

- So my name is Elizabeth Ouellette, and I just want to thank everyone for joining me today. You know, more than being a CMT advocate, and on the board and all that, I'm a parent of a child with CMT. I do not have CMT. Yohan--

- Presentations this morning. The pediatric neurologist said that 40% of CMT1A mutations are because of new mutations. And that's what my son has, is a new mutation. So, you know, let me get into my - So I used to be very, very, very active. Like if it exists, I did it, right? So I was doing racquetball, and caving. I was living in France. I walked everywhere. I would just walk everywhere. It was probably an addiction. I was very addicted to exercise, but I love it.

- The other one. The roast beef.

- Sorry Elizabeth, if everyone could mute them--

- Yeah, the ham.

- Ma'am, if everyone could mute themselves, would be really helpful.

- Ham didn't do well yesterday.

- Sorry, guys if you could mute yourselves, please?

- So I'm just going to keep talking.

- [Laurel] Okay.

- Did somebody talk about a ham? So anyway, after the age of 30, I was so active. And then I was pregnant with Yohan, and, you know, before I was pregnant, I have to say that I had a lot of foot problems. Always had really high arches, sound familiar? I was clumsy, I'm still clumsy. If there's something on the floor, I'm always going to trip on it. Neuromas in my feet, broken bones. And then I started getting plantar fasciitis, which is that tight band on the bottom of your feet. It was inflamed. And so I went to see this physical therapist in France, where I was living at the time. And he took this vibro-massage jackhammer machine and did it all along the bottom of my feet, both feet. I came out of there that day, and I'm like, "God, my feet feel weird." The next morning, and I'm sure a lot of you can relate to this, burning, burning. I felt like my feet were on fire. I was trying - I had my son at that point, he was three months old. I'm trying to walk him in the stroller like I usually do, and I am literally walking on fire. I'm like, what the heck? When can I get rid of this? When is this going to go away? Well, it didn't go away. I went to see all these people in France, I went to get orthotics. They didn't really have orthotics that managed your arch. They had all these weird things with I don't know, pads on them. So we moved to California and I was in a wheelchair. I really could not walk anywhere very far, very long. To this day I can't go to a museum without a wheelchair, but I had chronic pain. And I was like, what is going on? My whole world as I knew it just changed overnight. From this athletic person that was skiing and hiking, and randonee skiing. Just I'm a earthy person, you know? And then I'm like, "I have a baby, "I'm trying to get along in life." I'm one of

those women in Whole Foods in those little cars going around, and people are judging me. Like, "You are too young to be in that machine." I'm like, "Well thanks, that's really helpful." But I'm in this machine, this like, whatever you call them, those carts, those rolling carts. I can't help it. So I finally found a pain management program, and it was really hard because I still have chronic pain. So this is not a talk about chronic pain, but it's staying active and how to remain active when the odds are against you, when you don't feel well, when your muscles are tight, when you have chronic pain, you have a hard time walking, when you're clumsy. My body feels most of the time like it's 98. I feel like this lady right here in the picture. But my brain goes, "Oh, I can do this and I can do that. "And I can do this." And I just end up hurting myself even more. So I still have to bring those 28 and the 98 year old together because I'm really almost 58. And I'm not sure what that's supposed to feel like. So not being able - You know, disabilities are all different. Some you don't see, like a lot of people have CMT, and you wouldn't know you have CMT. If I had not had this foot pain, and these problems with tightness of my Achilles and my calves, I would have never, ever been able to empathize with my son, Yohan, ever. I just wouldn't have been able to do it, because there's something to say about having pain to be able to relate to somebody else who was pain. Or, you know, CMT, or disability. So, you know, I used to do a lot of self, self-talk. I'm crazy, there's nothing wrong with me. Why aren't the doctors finding out? I must be nuts. Am I making this up? And then love my body, but I have these big humongo feet. And I have size 10 feet, and with these huge orthotics, I have size 12 clown feet. I say that to myself still to this day, but then I go back, I'm like, at least these clown feet are allowing me to walk. At least these big orthotics are allowing me to walk. So I appreciate now. But you know how before you can really appreciate something, sometimes it has to be taken away. So my ability to walk was taken away, and to do all these things. And I said to my podiatrist the other day, "Thanks to you 20 years ago, you made these special orthotics for people with diabetes." And they were really big. If it hadn't been for that one person, I would be in a wheelchair unable to walk today. And he was the first one that really helped me. So on bad days I still use a handicap flip card. And or is it called placard? A handicap sticker for my car. But I look great when I walk, I'm going in and I'm driving. And I put my handicap thing in, and my feet are hurting. And I get out of the car and I'm like, "Oh my God, everybody's looking at me." Then I feel like I should start limping. Sometimes I do start limping, or I like hit my hip. I'm like, what am I doing? I'm pretending to have pain, but I have pain in my feet, but I can't show people. Then I just go, "Get this sign on my car." This spot is for handicapped people! Move your car. You cannot park here! And I'm like, really? What do I do? Am I supposed to fake it? Then I just decided what other people think of me doesn't matter. What other people think of me doesn't matter. If I have pain, I have to validate myself. If I can park somewhere else, I would rather park somewhere else. Those days I can, I do. What other people think of me doesn't matter, and this has been my mantra because I really believe it. And I've also tried to love these feet of mine. I've always been made fun of for my feet. Always, like my feet are so big, I don't need water skis, I don't need skis for the water, water skiing and pontoon boat feet, and you know it's just - I've had problems with my feet, you know? Oh, we had to send away for special shoes when you were little, and this

