

Patient Advocacy For Fibromyalgia

Rodger Murphree, DC, CNS
with **Melissa Talwar**



Rodger Murphree, DC, CNS

Hi. Welcome. I'm Dr. Rodger Murphree, and I'm the host of the Freedom from Fibromyalgia Summit at Melissa Talwar here. She's going to be sharing some information about patient advocacy. And as a functional medicine health coach, you can be sharing some information about just the steps that you can do yourself to start to empower yourself to be able to take control of your life again. For so many of you, so many of you out there watching, you know, fibromyalgia robbed you of so many things, including your ability just to have a normal life, whatever that is. But Melissa is really involved in helping those with fibromyalgia get the attention they need. And we're going to talk about a lot about that, about some of the research and the funding that's going on. Melissa, welcome. Thank you so much for being a part of the summit.

Melissa Talwar

Thank you so much for inviting me. I'm super excited to be here.

Rodger Murphree, DC, CNS

Yes. So you've got a kind of a unique position because you came from a background of having fibromyalgia when you were at 14. I mean, you know, that's had to be pretty traumatic. But I think people think for fibromyalgia, if they even think about imagine, but a lot of people still don't even know what that is. But if they think about fibromyalgia, they get somebody typically a female, but in their you know, in their forties or fifties, they don't think about somebody as a teenager developing fibromyalgia. And yet that was your journey. And then you were able to overcome that and became a patient advocate and now a health coach. So interesting journey. Can you share a little bit about how that all happened.

Melissa Talwar

Would happen in very clunky ways if you asked me, maybe in the past when I was actually going through the worst times of my fibromyalgia, I could have never said that I would be here at all. So I'm super grateful that whatever I had to do to reclaim my health, it worked because it was back then. This was the nineties, just for reference, juvenile fibromyalgia or just having someone so young with chronic pain wasn't a wasn't existing back then or finding the research or I mean, this is before social media and all those things to connect with other people as well.

So I faced a lot of adversity and the breakdown of different infrastructures with school, the medical system and working with doctors and even my family system and understanding how to navigate it. So I faced that adversity, but now I'm taking that information and helping other families, helping other patients as a patient advocate, working as the nonprofit executive director, and then becoming a health coach, which was a surprise to actually do. But I'm excited because this is a great bridge with other health care providers to.

Rodger Murphree, DC, CNS

Your work is so badly needed. So as the executive director of the Support Fibromyalgia Network, you see firsthand the lack of research dollars that's out there for fibromyalgia. I mean, it's really it's not even a thought. It's not even on the radar in comparison to some of the other illness, which, you know, we need a research dollars for for numerous different conditions out there. But and people here, I think 2023 is 14 million that was designated to fibromyalgia research. What you hear that number and that's a nice you know but you put that in perspective as some of these other conditions like COVID, which was close to 350 million and continues to grow. It's kind of minuscule, isn't it?

Melissa Talwar

It is. And that's what sparked a lot. I know there's an instigator in the group caught John said so we sent I was excited to send him a press release when we first established the nonprofit and I said, I we need to get a research and his say, you cannot do research without advocacy and I'm chatting with him and Facebook Messenger. I'm like, What do you mean? I know nothing about advocacy. What am I supposed to do? He's like, You're going to have to figure it out.

And he sent me the dissident Omega Organization, and I was like, Oh man, I don't know anything about advocacy, but there is a connection and I realized that if you want the dollars, you're going to have to speak up and you're going to have to talk to your representatives. So there is low funding, but they didn't know. But our representatives have been really responsive.

They ask us questions like, Why is it so low? That doesn't make any sense. You have the numbers, so there's a disruption, a disproportionate amount of funding based on the amount of people that have the diagnosis. So they are intrigued. We do need to increase research dollars quite a bit. We are asking at least to bump it up to 50 million. That is one of our goals, our first year goals. And hopefully you saw it bump up a little bit. But we have to continue to advocate and speak up for ourselves.

