0:04
Good afternoon, everyone. Thank you so much for joining today's session.

0:09
Today the foundation for peripheral neuropathy is pleased to present vetting sources of medical and scientific information with Cristi Townsend.

0:20
My name is Lindsey Colbert's I am the Executive Director here at the foundation for peripheral neuropathy.

0:26
And I just want to thank all of you for joining today's session and for your interest in this topic and your support in our organization.

0:34
Before we go ahead and get started, I wanted to just go through a couple of housekeeping slides Specifically, this webinar is going to be recorded.

0:44
Recording of the webinar will be shared with you, following the presentation, probably within the next day or two.

0:54
You can submit your questions anytime through the questions box. We'll try our best to answer them during this webinar, but please try to keep all of your questions.

1:02
General, we're not going to be able to answer any specific questions related to any specific treatments, modalities, or studies, but we won't be able to answer a lot of questions that I think will be beneficial to the population as a whole.

1:18
And if for some reason, you can't hear me now, but hopefully you are at least see the screen, or you're having trouble with the audio at some point during this webinar, feel free to dial in by phone. There's an e-mail with the dial in instructions, which is how you were able to login there.

1:34
And that phone number would be something that I would encourage you to use in case you're having connection problems on your computer or other device.

1:43
At this time, I'm pleased to introduce our guest speaker today, Chrystie Townsend.

1:48
Christy holds a PHD in neuroscience and has been investigating the brain and nervous system and the regulation of energy balance and metabolism for the past 20 years.

1:58
She is now associate professor in the Department of Neurological Surgery at the Ohio State's Wexner Medical Center.

2:06

Research in the towns and lab for neurobiology and energy balance at the Ohio State University focuses on neuroplasticity, and how the brain and nervous system impact appetite, metabolism, and energy expenditure.

2:21
Christy joined the Foundation's Board of Directors about a year and a half ago, and has been an invaluable member of our team.

2:27
We are so thrilled that she's volunteering with us and sharing her expertise with our patients and friends in these types of educational sessions. So, at this time, I'm pleased to pass the microphone over to Christy for her presentation.

2:41
Thank you again, and Christy, she's all yours.

2:51
Alright, great. I was just unmuting myself, so hopefully you can all see and hear me now. So I'm really happy to be here today to talk to you about a topic that's really been of great interest to me for my whole career.

3:04
And that's how we can use critical thinking and science to vet different medical claims. And obviously today we're going to specifically think a bit of this in the context of peripheral neuropathy, especially since there is no cure for peripheral neuropathy. I think there are lots of different fraudulent and misleading claims out there. So hopefully, today, we'll provide a toolbox for all of you so that you're able to start to vet these claims for yourself.

3:31
But I do need to start with some disclaimers. So, today's discussion is really a reflection of my own personal advice, and how I, that medical information for myself to determine what's accurate versus the status of the medical research literature.

3:47
I am not a medical doctor, so nothing today should be considered medical advice, And I'm giving my own opinions today, nothing that reflects the opinions of my employers.

3:57
OK, so let's start with this term, snake Oil, which I'm sure everybody has heard in various different contexts, meaning a quack remedy or a panacea.

4:07
This term actually came from the 18 hundreds and originated with an effective medical treatment. So starting in China, there was snake oil that was high in omega three fatty acids, and was a very effective medicine at the time.

4:22
But later in the 19th century, as we started getting more of these patent medicines that were advertized in the back of newspapers, these tonics that promise to care a variety of ailments, There was a particular snake oil salesman or the nail it name came from. That started at the 1993 World's Exposition in Chicago, so this was Clark Stan Lee, who was known as the Rattlesnake King.

4:46
He claimed that he had healing rattlesnake oil that he had learned from Healthy Medicine men. But the problem was, this was not real snake oil. His, his snake oil contained no snake oil at all.

4:58
So that's where we get the term. It also led soon after two, sort of a predecessor to the FDA, which was the 1906 pure Food and Drug Act that started regulating the sale of these patent medicines just like the bottle you see on the right.

5:15
And this is where the term came from for the rest of time that snake oil is now known as a sort of a symbol of fraudulent cars.

5:24
So the goal of today's webinar with the foundation is really this idea of caveat and tour, which is buyer beware.

5:30
So a lot of business people out there are trying to get hard earned dollars from from patients and people suffering from different ailments, especially those that have no cure right now, like peripheral neuropathy.

5:42
So there's a lot of risk when we are looking outside mainstream medicine for treatments.

5:48
So, the risks of these poor, inaccurate, or wrong scientific and medical claims, could mean that you lose time, and in seeking an effective treatment or therapeutic, it could mean money spent on ineffective products.

6:02
one of the higher risks is the potential that these products you're using could make your condition worse instead of better or have serious side effects and toxicity.

6:11
And, again, it really just comes back to the fact that these fraudulent treatments or fraudulent claims are preventing patients from having a clear and accurate understanding of their own physiology and their pathophysiology, which is what would make them sick.

6:25
There's actually a lot of money as you might guess that's made by selling products and services outside mainstream medical establishments.

6:32
And salespeople, of course, learned by this by this income sometimes use fraudulent practices to do vulnerable patients.

6:40
Especially those who, for very good reasons, might have preexisting distrust or lack of faith in medical professionals.

6:48

And I think that especially becomes true for people who are fighting chronic diseases or diseases where they're just aren't very good medical options right now. And I've seen this a lot, even with my own family members.

6:59
So this is really a topic that's near and dear to me.

7:03
OK, these are just a bit of data supporting what I just said from the Federal Trade Commission.

7:08
So, they find that people spend billions of dollars a year on health related products and treatments that not only are unproven and often useless, but are sometimes dangerous. So this is a big industry. And I really think it is the job of us as medical and scientific professionals to help educate the public, and give them tools to vet the claims that they're hearing, more and more in the age of the Internet, through ads, social media, things like that.

