manage a PM? What are your top three tips?

28:43

So the biggest thing for me I'd say, is that I try to spend my time and energy with the same sort of like conscious thought that I would spend my money. So like, you know, there are certain things, uncertain people in my life, that I think are worth spending time and energy on, and certain people and things that are not worth spending time and energy on. So, I basically treat my own energy as like a limited commodity. And I spend it on the things that matter to me. And that has also just helped me prioritize things in my life that, you know, like, I don't, like, I, like, I know it's important for me to eat, right? So I'm going to spend that time on cooking.

29:33

I know it's important for me to exercise, so I'm going to spend my time on that instead of, let's say watching an hour of like a TV show. So that has been big for me.

29:44

Also, just being in therapy and being able to like rationalize everything, 'cause sometimes like neuropathy and the pain that comes from it can often, like, lead to irrational thoughts and just like, when, I've found that when there's pain, kind of interrupting your thought processes, it's really easy for logic to kinda go down the drain. So it's really helpful for me to like vocalized things. So very often I even figure out that like, OK, this is where I'm not making sense to myself or there's someone else on the line who is helping me figure out, OK. This is what is not making sense.

30:27

So, that, And so, those are two things. And then, I would say, self, advocacy is, like, my third big one, and it's self advocacy.

30:35

Whether it's at work, whether it's with friends or, like, I tried to be as upfront with it as possible, because I was, This all happened during coven.

30:48

So, it was mostly zooms, and then when things started coming back in person, it was like, oh, by the way, I have walking sticks now, and, you know, just being as open. As possible.

30:58

And, and that's where writing about it comes in, which, I mentioned before, Which is a form of self advocacy for me. And then, for them, as, well, yeah. My, what have you.

31:12

So I'm going to tell you, the number-one thing for me is, when were diagnosed with neuropathy: we want answers. And so many times, they're not answers, We go for a second. And, third opinions, we get tested in a million different ways. We see pain, doctors, and neurologists ..., and you name it. We're there.

31:30

And at some point, it's about acceptance.

31:32

It's acceptance that maybe we won't go back to how we were 4 or 5 years ago, but maybe we can get on with their lives, Lead productive and fun lives. And for me, I think when I went through that door of acceptance, I was able to get on with my life in a positive way.

31:50

And I quit the sulking and quit the searching for answers that just weren't there.

31:56

And I was able to move on. So that would be number one, and let's just get to the point of acceptance.

32:01

Then the second thing is distractions.

32:04

I try really hard to stay distracted, whether I'm swimming, I paint rocks.

32:09

I paint like wooden boards, just kinda like folk art type things.

32:14

Also read, I read every day I go probably three novels a week I love to read and I like to watch Netflix can't help it.

32:23

I just watched all of the 10 movies that were nominated for Academy awards. You can you can stream all those that don't know what's crazy is doing or if we have time at the end, I'll ask you all what your what you would recommend of the movies you watch. But let's first and we'll get onto that stuff like the third thing. So the first thing is acceptance. The second thing is stay distracted. And also as a part of that just in communion with other people, keep other people close to you.

32:52

Then the third thing is just try to stay in motion whether or not for you. That's walking or swimming.

33:00

For me, you know, I'm in the house a lot. So I get in the car and drive up to Starbucks and get a drink. It's just an emotion is part of being healthy and keeping their mind distracted. So this would be my three things.

33:15

Terrific. The next question we've gotten, several of you mentioned, you know, going, talking to your adopters and going, having, talking to many specialist, in the healthcare profession, Who do you consider, part of your healthcare team, and how do you, communicate with them, so that they understand what you're going through, And you can work together, as a team, with those health care providers? Of Jeff, why don't we start with you, on that one? If that's OK, I have three that's my primary care. Physician.

33:45

My neurologist, and then the third one is me, myself.

33:50

My self advocacy.

33:52

And how do you bring your, self, advocacy to, your primary care, physician, and your neurologist?

34:01

Well, when I, whenever I go to see a doctor, before I go, I write down what I want to get out of the meeting.

34:09

So, it's planned, OK.

34:12

That's, that's great. Linda. What about you?

34:16

I also have, of course, my family doctor, but actually, I don't feel like she does that much. The chiropractor, I have a chiropractor who has neurological training. There's, there's ones that you can find across both countries. So, he helps me a lot.

34:34

And I have a for citrus here in Calgary, we have a neuromuscular clinic, So, I go really, just once a year, and they assess me, and if I need any help with nutrition or occupational therapy or physio, that's where I, that's where I can get.