and that. I'm like, you know, these feet, they have a purpose, and they're big because I'm tall. And so if I have sights size 12 feet, and they're sticking way out, oh well. I've come to love those sneakers and love those feet because they allow me to walk, all right? And sometimes when you have chronic pain, there were times when I was in a really bad place. I'm like, I don't even matter. It doesn't even matter. Like, why am I struggling to stay active? I, you know - I'm sitting in a wheelchair. I'm withering away. I have a baby. I feel like the world would be better off without me. And I've had these thoughts. And I came across this statistic and I'll never forget it. You matter because you know what the chances are of you being born? It's winning the lottery three times or more. How many people have won the lottery once? No, I can't see everybody, but I sure haven't. I haven't even won \$5 in the lottery, right? It's one in 400 trillion. That's your chances of being alive on this earth. So what does that mean? That you have purpose. There's a reason for you being here. There's a reason for my foot pain. There's a reason for me to be in existence. And what is that reason? That's for everyone to figure out. But while I'm here, I want the best quality of life possible. With chronic pain, how do you do that? So a lot of people say with CMT, there are no treatments. And Bethany Meloche gave a Skype meeting with me the other day. And I've been thinking, I've heard this before, but there are treatments for CMT. And one of them is, guess what? Staying active. The others are AFOs, surgery, occupational therapy. These are current treatments. We don't have a medicinal cure, but you can slow down the process by staying active. Now, do I mean, you can stop the nerves from demyelinating, or the axons from not working? No. But by keeping your strong muscles strong, and your weak muscles as strong as possible, you are going to fare so much better. Your quality of life is going to be so much better. But when somebody says, "You got to exercise." I used to do Jazzercise. Like I was one of those women in a leotard, like this picture. I'd be like, "Let's go, come on, come on, let's go! And one, and two, and three, and four. Let's go! Out the door, let's go!" You know, and I was like seriously gave aerobics classes all through college and I'd be like, "Get down on the floor! Get those abs working!" And I could do abs for like 30 minutes, and all the guys would be going, "Oh!" And I'd be like, "Do it!" Thank God I had something to slow me down, because I had no empathy for anybody. And actually at that time it was all these college kids. And it was Jazzercise, right? Jane Fonda, Jazzercise, leg warmers. And then sometimes after the whole change in my physiology, and the chronic pain, I'd be like, "Look, the only exercise I've done this month is running out of money." I'm a student, okay? So exercises have a great name for itself. It's like, "Oh, you got to do it for your own good." And that's sort of what I'm saying, you do for your own good. But, you know, if I go to the gym, which no one's going to the gym. You compare yourself with those, "Oh, look at that woman. Oh, look at that man. Oh, he had a six pack abs. Oh, look at those muscles. Look at that definition." Listen, I have tried to build definition in my arms, even when I didn't have chronic pain, way, way back. And there's just no way my arms are going to be defined at all. If anything, my triceps is now hanging down, and it's just never going to be defined, okay? It's not very comfortable when you start exercising again. It's a routine you have to get into. And for some reason lately, and it's a struggle still for me. But lately I go "Oh my God, it feels so good to get on my horse." And horseback ride. And everyday I have to just do some

