

- [Laurel] Everyone, this is Stephanie Poelker from Wash U as the locals in St. Louis call it, but Washington University in St. Louis my best friends live there. So I always hear it referred to as Wash U. We're so happy to have you. Stephanie is a physical therapist in the neuromuscular clinic that is an MDA and a CMTA Center of Excellence. So we are just thrilled to have you with us today. I'm going to go ahead and turn it over to you. And we have until about 12:30, Stephanie, I would love for some of that to be presentation and then some time for some questions at the end. If that sounds good.

- Okay, sounds good.

- All right, it's all you, thank you.

- All right, thank you. So like Laurel said, my name is Stephanie. I'm a physical therapist with Washington University in St. Louis. And just recently we did become a CMTA Center of Excellence with the help of Dr. Geisler, who is one of the neurologists that I work with there. So happy to be here with all of you today. So when putting together this presentation, I tried to put together some objectives for what I wanted to focus on with focusing on physical therapy with CMT. So some of the things that I wanted to address today are the goals of physical therapy with CMT, different treatment options that are available. I'll review some exercise guidelines, as well as some equipment and devices, and then also address some environmental challenges. So for physical therapy, your physical therapist is going to address a wide variety of goals. It's going to be goals that are important to you. It's going to be goals that they want to on for you as well. So I tried to sort of lump sum them into some general overall goals. So just some of the ones that I want to talk about today are addressing specific limitations and skills, and encourage and maintain functional movements, addressing pain relief, transfer, training, and mobility, endurance and then focusing on your independence. And you guys can also see my slides, correct?

- Yes, we can, thank you. I meant to check that in the very beginning.

- Perfect.

- Okay. So the first goal, is addressing specific limitations and or skills. So when you go see a physical therapist, they're going to do a wide variety of assessments and evaluations. One of the things that they're going to assess is your range of motion. So seeing how much movement you have in a specific joint or on your arm or on your leg, and they're going to address it by giving you certain exercises for stretching range of motion exercises. And so usually these exercises are ones that you really want to do three to five times a day, three to five times a week. It can be done more than that as well. It can never be harmful to do more range of motion exercises, because it's just you, were focusing on moving that limb in an active range. It could be in an active range, but it can also be performed passively too. So if you have weakness say in your bicep that you aren't able to reach and perform range of motion exercises to reach and touch your shoulder, you can have someone passively move your arm too. So there is a wide variety of range of motion exercises and stretching that you can work on. And I'll kind of

touch on stretching a little bit more later too. Your physical therapist will also measure your strength. And so that way they can target those areas of muscle weakness. And so once they measure every different muscle of a certain area where you're having trouble, say it's your ankle, they'll hone in on those muscles that are particularly weak and try to work on some strengthening. And so for strengthening, there's different resistance exercises that you can do. Usually we want to keep it light resistance training, but they also can do what we call a fancy way of calling it, is neuromuscular reeducation. So this is just a fancy way of saying that we retrain your brain to muscle connection. So focusing on changing those patterns or strengthening the patterns of how the nerve signals come from your brain down to those muscles. Excuse me. So that's one way that we can work on strengthening. Lastly, an important area to assess with CMT especially, is your balance and your gait. So your balance is made up of three components, and I'm just going to slide all of everyone's faces are on my slides. So I'm going to scoot everyone over. So your balance is made up of three components, your vision, your proprioception and your vestibular systems. So these systems are mainly being able to see, feel and hear in order to maintain your balance. So with CMT, when you are lacking sensation, you don't have that proprioception input. You don't have that ability to feel where you're at in space - that's a big problem. So your physical therapist can help with strengthening the other systems, your vision, your vestibular system, and teach you compensation strategies on how to improve your balance. And so that's a huge one to me, for CMT. As far as your gait, they can also review or assess how you're walking and see if it's appropriate to start using some assistive devices or to see how your balance is impacting your walking too. So, I think this is the biggest goal with physical therapy here its just working on that stretching, strengthening, and balance and gait training. Another goal that you can work on with physical therapy is working on encouraging and maintaining your functional movement. So we really want to maximize your abilities, those activities that you are still able to do. We want to keep you doing those. And say there's an activity that you're no longer able to do, we want to help you figure out new ways to still continue to perform those activities. So it might not look the same as how you used to do it, but we can figure out a new way to help you do it. Another thing that we can do for functional movements is evaluate how you're currently performing a functional movement and see if there's modifications to how we can do it. Some activities can be harder for you to do, but they don't have to be impossible. We just have to find a new way to make it work for you. A third goal is pain relief. CMT can be very painful. And so we need to address that as we're addressing your mobility and your functional movements. So for stretching, sorry for pain relief, there's different ways that we can use stretches or address how you're positioned. And so that we can try to relieve some of that pain, whether it's pain if you're sitting in a desk job for a while, we can try to work on your position. Or say you have pain when you're up and walking, we can try to address some of that with wedges and sort of devices. I'm having an echo. So I don't know if that's on anyone else's end.

