Introduction and Nick Demas' background

Hi. Welcome. I'm doctor Roger Murphy, and I'm the host of freedom from Fibromyalgia Summit. And I have Nick Demas here. He's an award winning producer.

He's, Tony Award winning Olivier, award winner, as well, which you just share with me what that was. It's a it's the equivalent. It's the, it's the Tony equivalent in London.

So, he's obviously very talented. And thankfully for the fiber magic community, he has, produced, really, I'm really excited about the, the film he's done on fibromyalgia.

We need to get everything we can out there to help us make people understand what this condition is, both the public and unfortunately, many doctors as well.

But, Nick, thank you so much, I can't wait. I want to talk to you about your history, about your mom and about the film. So tell me a little bit about you and and let's just dive into all about the film.

Yeah. So my background is in Broadway as first as, a dancer, as a, performer, actor, then as a director and producer. And this film was brought to me actually, as a project friend of mine said, hey, have you have you ever heard, fibromyalgia?

And I said, oh my gosh, my mother has it, but I honestly don't know enough about it. And I've always felt helpless, and I've always felt like, you know, how could I help or how could I get some more knowledge or understanding because there was so much conflicting information out there.

The general public. Yeah, that I just felt, oh, as her son, I felt this, calling, I guess you would say, to make this film, to dive in and explore your fibromyalgia so that I could help her.

Why the fibromyalgia film was made

And that's really how the genesis of the project was me just wanting to help my mother. Yeah. In this film, you said took a couple of years. It took a while to get this done. Right?

I mean, it's been an ongoing project with your busy schedule. I'm sure it was quite the challenge. It was an interesting thing. It's a combination of two things documentary filmmaking.

Independent documentary filmmaking takes quite a bit of time because there isn't a ton of money in it unless it is funded by an organization or funded, specifically by a network.

There isn't a lot of money behind it. So consequently, it's this process, raise a bit of money, some of it raise a bit of money, some of it through donations, through small investments.

And so part of it was that it took that time just sort of the nature of filmmaking, of documentary, independent documentary filmmaking. But also we were learning as we were going about fibromyalgia, we were learning about the community we were learning about, and we intentionally wanted to follow four women over the course of two years to sort of watch their journey with the syndrome.

So it wasn't just like we interviewed somebody once and that was it. We wanted to sort of watch because it is a syndrome, as you all know, that is a life long syndrome.

We wanted to follow people over time to see. Did they progress? Was it did they get what? Did they have better symptoms or were the symptoms worse? We sort of wanted to dig in and also get it into their interpersonal,

relationships and how it affected their families, how it affected their community, how it affected their job.

So we really intentionally spent some time, in the film. And I also was getting connected to experts in the field, which takes time, you know, takes time to sort of make those right connections and meet those people so that we were giving proper information.

It was really important to me that we didn't propagate, falsities that are out there in the world that we were getting real information and that we got to some of the leading experts in, the world really, to get that information out there.

So that's partly why it took some time, and it actually took us seven years total. Oh, wow, I didn't realize. Yeah, yeah. And part of it was that the film took a turn in that we the original intention, like I said, was to follow these wonderful four ladies because as we know or have thought, the majority of people with fibromyalgia, you know, people will say anywhere from 70 to 80% are, are are women.

So we want to follow this for women. But as we were going along and there were many twists and turns, honestly, we had somebody pulled our story, which then also affected us.

Making the documentary over seven years

But and so we had to re rethink a bit. But also as we were going along, I kept saying, wow, I have that symptom, I have that symptom. Well, I have that symptom.

And then I had a conversation with, fibromyalgia coach named Tammy Stackhouse, who informed me that there was a genetic component. I had never heard that, even though I'd been with it for two years.

Nobody had mentioned that. And when that happened, my producer said, Nick, I think you need to go and get tested on screen. So spoiler alert here. When you watch the film.

And I was diagnosed with fibro. Yeah. And and that of course, then completely shifted the background. Yeah. Because everything that we filmed for two years, over two years now suddenly needed tweaking.

And then it became a bit my story as well. And my journey to understanding fibromyalgia and looking at my own lifestyle and why I had been fairly successful.

Because while I say that I had symptoms, the reason I didn't believe it was fibro at first was because it wasn't ongoing all the time for me. Yeah, and part of that was the lifestyle in which I lived, which you'll you'll see when you watch the film of I'm a meditator, I practice yoga, I eat incredibly healthy.

All of this has going back to my days of being a performer, being a dancer, a being an actor, where you are the product. And so you have to take care of your product, you have to take care of you.

