

0:04

Hello, and welcome to today's program on idiopathic neuropathy hosted by the foundation for peripheral neuropathy.

0:12

Today's webinar will cover the specific cause of neuropathy, including its definition and diagnosis.

0:19

You will learn how to tell if it's progressive, and what to do if your neuropathy symptoms keep getting worse.

0:25

We'll also talk about various tasks you can consider undergoing as well as reviewing some off label, alternative and experimental therapies.

0:35

My name is Lindsay Colbert and I am the Executive Director at the Foundation for peripheral neuropathy.

0:41

It's hard to believe that I've been leading this organization for over six years, and this is the first time we've held an educational session specifically geared towards idiopathic neuropathy.

0:52

I'm sure many of you share those same sentiments. So, let's go ahead and get started.

0:57

Before we do, just a few logistical matters.

1:00

Yes, this webinar is being recorded, and will be permanently housed on the Foundation ...

1:06

website, along with the slide deck that is being used during this presentation. A copy of the recording will also be e-mailed out to everyone who registered for this program within the next 24 hours. So check your e-mail and our website for these materials.

1:21

A Question and answer session will be offered at the end of the presentation.

1:25

For those participants who are joining us live today, you will be invited to submit your questions through the questions box on the Dashboard at this platform.

1:34

Please try to keep all questions, general in nature and specific to this topic, and note that we will not be answering any personalized medical questions during this program.

1:45

Lastly, if you're having any audio problems during the session, please consider dialing in through your phone number it can be found in your registration e-mail that you accessed recently through after getting this link.

1:59

Now I'm pleased to introduce the Programme's guest speaker today.

2:02

Doctor Norman laid off doctor laid off as a professor of Neurology at Weill Cornell Medicine and the New York Presbyterian Hospital, where he also served as Director of the Peripheral Neuropathy Research and Clinical Center, and prior to that at the College of Physicians and Surgeons of Columbia University.

2:21

His laboratory is credited with the discovery of anti mag and jam one ganglia, side antibodies in neuropathy, and for developing diagnostic tests for these antibodies in clinical practice.

2:34

Doctor ...

2:34

also served as founding Board Member and Clinical and Research Director of the Neuropathy Association that was subsequently absorbed by us into the foundation for peripheral neuropathy and was partner in Therapy Path LLC. A neuromuscular pathology laboratory that was acquired by Inform Diagnostics.

2:54

He has over 200 publications including research papers, reviews, editorials, chapters sandbox, and is the author of Exclaiming, neuropathy, symptoms, diagnosis, and treatment or when the pain won't stop.

3:10

For people with neuropathy and their family and friends.

3:14

Now, without further ado, doctor ..., I'm pleased to pass the microphone over to you.

3:22

Hi!

3:23

Thank you for inviting me to speak at this webinar.

3:29

I'll be talking about idiopathic neuropathy, which is not commonly talked about because there isn't that much.

3:39

No, in a baggie first slide.

3:47

So this cartoon shows attempts to show a physician explaining to the patient what that they don't know what they have.

3:57

You have a serious illness.

3:59

And this closes nature.

4:01

You can see it, both those consternation, both on the project physician and the patient.

4:09

Uh, there isn't much information about it, and there are no guidelines as what to do.

4:17

Next slide.

4:26

Next slide. Next slide, please?

4:30

Yes, So, uh, where does the term come from?

4:33

Or a medically we used it to, to refer to any condition or disease for which to cause is unknown.

4:42

That's an entirely appropriate turn.

4:47

Idiopathic actually translates to a disease of its own, which has done entirely accurate because it's not unique to that patient. We just didn't know what it is.

5:00

A more appropriate term would be cryptogenic.

5:03

Which means hidden or unknown, it could be cryptogenic because the cause is not known or just hasn't been identified as yet.

5:12

From a patient's perspective, however, it's best described by one of my patients because it calls it a blend or in between idiotic and pathetic, it it helps to talk about it but it doesn't say what it is. Next slide.

5:33

So this slide shows how we derive a diagnosis of idiopathic neuropathy in the scheme of things.

5:44

AMG nerve conduction studies are particularly important.

5:50

Um, just to go through this table, patient with suspected neuropathy: undergoes electric diagnostic studies.

6:00

The neuropathy is then either classified as external or demand meeting, uh, or if normal, they undergo a skin biopsy, and if it shows neuropathy, it's classified under small fiber axonal neuropathy or small fiber neuropathy is external.

6:22

Now, there are certain conditions which cause the mine neuropathy in certain conditions which cause external neuropathy: We test for these, And then if a condition is identified, is treated, or causes identified retreat to cause.

6:38

Now causes identified Neuropathy is external, it's considered idiopathic, which means no treatment is available.

6:49

If the blood tests are all normalized, denominating S then classified as ..., which was diagnosed based on the patterns abnormalities in the electrode diagnostic studies and treatments are available.