- We don't hear an echo, you're okay.

- Okay good, just want to make sure. Okay so another way for pain relief is if you're seeing an outpatient physical therapist, they might use things like ultrasound, electrical stimulation, ice or heat to help us with temporary pain relief too.

- I'm sorry so we are hearing an echo. I just would like to ask everyone to make sure you're muted please, so please go ahead and mute.

- I think that's better now.

- Let's give that a try. I'm seeing some people who are not muted, but if you could go ahead and mute, that would be really helpful for the presentation. Thank you, all right. Stephanie, let's give it a shot.

- Okay, thank you. Okay, so the fourth goal of physical therapy that I wanted to focus on was transfer training and functional mobility. So as your disease changes, the way you move also changes. And so a physical therapist can help you address how your balance might be impacting your walking, or if you're trying to transfer in and out of the shower, different things like that. There might be times to start using some equipment. So if you are progressing and you start to have trouble walking, it might be time to talk with your physical therapist about using a cane, walking sticks, a walker, and they can help you assess what one is best for you at that time. And it might also be time that we have some caregiver training. So, say you're having issues with, some of your hygiene techniques or getting dressed. It might be time to have your caregiver who can be your family member, friend, spouse, parents, whoever it is. They can come in with your physical therapist too, and receive some training on how they can best help you. So there's a lot of areas that we can help with transfer, training and mobility. The fifth goal I have, was endurance. So aerobic exercise is important for everybody, not just people with CMT, but it's almost more important for people with CMT. So even if your mobility is limited, it's still important to get that exercise in and work that cardiovascular system to improve the health of your heart and your lungs and general health and wellness. So we want to keep you healthy, to avoid any further complications that could come with those effects. So a physical therapist can help show you how to continue to safely participate in some of those physical activities that you enjoy that you're getting enough exercise to have that optimal level of endurance and that optimal level of fitness. Some areas of aerobic exercise that are safe for CMT and that are usually recommended are to just do walking programs, biking, typically like a recumbent bike is almost best because balance on a standard bike or an Aerodyne bike can be a little challenging. Swimming, you can do on your own, or you can even do aquatic therapy with a physical therapist. Yoga, there's a lot of adaptive yoga out there. There's also, especially now with the pandemic, a lot of virtual yoga classes that you could even do in your home too. And then there's also the option for adaptive sports. The last goal of physical therapy was independence. It's a huge goal, especially I try to emphasize this with my patients too. We want to focus on what you want to do. What's important to you? Work with your physical therapist to find new techniques, to get around those challenges, to keep doing those activities are important for you. With the disabilities like what CMT can bring on. And some of the other diagnoses that I see, it's easy for