Rodger Murphree, DC, CNS

Now, you've been at this for a while now. And of course, Cort Johnson is Interview's owner. He's quite the character. I love him to death and his blog Health Rising. I encourage everybody to check it out that help rising dot org I think it's where to find that we had this long discussion about just this misinformation about fibromyalgia. And I've shared with the audience here a blog that he wrote a few years ago about fibromyalgia is real. You know, we still have that hurdle to overcome. There's a lot of people in even in the medical community that don't acknowledge that fibromyalgia is a real entity. But it obviously is. Do you see that that's changing over the last few years? Do you find that the conversation is more welcomed with folks out there that you're dealing with?

Melissa Talwar

It needs to change more. I have to be honest. And when I hear I think it's more of the language, especially when we hear it on social media and here's why, because we need these stakeholders, the representatives to invest. And so you would never ask people to invest in something like, oh, yeah, it's not real. They're not going to invest dollars. No one would. Right? So we need everyone on the same page because we need this research. We need more pathophysiology research to actually understand what's going on. We haven't really had that yet. We've had some really good quality research in neuroinflammation metabolism of the brain.

So let's get that going and more. And then also one thing that I always advise providers to understand is that what you say with these words and other people watching, it translates to other medical providers. And sometimes, especially with women in pain and women of color in pain, they get really dismissed in certain communities. So we have to really make sure that we understand there is a genuine chronic pain and a fresh sleep fatigue component that needs to be addressed in the doctor's office. So unfortunately, sometimes it gets translated well. That's not a real diagnosis and then the patients don't get treated adequately. So these are all things that we have to have discussions about.

Rodger Murphree, DC, CNS

So I think one of the difficulties with fibromyalgia is just the name itself. And, you know, fibromyalgia is a syndrome. So it fibromyalgia is just a name given to describe these common symptoms that people have in fibromyalgia. And because of that, that can be very intimidating to the physician or the researcher or obviously the patient. They've got all these different symptoms and we put a name on it. But really those symptoms are just warning signs and that lends itself to realizing that probably everybody's fibromyalgia is a little bit different than the next person. Yes, there's some commonality, but there are also some differences between each case. And so where do you know, where do you start? You know, originally, I think that with fibromyalgia, people were in sometimes even today, unfortunately, treated as hypochondriac, as a psychosomatic, something that they kind of imagine and make up.

Then it moved down into more of a muscular autoimmune type disease. So the rheumatologist took it upon themselves to really become a specialist in fibromyalgia. I don't think that's worked out very well. And now it's moved over now to the to neurology. So we're looking at, you know, the disconnect between the nervous system and the immune system with central sensitization pain syndrome. So it's kind of moving into different categories. And as we move, we're starting to understand a little bit more and a little bit more about fibromyalgia.

Melissa Talwar

Yeah, we definitely are. I think finding the right provider and system and training, but this is a great conversation and collaborate with health care providers and how we can provide better training, support, resources, and then really work towards improving the patient's quality of life because we know that it can improve. There's a lot of different factors in here. It's multifactorial getting them if they need to move, maybe potentially a physical therapy, occupational therapy, changing nutrition. Sleep, sleep is huge if we can get people sleeping better. So I think if we all work together and collaborate, we can really change the fibromyalgia community and how patients are getting their treatment. And I believe that we can do this.

Rodger Murphree, DC, CNS

I appreciate your optimism. And, you know, one of the things that really holds a lot of patients back is lack of hope because their role unfortunately, what we've seen in the medical community, health care community is they tell patients with fibromyalgia, you just have to learn to live with it. Now they've come to that conclusion because they see that traditional medicine alone, just drug therapy is usually not a not a long term solution can create more problems. And even those in functional medicine oftentimes become discouraged with complicated

fibromyalgia cases. However, and there are numerous people who have been on this summit, including yourself, who hate your own story, have shared that fibromyalgia is very much something that you can't overcome. You certainly can get your quality of life back in, and it's not for everybody, but certainly it's not hopeless and no one should settle with this idea of learning to live with it.