stretching, Stretching is so important when you have CMT, when you have tight muscles, And then the next day, there's this other voice in my head that says, "Oh, you don't need to stretch today." But, "Yeah, yeah, I do, I do." I have this conversation all the time. You don't need to stretch. No, you don't. Just take today off, it'll be fine. And I talk myself out of exercising, and I've never been like that, but I still struggle today. And I know I feel better when I get out and move, but I feel like I have like four voices in my head all telling me different things. And the days I get out there and I do anything, even if it's walking down the driveway and back, I feel better. But it's that mental part that goes, "Oh." So today is really hard to get moving. Sometimes I'm in bed with my little hairless cats and I don't want to get out of bed. Or I don't have the time, which is nonsense. Or, the gym is too expensive. Well now it's COVID, no one's going to the gym. So get a program at home. There's a lot of inexpensive ones. It's just too much. It's just, I'm too old. I'm too thin. I'm too tired. I'm too anything. But let's figure out this. Why is it so important to exercise or to stay active? Let's say stay active, all right? It does not matter how slowly you go as long as you do not stop. And I believe that, it doesn't matter. Listen, my husband is, he bikes. And when he, you know, biking is not like, "Oh, I'm going to go out for a 30-minute bike ride, or a 20 minute bike ride." It's like all day, 200 miles, double century, three-day ride. And I compare myself and I'm like, "Oh, I'm so lame." Then I have to stop the negative self-talk. It's okay. I'm going down the driveway, I'm going to look around. I'm going to see what's there. I'm going to ride my horse. I'm going to see my horse. Why is it important to stay active? You don't have to be super active, 10,000, 12,000, 15,000 steps. You don't have to do that. Get out there and do what you can and move. Why? At first, a long time ago, they said, "CMT don't exercise. "You're just going to make everything worse." That is not true. That is not true. That is not true. That is not true. Exercise will improve your independence, your quality of life, and your functional ability. But, you know, a lot of people, I think, should probably see a physical therapist if you have a hard time with balance and see what's safe for you. But water is great. And when Yohan, my son was growing up, I'd be like, "Oh, you better not play tennis anymore. You're going to sprain your ankle. Oh, maybe you shouldn't do this." Dr. Shy just said, "Let him do what he wants to do as a kid. He's fine. He will find his own boundaries." And he did. So with children and young adults, encourage them to stay active. It's so important, and it's hard during these COVID times. Right? So like I said, we do have treatments today. We have AFOs, many of you have braces, there's so many on the market. Surgery, physical therapy, occupational therapy. So with these things, staying active is a huge part of treating your CMT. If you have a dog, get out there and walk your dog, right? Moving, it releases endorphins. You start to feel better, you start to feel happy. And the benefit is strength, balance, independence, decreased fatigue. I know a lot of people with CMT are fatigued. Doing a little bit, not too much, will help you feel better. And it's a different fatigue. It's a fatigue of working out, or walking, or using your body rather than the fatigue like, "Oh, I'm so tired. I could barely get up." It improves mood, it improves sleep, weight loss. And some people have a hard time doing wheelchairs, but you can still do movement and activity when you're in a wheelchair, and I know. I was there, okay? And it makes you feel better and think better, all right? So what's important to exercise? We have to

work on balance, stretching, strength, and endurance - those four things. So on the CMT website, we have some great videos of people with CMT exercising in chairs, or with a chair and doing certain motions. People go, "Oh, what are the best exercises to do with CMT?" It's really individualized. I think the focus might be better to think a movement, what you can do. And if you have an injury, see a physical therapist to find out what's the best way to come back from that injury. But, you know, for balance is really important, because you have decreased sensation in your feet, and in your legs sometimes, and muscle weakness. So there are exercises to help work on balance, right? Proprioception involved, so you working on your balance. Some physical therapists will teach you to use your vision to substitute for the proprioception issues. And a lot of people do Tai-Chi, or modified chair yoga, or modified activity in a chair, or in a wheelchair, or against a wall, or holding onto something. So balance is really important because I don't want you falling, right? Stretching is also extremely important. And if you have kids, I really recommend that you stretch with them. Because when Yohan was young, I'd be like, "Okay, you got to stretch, you got to sit here. Just watch TV and do the stretch for like five minutes." Well, it's sort of like if you have kids and one of them or two of them have CMT, and the other ones don't, it almost feels like a punishment for that child, right? Go stretch, it's good for you. But at that age they're not going to understand that it's good for them. So if you do it with them, and it becomes family thing, then it's like part of your family and part of your life, and start young. But really your Achilles tendons get tight. Your hands get tight, stretching them back gently, your fingers. So stretch out those hands and keep them from clawing and contracting. Range of motion. Even as we grow older without CMT, we want to keep that range of motion, in your shoulders, in your body. Swimming is wonderful, and I know that a lot of things are closed right now. Heel core stretching, Achilles tendons, just a must for every day. And this ball under the foot, I use that all the time to stretch out that fascia to keep sensation from being, I'm overly sensitive, and some people are always sensitive with pain with CMT. Very, very important. Next thing is strength. Atrophied, you can keep them strong, but you can't bulk 'em come up. You can't make a huge muscle from a muscle that's effected by CMT has atrophied. But you can strengthen all the muscles, and there are quite a few that have not been affected by CMT. And that's really important in keeping you strong, walking, active and conditioned. Because some muscles may become weak. Strong muscles may become weak just because you're deconditioned and you haven't been using them, all right? So again, this goes back to floor exercises. If you can get off the floor, if not you might need to do it on the bed. But there are solutions, okay? And the last one is endurance. We really want to make sure that our cardiovascular health is good, that we get our heart rate pumping. So biking is a great thing, and I'm going to talk about biking a little bit later. Also on the CMT website, one of our board members, Steve O'Donnell is just an amazing athlete. He has CMTX, and he made this CMT exercise series to share with everyone with CMT to show them a little bit what his practice is, what his philosophy is, and what his exercise series look like. So thta's always a - And we also have a Pilates video a couple of them on the CMT website. So there's a lot of resources on our website that I'd really like you to look at, and take a look at and try them out. So a lot of you, and it's no laughing matter, the fatigue issue, okay?