7:35
So one of the first things I wanna teach you is comparing news headlines. And in this case, I'm gonna give you two examples that are actually very good studies.

7:44
People, scientists who I think have have some connection to the Foundation, actually, very reputable researchers, but I just want to show you how sometimes that the true research study gets spun in the media because, of course, media is driven by clicks and everybody, you know, reading these stories and based on a headline. Or a blurb.

8:04
So in this case, this is a biotech news source, but always a very top Google hit if you're searching for recent treatments or cures for neuropathy.

8:12
And the headline here is peripheral neuropathy could be reversed by FDA approved class of drugs.

8:18
So, if I'm reading this as a patient, I feel very encouraged by the statement. It seems to me, from reading this, that there might be a treatment that's almost ready to be available to me in my doctor's office.

8:30
This is the research study that that's pulling from. So, the research study says selective antagonism, of muscular anak receptors is neuro protective and peripheral neuropathy, which sounds like a mouthful.

8:42
But if you dig into the research study, there's lots of things to keep in mind here about how close we really are to having a treatment in the clinic.

8:50
First of all, this study was done in mice, so mice are very commonly the pre-clinical model to study diseases like neuropathy before treatment's get moved into the humans.

9:02
They looked at treatments and found that they improved the depletion of sensory nerve terminals, thermal ..., so sensing of temperature and nerve conduction so a function of the nerves in a model of diabetes. So again, this is a diabetic model in a mouse, and they saw some improvement to certain things.

9:22
And they also found that the a variety of anti muscular ... drugs are approved for use against other conditions prompting a possible translation.

9:31
So even the authors of the actual research study are sort of giving you a more accurate representation of their own data and saying this is possibly translatable to humans.

9:42
Versus the tone of this news headline, OK, let's look at one that in my opinion is a little bit better. So this headline says long colvin. Symptoms may be linked to nerve damage, a small study suggests. And then the sub headline says, A new study offers clues about a potential cause of lung covance symptoms, and perhaps avenues for treatment.

10:04
But experts warn against drawing major conclusions yet.

10:08
So, to me, this is a very responsible headline, You know, we're saying potential causes, perhaps there are avenues for treatment, and they come right out and say the experts say, don't draw major conclusions yet.

10:20
And the reason for that is that this is the original study, doctor Outlander, as well respected researcher in this field.

10:27
This was a study that got a lot of press for good reason, because there was lots of data indicating that covert was causing neuropathy, and this was one of the first systematic research studies, but they, in their own report tell you what things that you need to keep in mind. So, for example, it was a very small sample size.

10:44
For a human study, 17 people, all the people had long coded, but then you look at the breakdown, And we'll talk more about this in a minute. 69% were female, 94% were Caucasian, 19% Latino.

10:57
So whether or not that's a cross-sectional representation and and whether these findings could be relevant for every person. We're not sure Age could be another variable here, as well.

11:09
And of those that they tested, it was statistically significant, but only 59% had more than one test that confirmed they had neuropathy, along with their lung coven.

11:19

So again, I think when we look at news headlines, we need to think about where the study came from. In some cases, when they're open access, like this one here, you can actually open up and read the abstract of the original study, and start to think about things like, is this in humans? And if it is in humans, how many humans were tested?

11:38
Does it represent every type of human, and how reliable are their results? And then, you can go even further and say, Has this been replicated by independent research groups?

11:49
OK, so knowing your source of scientific news is the first key tip that we're gonna go over today.

11:55
So, scientific organizations, reputable source of news, scientific publications, yes. But, like I just showed you, if they're more targeted to the lay person and not the professional, you have to critically look at those headlines.

12:09
Respected professional bodies by this. I mean major research hospitals, scientific societies, research universities, and, of course, the actual trained and practicing experts.

12:22
If you want to look for yourself at some of the research literature around peripheral neuropathy, these are the top two sites I would recommend to do searches. The top one is called PubMed.

12:32
So this is a federally run site through the National Institutes of Health. This is the web link up here.

12:37
You all will get copies of the slides today, by the way, so don't worry about taking notes, We're going to send a PDF of the slides to everyone, so this will pull up all the research articles that have been published in peer reviewed journals. And in this case, the last time I did the search in 20 22, there were over 170,000 results.

12:57
Google Scholar is similar, although, just like the rest of Google, even though they're showing you research articles only, as the search results, there more of an algorithm about popularity. So, a lot of the articles that come up first are going to be the ones that are accessed more often. So they tend to be those open access ones, where you don't have to pay, and things aren't behind a pay wall on the website. There are also ones that tend to be cited more often. So, for example, this one says, Cited by 635 other papers, a highly cited article. So I like to search both places because you're going to see slightly different results, but regardless, you're pulling up peer reviewed, original research articles when you go to those sources, or you can look for the summaries through these other reputable sources.

13:44
OK, my next slide is a little wordy. And again, you're gonna get copies of these, but I just want to cover this before we move on.

13:51

So when you're looking for reliable sources of science and medicine news, first of all, think about the source and the intent behind sharing that information. So, is the intent that they're selling a product, or is the intent to disseminate reputable and current evidence based information?

14:08
And as we'll show you in a specific example, later today, the sites that are selling products tend to be a little more biased in the way they're presenting the evidence.

14:17
Also, keep in mind, like, I just showed you, PubMed, That's where all the peer reviewed journals go. But not everything on there is peer reviewed and reputable. So there are things called predatory journals, which have little to no peer review, and they're really preying on people who need to publish their work. but they're not very well vetted so that those do exist in there.

14:38
But even in the peer reviewed and very high impact, reputable journals, not every study is perfect. Not everything's well designed, not everything's well executed. So not all peer reviewers are created equal as well.

14:51
So the people who are actually vetting these articles and looking for flaws and trying to make improvements for the authors.

14:58
They're busy people.

14:59
So that process is not always perfect as well, just something to keep in mind.

15:05
In addition, not all research studies are reproduced and hold up over time and with further study. And this is one of my favorite things about scientific research is that it's self correcting. So over time, more work is done.