Melissa Talwar

Absolutely. And I always share that people are on their individual journey and it's trying to figure out where to start. And this is complicated for health care providers. I'm hoping maybe some machine learning will help out with all of that. I was intrigued by Dr. Bredeson work with the 36 holes in the room for Alzheimer's. So that's sort of the component that I used. And again, it's multifactorial. So maybe someone needs more assistance in a particular areas. And this is the challenge for health care providers to decipher.

When you look at the blood chemistry panels, when you look at deficiencies in different areas, symptomology, where did they get started? Was it more from an injury, a physical injury, or like I had a concussion. So did that ever get treated effectively? And that's this challenge that we're trying to figure out with all these different symptoms underneath the umbrella of fibromyalgia. I think we can do it. I'm excited to see what technology can help us with moving forward. But really, I mean, there's still principles here that I know you're a fan of. And as we talked about, different quality of life with nutrition, sleep, hygiene. I mean, these are all obviously important factors for everyone. So we can always start with those.

Rodger Murphree, DC, CNS

And in you know, I think I'm guilty, as is anyone who really loves the biochemistry, you know, I'm guilty of. Oh, yeah. Well, listen, cover or you probably had a problem with your thyroid or you've got a problem with adrenal fatigue or you got a problem methylation issue and all. That's great. I mean, that's the backbone of functional medicine, how we practice, which is looking for the underlying root causes of these symptoms.

But, you know, when you're got fibromyalgia and you can't even get out of bed and someone's telling you, hey, you got adrenal fatigue, one of things that you need to do is to make sure that you're exercising on a consistent basis to build up that stamina and resistance to stress, you know, so most people can't even get out of bed. So there's a you know, there's a definitely a disconnect between sometimes what is expected of them, maybe more so from practitioners that don't treat a lot of paramedic patients and then what they can really do. And so as a patient advocate, when you're coaching your clients, what are some of the steps that you share with

them that they can do to empower them to start to have more control over their life and their health?

Melissa Talwar

Well, you nailed it. It's the small things. And we really talk about smart goals and setting these very specific goals for them. That may be unique for them as an individual. And it might not meet the standards of some of the health care providers or it feels a little slow. And I have to remind the health care providers, okay, it's one step at a time. So there's patients who are more bedbound like I was, you know, maybe it's little steps having them stand out of bed and it sounds cheesy, but I did this myself. I did most of these things myself. It's like doing the Superman pose, like feeling better, taking some deep breath in or opening the back door and letting some sunlight in on their face.

They're still in their pajamas. Maybe they're breathing in nature, taking in their environment a little bit better with some sunlight, and then going over and maybe cooking an omelet with vegetables in the morning. So it's these progressions for improving their quality of life. They start to feel better, they start to feel empowered. Maybe they can play with their kids instead of doing their 10,000 steps like hula hoop, have fun, dance. So these are things we encourage them to do. So that way they start to see how they can improve their own life. And it might not be the stigma that they need to set from like a doctor's office, but we do see a lot of change just by that approach.

Rodger Murphree, DC, CNS

It's really so empowering them to be a little more proactive, I think. I think unfortunately, as you know, they almost beat you down so much that you have a tendency to become a little bit passive and give up. And that's not to step on anybody's toes or to meet anybody. I mean I mean, I totally understand. And you were there one time, you know, a lot of times are just told that you're just depressed. And, you know, it's not that depression causes fibromyalgia. It's the other way around. I mean, who wouldn't be a little bit down or feel low when you have an illness that kind of robs you of so many, so many things, so many joys in life, whether that's your career or your, you know, your job, your sometimes your marriage, your friendships, your social life, your hobbies. I mean, it really totally changes your the trajectory of your life.

But I think it's important to just give people like hope, but then give them some action steps that then allow them to start thinking that that way is, you know, that I can't there are some things that I can do to help myself. So what are some additional things that you recommend for

your clients to help them start to get in the habit of doing things that would help their health long term?