It's exhausting. My son has fatigue. I have fatigue. Some people take things like Nuvigil, which is used for narcolepsy, and you can get it if you have sleep apnea. It's not really a stimulant, but it helps, you know, keep you aroused and awake. Or get checked out for sleep apnea. That's a big one with people. It's all over the world, but especially with CMT. Restless legs can keep you up at night, even though you know your quality of sleep is bad. If you're anxious, depression, talk to your doctor about that, because that also can play into fatigue. And if your muscles are not working at a 100%, you're going to expend a lot more energy just trying to get through space and to do your task of every day. You're going to be tired. So, you know, my clock looks like it's tired. What time do you want to do that? Oh, tired time. It's like all the time. And it's hard to get out there and be active, right? Sometimes getting out there and doing a little bit, not overdoing it, but doing a little bit, will help you. And also, try and look for underlying causes of fatigue that can worsen your already fatigue that's from CMT. I've talked a lot about chronic pain. I have chronic pain, and some people CMT have pain, some people don't. Some people definitely have neuropathic pain, or pain of the muscles. Don't let your doctor say that people with CMT don't have pain. That's not true. Okay, so to really work with pain, and it's hard when you're in pain to do exercises. The last thing you want to do is move a joint that hurts, right? If you have chronic pain, and I have a whole other presentation on this, but please ask me the questions, 'cause I've had a lot of experience in this. But pain education, finding out what's causing your pain and why. Relaxation. Biofeedback, that's seeing how, for example, I don't know if everybody knows what biofeedback is, but you have monitors. And if it shows you, for example, if you want to bring your heart rate down, you can work on it and see your progress through a machine or a little device. And that just gives you the feedback necessary to bring your whole body down. And it really works. You can - I've gotten to the point where my, I have Raynaud's in my hands. A lot of you have cold hands and feet. You can actually have blood flow go back in through the power of your mind using biofeedback. And I never thought that was, like, something that I could do, but you can do it. It's almost you feel like you're a magician or something. See a psychologist if you need to, or therapist. And chronic pain really responds well to activity. It doesn't - When you have chronic pain you feel like, oh, pain is a signal to stop what you're doing. But when it becomes chronic, that doesn't work anymore. When it becomes chronic, you have to just overcome some of that. But work with pain medicine, a pain management team, to help you get through that. And there are not a lot across the United States that I've been really impressed with. But there's a lot of information and I would love to talk to anybody dealing with chronic pain. I just talked to a mom with a son with chronic pain the other day, and we came up with a plan, all right? So to put it all, you know, together, kids. Find activities - this is my son Yohan. This is him snowboarding when he could snowboard. When he went snowboarding, I couldn't go, 'cause I don't do well in snow. And all I kept thinking of, and I just listened to David Tannenbaum's emotional support group. And I'm thinking, I spent my whole day in a tizzy, anxious because of this. But here he is on a snowboard, going up the slopes in Vermont. All I kept thinking, he's going to fall. He's going to fall in the powder. He's not going to get up. He has a back issue. So it's a good thing that I have my husband there pushing him to do some things beyond his comfort zone. And