15:16
The scientific reddick record is updated, New information is integrated. So we're constantly learning and improving.

15:24
And then, of course, when you're looking at studies, think about those caveats, is there a low sample size that isn't representative, or that can be tricking the statistical tests.

15:33
Or maybe the model system isn't relevant for humans.

15:36
So a lot of our pre-clinical models are very close to humans and very good models to study before we move findings into people. But it isn't always perfect, there are definitely going to be differences.

15:49

So, a little bit more about reliable sources. So, a lot of scientists and doctors now are on Twitter, so you can actually follow researchers and clinicians themselves, and see what they think about the studies. They're posting.

16:01
Science communicators, and journalists usually are highly trained in science, and they're very good at breaking down the different scientific studies for a lay population.

16:12
And, as I mentioned on the previous slide, University Press Hospital newsletter's also have very highly trained scientific writers.

16:20
But if you really want to see what's currently happening.

16:22
So the current research that's actively ongoing in laboratories and clinics right now, you really would need to go to scientific and medical conferences or look at what's funded currently for grants or for clinical trials.

16:35
But often, again, there are journalists who cover this and you can find online news covers are posted talks from these meetings, these conferences. Just keep in mind that these are hot off the press pieces of data that have not yet undergone that peer review process.

16:51
So no caveat MTOR.

16:55
And if you want to know what's currently funded right now by the National Institutes of Health, so this is most of the clinical trials and most of the clinical research There's this tool called Reporter. And you can go in there and type peripheral neuropathy and see what's going on currently.

17:11
But one of the most important things, and I think with fraudulent snake oil claims, you're never going to hear people say this, But a reputable scientist, or a reputable clinician, it will be the first to admit, that even with rigorous research, the research can be wrong.

17:25
But the beauty is as I mentioned before, science's self correcting over time we incorporate changes and improvements and edits and the scientific literature does fix itself.

17:35
We also have a type of study called a meta analysis, that can look at numerous, similar experiments over time, from different labs, and sort of aggregate the data altogether, and statistically analyze it, and see if there's a real finding.

17:50
And then the other key is this process of replication. So, can another lab get the same finding that this lab got?

17:56

Clinical trials will often be run across multiple hospital sites, so that a finding is not just due to one site and their patient population, and how good their clinicians are.

18:07
They do it across multiple sites to replicate and increase the rigor.

18:13
And again, the key thing is a good scientist or a good doctor will be the first to admit that sometimes they're wrong. This is a highly cited paper right now. You can see the metrics over here in purple, called, Why Most Published Research Findings Are False.

18:27
So even though peer review and the scientific process is the best way to do things, the first thing we can admit to ourselves is sometimes things are wrong, and we need to be open to that. That's a key part of critical thinking.

18:41
OK, so let's move more deeply into how you look at medical claims. You might be seeing or hearing to figure out if they're rooted in science and medical evidence.

18:50
one of my favorite resources is called Kwak Watch, so I invite you to check out this website. Their focus is on Health Frauds, myths, fads, fallacies, and misconduct. They have a great list, they don't have a specific site for peripheral neuropathy but it's nice. Just sort of poke around and see what makes something fraudulent or a myth or a fad or a fallacy.

19:15
As I mentioned before, two clinical trials are all publicly listed on the National Institutes of Health website. You can go in and search for neuropathy and figure out if any of the treatments you're being offered have been studied rigorously.

19:29
So, you can search the term neuropathy or you can add in whatever treatment you might be interested in, So right now, you know, lots of people are looking at, could, can avenue aids or CBD oil be helpful, or different things like that, studies are happening. So you can look up and see which studies might have occurred, and whether any of them might be published at this point. And then you could look at the actual article.

19:51
A little bit more about clinical trials, because I think this is a key differentiator between a true treatment that's been rigorously studied, versus one that's being offered as a product to make money. And there's no science behind it.

20:04
So, true potential treatments go through this process of a clinical trial.

20:09
Some key parts of this are informed consent. So any patient participating is being told the risks and the benefits of participating.

20:17

Any study that happens in people is governed by what's called an IRB or an institutional review board. There's human subjects protection, they make sure the study as well designed, and they make sure the study is statistically powered.

20:30
So like we said before, you need to have enough participants for the data to be meaningful on the other end. And this board makes sure that that's the case.

20:39
And with clinical trials, there are four phases. They increase in the number of people enrolled as you go from phase one to phase 2, 3, 4. And the goals are to establish the safety first and then the efficacy of medical treatments.

20:53
They use rigorously designed, rigorously analyzed, and rigorously executed studies, and then the data is disseminated and peer reviewed.

21:01
So these are the key differences between true treatments that are backed by research and those that are not.

21:08
So I added in this slide, because I think it's a really nice elber overview to the different types of clinical research. So you'll get the slides to read this in more detail.

21:17
But I just want to draw your attention down to this scale down here, because not all research studies that are published using humans are a true clinical trial. So some of them are case studies. Some are cross-sectional.

21:30
And then the most effective and the most reliable is the clinical trial. So there's different types of studies and different types of medical literature out there.

21:40
OK, more about critically assessing the claims of a study. So if there was a clinical trial, think about who those patients were that were enrolled.

21:49
The sample size wasn't enough people. Was it a cross-sectional representation of different types of people at different ages, males, and females? These things do matter. Sometimes treatments are effective at one age, but not at later ages. Sometimes treatments respond differently in males versus females or in kids versus adults.

22:10
*** differences are real so male and females have biological differences and things like their nervous system, their immune system, their cardiovascular system.

22:19
There's also regional differences, so testing something in a population where there's a lot of groundwater pollution versus in a city or versus in, you know, groups different racial and ethnic groups, you're going to see differences in the data, so we need to make sure that the data is representative and cross-sectional.

22:37
And then, of course, there's a contribution of genetics.