Melissa Talwar

Well, health coaching is all about meeting patients where they're at, so that's the open discussion. So even coming prepared to talk about something, you know, you might be off track because they're prepared to talk about something and address something else. And that's the unique thing with health coaching and the other tools that can come up but preparation. So all of that is a part of it. And then just throwing away a lot of stigmas that get thrown at people. And we I don't use the word exercise, I use movement, finding joy play. I love utilizing play, like be a kid again, go out with the dog leg, enjoy time with your kids.

And that's a big part of it. And so even reframing movement better for the fibromyalgia community is huge. Taking nutrition and figuring out what that looks like for you. Even if you have to start with smoothies, make it as easy as possible if you're not good at cooking, adding all of those elements and breathing exercises, tools that are free are fantastic. You can do them at home. There's a lot of different tools. There's videos that you can do some maybe yoga at home if that appeals to you. But we're really trying to instill a sense of joy, like making sure there's some aspect of joy that it brings you just start there first.

Rodger Murphree, DC, CNS

You and I are both big fans of Chair Walls, and I know you've gone through her program. She's here. She's interviewed. I interviewed Eric here on the summit, big fan and really love her work. Do you find that your clients are resistant to her to her diet the materials paleo diet is there is there is there any is there any blowback from that when you start to bring that up and share that with them?

Melissa Talwar

Well, I think changing eating habits is always a challenge. But when we break it down, we try to figure out where's the preparation, where's the confusion, is it the nutrition, education, is it access to nutrition? What does that look like? There's always because it's challenging. You're given this information like take out stuff. So what we start to do and everything that I've learned from Dr. Terry was directly I was really inspired by her. And this is a life changing aspect, was to start adding things in and make it fun. So getting a variety of colors in from your fruits and vegetables to start with what you can do and add in and go shopping, adding in spices and herbs, different color, vegetables, and have fun with it. Explore. You know, maybe if you're only eating spinach, try some arugula, have fun, grow, maybe do a little herb garden with your family.

So those are these aspects that we start exploring to make it fun and just adding things in how you can get sneaky with some smoothies, can add some more veggies. In this view, these are soups and then maybe try to see if your family can adapt to it. But I think that's the unique thing about making nutrition more interesting instead of, you got to take this out, you got to take this out of they're like overwhelmed and then they can't eat anything, which makes it complicated. So what can we bring in? What can we have fun doing? We have potluck parties online, we have cooking, we introduce them to chefs so they can, like feel more empowered in the kitchen.

And we all relate to each other, too, because especially with cooking and nutrition, it's hard to have enough energy. But reminding people, you know, you don't necessarily have to stand. You can utilize a stool to sit there and cut and figure out different tools to help yourself have enough energy. There's a lot of ways to navigate that, and that's the kind of things we work on, too.

Rodger Murphree, DC, CNS

I like the idea it's not about what to take away. It's the idea about what to add. And you know, and once you kind of get that, then as you start to incorporate some new foods, new fruits and veggies, then then you start to look at, okay, how can I remove some of the simple carbohydrates, carbohydrates, the starches, the the grains that probably are not doing me any good, but it's a it's a series of steps that people have to make. And it doesn't have to be it doesn't have to be really that intimidating.

Although I found that when I first start mentioning her diet or got my diet, which is very similar in a lot of ways, you know, the first reaction is, oh, my gosh, well, you know, what can I eat? But then if you take time to really look at the diet, you see, wow, there's it's wide open. It's just a matter of changing your paradigm. But you what you've been eating because that's what you've always eaten to, okay, this is what I should be eating. And actually it's very enjoyable and satisfying. It's just something. It's just a change. That's all it is. It's just a change.

Melissa Talwar

Absolutely. And when I started growing my own food in a vegetable garden, it gave me a whole new perspective on what leafy greens look like. Different cauliflowers, there's different colors to cauliflower. So you start seeing this and be like, Oh, I can get much more creative. And you appeal to people too, in different ways. Some people are very creative and they want different things and tastes, so you're just trying to meet them where they're at and make it more unique rather than just telling them what to do.