And so it was so ingrained in me that I believe that I was who was sort of warding off these symptoms. As they would come, something would come up, let's say there was a dietary issue.

I I'd say, okay, let's get to the root of that. Let's figure out what that is. And I would shift my lifestyle, shift my diet, shift the way in which I was viewing it.

So that that symptom could, be mitigated. Basically. So it's really I mean, it's the film is fantastic, and it would have been great even if you had not been part of the the film.

Not no offense, but the but that but that's shift. You shift to where you started with your mom. You really wasn't you weren't really sure what this illness was.

Yeah. And you set out to really understand what she was going through and in these, these four women. Yeah. But then you had that shift. And what I loved about the film, there's a lot of things I loved about it, but I loved that we got

to see you being in these doctor's offices and going through some of the challenges that people with fibromyalgia encounter on a daily basis, and no one really understands what it's like to deal with an insurance company.

They won't pay for any complimentary or or alternative therapies that we know would be beneficial for these folks. Absolutely. And let me say this. I am very, very, very privileged.

And that, you know, most people, when they're getting diagnosed, it takes two years for people. Yeah. And here I am so privileged in that it didn't take that long.

It took many years for me to get there. But once I decided to make it happen right away from me because I had access to the leading experts in the world. Yeah, right.

Nick's diagnosis and personal shift

How fortunate for me. But. But and in addition to that, I should say yes, my insurance, for instance, they're not going to cover anything. I'm not going to cover it. Yeah.

And that well, you know, you're privileged, but you know, when you get that diagnosis, it's really the beginning. Yeah. And a lot of people think it's the end.

Finally 6 or 7 years go by, multiple doctors. You get on the medical merry go round is what I call it. And they pay. You know, they're trying to be helpful, but they don't really know.

And then finally, after they've ruled everything out, they tell you, you know, you get to the right doctor and he or she says, oh, I think you got fibromyalgia.

Now a lot of folks will say, oh, that's great. I'm not lazy or crazy. I'm not a hypochondriac. It's not on on my head. And they think, okay, now what do I need to do?

But then here becomes the big challenge, because in conventional medicine, we don't know what you need to do. You know, we just say you got to learn to live with it.

So the journey really begins once you get to diagnosis. I think that that's what really is, so frustrating. I think I experienced both relief and sadness at the same time because I had this relief that, oh, I'm not crazy that these these symptoms that I have.

There is something here that ties it together right. And then there was some sadness to me. Oh, you know, we say this is a life sentence, right? You're not going to I think in fact, I think it's Tammy in the film who says, you're not going to die from fibromyalgia, but you will die with it.

And so it becomes this management. And how do we manage it when health care doesn't even really fully understand it, nor do they fully know what to do?

Well, like you said, other than sort of like a lot of people are told, here's some pain meds. Good luck. Yeah, right. And that wasn't really for me how I wanted to deal with it.

I want, like I said, I'm that person that wants to get to the root. I'm the person that wants to dive in and take take full responsibility for my health.

And I want to take as comprehensive, of approach as possible. That doesn't mean that I won't take meds in the future if needed. I for term basis. That's not what I'm saying. But what I am saying is I knew.

So part three of that, maybe part. The third part was determination. It actually lit a fire under me to be even more conscious of everything I'm putting in my body, how my body reacts to things, how my mindset around it which is which is so big, how I could sort of, even amp that up, to be honest.

Well, I think that most people with fibromyalgia, that is one of the biggest hurdles is this mental mindset that it can be overcome because you get the diagnosis and and the children live with it.

You think, is this as good as it's going to be? Yeah. Or two years into it with all the medications that really and not not just step by step, but, you know, medications are a dead end for fibromyalgia.

Just there's too many symptoms to try to control. And all the all the drugs have potential side effects. But two years into it you're thinking is this it?

Yeah. So I think the first big step for people is I just realized that there is hope. You can feel tremendously better. And excuse me, and the experts that have been on the summit have already shared.

We all believe that it's very much treatable, but you have to be proactive, which you've been extreme proactive. And your paradigm, which is, is a mirror of my paradigm, which is functional medicine, to find and fix the underlying causes of the symptoms and not just to try to suppress them with medications or supplements or, you know, illegal drugs or whatever it is you know, that you want to do to try to cover these things up. So, you know, you've really been fortunate, but you've also been very proactive.

Living with fibromyalgia and treatment challenges

Yeah, very. And I do think, you know, that that is because of that background. Like I was saying that I had I had to have, you know, when you are, a Broadway actor or a dancer, you're you're we think of ourselves almost like Olympians.