22:40
I won't get into this today. But this is where the idea of personalized medicine comes in, that sometimes treatments affect different people differently because of their DNA, because of their genetic makeup. And that's something that research is still learning more about. It's a very active topic of research.

22:57
OK, so beyond the clinical trial, when a new treatment has undergone study, it then goes up for FDA approval, So all the drugs and treatments that your doctor would be giving you are having gone, usually through FDA approval, unless they're in a research based.

23:14
So what does it mean if you go through FDA approval? I'm not going to go through this entire slide here, but I did put the web link if you want to read more about the process. But, essentially, the FDA is just another level of scrutiny, Another level of regulation to ensure for the consumer and for the patient that a drug or a treatment is determined to provide benefits that outweigh its known and potential risks for the intended population.

23:41
And I think that wording is really key. So treatments and drugs and other different interventions will have side effects will have off target effects. You're never gonna get away from that.

23:53
The famous one that has zero side effects are homeopathy treatments, because they don't contain any active drug, but it's also about weighing the risk and the benefit.

24:04
So, if you have cancer and your drug causes you to get sick but it cures your cancer, then you have to make that choice. It's an informed choice. and also the intended population is the key thing here. So FDA looks at those things. We just talked about.

24:18
Differences between people and how they respond to treatments, looking at *** differences in the response, et cetera.

24:26
So the way the process works for a drug, and this is different for devices or for other types of treatments, but this is for a drug. So first, the drug is developed, and sometimes it's developed at a pharmaceutical company, sometimes at a research university.

24:41
First, it's tested in animals. So, as we mentioned before, this is a key first step.

24:46
To look at safety and efficacy, does the drug work, and do the benefits outweigh the risks.

24:52
And then the investigator fills out what's called an investigational new drug application or an IND. And this goes to the FDA, giving them the data and the information that they have to date about their their new drug. And then, they move it into this clinical trial phase 1, 2, 3, etcetera.

25:10
OK, after it goes through IND review. So, the FDA process is flawed, You know, I think most doctors would admit that it isn't perfect It's run by people as if people derive system. So there are going to be, you know, times when it doesn't work perfectly, but overall, this system, is designed to increase the safety for the patients, and make sure that anything getting to them in the clinic is something that's been, you know, rigorously studied ahead of time.

25:38
OK, so why aren't all health claims regulated? So clearly, there's things out there. You know, there's Google Ads popping up based on our search terms, or there's things coming up in social media, and those don't have clinical trials behind them. Or FDA regulation behind them.

25:54
So a lot of this is just catching up. So the FTC, who I mentioned earlier and the FDA, they're cracking down now, especially on food and supplement health claims. So right now, they're looking for what they call an SSA, which is significant scientific agreement before something, like a supplement, can make a claim about the benefit on your health. And again, that's to protect the consumer to protect the patient from being duped and spending their money on something that could be either ineffectual or harmful.

26:24
And also keep in mind that many treatments and therapies are outside the insurance system. So insurance for good or bad, is another way of vetting a treatment to make sure that it's reputable. And so a lot of what's considered alternative or complementary therapies can slip through the cracks.

26:42
So there are systems if you think you've been exposed to a scam and you think there's a fraudulent claim that you've come across, you actually can report that to be acted on.

26:52
Either through the FTC or through your state Attorney General.

26:56
OK so let's build some more tools so this is a website I really love. I highly recommend it to you. It's called Thinking Is Power.

27:03
It was created by a scientist to train the general public to think more like a scientist. So the first set of tools is how to identify pseudoscience.

27:14
So pseudoscience.

27:15
That's the snake oil. So anything that's a fraudulent, misleading or inaccurate claim, how do you tell that it's pseudoscience?

27:23
Number one, you can't falsify it. So this is what the scientific process does. It tries to disprove claims.

27:30

So, if there's a claim that's vague or something that you can't observe and measure, then it can't be disproven or potentially just proven, so it's not scientific.

27:40
Number two is that it relies heavily on anecdotes, personal experience, personal testimonies. That's a big red flag. We'll talk more about that.

27:49
Number three is that they cherry pick the evidence, so they're picking things that confirm their worldview or confirm that their product works and ignoring evidence that doesn't. And I hope, as I convinced you earlier, reputable scientific and medical research is very open to the downsides or the negative data in their own research study.

28:08
Number four is using technobabble, so lots of jargon in scientific terms that don't make sense. Scientists obviously do that with each other, but if someone's trying to convince you of a product working, and starts to introduce terms that make your red flag go up, think about techno babble.

28:27
Number five is that that lacks a plausible mechanism.

28:30
So this is what scientific research usually is doing is figuring out how do the drugs work? How do the treatments work? How is a disease happening at the cellular at the molecular level?

28:40
So if you can't come up or a scientist can't come up with a plausible mechanism for how this works, it could be pseudoscience.

28:48
Number six is that it doesn't self correct or progress. And as I told you earlier, this is one of the best things about science. Even with all its flaws, is that over time, it will self correct.

28:59
The system does work, we eventually get to better and better understanding, especially if human health and disease.

29:06
Number seven, it makes extraordinary or exaggerated claims, with insufficient evidence.

29:12
Number eight, it provides certainty.

29:15
Very, very confident proof, red flag, commits, logical fallacies, so making arguments that have errors and reasoning, it lacks peer review, or claims that there's a conspiracy to suppress.

29:30
What they really have. They really have the real answer and there's a conspiracy out there, which could be the medical system or pharmaceutical companies.

29:37
But there's a conspiracy that's suppressing this, you know, miracle care that they have.

29:43
So the antidote to pseudoscience is to be a critical thinker.

29:48
So critical thinkers are aware that their thinking is flawed and prone to errors. They're able to have metacognition, and think about how they're thinking. They're curious and inquisitive, they want to know like what they're looking at is real.

30:01
They separate their identity from their beliefs. They welcome criticism. They use evidence to arrive at conclusions. They have a healthy level of skepticism.

30:10
They enjoy Avoid Black and white thinking, and they're OK with ambiguity and uncertainty, which are big parts of science and medicine, and they remain humble.