patients to fixate on some of those activities that they've lost or some of those abilities that they can no longer do. And so that can bring people down. And so I try to really turn it around and encourage looking and focusing on what you still can do, even if it looks a little bit different. So your physical therapist can help you still find ways to perform some of those activities on your own. And if it comes to the point that you aren't able to do it on your own, it's okay to still have help too. But we want to encourage that independence for as long as we can. Okay, so that was the general goals of what a physical therapist will usually work on with you. And so now it's an option of where you're going to see a physical therapist? So there's different areas you can see a physical therapist. One of the areas is in a school setting. So if you have a child in a school who has CMT, you can work with your school system to develop a contract, which is usually called an individualized education program or an IEP. This is a contract between your child, the parents and the school on what to address to keep your child safe and to provide optimal learning and functioning in the school setting. So they usually will address stretching safety training. For instance, if you have a child who has difficulty with stairs and they want to go play on the playground, say they're a third grader who wants to go play on the playground with their peers, your physical therapist in the school setting can help make sure that they are safe on the playground equipment and that they avoid any falls. Hallway safety is a big one, especially as they get older and have to go with in more locations within the school, ADL accommodations, such as can your child get in and out of the bathroom on their own, or do they need some help? Say, they are walking in the cafeteria trying to carry their tray from the line over to their table? Can they do that? Or how is their balance and their walking? Is it a little off because of that loss of proprioception and sensation? They might need some help with that. So a PT can help address those needs. They can also address making adaptations to the PE class and also looking at optimal positioning and seating in the classroom for that optimal learning. Excuse me, it's also good to have an OT on board when you have an IEP, because they can look at technology assistance. If writing or using a pen or pencil becomes difficult, they can work on introducing a computer or different other technology, assistive devices in the classroom. More commonly, most of our patients with CMT will see a physical therapist in an outpatient setting. So these outpatient physical therapists will usually address the goals that I had mentioned in the previous slides, your balance, your walking, strengthening, stretching. They can also help you learn new skills or techniques. Or, say you get a new piece of equipment or a new device, you can bring that into your physical therapist and they can help train you, show you how to use it, make sure you feel comfortable with using that new device. With outpatient physical therapy, there's different models of care. So you may be seeing a physical therapist weekly in order to address some of those specific limitations or challenges, like say you just recently sprained your ankle. They might focus on that and you might come in more weekly for that reason. Or, if you're doing pretty good and you're just needing those monthly, quarterly, or even yearly, check-ins, that's another option too. So, with these check-ins, it's good to have that routine therapist that you are always seeing throughout your lifespan, because they can continuously measure and reassess your progression over time. They can see how you looked a month ago compared to now or a year ago

compared to now and help make some of those recommendations that might be necessary at that time. And one of the most important things is if you are doing more of a routine check-in like this, you're usually going to have a home exercise program or an HEP. The most important thing with this is you have to keep doing it. So if you see a physical therapist in January, and you're not going to see them again until July maybe, it doesn't mean you'll only do your exercises for the month of January, and then try to catch back up in July when you come back and see them. It means you have to do them all the time. Otherwise it's not going to be effective. And it might not mean that you're always doing the same exercises. Your PT can help you progress those as they become easier, but you can try to progress those exercises and just make sure that you're still ongoing with them, especially your stretching. So in addition to physical therapy, it's also good to have some other services on board. An occupational therapist is a very vital tool for patients with CMT. It's good to also have an occupational therapist overlapping with your physical therapy plan of care. They can focus on more dressing, bathing, feeding. And as I mentioned before, some of those technology adaptations. Occupational therapists have a wealth of knowledge of every little assistive device to help with every little aspect of your daily living. And it's amazing. There's some big catalogs that you can help find some different equipment, and they will help guide you to what equipment is best appropriate for you. Another good service to have is a hand therapist. This can be a PT or an OT, but it's just someone who specializes in hand therapy with CMT. When you have that hand weakness, or maybe you're getting some contractures in your fingers or in your wrist, they can work on some exercises for some of that fine motor strengthening, fine motor exercises that they can do with you. They can also help with making some custom splints and braces for you too. Another recommendation that I typically give for a lot of patients, whether it's CMT or other diagnoses, but for CMT fairly regularly, is doing a home safety evaluation. This is usually an OT, but it can be a PT or sometimes it's a combination of both, but it is basically having a therapist coming into your home and setting up or assessing your setup. So they'll look at your bathroom. They'll look at your bedroom. They'll look at your kitchen. They'll look at how you're doing your typical daily routine and they'll help you make modifications. This is something I usually start to talk about with patients if they're having more falls in the home, or if they're going through a sudden change, that really is going to impact the way that they're doing those normal activities like getting in and out of the shower. It's hard for me or any other outpatient physical therapist to really give those recommendations, if we can't see are set up in the home. So it's a huge benefit to be able to have a therapist come in your home and be able to see exactly what you're working with and make it best and safest for you. The last service that is good to have in your regimen plan of care over the course of your life is to have an orthotist. So they can work on the making custom braces for your hands, legs, and feet. And so if it comes time that your doctor or your physical therapist recommends that you have a brace made for your ankle or your foot or your hand, that's when you'll want to reach out to an orthotist, and your physical therapist can help with collaborating with your orthotist on what is best for you too. So, I then wanted to just review some exercise guidelines. 'Cause even if you aren't seeing a physical therapist, it is still important to exercise regularly. So whether you're working with a