7:03

So again, since the EMG is not done carefully or in sufficient detail, they might miss the myelination in which cases, diagnosis that's shown all and therefore, idiopathic diagnosis is demanding there is treatment available.

7:23

So it's important that the AMG be done thoroughly.

7:27

At least two lenses are, um, I studied at least two nerves in each limb.

7:37

So, moving on to the next slide.

7:45

Now, regarding the specific causes of line neuropathy, these include Jamboree Syndrome or typical, like your telemetry tamale pie neuropathy.

7:57

See I didn't clear chronic inflammatory Demining Robert Multifocal, Motor neuropathy, mad neuropathy syndrome So, it's a limited differential.

8:08

Um, also, the minor rocky's could be caused by genetic mutations that are already carry conditions, and sometimes could be drug induced, such as embryo their own of the Christian.

8:23

..., however, could have many more causes that could be endocrine, or metabolic such as diabetes, thyroid disease, kidney failure, conflicts such as Lyme disease, hepatitis, C, or HIV.

8:38

Autoimmune, such as exon Guillain barre Syndrome, sjogren's Syndrome.

8:43

Vasculitis, Celiac Disease, Star Chord, among others.

8:48

That could be occurring neoclassic associated with lung cancer, or lymphoma, myeloma, ..., myopathy.

8:57

During nutritional causes, most commonly, alcohol or 12, B, one deficiency, or, B, six deficiency, or toxicity.

9:06

It could be toxics, such as from lead, mercury, kiefner, drug induced or hereditary, and it's all the negative that is classified as idiopathic.

9:19

Next slide.

9:27

Now, if your diagnosis having idiopathic neuropathy and you're not sure sorted by diagnosis, what else can it be?

9:40

Well, an important distinction is whether the neuropathy or the symptoms are stable or progressive or worsening.

9:49

If the symptoms are stable, it could mean that you had residual nerve damage From our past illness or insult.

9:57

This can include guillain barre syndrome.

10:00

See IDP, which is in remission, treated Lyme Disease, acute viral disease from which she recovered, dogleg, toxin induced, or other, inflammatory conditions.

10:14

These conditions can cause nerve damage.

10:18

After the acute insult, the nerves may heal to some extent, but often not completely, and people left to its symptoms which could be fluctuating, um, and sometimes, believe they have an ongoing disease, but it's really only leftover damage is known.

10:35

There's no active disease. It's ongoing.

10:40

This happen, sometimes, in Lyme disease, where people have Lyme disease and it has continually symptoms from the neuropathy, such as tingling or weakness or fatigue, and they think they have diseases still active.

10:56

They could be treated with antibiotics for months, which doesn't seem to make a difference.

11:03

And again, the way you could tell whether it's active or whether it's a prior disease is by whether it is diseased condition is worsening or progressing.

11:14

If not, then it's probably leftover.

11:19

Symptoms.

11:20

This is actually very common in small fiber neuropathy, which is often self limiting patients have acute onset or subacute onset, and then they're left with sensory symptoms, um, but the disease doesn't progress to any too large firing a rocket.

11:41

Um, if the disease is progressive, however, and new classifies the ..., it might be that there's no, it doesn't recognize the underlying cause which was missed, because it wasn't tested for, or, because it's not sufficiently progressed to be diagnosed, that could be, as it identifies genetic mutations.

12:09

Some conditions can only affect nerves.

12:11

It can only be diagnosed by biopsy.

12:15

These can include non systemic, thus colitis, facades chord.

12:20

Both of these usually affect other organs that can be recognized by other tests, but at times, they only affect the peripheral nerves and can only be diagnosed by biopsy.

12:33

Sometimes see, IDP, which is diagnosed by electric physiologic criteria, may be low threshold or diagnosis and not me.

12:43

Electrodiagnostic criteria for the modeling neuropathy in classified is external, um, but if the disease progresses, then it could be identified.

12:55

Also amyloidosis, which is associated with monochrome come up with these are different proliferative disorders, um, which are usually diagnosed by blood tests The abnormal proteins could be too small to be detected and the disease only identified by nerve clamps.

13:21

Now having said that, it's important to be able to tell if the neuropathy is worsening. Next slide, please.

13:31

So fluctuating symptoms, those that come and go most often indicates table underlying disease.

13:40

And the fluctuations due to environmental factors are internal, gotcha, such as hormones, fruit intake, etcetera.

13:51

The environment can affect the symptoms.

13:53

For example, increased tissue pressure which occurs if there's a low barometric pressure, depending on weather, can cause more pressure on the nerves and more symptoms.

14:04

And that is the case often for example on people with arthritis, rheumatoid arthritis, work, they feel worse before a storm because of lower barometric pressure, neuropathy, symptoms could respond to the same types of fluctuations.

14:22

In general, I'm measuring motor functions is a more reliable way of evaluating for progression than sensory symptoms.

14:32

They're more consistent, easier to measure and more reliable.