30:19
So, keeping this Toolbox in mind, we're going to go through some examples in a few slides.

30:27
Again, underscoring the fact that reputable science and medicine will be the first to admit they're wrong. I love this paper that I came across from a dental group called 15 Common Mistakes Encountered in Clinical Research. I think this is just fantastic, and I'm just showing you the subheadings of the article, but I think this is open access so you can get the whole thing online.

30:47
But number seven here is failure to implement adequate bias control measures.

30:52
So, I think this is a common thing that patients are told when they're led to mistrust or not believe the medical experts is that there's some sort of bias in this clinical trial process or in the way that doctors are prescribing drugs.

31:08
I have to tell you that the system probably isn't perfect yet, but it's improving all the time, but you might be wondering is is pharmaceutical company sponsored research biased?

31:17
Or are these doctors prescribing me this drug, are they biased, they could be, but there's a lot of work that's been done to try and remove that bias.

31:25
And even in recent years, there is what's called the Sunshine Act in 2010 that made sure that people are disclosing what used to be called kickbacks.

31:35
And also, in a lot of parts of this act forbade doctors from receiving financial incentives to prescribe drugs.

31:43
If you if you've followed at all that the Sackler opioid oxycontin story, then you'll you'll know that that was a big part of that, that those those drug reps and the doctors were getting major kickbacks to prescribe oxy cottons. So that's really been clamped down in recent years is just constantly getting better and better to improve the bias.

32:04
That goes into this whole system OK, and lastly, this term, I really like, which is evidence based medicine.

32:13
So, this is what most doctors are practicing, and I'm going to draw you to this definition here, but they're showing you the definition of evolving over the years from 19 96 to 2000 to later. So, it's the integration of the best available research, evidence with clinical expertise, so people with boots on the ground, actually treating patients, and incorporating patient values. So that care centric approach, and taking all of those together, that's evidence based medicine.

32:42
And for me, personally, when I go to doctors, this is what I'm looking for. I'm looking for practitioners who bring these values into the treatment of their patients.

32:53
OK, one thing to note, when you're looking at whether a neuropathy treatment is real, or whether it's backed by science and medicine, medical evidence, Something to keep in mind is that the placebo effect is real, so this is an article from Harvard, and they also have a research program at Harvard about placebo studies.

33:14
So they found from doing research on the placebo effect that healing itself can arise from the medical ritual, the context of treatment, and the patient provider relationship that power, imagination, health, and expectation. So this is psychology, OK, our brains are very powerful. And so sometimes, even if something contains no active drug or the treatment isn't really working on the cause of our ailments, sometimes the placebo effect is very effective.

33:44
So I would say if something's working for you and it's working consistently and you're able to afford it and it's not causing you any harm, then let's just embrace that our brains are able to do this placebo effect.

33:56
And that's a beautiful thing when it works, and it's fascinating to me to follow the research that's coming out of Harvard in this area.

34:04
OK, so let's use these tools that we've talked about so far and look at some real examples and look for some red flags.

34:12
OK, so I think when you're vetting online sources of medical information, especially in ads sponsored or paid content and social media posts, you need to use these tools that we talked about earlier to think critically for yourself and find these red flags.

34:27
OK, So I just went online and I Googled care for peripheral neuropathy.

34:32
And I followed a website that popped up, and it led me to this video. And I'm not going to, you know, tell you where the video came from, or who made it.

34:40
But I just want to use it as an example, because I think it hits so many of the points that we talked about today when you're trying to vet and critically think about these claims.

34:49
OK, so first of all, we have someone who's clearly distraught, very vulnerable at their Wit's end feeling like there was no help help for them and very discouraged that what their doctor had given them for options were not good enough.

35:03
OK, clearly red flags, supporting that mistrust of the medical establishment, they were finding that this new approach being sold to them could cause them to never have a symptom ever again. So remember when he talked about big, bold claims?

35:19
And it was incredibly simple to do, Wow, OK, red flag, red flag, red flag, red flag OK, so let's go further in the video.

35:28
So now the video is saying they know the real reason people are getting neuropathy they found something that turned their worries into help.

35:37
They know it sounds a little odd. Again, They're appealing that because they know that you're gonna think that some of this isn't logical. So they're telling you that right out front. It sounds a little odd.

35:46
It's gonna make your red flags go up and they're trying to say that all the different conditions of peripheral neuropathy have a single cause.

35:56
Now, I'm sure, pretty much all of you know, since you're, some of you may have peripheral neuropathy, there is not a single cause. There are over 30 different causes of peripheral neuropathy. So this should be the one of the things that raises a red flag.

36:09
They're making this claim, so they're, they're mixing in, logical, accurate statements, with inaccurate fraudulence statements.

36:16
So, again, red flag, red flag, red flag, red flag, OK, now we get to the part of the video where they tell you what the treatment is. But first, they want to relieve your skepticism.

36:29
They're saying, oh, yes, I used to be skeptical about natural health treatments.

36:34
Those are the ones that modern medicine hadn't given up on.

36:37
I was skeptical, but I watched this documentary, and it was clear that natural treatments were very, very impressive. So we've got anecdotal evidence, we've got fostering and mistrust of modern medicine.

36:48
Red flag, red flag, red flag, red flag.

36:51
I want to say that mainstream medicine is not at all dismissive of alternative and complementary therapies. There's actually a whole center at the National Institutes of Health, where I put a web link here, that does research uncomplimentary health practices.

37:05
So a lot of research ongoing about acupuncture and peripheral neuropathy, things like that. So it's not that mainstream science and medicine dismisses them. It's that they want evidence. They want scientific studies just like a drug goes through for the FDA.

37:20
So keep that in mind, and check out this website if there are any complimentary therapies that you want to look into, OK?

37:27
So now, in the video, they're saying my nerve pains are getting so bad, I was prepared to take a leap of faith, OK, so appealing to desperation and frustration with what's available for treatments.