34:51

Yeah, great too, but what about you?

34:56

So I actually had an orthopedic from when I fell off the horse who has kind of helped me through the process like, I know I went to her initially for the pain because we all thought it was an extension of falling off the horse. And she has kind of been serving as my primary care provider a little bit. Just like telling me, OK, maybe you should talk to this specialists next. And that specialists night. So having her guidance has been very helpful and I just e-mail her. And I have a neurologist and a gynecologist over at Johns Hopkins who have both been helping me. I also have polycystic ovary syndrome, which is where the gynecologist comes in. So a big thing for me has been to make sure that each member of my team knows what's going on with the other aspects.

35:49

So, know, I talk to my gynecologist about peripheral neuropathy even though she doesn't know all that much. And like, she asked me, questions answered, and I was kind of educating her, just as much as she was educating me, about, like, you know, her department.

36:06

And my neurologist has been great, in terms of, just like, not only, in terms of, like, the medical stuff, but in terms of, like, I'm going to six flags and they need a doctor's note, and if I'm gonna be able to not stand in those lines. So I try to stay as communicators as possible. A lot of portals, these days have messaging options. So, I usually use that. And I've found that people tend to be pretty responsive. And I just, like, write down the concerns I have. And, you know, I get a response on that.

36:43

And then I have kind of, like, supplemental members of my health care team, like my hand specialist, my GI, who I kind of, like, consult whenever there's an issue.

36:57

And those, I would say, like, you know, I tend to only consult when there's an issue, and the main core members are my ortho my neuron in my gut and ecologist.

37:07

Perfect. Thank you. And you It sounds like you're like Jeff, self advocating to all of them.

37:14

Yeah. And Michael, what about you?

37:17

So, my neurologist actually left this earth at 36 years of age, and I haven't found a new one yet.

37:24

but she had already done the work up and she referred me to a pain doctor. So I was going to the pain doctor who was doing injections were weren't really helping.

37:33

And he did prescribe a drug called Belt Buca, which is a class three opioid.

37:39

I took that for about two years, before, realizing that there really wasn't doing anything. So I stopped that. I'll take that anymore. So therefore, I really don't go to a pain doctor.

37:48

I did go to a different Pain, Doctor out of town for a spinal cord stimulator implant, which really helped a lot.

37:57

There's really no need for follow up with them. So I'm pretty much done with pain doctors. I do have a desire first.

38:04

I'm actually going for a FAFSA Injection tomorrow in my back, he does different injections for me. I've got an orthopedic foot and ankle doctor. He's removed, a couple of bone spurs from our feet.

38:17

And then I get them a primary care doctor who prescribes the gabapentin that I take.

38:22

And that's pretty much my health care team. There's really no one.

38:25

There's really no one else at this point. You're co-ordinating all of that, as well. So I think that's the stream of this message is a lot of people, but keeping track of it yourself.

38:38

The next question I have is no, of course, your first answer to this question is going to be the foundation for peripheral neuropathy but your second answer where what resources have you found to be?

38:57

To be the most useful?

39:03



We lost Nanci, did you lose your back? Or? Oh my goodness, OK. So, sorry, everybody. Did you hear my plug for the foundation for peripheral neuropathy? Yeah. You plug for all the other resources that you have found useful on your journeys.

39:22

Jeff, why don't you start? I know you were, you're a researcher.

39:26

Yeah.

39:27

Well, I even though you said foundation, I'm gonna mention that anyway, the foundation for peripheral neuropathy is very good.

39:39

They have a great website with a lot of useful information on there, then I mentioned before that Facebook has the group peripheral neuropathy, success stories I think is very helpful to me.

39:52

And then the the third, and last one would be books on peripheral neuropathy.

39:58

I don't think there's enough books out there. But you know, the ones that are out there are helpful.

40:04

And you have to be careful which books you pick.

40:06

Yeah, we, it may be, well, if anybody's interested, there's a couple that you read, the or Good that let us know, and we can share some of those. But what about you?

40:22

I would say, I was lucky enough to find him to find a really good neurologist. So I bother him a decent amount and just ask questions. And if there's anything, he tells me, I ask for more explanations on, like, well, yes, this is what's happening. But why is it happening?