14:37

Sensory symptoms such as numbness or tingling or pain or less consistent.

14:42

Pain is more variable.

14:45

You can have more pain either because the neuropathy is getting worse or because the neuropathy is getting better and the nerves are more sensitive.

14:53

Sometimes for example, in early diabetes the neuropathy can be very painful.

15:00

Progress has become more severe with more tissue damage.

15:05

Patients feel numbness instead of pain.

15:08

They think they're getting better, Christian more comfortable, but it's only because they no longer able to feel pain.

15:16

However, keep in mind, if you suspect progression, that has to be current firm by the examination, in Electra Diagnostic Studies.

15:25

Sometimes there's other things going on in the body, which can cause you to feel worse. It doesn't have to create the neuron.

15:32

So you use your monitor progression, if you suspect that there's growing progression, Then you need to have repeated examination and AMG studies.

15:49

Now, how to measure motor functions at home.

15:53

First, a useful way of doing is using a handheld dynamometer to measure grip strength. Could you go to the next slide, please?

16:06

Yeah. So, this shows a picture of that a nominator use the one with a bulb. You can get that, an Amazon, or other websites.

16:15

Gripping the broad measures, strengthen the palm, and fingers.

16:20

Or the Other donor nominators only measure finger strengths.

16:23

So this is the preferred way to do it.

16:26

Squeeze as hard as you can, 3 or 4 times, take an average.

16:31

Can you repeat that couple of times a week, log the numbers.

16:35

And over time, you'll see if there's a change. Everybody has good and bad days.

16:41

And the results can Numbers can fluctuate day-to-day.

16:45

But the fluctuations will be within the range have to arrange starts to improve getting better.

16:53

Stronger. it means you're getting better if the range strikes sloping downwards.

16:57

It means you're getting probably getting weaker.

17:00

Could you go to the previous slide, please?

17:04

OK, so, also in other ways, Matress Trent is it's measuring leg strength.

17:13

So, the most sensitive functions are those that you could do with some difficulty if you could do them easily and you get worse, you might still be able to do it.

17:21

You can't do it. You might be getting better or worse and you won't know if there's a difference.

17:26

So, finding something that's difficult to do would be the most useful measure of whether there's progression for a set of pending specific symptoms or signs, Walking on the heels that toes could be difficult for them could be monitors getting up from a chair without.

17:47

So walking on the heels of tau is measured at the muscles in your legs your feet getting up from a chair or from annealing position measures proximal muscles in your legs distance without using arms.

18:02

Walking up and down stairs, walking upstairs measures to strengthen the crux of the leg muscles downstairs.

18:07

And the digital leg muscles you can actually tell by touching your muscles as you do these to see which ones are tightening.

18:17

It could show around.

18:18

You could see whether that's getting easier or more difficult.

18:24

So all these could be used to monitor change, Walking speed is also very useful, Walking is really a composite of strength balance.

18:36

How wide up quite you keep your feet?

18:40

Stride length. How long you keep here?

18:43

Leg above ground as you're walking. so all and so this is a composite of all these functions, which could be affected by neuropathy.

18:51

So typically people can measure about 25 feet somewhere indoors flat.

18:57

Walk it as fast as you can and time yourself, a pre 3 or 4 times, take an average.

19:03

Keep a log, do it once or twice a week and there are two, you should be, it could be fluctuations day-to-day.

19:11

But the results should be within their range to see whether all the time the range improves or deteriorates. Next slide, please.

19:26

Next one.

19:30

What to do if the neuropathy is progressive?

19:33

Well, first, it's important to repeat testing, um, praetor neurological exam and also AMG nerve conduction studies.

19:45

These are my reveal change is indicative of the IDP, which is treatable causes that were previously undetected, um, also previously, borderline abnormalities might become more obvious.

20:02

On these however unchanged, you might have something else going on. For example, sometimes people come with neuropathy, come in, and they're weaker.

20:11

It turns out it's not because of the neuropathy, but because they have a spot, another conditions affecting the spinal cord, such as disk disease, or, or blood clot or tumor.

20:23

And there we can because of this other condition that because of the neuropathy.

20:29

Too often, patients are evaluated by their, uh, internists or family physician.

20:39

There diagnosed with neuropathy.

20:43

They're sent to a specialist.

20:45

They do electrode diagnostic studies, do some blood tests.

20:49

The diagnostic a pratik neuropathy and they're sent back to the referring physician and they're not evaluated again even if the neuropathy or symptoms get worse, the assumption is that they have the same thing.

21:02

as originally thought and there's no reason for evaluation re-evaluation but if you're getting worse, ideally it should be re-evaluated again because something that wasn't identified earlier might show itself an EMG or blood tests.

21:20

Genetic testing my feeling underlying mutation even if other families members are not obviously affected.

21:33

It could be the first one in your family or it could be very mild or people may not.

21:38

one to admit they have neuropathy, especially men they usually tend to dismiss any any illness.

