Introduction to Fibromyalgia Advocacy

Hi. Welcome. I'm doctor Roger Murphree, and I'm the host of the Freedom from Fibromyalgia summit. I have Melissa Tower here. She's going to be sharing some information about patient advocacy.

And as a functional medicine health coach, she's going to be sharing some information about just the tips 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, for so many of you out there watching, you know, fibromyalgia robs 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 a little bit 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. Thank you so much for inviting me. I'm super excited to be here. Yeah. 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 that's can be pretty traumatic, but I think people think for fibromyalgia, it they even think about it. But a lot of people still don't know what that is.

But if they think about fibromyalgia, think of somebody, a female, but in their, you know, in their 40s or 50s, they don't think about somebody in as a teenager developing fibromyalgia.

And yet that was your journey. And then you were able to overcome that and, and became a patient advocate and, and now a health coach. So interesting journey.

Can you can you share a little bit about how that all happened? What happened 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.

Melissa's Fibromyalgia Journey

So I'm super grateful that whatever I had to do to reclaim my health had worked because it was, back then, this was the 90s, just for reference. Juvenile fibromyalgia or just having someone so young with chronic pain wasn't, wasn't existing back then or finding finding the research.

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, well, 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 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 we need to research dollars for, for for numerous different conditions out there.

But, and people here, I think, 2023 is 14 million that was designated to fibromyalgia research, which you hear that number. And that's a nice, you know, but you put that in perspective with some of these other conditions like Covid, which was close to 350 million and and continues to grow.

It's kind of minuscule, isn't it? It is. And that's what sparked a lot. I know there's an instigator in the group caught Johnson. 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 couldn't do research for that advocacy. And I'm chatting with him in 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 disordered 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 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 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. Yeah. You've been at this for a while now.

And of course, Cort Johnson is interviews on areas like the character loving to death and his his blog, Health Rising.

Research Funding and Policy Advocacy

I encourage everybody to check that out. But health rising.org I think is where you find that we were we had this long discussion about just this, 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 the even in the medical community that don't acknowledge the fibromyalgia is a real entity, but it it obviously is. Do you see that that's changing over the last few years?

Do you find that the conversation is more, more welcomed with, with folks out there that you're dealing with? 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 here's why. Because we need these stakeholders of the representatives to invest.

And so you would never ask people to invest in something like, oh yeah, it's not a 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 on refreshed 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.

So I think one of the difficulties with fibromyalgia is just the name itself. And, you know, I mean 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, some differences between each each case. And so where do you you know, where do you start? You know, originally I think that with fibromyalgia, people were and sometimes even today, unfortunately treated as hypochondriac, as a psychosomatic, something that they can imagine and make up.

Then it moved down into more of a muscular autoimmune type disease. So the rheumatologist took, took, took it upon themselves to really become a specialist in fibromyalgia.

But 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 the, 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.

Yeah we definitely are I think finding the right provider and system and training. But this is a great conversation on collaboration with health care providers and how we can provide better training and 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, get sleep.

Sleep is huge. If we can get people sleeping better.

Changing the Narrative Around Fibromyalgia

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.

I appreciate your optimism. And, you know, one of the things that that really holds a lot of patients back is a lack of hope because they're wrong. You know, 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, along with drug therapy, is usually not a not a long term solution can create more problems.

And even those in functional medicine oftentimes will come discouraged with complicated fibromyalgia cases. However, and there are numerous people who've been on this summit, including yourself, who hate your own story,

have shared that fibromyalgia is very much something that you can overcome.

You certainly can get your quality of life back. 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.

Absolutely. And I always share that people are in 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 Doctor Edison's work with the 36 mo holes in the roof for Alzheimer's.

So that's sort of the component that I used. Again, it's multifactor, so maybe someone it 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 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 obviously important factors for everyone. So we can always start with those.

And and you know, I think, I think I'm guilty is anyone who really loves the biochemistry. You know, I'm guilty of. Oh, yeah. Well, listen, cover, you probably had a problem with your thyroid or you got a problem with adrenal fatigue, or you've got a problem, methylation issue and 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 the things that you need to do is to make sure you know that you're exercising on a consistent basis to build up that stamina and resistance to stress.

You know, some of these 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 fiber magic patients and then what they can really do.

And so as a 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 their life and their health?

Well you will 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 if there's patients who are more bedbound, like I was, you know, maybe it's a 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 breaths in or opening the back door and letting some sunlight in on their face.