37:39
This particular treatment is trying to tell us that every single claws of neuropathy comes down to the gut. And again, they're trying to relieve your skepticism here by saying, I found that a bit weird to when I first heard about it.

37:51
And then comes the ask, They're selling you a product.

37:55
They want to sell you a system to teach you how to eat well so that your gut is happy, so that you cure your peripheral neuropathy. And lastly, they end by telling you it's a choice.

38:05
I chose to be rid of it, so why aren't you choosing to add this to cart, so red flag, red flag, red flag, red flag.

38:14
OK, so let's go a little bit into the research behind those claims specifically and just to give you an example and I'm sure there's many different claims you can think of that you've seen on social media or on the Internet, but the key thing here about gut health causing peripheral neuropathy is that there's very few studies, inconclusive, evidence right now and it's really too early in the process of testing therapies to make any strong claims like that video is trying to do.

38:42
So here's an example of a paper from 2020.

38:45
Not a huge high impact journal. But they are finding that microbes So those are the bacteria that live in our gut.

38:52
Control neuropathic pain.

38:53
OK, so there's a little bit of research evidence out there, but it's far from being considered trustworthy, medical cause, whoops.

39:03
Then same thing about how we treat it. So probiotics and prebiotics are thought to be the best approach right now, to fix the dysregulation of the bacteria that live in our gut.

39:14
But as you can see on this NIH site, which is actually the complimentary health site I showed you earlier, They found that in most instances, we still don't know which probiotics are helpful and which are not.

39:25
We don't know how much people would need to take or who would most likely benefit even for conditions that have been studied. The most researchers are still working toward finding the answers to these questions.

39:36
So again, it's uncertain, and that's what a lot of the snake oil salesman prey on, is our natural human tendency to want certainty.

39:45
We want a confident.

39:47
Simple answer, And that's not what Science and research are going to give us most of the time, because the truth and the current status of research is usually a little bit more uncertain and vague than that, OK.

39:58
So when you see something like this on social media, telling you to click on a video and learn more about a potential treatment that was a miracle for this one person, then use the tools from today to that that caveat Emptor.

40:14
OK so I'm not gonna go through each of these, but I just will end with some more examples that some of you might have seen.

40:19
Could THC relieve burning feet? does this electrical foot massager help with peripheral neuropathy? Has anyone used an infrared sauna?

40:27
OK, so now we have hopefully some tools and some approaches to look at these potential claims for treatments or therapies for peripheral neuropathy and be able to figure out if there's any scientific and medical evidence behind them.

40:42
And with that, I'm happy to take any questions that anybody has. So thank you for joining us today.

40:48

Christine, thank you so very much. This was really fascinating, and actually, quite a number of questions were received as you were talking.

40:57
So, we'll start with some of the generic ones, and we'll get into some of the more specific ones.

41:05
So, could you tell, tell the audience, how you tell the difference between a vetted journal, and a predatory journal? I really actually like that word predatory because I think it, it hits the nail on the head.

41:19
Yeah, that's great. So number one thing I do is I lookup whether the journal has an impact factor score.

41:25
So, the impact factor score that journals get, is how often their papers are cited by other scientists in their papers. And so, if a journal doesn't have a score, it could mean they're new. New journals don't get scores until they've been out for awhile, Or it could be that they're predatory.

41:41
The other thing I do, because I get e-mails every single day asking me to submit or review for these predatory journals. And so the first thing I do, if I haven't heard of one, is I'll just Google the journal and go to their website and look at who's on their editorial board.

41:55
So, if their editorial board is not reputable clinicians and scientists that you can find a website for at a university, or a hospital, then it's probably predatory.

42:05
Some predatory journals don't even list anybody on their Editorial Board page.

42:11
So, I would think that those are your two top red flags. There used to be a great website that would list all the different predatory journals. But, then, they got to be some that were kind of a gray area, whether they were truly predatory or just didn't have very good peer review process. So, that lists got taken down. But, But those two things are What I do.

42:29
That's, that's fantastic and as you were saying, that, in my head, I was literally repeating when you were saying. Red flag, red flag, red flag, red flag. So, I'm hopeful that those that are watching will kind of have that. I mean, I literally can hear your voice saying that. So, I'm going to be probably hearing you as I have red flags in the future.

42:52
So, thank you for that, but that's really helpful.

42:55
Um, So, we, you were talking sometimes about, you know, drugs, they, they haven't maybe yet received FDA approval, But, now, they're available for compassionate use. It's probably going to be fully up the patients expense. There's going to be no insurance coverage. Do, you know, off hand in general?

43:13
Do referrals need to happen from a PCP.

43:18
Um, for an individual to try something like this?

43:23
Are there any kind of hoops or steps that someone needs to walk through in order to try something that is more for compassionate use? So compassionate use, I'm not sure. But I think, you know, maybe what part of this question is referring to is is, you know, trying some of these when they're in the investigational stage. So when they're going through research clinical trials, they're not yet FDA approved. So they're not yet prescribed by clinicians. But if you qualify, you can join the research study. In those cases, though, you could be randomized, placebo versus drug, and you might not know, but for people, especially, you know, I know a friend of mine going through cancer treatments right now, who, you know, drove to Boston every few weeks to get into this trial. She doesn't know if she got placebo or the drug, but she was in such a desperate situation.

44:11
So, there are at the clinical trial website that we put up earlier places to find out where trials are enrolling people. And then find out through that clinical trial manager if you qualify to be enrolled, and they'll give you informed consent, like we mentioned earlier. So they'll tell you the risks and the benefits they'll walk you through, whether there's a placebo group or not. And so that's one way to try things before they're fully out on the market.

44:38
What does it mean to be FDA cleared?

44:42
So FDA clearance is FDA approval.

44:45
Sure.

44:45
Yep. That's the term the FDA uses. It's anonymous. It's pretty much the same, OK? And I couldn't even my head calling it FDA approval, but technically I think they say clearance.