PT or not, you still should work on your physical activity. The department of public health recommends 30 minutes a day for adults and that's seven days a week. And then for children, they recommend 60 minutes a day. For strength training exercises, it's good to do a couple of days a week of more of that resistance training exercise. And so I just thought this little comic was a good little laugh. Halfway through the presentation. Refusing to go to the gym is not the same thing as resistance training. I feel like I tell myself this sometimes and my own patients. And so these numbers are still the same for people with CMT. It doesn't mean that we have a decreased amount of minutes that are still expect of patients with CMT too. It just might look a little bit different and that's where physical therapists can help you make adaptations to your workout routine. So your workout routine can include a variety of different things. You can do some strength training exercises with your body weight, such as performing squats or with dumbbells or cuff weights, which is like an ankle weight that you can either put around your ankles or you can put some around your wrist./ Or you can focus more on cardio with walking, biking, swimming, dancing, yoga - some of the things that I mentioned before. As long as it gets you moving, it's exercise. Get your heart rate up. Get those muscles pumping. Get that exercise and that blood flowing. So let me make sure I'm hitting all my points here. Sorry one second, Oh, so I wanted to say here too make sure you find something that you enjoy. So exercise is only going to be a part of your routine if you enjoy it. If it's something you have to continuously force yourself to get into, it's not going to happen. So if you really enjoy biking, make that your exercise routine. If you like swimming, make that your routine. The biggest thing I caution with my patients with CMT is just watching for that muscle fatigue. If your muscles are worn out. They're burnt out from overdoing it with your exercise. Maybe you went for an hour long bike ride. Instead of 30 minutes, you pushed it a little too far. That's going to put you at a higher risk for falls. So, say if you go for a bike ride in the morning. You overdid it 'cause you were just feeling great at the time. You get home, you try to get yourself into the shower, and those muscles are so shaky from that bike ride that they're going to not hold you up as well as they might normally. So you're in a higher risk for fall. The other things to be aware of, are just burnout. Sometimes if you're doing the same thing over and over, you can just feel burnt out with it. So take a break, exhaustion - build in rest breaks within your exercise routines. So, if you're bike riding for 30 minutes, if you know you're going to need a break halfway through, try to plan that out. See how you feel, and then gradually build up to that. With the rest breaks too. You could just be, you need a rest break from the entire activity. Maybe you need a week off from your exercise routine, or maybe you even need a break from therapy. That's okay too, because we can get burnt out and exhausted from some of those things. Make sure you allow yourself some recovery time. So, if you're still, you know, if you were to still go into work, I know it's different now with the pandemic, but if you're someone who still goes into work, maybe don't do your workout in the morning before work because you need some recovery time between those activities. And the biggest thing is being able to balance your exercise routine, but also being able to keep up with your routine ... so if you ... daily routine. So if you exercise, but then you're not able to get yourself in the shower, brush your teeth or cook yourself dinner because you're still