40:43

And like, can we figure out like how this will evolve and all that? And I also, in addition to what everyone else said, because I use all though, so I have not had time to read a book about that yet. I continue to read books about like fantasy. But I also have been working on a resources directory for the peripheral neuropathy support network where I've been trying to compile resources from a bunch of different places and that has also helped me find resources like podcasts and stuff. If I wanna listen to those, if I decide to have the time to listen to podcasts again, but many me, it has been that, I really got lucky with my medical team. So if anyone is close to Baltimore at Johns Hopkins, I would recommend that.

41:34

And apart from that, just resources have been like my now my other doctors who might not necessarily know the peripheral neuropathy but can help me with my other issues and like working on the ... has helped a lot with the neuropathy.

41:54

Working on the neuropathy has helped a lot with a piece ALS and just like realizing that everything going on in my body is like pretty connected, so like, I need to focus on taking care of like everything.

42:07

Right.

42:08

That goes back to, like, just keeping track of everything myself. I have a a database like, of my own medical information. It has all the dosages and everything.

42:17

So that helped.

42:20

Yes, thank you.

42:21

And Linda, you please plug the neuropathy Association of Calgary, which has the incentive. I do have the foundation for Peripheral RP on my list. But Yeah. Our resources I'm always going back to our is, I'm sorry. It's super time here.

42:42

So, yeah, I always went back to our own resources.

42:45

We have a directory of directories for all kinds of the doctors in our province, which would be like a state, right, or in Canada. It's kinda, so we have a whole directory of the different kinds.

43:00

You know, the ..., the psychologists, the neurologist's, on that.

43:09

But, you know what, one of the biggest resources is the people in our group, know, we we have what we call CNA connection's meetings twice a month where we get together, it's usually a smaller group, not usually more than 10, and we just talk about stuff, and I I, quite often somebody will mention something that I just have to write down and then go look up about it later on.

43:37

Then, I try to be careful when we are planning stuff, for our site, our website, that we're using credible sources.

43:47

I'm sure all of you know about this, that there's different ways to tell, if you're looking at a credible source, on, on the web are not, and one starting point that people could use is Google Scholar.

43:59

So, don't just Google. Go to Google Scholar, and you'll find, you know, actual research papers, and stuff like that. That's a great tip. We had a webinar that's up on our website from our board member on how to that scientific information, and I've watched that one, too. Yeah.

44:20

And Michael, I'm gonna ask you very quickly to say, besides your Facebook page, where do you get other resources? So there is a really good organization called the American Chronic Pain Association.

44:33

They've got a lot of resources on their website, it's free membership.

44:37

So I encourage all of you with pain, to look into that.

44:41

Of course, nanci, you've been a big resource for me, along with everyone at the foundation of connected to.

44:47

I have to say, even though you told me not to, that the group that I started. We do educational zoom calls about every 2 to 3 weeks.

44:55

We've had several neurologists. We've had pain doctors.

44:59

We've had people experts talking about so many different things that might help our community. So, those are all recorded there on the site. If you guys are members, you can just search on Zoom, Zoom calls, and you can pull those up. And that's a great resource with a lot of really valuable information from credible people out there, so we plan to continue doing those calls.

45:23

I think that would be a really good resource for people.

45:26

Yeah, I encourage anyone and everyone. To go to the Foundation website, we have a list of support groups and Linda's group. Is there a microscope? Is there the DC group, the ... mentioned and the nice thing is, is that most of these are still virtual. So, that can be accessed anywhere. While I'm looking at the time, and I want to get a couple of questions in life.

45:51

In the next one line, if each of you could give me, what keeps you going, What's give me a model to live by? And Michael, can you start first? You know, my least favorite scene in the world is when people say it is what it is.

46:07

Because I don't believe that I do believe it, is what we make it, and I think once we accept what, what's going on here, and we've done everything we can to help ourselves every day. We just get on with their lives and stay positive and lead productive lives.

46:22

Thank you! Linda, what about you?

46:25

Um, I learn more, try stuff that makes sense to you, and then help somebody else do it.

46:33

I've been a lifelong learner about everything my whole life.

46:38

And this has just given me a project. That's very personal to me to learn more about, and then share with other people.

46:46

Perfect. Geva, what about you?

46:48

Just keeping in mind that I can get better that there might be setbacks. You know, I sprained my ankle on Monday and caught my thumb on Tuesday. It's been an eventful week, but, like, you know, things have been generally going uphill for me and even if it like, dips back down, it can graph can keep going up.

47:10

Thank you.

47:10

And last but not least, Jeff, live in the present, and make the most of every day.

47:17

Just by way of explanation, that the reason I say that is, because when I got, when I got the diagnosis, I was worried about the future. And I was worrying about, I was, taking problems, imagined problems for the future and living them today.