44:55
Yeah, understand, understood.

44:59
So, um, someone had mentioned that there was a great site to chat called retraction watch dot com And it has some peer reviewers, how publications are recalled and get used in other articles. You're nodding. So would you be able to comment at all and confirm that this is, in fact a great site?

45:20
It is. Yeah, retraction watch is great. I have to say, we kind of watch each other as scientists and see what papers show up there. But and sometimes the PEAT things are attracted self attracted, like a scientist will realize, oh, shoot. Like we really made a mistake and we need to retract this paper, that happens to, but sometimes it happens because of fraud, because of research fraud.

45:39
Regardless, you can find on that website.

45:41
So one of the big examples that's on Retraction Watch is the study that showed that vaccines cause Autism so that study has been retracted.

45:50
It was a fraudulent research study and I think retraction watch has has coverage on there. But yes that's a very good site. Kwak Watch also covers some retracted papers as well.

45:59
OK fantastic. Yeah that that's also a really good source it sounds like.

46:05
So moving a little bit to our particular therapy and medical marijuana. So how would you bet information on medical marijuana?

46:15
It seems like a lot of the research and vetting is done with big pharma drugs and right there there might be a bias there might not be. So how would you broach that when it comes to treatments and therapies for symptoms related to neuropathy?

46:32
Yeah, and that was fascinating to me because that has a history of the research being prevented because it's a narcotic. So the Federal government didn't want to fund research around a lot of these psychoactive drugs. And now we're seeing a lot of Federal funding for not just THC in the cannabinoids that are also in the marijuana plant. But psilocybin mushrooms, you know, MDMA, and they're finding that there's real clinical benefit if you use these properly, but there's more research happening now. So I think the first important thing is, yes, there are bioactive compounds. So this is not just, you know, inert plant it could be bioactive.

47:08
It could be beneficial, but we do have to contend with bias, placebo effect. All of those things. So, I would say, the research is starting right now, I, personally, wouldn't think there's been enough time for definitive studies. But, But, you know, I would look in the research literature and see what's known right now, The, the pure compounds coming out might be more effective than the whole plant. But that's something I would pay attention to.

47:35
OK, fascinating.

47:37
Another question that came on, had to do with, no, I mean, it's kind of like, I don't want to put a bad notch on chiropractors in general, but some medical practices suggesting that they can really, really help you. But they really can't. And they charge you $5000 for a session.

47:56
And by the time you just forwarded all of your life savings so to speak towards that therapy, that's when you kind of start realizing, oh, this isn't working.

48:07

But there are other treatments that do in fact cost that much ands either have a potential placebo or a factor of 10.

48:15
In fact, here I shouldn't say cure. But manage the symptoms more effectively than some of the other treatments.

48:21
So, do you have any suggestions on how people can be concerned about kind of some of these expensive advertisements. I mean, we don't want to just have automatic red flags because this might actually be something that's helpful.

48:37
The Better Business Bureau, one that does the review.

48:40
I mean, who, you are, how can you, how can you vet that?

48:45
Great question and I think that, you know, more people wanting to question claims they're seeing is the first step because the reason there's so many out there is that they're profitable.

48:55
I mean, that FTC number, I looked up the number for this webinar actually, and I was shocked. That was that, it was in the billions. I guess not surprised, but it's shocking to me.

49:05
So my first instinct, when anyone wants my money, I want to know why And it could be that, yeah, treatments costs money, clinicians, time, costs money, things can't be free. So that could be the reason you're right. There could be a real treatment there, I mean insulin right now. Even with insurance coverage is like, yeah, the route how much it costs, right? So things do cost money.

49:25
But if something is costing money but someone's making a claim that hits one of those red flags we talked about today, there's no medical evidence to support it or worse.

49:36
So there's medical evidence out there that it absolutely doesn't work or can cause harm then I think you really need to be skeptical like red flag. That's right, that's right. So especially a lot of the you know Bodywork type treatments. I mean you can't regrow your peripheral nerves by doing this.

49:53
Some things might make you feel better but I think that's where you've got away. You know, do you have dispensable disposable income to pay for those and they make you feel better or is it not a good use of your money if you have limited budget?

50:04
Because it's not going to reverse recourse disease?

50:08

No, that's interesting. And I think at the end of the day, and you you save, as you've said this before.

50:15
I know the foundation for peripheral neuropathy always says this is, at the end of the day, we're, obviously, we want our patients to feel educated and supported, you know, they can reach out to us, but also, to their primary care physician or their neurologist.

50:30
So kind of say, hey, have you heard about this, and is this snake oil?

50:34
Is this something that you think could be helpful for me, because we don't want anyone to undergo any type of new treatment, especially one that's pricey in this, in this case, without discussing with their doctor to see if it also aligns with their own personal treatment plan. Absolutely. My number, one piece of advice is talk to your doctor. And most doctors are keeping track of this research literature as well, I mean they're busy, but they're happy to look it up for you. They have access to all these journals even if they're behind a paywall. So, yes, ask your neurologist or ask your doctor if you're hearing any of these claims, and then I'm sure they will share literature with you. I have doctors who prints out, articles for weeks. They know I want to know. So they'll print a research article for me backing up some treatment are doing so. Yes.

51:19
And, you know, we, we highlighted in this session a lot of the red flags. Right.

51:24
Are there any specific trials or specific websites where they are legitimate? They're great, there's stuff that's something great going on right now for peripheral neuropathy. I know the answer is yes, and it might be too tricky if a question for you to answer in in a, In a verbal answer at the moment.

51:41
But could you maybe speak a little bit more to some of that and just kind of guide people so that they can in fact, find the, the right studies and the right plans and treatment options online or in advertisements.