exhausted, it's time to look at your routine and see if we can modify that so where you can still balance your life appropriately. Another big thing with exercising, so again, even if you aren't seeing a PT, still stretching on your own is huge. So three to five times a week, I even try to tell my patients, daily stretching is best because even if you miss a couple days a week, it's still okay. But if we shoot for that daily stretching, that is optimal for maintaining range of motion, avoiding contractures. So usually about five minutes out of your day. Sometimes if you're really focusing, you can even do 10 minutes, but you want to focus on shoulders, elbows, wrists, and hands, especially, and then knees and ankles. The difference between a stretch and an exercise - so your outpatient PT, or a PT that you might see, like if I saw you in clinic, that we might tell you to do 10 repetitions of arm raises. That's an exercise, whereas a stretch, we want you to come up and hold that for 30 to 60 seconds and only do a couple of them at a time. And so that's the difference. I have a lot of patients who will come in and say, Oh yeah, like I kick my legs up and down 15 times when I ask if they're stretching and then I have to reeducate that that's not stretching, that's strengthening. That's still good. But we still want to focus on that stretches. That long duration hold stretch too. So 30 to 60 second holds for each of your stretches. And like I said, a couple of stretches on each side too. So another way to exercise is to go to the gym. Whether ... so, if you're not seeing a PT, you can go to your local gym. Here in St. Louis, we have a place called Paraquad, which is a specialized gym with different equipment, modified equipment, so that people with disabilities can exercise. I know there's some cities that have similar gyms and similar setups so it might be worthwhile to look in your area and see if you have something like that. Otherwise you can go to a standard gym and some of their staff members may be able to help you. It would just be good to maybe approach that before you get started with them. See if there's someone who can help you. This is where I tell my patients that you have to advocate for yourself because people don't know what CMT is. You know what's safe for you better than that trainer, than that gym instructor. You know more than them about your diagnosis, so you have to tell them that's not safe for me to do, or I can't do that, or that's too much weight. And so being an advocate for yourself is huge. You can also have your PT help you by - they can set up a program for you that you can then take to that gym and work with a trainer there, too. So they can help guide your exercise routine a little bit more. For equipment and devices, a lot of you have probably seen some of these things before may already be using some of them. But for gait and functional mobility, there's different devices you can use. More commonly there are shoe inserts and AFOs. So ankle-foot orthotic, which is shown in the picture there. Those are typically seen for ankle and foot weakness or to accommodate for a contracture, a toe curling, things like that. You can also start using canes and walking sticks, walkers, wheelchairs. Typically you just want to talk to your physical therapist about what's best for you at that moment. You might be starting with some cane or maybe two canes, or you might already be needing a walker for your balance. There are a lot of different transfer devices, too, depending on what you're needing. If you get to a point that you're not able to stand yourself up all the way, to get out of a bed and into a chair, or if you're needing a full assistance for lifting yourself out, there's different things like a pivot disk, lift systems, sliding boards.