You have to be in that great of shape. And so consequently, I think that that discipline around that was instilled in me at such a young age that I always knew that that's how I wanted to live my life.

And so I'm very fortunate in that way. And for those that are out there that are listening, that maybe are just saying yes with my eyebrow or are struggling, I absolutely say I would say to them, encourage them to, you know, work on that mindset and look inward.

Look at all these resources that you're providing these experts, and listen and be proactive about listening to the body. It's about tuning in to what your body is saying to you.

Yeah. And that's a practice. Yeah, it's a practice. Sure. So to tell us a little bit about some of the the women that were in the field, really sad stories.

And for people that don't have fibromyalgia, you know, they can't even really understand what these folks are going through. Now, you know, the audience, you assume that most everybody watching has fibromyalgia.

So you can totally identify you identify with these these wonderful folks that are in the film. But share with us a little bit about some of their stories.

Yeah. It was really important to me that we showed the spectrum, that of how fibromyalgia can manifest. We had sort of a best case scenario of somebody who was fully functioning in the world who was an, an Olympic athlete, like, you know, that really, had found a way to to manage the symptoms in a way that was really, proactive.

And she's actually the original inspiration for the film, which is, a woman named Megan. Densmore. Then we also, wanted to show somebody who is an advocate for fibro and who and Millie Velez, who really, was taking control of her fibro, which you see in the course of the film that she begins, she starts in a place where she's just taking the meds and is not really as proactive as she maybe could be, but is still trying to advocate for others.

She starts the The Caterpillar walk, in New York, and we followed her journey, which was beautiful to see, which you kind of will see in the film. Her, her learning and coming to understanding of her own fibro.

And then we also show, somebody named Johan, who is a from Puerto Rico. She had moved to Newark, new Jersey. Paterson, actually to get better health care.

She wasn't getting health care in, Puerto Rico. And unfortunately, she was really wrapped into the system of not getting the need, the care and the need that she asked the things that she actually needed.

And really, and this again, not to harp on the the drug thing, but was handed drugs and said, take these. You know, they would give her surgery, give her all kinds of things, but they wouldn't give her the things that she actually needed to get healthy.

And thankfully, after the filming we had we've been able Mily actually, they became friends from the making of this film, and Millie's really helped her.

And we've really been able to get Johan on a great path. But you'll see in the film that she's struggling desperately, desperately struggling on disability, unable to work, unable to function ultimately.

And so that was really important to me, that we sort of showed the range. And my mother, of course, is, is in the film and she's in the in the film. She's functioning.

You know, she had had moments where, you know, she was at the E. R. and she was struggling.

The women featured in the film

But in the film, she too has a bit of a journey of healing. Now, in the film, there's experts that I that are both know. You know, I know them. I've been I've been on summits with them and Jennifer looked and so, Yeah.

But, how did you find out there that a lot of doctors that you interviewed that really you thought, wow, they don't. Are that you, you thought about interviewing or you talked to that you came away with it pretty quickly, realizing that they really don't have a clue.

Yeah. I think, you know, a lot of pre screening. Right. Because again, it was really, really important to me that we weren't putting out false information.

Yeah. And so we prescreened the experts. We had pre phone calls with all of them before deciding who who to sort of. And that was part of it for me too.

As I, as a filmmaker I and as somebody then with fibro I'm like learning as I'm going wow. How is it that these doctors don't know or why are we getting conflicting information?

One doctor saying this and another saying that about the same exact thing like that was fascinating as a filmmaker, of course. But even then, as somebody with fibromyalgia, it was even more interesting.

We were really careful, to be very honest. It was really, really important to me not to spread false information in the film, though. Some of the some of the folks talk about the the challenge of getting someone to really listen to them.

Yeah. And to understand, I mean, that is such an uphill battle for those with fibromyalgia. I would say that's the majority, right? Oh yeah. Yeah. I mean, for me, I've been I've been treating fibromyalgia for 20, almost 23 years and I've seen that I've seen the, you know, the, the highs where we thought, wow, we're really onto something.

And I've seen the lows where and unfortunately the last decade it's really it's been conventional medicine has really given up on fibromyalgia. And you know, because what they say is we're going to give you these drugs and see how you do, but you're just going to have to learn to live with it.

We don't really understand it. We don't know what else to do. That's their position. And because of that, the fibromyalgia community, a lot of folks have accepted that.

They just think, well, this is a a lifelong thing I'm have to live with. I can never get better. And they have that mentality. It's a shame that that that that's been fostered in this community because it's not true.