Collaborative Care and Hope for Patients

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. It's really so empowering them to be a little more proactive, I think. I think unfortunately, you know, they almost beat you down so much that you get 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 anybody. I mean, I mean, I totally understand. And you were there at one time, you know, a lot of times they're 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, your, you know, your job, your sometimes your marriage, your friendships, your social life, your hobbies.

I mean, it, it it really totally changes your the trajectory of your, 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 it.

You know that I can't. There are some things 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 help their health long term?

Well, health coaching is all about meeting patients where they're at. So that's the open discussion. So you've been 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, like enjoy time with your kids. 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, so 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 to start there. First. You and I are both big fans of Tear Walls, and I know you've gone through her program.

She's here. She was interviewed. I interviewed her here on the summit, big fan and really love her work. Do you find that your clients are resistant to the to her, to her diet?

The interior walls? 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?

Well, I think changing an 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? Like what does that look like? There's always because it's challenging. You're given this information like takeout stuff.

So what we start to do and everything that I've learned from Doctor Terry was directly I was really inspired by her. And this is, it's 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, just start with what you can do and add in and go shopping.

Small Steps for Daily Empowerment

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. You can add some more veggies in this move.

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 there 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 have to 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 to.

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 to no food, no fruits and veggies, then then you start to look at, okay, how can I remove some of the simple carbohydrates?

So the starches, the grains that probably are not doing me good. But it's a, it's a, it's a, you know, 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 find that when I first start mentioning, her diet or not, my diet, which is very similar in a lot of ways, you know, the first reaction is, oh my gosh, what?

You know, what can I eat? But then if you 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.

What 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. 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 to in different ways.

Some people are very creative and they want different things and taste. 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.

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 journey is different.

But I don't think you can get there. You can't get healthy without a healthy diet is just no way right now. Diet to me is a long game. It takes time to see those results.

And so you can 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 it the diet is something you can't cheat. And eventually you got it. You're going to have to pay attention to that. And, and, I think that her book is it lays it all out.

It's a great book. I highly recommend it. Yeah. And I, 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 you 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 did learn 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 they can implement? It may not be as fast as we want, but they'll get it.

I'm positive we'll help them.

Nutrition, Movement, and Sleep Habits

And along with changing your diet, there's just certain daily health habits that people can 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?

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 into movement again, we talked about it.

You can be fun, you can still dance and enjoy music and still do. Maybe do your laundry, answer on some music, sleep, Sleep. We all need 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 having maybe taken 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, good light patterns, you know, morning light 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 groups now as a health coach and then as the, executive director of your group, do you see that there is this trauma?

Do you see trauma playing a part in your client's, illness? 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 a doctor's office, and if you do get dismissed, that in itself become very traumatic in the process because you're not being heard.

And it's not only healthcare, 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're trying to change.

Yeah. And I think, you know, unfortunately they do get what I say. The on the medical go round, I get passed from one practitioner to another because he or she doesn't really know what to do with that fibromyalgia 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 that 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 that will give you some medications to help with the symptoms.

But that's that's kind of where we're at right now. And then the the patient has to take that information. And where do you you know, where does that leave you.

Not you know, it doesn't really help you a whole lot, does it. You know, 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 that training and continuing 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 I again, I do think that we can get there. I 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 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. 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, tried everything.

And even some of those patients we were and we were. I thought we did a really good job with these, 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 is out. Every test is normal or every test has come back positive that we followed up on that's not worked either. And eventually only 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. Fibromyalgia and some of the co-morbid, you know, conditions like gravity syndrome and even now of these things that we see.

But I think, you know, I'm guilty and that 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.

Education, Community, and How to Connect

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, our, our due diligence to educate other practitioners about this condition.

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, 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 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. 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. You have a very active Facebook page. But what's the best place for people to find out more about you and your work?

Support fibromyalgia.org or its support. Fibro.org is the best place for our website. And yes, we are on social media so you can find us with our YouTube channels, 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.

Well, in closing, I just want to thank you so much for your advocacy. And, you know, this is something that we we desperately need. And so I really appreciate your enthused ASM, your tenacity.

And, so thank you so much. And thank you for being part of this summit. I really, really appreciate it. Oh, I appreciate it too. And we welcome people to join us on virtually or on Capitol Hill.

We're looking for 50 delegates, so and one in every state. So please join us. Thanks again. Thank you.