There's a lot out there but I really just encourage people to talk to your therapist about what is safest for you. With learning some of this equipment, too, that's where having a home safety evaluation can also be helpful because they can see your home setup and see what device would be best and safest for you. Again, with occupational therapy, they have a lot of tools out there like I mentioned for getting dressed. They have button hooks, shoe horn sock aids, and your PT can help with these too. I recommend these a lot to my patients as well, but I think the OTs are the gurus for a lot of this stuff. Feeding devices, there are a lot of different types of built-up utensils. There's different grab - grip assistance, so that you can open jars, different things like that, that you might find useful throughout your daily activities. One of the last things that I wanted to address in this presentation is something that I think is just really important. From what I just hear from my patients in clinic, is that there are so many environmental challenges that need to be addressed, that I feel like PTs can step up and try to help more with. And so one of the first areas going back to the school setting, if you have a child in school and they have no matter their age, they might have a big campus that they have to go across. So say they have to go from one building to another and then up four flights of stairs to get to their classroom. And they only have five minutes to get from this classroom to that classroom, but have that long of a distance and that many stairs to get. Is that doable for your child? Is that safe for your child or you as a student? And so if that's the case, is there elevator access? Can your IEP allow more time for you to get from class to class? That's something that we can build into the IEP. The other thing is navigating through the hallways and through the classrooms. That can be a safety issue 'cause I thinking back to my own days in high school, how busy those hallways can get, how fast paced they can start to move. If your balance is a little bit off, that can make you stumble and fall. So having something set in place to keep you safe in the hallways. The biggest thing I would hear from some of our younger patients with more disability, not always CMT, but they would have issues with emergency situations. The schools had concerns for how they would get a student out if they needed to get out for a fire or a tornado or whatever it might be. And so addressing some of those, I've helped some schools, put plans into place of how to keep their students safe in emergency situations. So that's something you can talk to your PT about too, for your child or for yourself as a student. For work there's just as many obstacles and environmental challenges that you can run into too. If you work at a campus like Washington University and you park three blocks away from office, is that something that you can do? If so, or if not, can we get you closer parking? One thing I think, that isn't as well known, and I know this is at least true for Missouri, and I know there are other states that have it as well, is PTs can sign off for handicap placard cards. So if you are needing handicap parking, you can talk to your physical therapist about that and they can help you with the paperwork to get that in place for you because maybe that's something you need for your workplace. Same thing with the school. Do you have a lot of stairs to get up to your office? And if so, is there an elevator for an option? I feel like that's usually more common in workplaces than in schools. Schools don't often have elevators, but work offices or places do, but it could be a case that maybe elevator's down. Do you have a backup plan? Another thing PT can help with is just the setup of your workspace too. We can do an full ergonomic assessment of



how your setup is and make modifications to that to improve your typing skills or whatever it might be to help relieve some pain. If you're sitting in work and have pain at your job, things like that to make your workplace a better setup for you. And lastly, environmental challenges just around the community. So parking can always be an issue. Sidewalks and intersections can be an issue. Construction and repairs - that maybe a sidewalk is torn up and you have to go all the way across the street to continue walking down a busy street or whatever it might be. Is there a ramp access? And if there is no ramp access, is there at least a stair rail or sorry, a hand rail? And so this comic or this picture can be a little funny saying, thank you, ramp. I needed help with just those three stairs because then it's no longer helpful. And that's meant to just give a little chuckle, but at the same time, it's very frustrating. It's not always a laughing matter when you can't get from point A to point B. Or say, you're going to your grandson's football game. But the only way to get down to the seats is down all these stairs or up a bunch of stairs, or you can't go to an event or a carnival because there's not enough handicap parking available to you. It can be a very frustrating thing. And so trying to advocate for yourself there, is also a huge part of this project, I guess. So, what can you do about it? I kind of alluded to this in my last bit, but advocating for yourself and for your family members or for your friends or anyone else with a disability. So reaching out to your office managers, your school principals, your coworkers, your peers, trying to get more people.

- [Laurel] Stephanie, I'm so sorry to interrupt you. Now they're muted. Sorry, we had some new people join us. Who hadn't muted. Thank you everyone for muting. Sorry, Stephanie, go right ahead.

- That's okay, so advocating to your office managers, school principals, teachers, it takes a lot of people to help be on board, to help keep you as a patient safe to help get you around the community or around your environment safely and without any issues. And so a physical therapist can also help with writing any letters for advocacy. We can reach out to government officials just as well to help advocate for you. And so this is another thing that you can talk to your physical therapist about ways to problem solve any issues that you run into on a regular basis, or they can help you with any letters for accommodations too. I've had a couple instances where I wrote letters just for patients to keep with them, stating like with CMT, my balance is off. So if I'm for instance, you like have to take a sobriety test. My balance may be off because of my diagnosis. It's not necessarily because I've been drinking. Not that I encourage people to do that either, but it's just another way of educating people in the public that you have a disease that can affect your mobility. So that was all that I had for you guys today. I don't even know what time it is, but...