Rodger Murphree, DC, CNS

Yeah, and you know, really. So for fibromyalgia, the only way to feel good again is to get healthy. And I know that's so simplistic. It's really quite difficult because there's a lot of steps involved in your journey and everybody's chart is different, but I don't think you can get there. You can't get healthy without a healthy diet. There is just no way right now. Diet to me is a long game. It takes time to see those results and so you can accelerate that with nutraceuticals. And then sometimes, if needed, you know, there's a time and a place for prescription drugs, short term use judiciously, but the diet is something you can't cheat. And eventually you got it. You're going to have to pay attention to that. And I think that her book is Lays it all out. It's a great book. I highly recommend it.

Melissa Talwar

Yeah. And I'm biased now because I really had to find the right nutritional path. And her level three, I had to go all in 100 days at 100%. I went to her conference and that's what she said. And that really was a game changer for me, how we implement this with other people and figure out preparation and these aspects and support them. Because it wasn't easy to do. It was not easy for me to do the preparation, figuring out, okay, I can't socialize if what do I do? If I need to eat out, do I need to be cooking every day? I had to learn batch cooking.

I learned all kinds of things really quick. So that's why I understand. It is not an easy thing to do. And what we want to do is this sustainable long term change. So what can we do to give them the tools so that they can implement? It may not be as fast as we want, but they'll get it. I'm positive we'll help them in.

Rodger Murphree, DC, CNS

Along with changing your diet, there's just certain daily health habits that people can start to add that will make a big difference. It's like a snowball just builds on itself as it goes down the mountain. What are some additional health habits? You know, staying hydrated, maybe taking time to de-stress? I mean, what are some of the things that you really encourage your clients to do that you think are really, really important, even though they may seem to be kind of trivial in the beginning?

Melissa Talwar

Well, it's interesting. It's all the foundations of functional medicine, the functional medicine tree. When you look at the roots, some of these aspects of getting in some movement, again, we talked about it, you can be fine. You can still dance and enjoy music and still do maybe do your

laundry and throw on some music. Sleep, sleep. We all need a better sleep, all of us. And especially in fibromyalgia, doing sleep hygiene, really making it a good sacred time that you're going to be intentional about getting sleep. So that's a huge part of it, is just helping people through that, understanding the mechanisms of what maybe maybe taking away your cell phone right before bed, right in front of your face. And the reasons why there's some really good science about that, creating a good light pattern, you know, morning lights, taking away, minimizing it in the night. So all of those aspects is stuff like is huge. And then of course, you mentioned with relaxation techniques which don't need to take that long, like breathing exercises, being creating awareness on how you're breathing. I think we know with chronic pain, some of us maybe have shorter breath work or we kind of constrict. How are we holding ourselves? How are we actually breathing? Are we more hyperventilating? So these are all things that we talk about in our.

Rodger Murphree, DC, CNS

Groups now as a health coach and then as the executive director of your group, do you see that there? Is it does trauma do you see trauma playing a part in your clients illness?

Melissa Talwar

Yeah, and there's different levels too, because that may be the trauma in the beginning and we can diversify it to like emotional versus physical. But then this whole medical gaslighting, unfortunately, when you go and you're doing these patterns from doctor's office to doctor's office, and if you do get dismissed, that in itself becomes very traumatic. And the process because you're not being heard and it's not only health care, it can be schools like I have a big heart for people trying to get through college and high school. So all of that is part of the system that we trying to change now.

Rodger Murphree, DC, CNS

And I think, you know, unfortunately they do get what I say the on the medical Mario round they get passed from one practitioner to another because he or she doesn't really know what to do with that problematic patient. And, you know, eventually they finally get the diagnosis of fibromyalgia. And you know, but then that's really when the journey starts. It's not where it ends. It's really where it starts. Because at that point, most of the time, the practitioner, he or she, that finally makes a diagnosis is telling them, we've ruled everything out. This is what you have, you know, and you're just going to have to learn to live with. It will give you some medications to help with the symptoms. That's kind of where we're at right now. And then the patient has to take that information. And where do you know where does that leave you? Not, you know, doesn't really help you out a lot, does it know?