it wasn't me, because he would be completely neurotic right now if it were just me raising him. But this picture down here on the left, they went camping when he was young. They came back and showed me this picture, I had a fit. I'm like, "What, are you crazy? He has balance issues!" But for him, this was one of the best experiences of his life. He succeeded in crossing this log. He was - And my husband goes, "Oh, it wasn't that high, it's just the way the photo is framed." And I don't believe that for a second, but he's still alive, so everybody's alive, everybody's good. Archery, he took up archery. That was awesome. Here's my son and my husband down here on a hike. It was in Australia, we did a lot of traveling. We also took up horseback riding. We - he did, and I took his horse later, that's why I'm saying we. And he goes to physical therapy every single week to keep his core strong. And that's really important in CMT is to keeping your core strong, all right? And kayaking, they did this. They did so many things when Yohan was young, it's just amazing. If that had been me, I can't do those things, so it was great that my husband, who is a huge athlete, that he took the time, the energy, and he found activities that Yohan could do. I'll always be grateful for that. So this is how I feel right now, because Laurel made me get up at six o'clock. This sloth. So let's go back through this, okay? Treatments for CMT. AFOs to walk better, to be safe. Talk to your primary care physician, see a sleep medicine doctor if your fatigued. Pulmonologists, we have a pulmonologist on our advisory board who's wonderful. Ear, nose, throat doctor, make sure everything is clear. You can sleep, have great hygiene. There's medication you can take for fatigue. And activity. So it's really important that you feel the best you can feel so that you can allow activity into your lives. And we have some super, really strong people with CMT in our community that do triathlons and, you know, races. That's the minority. I'll be glad - I'm just happy I can walk around the block. So whatever you can do, accept it, embrace it and keep doing it, right? Safely. So again, work with a physical therapist, have fun. I love this next one, listen to your body. But this one, no gain with pain. Do you remember when I was in the Jane Fonda phase, I'd be like, "You're not going to be able to make any strides if you don't have pain. Just beat the pain, beat the pain." And that's been something that's been really hard to get out of my head, no pain, no gain. It's really no gain with pain. So put that into your mind. And people find the funnest things to do. You can just vacuum or rake leaves, or pretty soon we're going to be shoveling snow, if you can do that. That is awesome exercise. And I'm sure your dog will always love to go out for a walk, right? This guy was here - I was at the airport, and he's like, "I'm stretching." So he was at the airport stretching, and this is before COVID. But I thought that was pretty, I took a picture of it 'cause I'm like "good for you. "You don't care what they..." What other people think of me don't matter. So I have to say, there's so many people in the CMT community, in the CMTA community that really inspire me. And those are just a handful. This is my son here, Yohan, who I've showed you in the past with my husband, Gilles. And he could never bike. He couldn't get the balance, I would bring him to physical therapy. He would try to bike. He'd fall. He told me to throw the bike in the garbage. He hated it. He hates exercises. He hates being active. Don't ask him to be active 'cause he'll never be active. And that was the end of it. That was like when he was 15. So when he was in college, one of my brothers came and helped him get his balance on the bike with no

judgment, no pressure. And at that time he learned to bike, but he didn't really use that skill until recently. He did this - we host a Cycle 4 CMT every year. And for the first time ever this year, Yohan - this is an electric bike - used his electric bike to peddle 20 miles on hills with my husband. And it was one of my proudest days ever, because he overcame his fears and challenges. And now he bikes on a regular basis and he's enjoying it. So when he was 15 he said he'll never exercise, that was a moment of frustration. Today he understands the value of physical therapy, but it just takes time and biking. And then even when mountain biking with an electric bike, and I'm like, "Whoa, this is getting way out of control." Right? So this is Jeana Sweeney, she's dancing. That's a form of exercise. Come on, just put that music on and just go for it. Get down tonight. This guy right here with his AFOs, he's out there traveling, walking and traveling. You know that's exercise; it is exhausting. Then some people have bikes where you can walk and it supports you, and you can move through space, and that that's exercise too. So there are a lot of things out there that you can use to exercise. This little girl is a champion karate. There is skiing for people with disability. And I was thinking, when I saw this picture - this is Sarah Kesty, and she's on our advisory board. And she had a blast out there on the slopes. And I was thinking, I should do that, I used to ski. I bet you I could do that, that would be fun. This guy here, he rowed for CMT for his fundraiser this year. So rowing is a sport I never even thought of. And then this person is on a gun range, in a sort of like a seat walker kind of thing. And this person is on a horse, why not horseback riding? And biking of course. So this is, I think I can't see it the screen. Sorry, I believe this is one of our friends, John White. He came to the Cycle 4 CMT in Vermont. He did those hills. When he couldn't do 'em, he walked his bike and he kept on going, and he's training. And he's an awesome guy. So to sum things up. Be CMT Active. Any way you can, you don't need to run a marathon. You don't have to stretch, work on your endurance and balance. Join our Facebook group. We have a wonderful Facebook group. If you're on Facebook, it's called CMT Active. And it's people that join together, and they talk about their activity levels, and what they do. And they kind of either commiserate or give each other tips. It's a wonderful group. Also on the CMTA website, cmtusa.org, we have a lot of videos. We came out with this guide to physical and occupational therapy, which is on our website. It's a flip book. Steve O'Donnell's exercise series is there. We have balanced walking with poles, I don't know if anybody uses poles to walk. And we have articles, and webinars, and so much more. And if you're interested in doing the Cycle 4 CMT, it's a cycle and walk for CMT, check it out. Check out what we've done. Cycle4cmt.com And so just to close, this is Yohan on his bike training for his ride, and he has such a great attitude. Never give up, stay focused, stay positive, stay strong. Thank you. I'm going to stop sharing my screen, and I would love to entertain any questions there are. I hope you enjoyed that.