21:48

Um, also if that are off the fee.

21:52

Progress is the EMG. Studies still don't reveal the cause the blood tests don't show anything.

21:59

Then, in about 20% of the cases a nerve and muscle biopsy couldn't reveal tradeable cause, as mentioned earlier.

22:10

My two real or non systemic, vasculitis, or amyloidosis, or ..., which, again, usually shows, quite often the closest, shows up in the lungs as ...

22:22

can cause skin and other organ to be damaged.

22:26

Amyloidosis can affect the heart, liver, and other organs.

22:31

In most cases, these conditions could be detected by blood tests but sometimes, if they only affect the peripheral nerves, you have to have biopsy for diagnosis.

22:45

This is particularly the case in non systemic vasculitis where only the blood vessels in the nerves are affected.

22:54

Um, biopsy can also, we, we really typical, C P C P.

23:01

Again, usually diagnosed by AMG nerve conduction studies, but sometimes these are indecisive and then your biopsy might show the cause.

23:12

The nerve biopsy needs to be done a specialized referral centers for two reasons.

23:17

one, if it's not, If the surgery is not done well, patients could be, uh, left with chronic pain because trauma to the nerves.

23:32

So we need to have an experienced surgeon and two, you need specialized pathological skills to evaluate the nerves properly.

23:44

And these are not available at all.

23:48

Medical centers, all these specialized medical centers, or at least a biopsy needs to be sent to those specialized centers where they could do the pathology.

23:59

It's better to go to one of these centers because sometimes the nerve has to be processed immediately to look at certain changes.

24:12

Next slide.

24:16

So this shows basically an electron micrograph picture of the peripheral nerve you could see the myelin sheaths and as dark circles.

24:28

Um, some of these circles pointed out by arrows, myelin sheaths, thin.

24:40

And indicating that there is the myelination, the axons are preserved, demolished sheets are gone. This could occur in ..., but also in other conditions in the demand nation could be secondary to accidental damage.

24:53

Next slide.

24:56

But there's something called ... fiber. These are individual fibers, which are teased and stained.

25:02

As you could see, Milan is denoted by the dog staining where the arrow is pointing at nodes or spaces between the fiber between the days of myelination, then you could see long areas, which are denoted. There's no myelin sheath.

25:24

And these occurrence should have skipped lesion type fashion throughout the nerves NC IDP.

25:30

So, um, nobody can identify the presence of the IDP or confirm that when the AMG studies don't, uh, show the core if the AMG studies are, um indeterminate.

25:48

Now, again, we don't do it ... lightly because there is a certain risk for infection or lingering pain.

25:56

So, we only do that, if the neuropathy is progressive and no other cause can be identified, which is where it's important to monitor for progression.

26:08

Next slide.

26:12

Again, next time yeah, sorry. So this just shows a picture of the nerve with less Could you go back one?

26:19

So this is a blood vessel in a center, surrounded by inflammatory cells.

26:24

The blood vessels has a clock note, so this is a typical picture.

26:28

Michael Vasculitis in peripheral nerve, next slide.

26:35

Just shows nerve with amyloid appointed by the arrow it's up.

26:40

This is a Laxative Proteinaceous substance, it could result either from immunoglobulin, light chains in patients with monoclonal come up with these little proliferative disorders where else and hereditary amyloid from Trustee

26:57

Next slide.

27:01

And this shows could recall Granuloma or Salt Chord with these big, giant cells in the center, which are agnostic.

27:11

Again, these are usually affects the lungs with that could be identified by x-ray or CT scan of the lungs, but sometimes only affect the nerves OK, Next slide.

27:26

So what to do? The neuropathy is progressive, and all the tests, including Revives negative.

27:32

Unfortunately, this doesn't commonly happening but can happen on occasion.

27:38

And There's really no consensus. It might be auto immune. Some autoimmune conditions don't show up in tests.

27:48

For example, more, you know, typically we think if the neuropathy is demanding it, auto immune untreatable ... and none of the tests showed immune.

27:59

Underlying Arabian conditions, we construe the classic, but some external GMU, ... conditions. Don't show up and testing.

28:08

More recently, there's, for example, with checkpoint inhibitors sometime, which sometimes, which actually, dis inhibit autoimmunity, people develop exon. Neuropathy is the only way we know.

28:21

Autoimmune is because they occurred after treatment with checkpoint inhibitors.

28:26

Otherwise, there would be no test for them.

28:30

So, the neuropathy is multifocal which happens with inflammation.

28:39

Rapidly progressive some physicians would advocate treating with the off label experimental treatments such as corticosteroids, IVIG, or toxin that, but creating conditions where you're not sure what you're treating with potential side effects.

28:58

Is there a risk?

28:59

So, uh, your pending on risk tolerance of the patient and physician or both petition may or may not consider it or recommend it?

29:13

Um, this has changed over time, for example, when I used to give talks on neuropathy beginning in the eighties and 19 eighties. Or, I would ask the audience.