Melissa Talwar

And they've been we're doing our own research as patients. But I do actually encourage patients to have some more patients with the provider, because in the history of fibromyalgia, we've really mostly focused on rheumatology and that training and continue a medical education in that field. And now that rheumatologists are deferring to primary care physicians, we've never effectively given that medical education across the board.

So we're in a hurry to do that. And just this collaboration piece, because, again, I do think that we can get there. Everybody that's going into medicine really wants to help their patients, but we've never given them adequate resources. And then if you look at all the public health websites, they all have a different definition of fibromyalgia. So who is if you look as a medical provider and like the CDC website, it's still listed under arthritis, which the ACR says it's no, it's not arthritis. So it's very confusing for everyone and we need to get it straightened out very soon.

Rodger Murphree, DC, CNS

I think that's an important point that you bring up about educating practitioners because it's just human nature. I remember when I had my medical practice and we would have patients that would come to us that were what I'd call medical misfits, that kind of had been everywhere. I tried everything and even some of those patients we were and we were. I thought we did a really good job with these folks. A lot of them were fibromyalgia patients. But there were some that and I first to admit that eventually you just think, oh, my gosh, I don't know what to do with this person. Nothing I've tried has helped. Every test is normal or every test has come back positive that we followed up on. That's not worked either.

And eventually you get to where you just don't want to see that patient on your schedule anymore. And I'm just being candid here now. I'm not that way with fibromyalgia. I feel very comfortable in fibromyalgia and some of the co-morbid conditions like Gravity Syndrome and even Lyme. Now, most of these things that we see but I think, you know, I'm guilty and that's gives me a little bit of appreciation for the doctors out there who don't see a lot of fibromyalgia. Patients don't really understand it. They feel inadequate. They feel stupid, that they can't help this person. And so they get this, you know, they get a little discouraged. And then that bleeds over into the conversation with the patient and then the patient loses all hope. So I really like the idea of what you're saying, that we need to really continue to do our due diligence to educate other practitioners about this condition.

Melissa Talwar

Well, and just as we talked about earlier, our research is old like we're going we're seeing some new research again with neuroinflammation, how the brain is involved, but it's not translated. So all we've been going off of older research and we're finding new things that we might need to uncover. And maybe we need to do more advanced inflammation, blood panels to unlock some more information for all of you health care providers. Yeah, but I do love this group approach to as a health coach because we give them that community and we help with some of these lifestyle changes that might be a part of the change that needs to happen if they're struggling. So you're doing all the education and expert approach, running the blood chemistry panels and then coming in and implementing some of these lifestyle changes. I think it goes hand in hand and we're learning that with the fibromyalgia community.

Rodger Murphree, DC, CNS

Yeah, Melissa, this has been great. I want to make sure that people can reach out to you and learn more about your work and about your practice, your health, coaching practice. What is the best website? I know you got the Facebook. I know it's very active. Got a very active Facebook page. But we're at what's the best place for people to find out more about you and your work.

Melissa Talwar

Support fibromyalgia dot org or its support fibro talk is the best place for our website and yes, we are on social media so you can find us with our YouTube channel is Facebook, Twitter and Instagram. We're always doing that as well. And then we are the new network for the Inspire Health Network as well. So you can interact and join your community there.

Rodger Murphree, DC, CNS

Well, in closing, I just want to thank you so much for your advocacy. And, you know, this is something that we desperately need. And so I really appreciate your enthusiasm, your tenacity, and so thank you so much. And thank you for being part of this summit. I really, really appreciate it.

Melissa Talwar

Oh, I appreciate it, too. And we welcome people to join us on virtually or on Capitol Hill. We're looking for 50 delegate, so and one in every state. So please join us.

Rodger Murphree, DC, CNS

Thanks again.

FREEDOM FROM FIBROMYALGIA SUMMIT

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Melissa Talwar

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