- Yeah. Your presentation is so wonderful Elizabeth, and in the chat room, most people were sharing stories and comments. So not a ton of questions, but one of the questions I noticed that came in is, and I don't know if you can speak to this or not. It sounds like, Audra, when you wear a AFOs that your feet go numb, and they can't seem to prevent

that. Are they not numb without them, but then they go down when you wear AFOs? I'm going to go back to gallery view so we can

- Yeah, so we can see, let's see. Let's talk about that, because AFOs, I was transcribing one of Dr. Pfeffer's talks the other day, and he said, "It's too bad you can't just try AFOs, bring 'em home, and if they don't work, you bring 'em back." They're sort of like horse saddles. You buy a horse saddle. You put it on your horse. You can't give it back, and it's like \$3,000. And AFOs are very expensive, but there's so many types of AFOs. And he really believes in AFOs that move with you, I think he calls them ground reaction braces. So a couple example of those are like the fat brace, the Ottobock. If I can remember the ones from Las Vegas, the Helios. And it might be that the AFO is impinging on a nerve, 'cause that makes me think it's impinging on a nerve and causing something. Because I have a sciatic problem, so when I sit down for too long, my whole last leg feels tingly. So is that Sandra, where are you?

- It was Audra, I believe. I don't know if you would like to unmute and share your experience. I'm just looking to see if I can find her.

- So AFOs, you know, it's - some people don't want to wear AFOs. Some people want to for their safety. I think it's great, but it is hard to find a good brace. It's hard to find the right brace for you because they are really expensive. And insurance will only pay, if they pay anything, a certain percentage over a certain amount of years. Some of the braces can be \$12,000 each, who has that kind of money? I would definitely try to work with your orthotist, because that should not be happening. Does anybody else have a problem with their braces like that? How do you start the process for getting AFOs?

- [Laurel] That's a good question.

- Yeah, you can get a prescription from your neurologist or from your primary care physician, and then you go to a place that makes orthotics, like Hanger or there are many, many companies. Laurel, what braces do you find? What are you wearing for a brace? Oh, the noodle was another one, of the ground force reaction braces.

- Yeah, really the carbon fiber braces are so highly recommended for most people with CMT. There are a few situations where they're still recommending the kind of old white plastic brace, but the carbon fiber, those ground reaction braces really give energy back into your walk, which is so wonderful. So I was one of those stubborn people who refused to wear braces, even though I was high stepping and tripping all the time when I kind of got into my late 30s. And I finally realized I was on the sidelines of life, instead of in the mix, and I like to be right in the mix of everything. So I figured people were either going to be staring at me because of the way I walk by high stepping around, which was making me very nervous and uncomfortable, or they could stare at me 'cause I have these awesome braces on my legs. So I finally, at the age of 41, I decided to try braces. I'd learned a lot about the Allard BlueROCKERS, and I tried those, and I was one of the very fortunate people that they worked for me immediately, I didn't have to. I mean, we had to make some adjustments in terms of padding and whatnot, but that was the right brace

for me. And so they take me everywhere I need to go. And just sticking with the theme of being active, I don't come by it naturally. I'm not one of those people that wants to work out five days a week. I have to dig very, very deep to motivate myself, and I put little things in place to help with that. First of all, I have two teenagers, and one of my top parenting philosophies is to lead. So I make myself exercise, so that my children see me exercising, and that is a huge motivating factor. And I just started doing some weightlifting, light weightlifting with my son, because he's really into fitness. And so this is really up to my CMT Active, what I'm what I'm doing, because I have committed to be in our home gym with him, the garage, three times a week. So that was a really long answer Elizabeth, but I wear-- BlueROCKER braces. but I do want to share my CMT Active story 'cause I love... I think staying CMT active is so incredibly important. I talk to community members all the time, and the ones who are doing okay are the people who are staying active. That's a very generalized statement, so please take it with a grain of -

- No, it is. In general, you can't say for every case. In general, people who exercise, or rather stay active, do much, much better over time than people who are sedentary, okay? And somebody asked, when did that change? Because 10 years ago, her neurologist said something about exercise is bad for you. There were papers that came out not too long ago. Maybe, I don't know. It's probably been that amount of time, it was very questionable. Like how much is too much? If you're really sore for 24 to 48 hours, you've done too much. Back it up and work towards your goals. But exercise, there have been studies, and exercise is definitely encouraged. So I know that Dr. Shy doesn't encourage like jogging, or like really hard impact stuff because the way way people with CMT walk, it puts more stress on your knees, your ankles, your hips. So you don't want those things to go out of whack either. And they really think that weightlifting is good, swimming, biking, anything that gets you moving, Tai-Chi, anything, pilates, that's not really hard. Some people don't have a problem and they can do it, more power to them. But for most people, a softer, low impact activities are recommended.