29:29

If the patient had a progressive condition, and no cause could be found, would you treat with steroids?

29:36

And almost everybody raised their hands.

29:40

In the nineties, I would ask the same question, and people in private practice raised their hands, people in academics would not, um, in the 2000, 2010 range, nobody would raise their hands.

29:56

Risk tolerance has really decreased over time, or people are more cognizant of potential dangers.

30:06

These are not trivial, are the risks because, both for the patient and a physician.

30:13

An extreme examples, but how could, Michael Jackson, he was Chair would corporate follow, which helps to relax and help sleep, and he ended up, um, dying and his physician ended up in chain, in jail, so, it's not a trivial issue.

30:33

I think we need better guidelines on when to try off label experimental conditions and otherwise progressive idiopathic neuropathy.

30:42

Next slide.

30:47

What about alternative treatments?

30:50

Well, they're called alternative, because they're unproven, um, most naturally occurring, such as supplements, not proprietary.

30:59

So, they're not deregulated, sometimes include chemicals, which are, could be toxic.

31:07

There's still funding for clinical trials.

31:11

However, know, it might be possible to use social media to get more information about the effectiveness would be useful to establish an online database with responses could be tabulated and compared although it has to be done in a way that the reports are validated in some fashion.

31:36

Next slide.

31:40

What else could be done?

31:43

Well, we have supportive therapies so patients with weakness could be helped by physical therapy or orthotics.

31:51

two M relation.

31:53

We have treatments for neuropathic pain, which in most cases are effective.

31:59

Uh, they deal with those treatments. It's almost impossible to make the pain go away entirely at the ughurs too.

32:06

Get it down to a level where they are tolerable and in the background if you try to ilham to eliminate completely off and get into toxic doses.

32:17

And again, if you have a dynamic symptoms whether it's postural hypotension, hypertension, there are medications to manage these symptoms.

32:27

They don't treat the underlying disease but they do help the centers.

32:32

Also, people helpless, but they're really not, if you're wealthy, you could directly support research to the Foundation or through local medical centers.

32:46

Um, everybody can join political action committees to advocate for research funding by the NIH.

32:54

As Tip O'Neill, quoted to say all politics are local.

32:59

Um, representative's main goal is to get re-elected.

33:03

If you get 50 people together and visit them, they'll always be available to talk to you.

33:12

It's hard to get Congress to actually mandate funding for particular programs unless it's a national emergency.

33:19

But you can certainly ask them to direct the NIH too.

33:24

report on what they're doing for neuropathy, which will alert NIH administrators to make sure that the research is funded.

33:32

Right now, research in peripheral neuropathy is way underfunded compared to other conditions, in part because of lack of no information, which can be provided, base edge committees, individually or through organize through the foundation.

33:56

So everybody can help. So.

34:01

So, again, you know, it's a short presentation. That's because there isn't much nobody backing up the noise.

34:08

More research is needed. And I'll be glad to take any questions.

34:15

Tom, thank you so very much. We have a lot of questions that have come through. We'll try our best to answering as many as we can. So let's go ahead and get started.

34:28

Lots of people are asking about diets specific for idiopathic neuropathy. Do you have any recommendations whether it's an anti-inflammatory diet or a Mediterranean diet?

34:41

Well, again, all of these are unproven. They might help.

34:46

I think that is important in general, for if you're generally in good health, you'll feel better and it'll be easier for the body to, to deal with the symptoms and the disease and to heal.

35:02

So, and my understanding of diets is, certainly, if you're overweight, if you lose weight, that would be helpful.

35:10

Different people might respond differently to different types of diet, depending on metabolism.

35:17

You could show a experiment, wisdom is, but there isn't any one diet that's known to her help everyone.

35:27

But again, it will be useful for people to share information about what works for them.

35:33

And I assume that you'll probably have a similar answer when it comes to exercise.

35:38

And if there's any specific exercise program in general that you would recommend someone looking into to help the symptoms that they have from their neuropathy, or is that also kind of a trial and error?

35:53

Well, again, every exercise helps you get stronger, you can get about 10% stronger or, regardless of your baseline.

36:04

Obviously, different people start from a different baseline, and if, if you're just slightly weak, any exercise, we'll do some things to keep in mind, first of all, It'll be useful, too.

36:23

Uh, do exercises where your stationary for a simple, elliptical trainer or strider's approach to platform moving platform or running Because two: you'll be less likely to fall and hurt yourself and the pounding.

36:43

For example, when you run, could, could cause, can cause pain, Which would limit how much you could do.

36:50

So, swimming or elliptical trainers is used, two, something to keep in mind, is that, usually, when you exercise, when you build muscles, the process involves both muscle breakdown and rebuilding.

37:07

Um, if you have neuropathy, the rebuilding part isn't as efficient, so you have to limit the exercise in some way.

37:19

So one way to monitor that is if you start feeling weaker during the ride after the exercise.