47:36

So forget about the future.

47:38

Make the most of every day.

47:40

Terrific, Thank you. We've gotten some questions, and I'm going to apologize to the people whose questions we won't get to, But let me ask a couple of these, of you all. I'm going to direct this one to Linda.

47:54

Linda, you specifically said, talked about being sensitive to certain things, how did you discover you were sensitive to these things?

48:05

I went actually to a naturopath who put me on an unlit, an elimination diet, so for a week, I ate nothing but like white rice. I think it was.

48:17

And then every three days introduced something else and then something else and then something else.

48:23

And then when I introduced dairy, all of a sudden, my eye was puffy, my throat was scratchy.

48:33

And my nose was stuffy, and then when I introduced wheat products or gluten, I, my neuropathy was a lot worse.

48:44

OK, great.

48:48

The, this was A Question for Dave. You mentioned getting your level's checked regularly. What do you mean by that?

48:59

Basically like vitamins and minerals basically like diamond B D, I tend to kind of always be lonely iron. I've been anemic for a bit, so just staying on top of that, because of the PCORI's my insulin can go up sometimes.

49:16

So staying on top of, like, are those insulin levels where they should be just like getting like a full, comprehensive, like blood work up, I guess, way more often than the average person. So I tend to get one of those, like, every six months. And if there's anything where I'm like, I'm feeling I've been feeling a little tired. They'll throw in a B 12 and check those levels as well, and, you know, Just keeping in touch with your doctor, as you're taking the supplements, which I think is important.

49:50

Definitely.

49:51

This is a general question, and maybe no.

49:54

Raise your hand if you want to answer it, or you all still driving, or finding you having trouble driving, Michael, are you driving or having trouble driving?

50:04

No trouble driving at all. I love being in my car. I love cooking places.

50:08

Yes, I still do drive. I haven't lost any sensation on the bottom of my feet or hands.

50:15

But I would tell people that if you have lost that sensation, there are hand controls that you can get installed in your car that will make it possible for you to continue to get around on drive.

50:30

OK, great. What about Jeff, Linda, you're still driving?

50:35

Yep. Yeah, I'm still driving.

50:37

OK.

50:38

I've told myself, because my dad from my dad's experience, he drove for way too long. His foot kept slipping off the brake pedal, and he hit a number of things.

50:49

So I've told myself the first time my foot slips off the brake pedal. I'm checking into those hand controls.

50:58

OK, and, Jeff, you're still driving. Yes.

51:02

OK and Deva, you had a comment developed PM while I was learning how to drive so I kept getting yelled at by the instructor for slam on the brakes and I thought I wasn't doing it. It was just that the pressure sensation on my feet, Wisdom mood. So I just like haven't been able to learn and haven't invested the time into like learning with hand controls because I live in the DC area and public transport is great.

51:30

So as of right now, I don't need to know how to drive. Hopefully it stays that way Or I can find the time to learn with hand controls Because my feet can't really tell how hard I'm hitting anything.

51:43

Can you see me now again?

51:45

I seem to be slipping off no, OK, but you're going to hear me So we'll keep talking and I'll figure out why you can't see me, but that's OK.

51:56

This is there We go That should come back. All right.

52:03

The Let me see if I can.

52:09

Asked this question of Dave, I'm gonna ask this question of you again.

52:16

Um, you've, somebody asked, How do you manage energy when you're working. And I, Linda, I'm not are you. I don't think, I think the rest of you are retired. Is that right?

52:29

But I think what, Dave, when you are working, how do you manage energy when you're working?

52:34

So, working remote has given me the opportunity to kind of step away and take breaks, and go on a walk and then come back. So I don't usually stop working until 11. Not 11. 7, until seven. But I will take a break in the middle of the day. Going back in person, that's a little harder.

52:54

But I'm trying to kind of maintain that, they're just like step away.

53:00

And, you know, mainly, what I've been trying to do is keep the food intake kind of constant. Like. So I got a bunch of healthy snacks. I put them in my desk drawer, and I'm trying to just constantly be munching on stuff For my autonomic neuropathy. I've been told to drink salt

water to keep my blood pressure up. So I have one bottle saltwater at home, one bottle, salt water in the office, and I try to make sure I'm like, drinking water. Sleep is a big, big one.

53:34

If, like, just like, If I lose an hour, I'm completely off, and I feel like wrong, so I prioritize sleepover, everything led me, one of the questions did come in about sleep. Do you both hands, who has has trouble sleeping due to pain or your symptoms, and what do you do about it?