- Yeah, and Elizabeth, I just want to add. I was hoping to say this and you brought this up. But I love the fact that you have brought exercise to light for the CMT community. I mean, you've done so much, but really bringing the CMT Active to the forefront for CMT patients. Because even myself, I was told, "Oh, exercise is not good for you. Do not exercise. You can't exercise." And that word can't was instilled in me for a good couple of years. And to see the mindset of CMT patients change with this time, and you giving this presentation, and you bringing it to the light, to the CMT community, I think is so incredibly important. So that's one thing that I try to instill in Riley, my daughter. So I really - I think this is really important for everyone to hear.

- Thank you Jeana. Thank you for that comment. And I was going to mention you, because I'll talk to you on Monday morning. "Hey, how was your weekend?" Oh good, we went for a bike ride." And that means when we, she means Chris, Jeana and Riley went for a bike ride, and the dog. Of course she is probably bringing the dog and trying to bike at the same time, you know. But she keeps Riley active. "Oh, I have to bring Riley to dance,"

or, "I have to bring Riley to Pilates." So Riley is learning growing up, staying active is really important. She has to, you know. She has to.

- And I hope that the world of CMT, and new diagnosis, and even those of us that are on this call right now really take what you're saying to heart. I remember when I first met Dr. Scherer, which we heard from this morning, I don't necessarily run, I trot. But at that time I was like trying to, he's like, "Jeana, what are you doing? Don't do that." He said, "You can walk fast, but, you know, I don't want you to hurt yourself." But I think that if everybody can find their own pace of exercise, whether that be whatever it is. I do yoga, but I do yoga for me. And, you know, they always say, "Well, you got to take off your shoes. You got to do this. You got to do that." Well, I don't take off my shoes. Just because everybody else is taking off their shoes doesn't mean that I have to take off my shoes. There's no written rule or law, and I stay by the wall. So I think that everybody learning their own CMT Active is incredibly important. And I hear from Riley, "Oh my gosh, I'm so tired. I had such a bad day." No, we're doing this. And, you know, so I'm hoping that I can teach her as she gets older as well, so.

- Thank you for that. Other questions about pain and walking, or exercise or anything else?

- Yeah, and people were asking about, can they find braces that actually make them tired instead of returning some of that energy?

- So again, that ground reaction brace that actually you walk and it gives you spring is really important. So again, maybe a different brace. And it's hard in this country. I don't know how many people have braces, but they're expensive. They're expensive. Bethany Meloche was part of the CMTA. She's 28, she lives in England. She's like, "This is great. I can just bring braces home, try them, and give them back if they don't work." And yeah. I wish we had a system like that where we could do that. There's another brace I want to mention. It's more for foot drop, but there's a big following in the CMT community, is the TurboMed brace. And we'll be having a Zoom meeting with the people from TurboMed at the beginning of December. And it's a brace that goes on the outside of your foot, on the outside of your sneaker, and you can change them from one shoe to another. You can wear them with sandals, and you can wear them with boots, and you can wear them with sneakers. It takes two seconds to change the braces. So on the outside. Braces should not make your feet go numb.

- So Audra's back. Audra, we actually were talking about your comment earlier, but I think that you had maybe left the Zoom. Are you with us now? Are your feet not numb before you where the braces, and then they go numb with the braces?

- [Audra] No. They just go numb whenever I put the braces on.

- [Laurel] Wow.

- So that means there - something's impinging on a nerve. They're not fitting right. What kind of braces do you have?

- [Audra] The AFO?

- [Elizabeth] Yeah.

- [Audea] Yeah, they go in my shoe.

- Well, that should definitely not be happening. It's sort of like, my whole leg has been going numb when I get in the saddle on my horse, but it's because I'm sitting on my sciatic nerve and it's being overused. So I need to lift the pressure off that. And then I get off and after a day, I'm fine. So there's something. It sounds like, I'm not a doctor, but it sounds like a nerve is being irritated, and that you need to really figure out 'cause you already have CMT. You don't need more nerve issues.