37:27

You've done too much So you could do less strenuous exercises and more perhaps more frequently, but you could maintain a pace where you're not getting weaker. That should be fine.

37:40

Also, if you have actual weakness such as a foot drop or Clarke's similar weakness, it should be done under the guise of a physical therapist, or at least periodically because the exercises need to be tailored to the weak muscles. You would be, exercise them differently than X then.

38:05

Muscles, which are strong, um, both to opt to maximize the benefit of exercise, tend to, to avoid exercises, which might further damage, they ensured nerve and muscle.

38:20

So physical therapy would be helpful. Other than those points, it's important to find something that you like to do. otherwise, you're less likely to do it.

38:33

Yeah, 100%.

38:35

And switching gears a little bit as well, there's a lot of questions about vitamin supplements.

38:43

If you have any additional comments about that, lots of questions about E six, Obviously we know that it's always advised to get tested to know what you might have a deficit in before you start adding supplements to your diet.

39:01

But do you have any other comments specific to vitamins in general?

39:08

Well, you know, traditionally, people should take vitamins because we know vitamin deficiencies can cause various problems.

39:16

You know, B one, B six deficiency, and B 12, certainly can cause neuropathy but those guidelines were developed prior to our ability to measure levels and certainly most of the diminished if you take them in excess.

39:39

Not a problem.

39:40

You bake stage of bodies, just rid of them and there's no damage done by certain vitamins such as B six, actually be damaging if you, um, take too much. Now different people are susceptible.

39:55

Have different abilities to cut the prefix, sexist depending on whether they break it down and some people to take just a few milligrams of B six levels should weigh up.

40:07

Others could take larger doses so it's important to test yourself.

40:13

It's also important, if you're pregnant, often people who are pregnant are prescribe large, right, doses of vitamins because of the additional nutritional needs of the mother and heeded by.

40:28

The fetus also is, um, uh, know, could could be exposed to the toxicity of two high vitamin B six levels has been shown in experimental animals, so it's important to measure the levels we took before taking a supplement to a deciding on that and the dosage should be taken.

40:50

That's great advice thank you.

40:53

Could you talk a little bit more about the difference between small fiber and large fiber neuropathy and if there is ever an opportunity for someone to develop a difference?

41:07

Cause there.

41:10

So The way we define small fiber neuropathy is someone comes in with symptoms of neuropathy and they get an EMG done an EMG is normal, uh, traditionally the physician would say, Well.

41:29

You don't have neuropathy, I don't know what you have, maybe followed my algebra or some other pain syndrome.

41:36

Um, or they might say, you might have a mild underlined neuropathy, which he doesn't pick up, you can't prove or disprove the diagnosis.

41:48

In the past 10 or 20 years, we've developed the ability to measure nerve fibers in the skin.

41:57

And we found that some people, with neuropathy, symptoms, BMG, is normal, then your skin biopsies showed a decreasing number, nerve fibers. And these are small fibers in the skin.

42:12

And we would cause small fiber neuropathy, know these small fibers can be the nerve in the skin, could be the nerve endings, small fibers in a nourished because the nerves can have large, small and medium sized fibers could be the terminals of large fibers, which leads to my own shapes, and look like small fibers in the skin.

42:34

So, when you diagnose more fiber neuropathy, he might have an underlying large fiber neuropathy, which is very mild and only picked up because the skin biopsies more sensitive or it could be small fiber throughout the entire nerve fiber.

42:51

So it's really the causes for small fiber neuropathy are the same as for large fiber neuropathy.

42:59

So an example, all the cool all day causative. We know that can cause a large fiber. Neuropathy can also cause small fiber neuropathy and vice versa.

43:09

So it may just be that a milder form of neuropathy which is self limiting and doesn't progress, tillage fiber.

43:19

Having said that, that's in about 80% of the cases.

43:22

So in about 20% of the cases, there's still an underlying ongoing nerve damage and it can progress to large fiber including things like C I D P.

43:33

So if you are we in our center, for example, if we diagnose small fiber neuropathy, we tell the patient, there's an 80% chance that it's not going to get worse. And it was a street to symptoms.

43:45

But come back in 3 or 6 or 12 months, depending on how you feel. It's just to make sure.

43:51

it hasn't progressed to large fiber.

43:53

If it has to progress the large fiber exam, shows that it has progressed, then we will repeat the electrical studies because there is a chance that you might identify something underlying that's treatable.

44:05

So again, it's, it's important to follow up.

44:09

repeat evaluation periodically to make sure it's not progressive, OK.

44:16

And is there any hope for restoring nerves that have been damaged?

44:22

Well, it could regenerate to some extent but it's limited. Sometimes regeneration is sufficient so that you're not left with any symptoms.

44:32

Although EMG might show this so some nerve damage because it has to be a certain level of damage before you feel it or it may not recover or only partially recover.

44:46

Right now, we don't have any medications which would, hasn't recovery.