51:56
Yeah, so I think the slide where I had the reputable sources, that's where I go. So, you know, I think, like Cleveland Clinic has great news about about medical updates. They have a great website with reputable information. The ..., the New England Journal of Medicine, I mean, these big medical journals tend to have some news coverage as well. The very good journalistic sites like Science News is one I like. I mean, they tend to be short coverage. But they tend to be pretty accurate. But sometimes it is a matter again, asking your doctor, because sometimes the study comes out, or the clinical trial finishes, but you don't know what's yet on the market and what's available to you through the clinics.

52:34
So I think a combination of those two approaches talking to your doctor and reading some of the reputable Medical news is helpful.

52:42

Perfect. Now kind of going to some specific therapy's and vetting.

52:50
So how would you go about varying and client and trusting claims surrounding some vitamins and supplement usage specific for peripheral neuropathy?

53:03
Yeah. So I think for peripheral neuropathy, they're definitely has been very good research, including some using samples through the Foundation, the foundation for peripheral neuropathy. Looking at things like B vitamins, and whether it be vitamins. deficiencies. In some cases, it could cause or worsen neuropathy and whether supplementation can be helpful. So yeah, I think there's research out there, for sure. So, not all supplements are bad, or, or claiming, you know, things that they don't do. I mean, our body needs vitamins and nutrients, and sometimes we have a genetic deficiency, and an enzyme that processes things, and so we need a supplement. But, again, I would just love to see, you know, who's selling this treatment to me. What is their motivation? And what's really out there for evidence to show that there would be significant benefit. Because there can be too much of a good thing.

53:51
I mean, taking too many vitamins are, you know, certain supplement side effects are toxic to your liver or contain contaminants. So you do have to be careful, not everything that's natural is good contract Alice and it's also interesting. We the foundation for peripheral neuropathy. We hosted a webinar on something like this with respect to supplements and vitamins.

54:12
And I remember our guest speaker was saying, you know, Vitamin D deficiency, right. And so we're going around through a lot of those, and kind of what to eat.

54:21
But at the end of the day, it's actually really more important for you to get your own levels Chocked, because if you're not efficient, then it's actually not great to assume that all neuropathy patients have a vitamin D deficiency, because you might actually have the exact opposite, or be right on target, and then those vitamins Would not be doing you any benefit. And, in fact, could do you more harm?

54:44
So I think, again, going back to your primary care physician and getting some of those levels tested, so that you can understand your own personal chart to then identify what you're lacking, and, or, You know, needing to cut back from, for example.

54:59
Yeah, and doctors will tell you, I mean, if they think you're deficient in iron, or B vitamins, or D, they'll tell you to take a supplement and buy it wherever you want. You know, so in that case, they're not trying to sell your product, there, legitimately, use something that you're deficient and how to fix it. So, yeah, and it's same with the food that we eat, the alcohol that we consume. There's some questions and comments going on that, through the Q and A at the moment.

55:23

And I think, again, we, we did a session on diet and, and some of, you know, alcohol, some of that, and vitamins and supplements. So, I would encourage the individuals who are talking about this in our chat right now, too.

55:39
Reach out to us if they can't find it. But we have a recording of that webinar in the past.

55:44
and I think it's, it's one that we won't be able to discuss in the next four minutes before we end here, But I think it's, it's definitely important.

55:53
Yeah, I think general health is important no matter what your ailment is no matter what disease or disorder or general health is important. Also, mental health, physical activity, and diet, and nutrition.

56:05
Yeah.

56:06
And the last question that I want, it's slightly off topic, but it's, it's within the round, but slightly off topic to what we were just discussing.

56:14
And apologies for not being able to answer all of the questions.

56:17
These are all fantastic and we will do our best to follow up after this webinar, but spinal cord stimulators. So that's obviously a very hot topic, and it's it's one that I know we at the organization are trying to do a new educational learning session on similar to this dedicated to this treatment modality.

56:36
But, again, how do you, how do you feel about, though, is how do you vets?

56:41
Which ones, which products are good or, again, just how would you react to something? Yeah. So, I think that's actually a really exciting research area right now and actually, the NIH and trying to think what the what they're calling it. But that they're the neuro mod price. So, the NIH just released a fund called the ... Prize to fund cutting-edge research in this exact area, not just for peripheral neuropathy, but looking at neuromodulation, spinal cord stimulation, peripheral nerve stimulation, and how those improved nervous system function and pain and things like that. So this is an active research area, but it's also an active area of clinical treatment. So I think it's exciting.

57:22
I think it's an exciting thing to watch, but I think, you know, for a lot of the small fiber neuropathy, is there's not enough known yet, and I think it's exciting that NIH is putting money behind this, to help us learn more.

57:34
No, that's fantastic.

57:36
Well, again, thank you.

57:37
I think this has been an extremely interesting Sasha, and as I said, there's going to be some outstanding questions that we will try our best to get back to. Perhaps we'll reach back out to you, Christy, if that's OK. For some of the more expert related questions that we'd feel more better for having having you answer than than having us answer, but, now this is great. Again, everyone that has continued to stay, and listen through the Q and A Thank you.

58:07
We, we really enjoyed this session and will continue to do similar sessions in the future.

58:13
We are going to be sending out a survey at the end of the webinar. I really encourage everyone to respond to it.

58:20
It helps us kind of make sure that we're doing what you guys are asking us, and we're not missing anything.

58:28
We hope that you continue to support us financially as well.

58:32
We are a non-profit organization, so this is This is something that we enjoy doing with the money that we receive, so that we can better educate everyone.

58:42
And make sure that people are making some good decisions about what they're doing with their own personal bodies and treatment modalities. So I think this was a great session to talk about that.

58:53
As far as everything else, if anyone has any other questions, you know how to reach us. Our information is at the bottom of the slide. And, again, thank you so much. Thank you, Christine, for anything else you'd like to share before we close now, Just not just to say that this is difficult.

59:09
Like, I know that this is, you know, a tough thing to navigate when you're trying to make yourself feel better. So, I totally commiserate with everybody going through this and I hope this is helpful.

59:20
Yes.

59:21
Thank you again, and thank you everyone.

59:23
Have a good rest of your day, and happy spring, right?