53:59

Um.

54:02

Linda, do you? I know you mentioned that, the issues with sleep, and what do you do about it?

54:08

Yeah.

54:08

Um, like I said before, all if, if my feet are burning, oh, I'll use the Camphor and menthol and a fan.

54:18

If I'm, if I'm really having trouble.

54:23

I have some special socked that I can use sometimes.

54:26

There's also, you know, melatonin or valerian, but I don't take those regularly because that can cause you problems. So you don't want to get sort of dependent on those.

54:39

There's guided meditations. I do that sometimes.

54:43

If I'm really having trouble getting asleep, I'll put them on, you know, and just listen to them and go that way.

54:51

Great.

54:52

Anyone else have anything to add to sleep?

54:54

Otherwise, I'll direct a question to Jeff.

54:58

Um, You do a lot of research. You are, I love your idea of self advocacy.

55:06

How do you get your doctors to take you seriously, to listen, to you, to take into consideration? Do you have trouble with that with your current medical team, or how you had to address that issue?

55:19

Um, I don't think I have trouble with it.

55:22

I think it's just a matter of no, Because I go into the meetings with them, prepared, I think of the commands a certain amount of respect.

55:33

Recently, my neurologist's made a comment to me, something about, well, you're dependable, and I don't really, or he got that idea.

55:41

But, but anyway, I think how you, you'd be careful how you present yourself to doctors.

55:46

Because you don't present yourself well.

55:49

You know, you could think may not taken as seriously as they would.

55:55

No, thank you. Well, we're just about out of time.

55:59

I would like to thank you all for your insights, for sharing your stories. I know this is all personal.

56:10

I'm gonna give you NaN each to give final words, And I'll start with Michael, because I can see he's got a final word for us through gus?

56:22

No, I just preach positivity. Negativity doesn't get us anywhere. I read something yesterday in my group that I liked.

56:28

It was an analogy of like if you think of yourself as going through high going on a hike every day.

56:35

You're going up the mountain. You can either moan and groan and complain or you can sing a song.

56:41

And so I like the whole genome.

56:43

I think we all just need to learn to sing a song and get through one day at a time and stay.

56:48

as positive as we can And it's not always easy, I don't deny that.

56:53

There are days that are tough, but we still have to keep on smiling and keep on singing and getting through it one day at a time.

57:00



Perfect. Glinda, what about you? Give me your 10 second wrap up for everybody? Well, I want to apologize for all the distractions with the cat silly, but I'm just gonna put another plugin for Calgary neuropathy dot com is where you can find us. And like Michael, we have guest speakers, but not as frequent as he does. And support groups and, yeah.

57:25

Just trying to keep positive.

57:27

All right. Thank you, Dave.

57:30

Um, I would say takeaways are just I know, like, maintaining, like a healthy level of confidence because I got overconfident and I made a misstep and then I sprained my ankle. So, like knowing your limitations and keeping them in mind but also trying to cautiously push past them is something that I've learned this week from my series of Unfortunate Events.

57:57

So, that would be my takeaway. It might have been different last week, but somebody asked where they can read your, your blog post, You have it up, where people can read.

58:09

Should I send it on the chat?

58:11

Uh, know, why don't you send it to us, and we can, we can put it in there?

58:20

And, Jeff, what is your final 10 second thoughts?

58:25

Oh, that's hard.

58:26

Um, I would just say, no, I often remind myself that those people that have it worse than us, you know, there's people that have cancer and terminal diseases, and other things like that, and as long as you don't have a terminal disease every day, I'm thankful for that.

58:46

And just, you know, look on the bright side, kinda like what Michael said. Be positive every day, you can do it.

58:53

Thank you. Thank you all. We're just at 6 30. I want to thank everyone, and, and sorry, with the questions we couldn't get to. But I want to.

59:08

Again, thank you for coming.

59:11

I have to give a little life to give a thanks to our sponsor live on labs, who has been very generous in their support of our organization and and bringing educational materials to you all. I also need to put a plug in for the foundation for peripheral neuropathy. If you like this webinar,

you'll get a survey at the end. Tell us what you liked. Tell us what else you'd like to see, if you like what you do, what we do.

59:42

We do all of this with the support of donors, so we ask you to support us and go to our website for more information. And if we have any more questions, feel free to come to, contact us, we're here for you.

59:57

So other than that, I thank my panel.

1:00:00

I thank everyone to join us for joining us tonight, and have a good evening, Tonight, PP.