44:53

Exercise might help, just because it, you release trophic factors, but, again, that has a limited benefit.

45:00

And, but, there should be some way of stimulating stem cells within the nerves, too, help with generating, here. We just don't know enough about it.

45:13

Again, the only way that would change is through research.

45:18

Got it.

45:19

And I know someone asked and it was it's an interesting question I've never even heard before, but surgery for patients that suffer from idiopathic neuropathy, are you familiar with any surgery being performed too?

45:36

To help neuropathy, specifically?

45:39

Well, there are a couple of types of surgery: one.

45:43

Any of the nerves a compressed, for example, at the elbow ankle.

45:47

The compression could and if you have an underlying neuropathy, a more susceptible to compression.

45:54

For example, if you have done diabetic neuropathy, it's not uncommon to develop carpal tunnel in addition, because the nerves are more susceptible, level of compression, which would not cause symptoms and somebody who doesn't have an underlying neuropathy.

46:08

So relieving that compression surgically can help relieve the pain and maybe some, the nerves to heal, other than that, if terrorists Pacific nerves, which are damaged, for example.

46:24

Compression, correct your elbow are at the knee or ankle.

46:31

It's causing we can sometimes surgery, could I transpose nerves or use other nerves to innovate. damaged muscles.

46:41

And it could we create a connection which will allow you to be able to move that muscle.

46:47

But again it's it's very, very specialized and can be only done it certain centers with experience in those particular procedures.

46:57

And you know there's been a lot of questions about you know various tasks and you mentioned several of them earlier in the presentation including the EMG, nerve conduction, even biopsies. Could you speak a little bit more to the frequency of how often those tests should be performed or repeated? When, why, and then, you know, how intrusive, if at all, some of these tests might be for a patient.

47:28

Again, at the initial presentation, we would perform all of these tests.

47:33

The idea is to try to find a cause. if you have a tribble cause.

47:39

The sooner you're identified and treated the lesson and damage there'll be, so, it's important to test for all the possible causes.

47:50

After that, it's important, if they find a cause, obviously, you would treat it and then you follow that, see where they are, there is improvement or if the treatment is sufficient.

48:04

So, usually when we start, if we find a cause and we start treatment, we tell the patient to come back in three months, if it's still worse or everything as well.

48:13

We come to come back in six months, have to that, add to that.

48:17

Perhaps annually, Um, if we can't find a cause, we again, tell the patient to monitor at home.

48:27

If they fall, if they get worse by any of the measures that we mention, you know, grip strength, walking speed, functional.

48:39

Tests decided to come back as soon as the tech worsening, otherwise, again, come back.

48:47

In 3 or 6 months or after that, if they feel weaker for evaluation.

48:53

If we repeat our test and we shouldn't neuropathy is progressive and we still haven't signed a cause, we would then recommend a nerve and muscle biopsy for a possible cause. Nerve muscle biopsy doesn't fit.

49:08

We feel it cause then we just treat the symptoms.

49:12

Although I must say, if we do a comprehensive evaluation, including all the tests, and um, It's rare and we don't find A cause it's rare that the neuropathy is so progressive.

49:29

In most cases, we can try and cause, um, if we don't find a cause, then we sit down and discuss where they have trialogue therapy.

49:39

With steroids, you're either an anti-inflammatory condition is truly understanding the potential risks and benefits.

49:50

OK, great, thank you so much.

49:52

Um, lots of questions on various therapy's has have come through, whether it's, you know, acupuncture, even medical marijuana, right?

50:04

A few that you didn't really address, and just curious what your thoughts are on some of these therapies, even, you know, red light therapy.

50:13

But then, more importantly, you know, do any of these therapies, and, obviously, it's dependent on the individual, I'm assuming, but what's the likelihood that some of these therapies will help someone walk better, right? Just live their day to day better, Right?

50:29

Could you speak a little bit more about how some of these therapies are used and, you know, what the expectations realistically should be for a patient.

50:41

Sure.

50:42

So, um, half a puncture, for example, does help relieve muscle spasm.

50:49

It doesn't relieve.

50:52

And, you know, Fathom actually is a significant occurrence of neuropathy.

50:57

The nerves are irritable, the flying off. The muscle zodiac, you know, they go into their achy.

51:06

And if there are sufficient ... limited mobility.

51:12

So if you can relieve the spasm, patients feel a lot better.

51:18

So certainly exercise, physical therapy can help relieve muscle stiffness, dispassion.

51:26

Acupuncture does massage, some of the she must have stimulated to do that.

51:36

Like therapy increases, blood flow releases.

51:40

reduce the spasm.

51:42

So lots of these treatments, which are being advertised, I really directed relieving muscle reaction to the neuropathy.

51:51

And they do help, but again, to know within boundaries at home actually heal the underlying nerves but they do make people feel better.

52:08

Great.

52:09

Thank you and What are your thoughts about how people can, know, heal their neuropathy?