It's not true at all. And what I would say is, yes, for right now, right now, there's not a lot of options in terms of what the medical community is handing you, but you do have options for yourself if you take control, like we were talking about.

Yeah, that you can live with this life sentence, but you can you can not only live, you can be fully functioning. You can be doing great things in the world.

It is absolutely possible. I'm a living example of that. Rose Megan in the film is an example of that. There are many, many people out there that are making it happen.

It is possible. I know there are people out there that when they hear that, they're like, oh, maybe for you, not for me, but I want you to really dig deep because I know that it's possible for you.

Yeah, but this is why I want to support the film for many reasons. But this in particular because we need to let people know that there is hope that you can get better.

And, you know, unfortunately, when people when I share the fact that I've helped and not to be braggadocious about hundreds, I don't know how many patients I was 22 years.

I mean, it's a lot of patients, a lot of people on my website, I have hundreds of testimonials and sometimes people will say exactly what you say. Yeah, well, that works for them, but it's not going to work for me.

Doctors, validation, and the need for hope

But what you may not understand is fibromyalgia is different for everybody. Next, fibromyalgia is different than Mary Johnson, who I'll talk to you tomorrow.

She's got, you know, some autoimmune diseases, associated with her fibromyalgia. Everybody's fibro is different, but that doesn't mean that yours is any more of a challenge than anybody else's.

It's all about getting healthy. And that means different things to different people. But there's common denominators. You've already shared some of those, and mentally staying active if you can physically, you know when you can as you're getting healthier and then your diet.

And then there's other things as well, but there's some common denominators. If you get those right, you're on the right track. Then you may need to reach out and have somebody work with you, whether that's a health coach.

So a fibromyalgia expert like myself or whomever, multiple people on the summit. So yeah. Yeah. You know, and, I would say that it's been, you know, the great part of the film for me personally, is that my mother is so much healthier since the film came out because she watched it, and that inspired her to take even more action.

Millie is is one of the characters is really impressive. Yoga has taken most massive improvement. And so thank you for sharing the film because that is why we created the film, right?

I created the film so I could get more information to help my mother and help other people, and that's really what we want to do. And that's really the reason for the film.

So the more people we can get out there to watch this film, to share it with their, friends and their family so that their family understands and to encourage them to take these action steps to to be proactive.

Yeah. Because that's really where the healing lies. And as Nick shared with me before we started recording, this is a self-produced documentary. I think you mentioned that, but they don't have any funding.

And the reason why I don't have any funding is no, I think it's going to make any money. That's, you know, what it's all about. Yeah. And that's what we here in fibromyalgia.

I mean, that's what is holding up the research. There's no there. You know, they don't think they can make any money. The pharmaceutical companies don't think they can make any money.

It's sad, but it's true. I mean, I hate to say it that way, but it is very much true. I mean, this has been going on for 30 years. Yeah. And we've got three approved drugs.

And those three drugs, the three of them, Lyrica Savalas and Barton, are notoriously ineffective for fibromyalgia. They're recommended. They're commonly recommended.

But if you look at the the statistics, those taking Lyrica, 50% of them are some, sorry, 30% one notice improvement. Of those 30%, 50% will have to discontinue that medication within some period of time.

One year 2 or 3 years because it side effects working. And it not just that one step on anybody's toes about the drugs don't make you feel bad. But what I do want to encourage is a you look for other options.

And that's really what this whole summit is about. And, and very much your film really focuses on that. You've got to look in other and other directions, conventional medicine.

Thank goodness we have it. But it's a dead end for fibromyalgia. You cannot drug your way out of fibromyalgia and you absolutely cannot. And I had, in the seven years now, you've got 20 some years on me, but the seven years that I've been studying this, that I've been following people, that I've been talking with, experts, that's really the the hypothesis that I came to and why we said that in the film.

Yeah, yeah. So what I want to ask those that are watching this or listening to this, please help us spread the word about this film. So you're going to have a link on here. We'll have a link here in the summit.

You'll be able to access that to see how to help us with promoting this film, that we really need to get this film out and hopefully we need to get some funding.

So I don't know. We'll talk more about that. I've got some ideas for you, but I think this is a film that the public needs to see. And and certainly, health professionals as well need to see this film.

Absolutely. Thank you. Yeah. Nick, I want to thank you so much for being part of this summit. And I look forward to, helping you spread the word about about this film.

I think it's going to be very helpful for those who get a chance to watch it and realize they're not alone, and that there is health out there. Do not give up. There is help.

There is help. And, I thank you so much for having having me today.