- [Laurel] Yes, yes.

- [Audra] Yeah, they've tried different pressure points, like up the side of my leg, one in my foot, and it's still causing, it causes half my foot, from half my foot to the end of my toes to go numb.

- Oh, I'm so sorry to hear that. Well, I hope they can find a solution for that.

- [Audra] They've worked on them three or four times now, and it doesn't seem to be--

- No it's such a pain, and you have to keep going back, and coming, it's very time-consuming. But if you can get it right, it's great. If you can get one that works, it changes your life. Right, Laurel? Like you just said.

- [Laurel] Oh my goodness.

- Life-changing.

- It was life-changing, I speak to a lot of people about that. I got to do some of the things I had stopped doing, like shooting hoops with my son, or playing with my daughter. And I'm not the fastest person ever. I'm always the slowest, but I'm out there staying active. And it makes me feel better. When I don't exercise, my body hurts. That's when my CMT actually feels the worst is if I'm not moving, I have a standing desk, which I'm sure is going to sound crazy to people, because my body aches so much when I'm still, when I'm sitting. And so it's that moves me moving around that keeps things, I don't know why I am that way, but it just keeps flowing, I guess. I don't know.

- Yeah.

- So I'm curious to know from our audience, what do you do to stay active? Do you do anything, do you struggle?

- [Audra] I struggle, I can't do anything hardly. I take care of my grandkids on and off, but I don't go out to the grocery store much

anymore. I don't do much of anything now, especially since the braces aren't working properly.

- Can you do some stretching and movements of your upper body or your core?

- [Audra] I do some. Right now I'm having a lot of back issues, they're getting ready to do some X-rays.

- All right. Pole walk, that's great. Dr. Greg Stilwell is a big pole walker. He's great. Somebody goes to the gym, even though he's in a wheelchair. That's awesome. Sled hockey, what the heck is that? Catherine, where's Catherine? Catherine, what's a--

- [Catherine] Hi!

- Hold on, I'll get it, I'll get it.

- Sled hockey, that just sounds so exciting.

- And Yung was playing badminton. Yung, I love that you were playing badminton before COVID, that's fun. I mean, hearing about everyone's experiences on--

- Strength training, that's awesome. Oh my gosh, you can't even find somebody that specializes in chronic pain. That's awesome. Okay, let's see this sled hockey thing. Now, what is this contraption?

- She sits in the sled, and she uses her arms with the hockey stick to push her around the ice. And the whole team is all children playing sled hockey.

- [Child] And when I get on the ice, I make a circle.

- Yeah.

- [Child] And then I, that's how I watch where I'm going, 'cause now I'll fall.

- [Laurel] That's awesome.

- I want to do that, trekking poles. That's really great, this sled hockey, I've never heard of that. That's awesome.

- And did someone play a sport that since their CMT progressed, they've learned how to do it. You didn't quit, you didn't give up, but you've learned how to do it with your CMT body?

- [Child] I do it however--

- [Woman] You're not muted.

- Okay, pickleball. What in the heck is pickleball? I'm learning all these new activities, I got to to put it in my thing. What's a

pickleball? I would think that'd be a Jeana thing. John. Was that John? John, can you unmute? Tell us about--

- From Poland.

- It's like tennis, but you use a wiffle ball and it's a smaller court.

- Oh, that sounds so fun. Where are you from? Are you on the beach right now?

- If you want me to be. I wish I was. No, I'm not. I'm actually in Wisconsin, but picklball is really big in Florida and the YMCAs. And it's mostly adults. The court is half the size of a tennis court, so you don't have the running around that you would have as much with tennis. And you don't have the hard serve that you have with tennis, so it's a lot easier. Yeah, it's fun.

- [Elizabeth] Good, good for you. Let me say one more thing. On the website, I learned about the balance walking.

- Yes.

- I was a huge downhill skier, I can't downhill anymore. I don't have the balance or the strength in my legs to turn the skis. And it was probably worse than, that was the worst worst thing for me. But now I'm snowshoeing in the winter here. The pole walking though, I prepped before, and I was diagnosed late. I was diagnosed when I was 66, I'm almost 70 now. And all these little symptoms were there, but I didn't really realize that it was an issue, or, you know, it was CMT. And my feet were always cold though, skiing or anything. There were all these little things out there that I just thought, "Oh, that's just what it is." But the pole walking is awesome. I used to trip a little bit, and never thought anything of it. But with those poles, no more tripping. We were hiking last year at the Grand Canyon. I couldn't probably walk around the block without those poles, and we were walking five miles a day with poles.

- That's awesome. Thank you for that testimonial. That's great. That's wonderful.