52:18

A lot of what this organization, the Foundation for peripheral neuropathy does is offer some treatment or therapy options to kind of help curb some of those symptoms, but is there anything that anyone can do to really get into the problem their original problem itself, which is the actual neuropathy.

52:39

Again, if you can find it cause the Katrina.

52:42

Otherwise you just treat the symptoms knowing, um, certainly, making sure that you test for all the possible causes, knowing what they are.

52:57

Reviewing the medical records, is important.

53:02

Usually, if you go too much for a center, they're pretty good at broad comprehensive testing here, a general physician, or, um.

53:14

Less specialized centers might miss some potential causes, So, it should probably have a list of potential causes the test for them, and then make sure you're here, where I could show that, if you see the results.

53:30

And after that, really, lots of times, you know, you learn all you can about neuropathy.

53:37

You talk to other people, a, to an organization's you.

53:42

Read books to buy, hit.

53:45

You try faith, healing, diet, grace exercise programs, and you're still left with symptoms and then, really.

53:58

You could still do something, but it really involves helping support, research, you're directly or through political organizations to find out more bad habit.

54:13

Develop treatments which allow nerves to regenerate inhale.

54:19

Great, you know, on a lot of times, the cause is really, to your point, what a patient should address.

54:26

But for people, especially those joining today, that have idiopathic neuropathy, they don't have a known cause.

54:34

So, how would you suggest that they brooch their treatment plan for this condition and keep, obviously, an optimistic and positive light in it, knowing that?

54:47

No, they don't have the answers, they don't have the cause, they're extremely frustrated, But, you know, what, what would you say? What would you say to all of our idiopathic friends on the line today?

55:00

Well, if the neuropathy progressive and you haven't had a biopsy, then you should have one, assuming all the tests were done.

55:07

Could a neuromuscular centering for consultation and, you know, discuss it.

55:16

It's not progressive.

55:18

Then it's really a matter of focusing on treating the symptoms.

55:24

So if you have weakness, excess exercising, regularly, physical therapy, optimizing these finding, you could do those comfortably, which wants to do is HR helps.

55:42

If it's still attacking pain, it's a matter of trying various medications. You mentioned yes by medical marijuana earlier.

55:54

Certainly sufficient number of patients, they report it, helps them.

55:59

It does help. Also, in terms of dealing with the anxiety of chronic pain.

56:05

It helps your relaxed and sleep better, which which helps deal with saint James.

56:12

If you're tired, tired, you're less likely to be able to deal with the frustrations of the centers over the chronic pain.

56:21

If you're more relaxed, you're able to deal with it better and try to think about other things and go about your work regularly.

56:31

When in terms of treatment for neuropathic pain?

56:37

Make sure you've tried everything available. Again, you discuss that with your physician, also.

56:45

Sometimes people start with too large a dose, in which case the side to side effects, and they just drop it and don't try it again.

56:55

It makes more sense to escalate with a low dose because they might benefit from a lower dose than that, which can cause side effects. So escalating we take care of that.

57:06

Also, if you do try something, low dose.

57:14

Too many people just give up before trying a higher dose.

57:18

Escalating might help combinations of medications could help poor one or the other, by itself may not help the benefits. The often additive side effects are not. So we have to keep trying and Medicaid.

57:33

Same thing with ... mixed in terms.

57:35

It's a matter of finding a combination of medications that works best for you, rather than just trying something.

57:43

And I've given up.

57:47

So, it really can matter, optimizing the treatments for your particular symptoms.

57:56

Yeah, that makes complete sense, doctor, laptop. And thank you so much for all of your your help. You know, We have probably a couple of hundred questions that we haven't been able to address today. And for those of you that have been asking them, I'm so terribly sorry. What we can do is make sure that we file all of these questions and try to address them as fast as we can over the course of the next several weeks and months on our website and various e-mails.

58:25

And know that a lot of these answers are also up on our website, so feel free to reach out to us specifically if you have some questions that we can help point, too, in that direction. But, at this time, we did run out of time. So, again, I just want to thank you, doctor ..., for all of your help and support today, and for the knowledge that you shared with us. It was an amazing program, we had so many people joining, and plenty more who will be watching this recording at a later date.

58:55

For those that are attending right now, we, we hope you liked this. We will be sending out a survey shortly after this meeting ends, and we value all of your input, whether it's positive or or not as positive. So, please share that with us so that we can keep making sure that we're meeting the needs of everyone.

59:14

And we hope that you will continue to support us, whether it's by volunteering with us or giving us a donation, so that we can keep doing these types of programs.

59:25

But you do know how to reach us. We are available through e-mail, phone, and have a great website. So, again, thank you so very much. I'm so thankful for everyone that joined, So thankful for you. Doctor laid off, and wish all of you the best.

59:42

And I'm sure we'll be speaking very soon.

59:45

OK, thank you, Kathryn.

59:47

Thank you. Bye, everyone.

59:49

Bye.