- I think you're in great shape and I am just going to feed you some questions if that's okay.

- Sure.

- I'm going to stop sharing your screen. So one of the top questions, I saw it in here. I saw it in the chat feature and I also get it all the

time. Jonah and I take the 800 number calls that come in and we talk to community members all the time, all of us. The number one question, Stephanie, of course is, "How do we slow the progression of CMT?" And so I think you hit on all of that in what you talked about, but how do you answer that question?

- It's always a very hard question 'cause there's not a lot of ways we can clearly slow the progression. What I try to emphasize instead is maintaining what strength in what areas you do have. So rather than looking at those areas where you're growing more weakness, but just trying to maintain that strength that you have and keep those areas strong, can help slow that progression a little bit. It's just like it is for anyone else. If you don't use it, you lose it. And so keeping up with that exercise, keeping up with your mobility can help slow some of that progression of that muscle weakness at least.

- That's an excellent answer. And that's also what I hear the doctors say. We do have muscles. We do have muscles that work that we can strengthen and on that in that core training. So another question came in and that really answers it. She asked, are there any suggestions or hope for calves that are thin and atrophied? And it's my understanding that once they've atrophied, you can't bring that muscle back, but again, keep everything around strong.

- Exactly, yes, it is unfortunate once it has completely atrophied or once it's a good percentage atrophied, we can't bring that muscle back, but, like if it's your calf, we can work on strengthening the muscles around it, the muscles up in your thigh, the muscles on the front of your shin and then your ankles. That's exactly what we do. We try to strengthen around it to help support still.

- Okay, and I think you covered that swimming is great for people with CMT, but someone also asks, "Is karate good for people with CMT."

- I wouldn't see why it could, I try to think too, like, well, is there any negative effect of doing it? I don't think there'll be any negative effect of doing karate, if anything, it's almost - it would be - I think it would be very appropriate because you could work on some balance technique with that too. Some of those moves, I'm not a karate expert by any means, but some of the moves you do, I think you could really work on some balance and some coordination with that too.

- Yeah, I think I've talked to quite a few community members who do I believe it's Tai Chi and some other things in that same family that really can help with balance as long as you're being safe, obviously by not falling.

- Right.

- I'm just going to keep rolling through our questions if that's okay. So one attendee asks, "As we know, not all neurologists are created equal, with respect to CMT. They don't all know as much about it, as other neurologists with CMT. Each has their own area of expertise. Does the same apply to physical and occupational therapists?"

- Yes, I actually meant to say that at one point in one of my slides. Not every physical therapist, is going to know what CMT is. I see a wide variety of neuromuscular diagnoses, and I have to tell that to a lot of my patients. When we are in physical therapy school, out of a three-year doctorate program, which is what it is in most schools now, we maybe get one slide that maybe mentions Charcot-Marie-Tooth, and that might be about it. And it's just kind of built in as we're learning our neurology, our neurological processes, but it's not something that's focused on. And so as any good therapist and I've even had some students or some physical therapists I went to school with, who have reached out to me and said, Hey, I have a CMT patient coming in. Can you help me like troubleshoot? What should we go over? What should I do? So I make sure I don't miss anything. But any good therapist if they see that diagnosis coming in, would do their own research, would look into it ahead of time. And I will tell my patients, and you can tell your, if you see like a PT in clinic, like if anyone else goes to an MDA type clinic where you go see your neurologist, plus your PT, plus your OT, MDA rep. If you're in a clinic like that, I have given my card to my patients and I will tell them that when you see your outpatient therapist, they can call me and we can help problem solve and go over goals too. They're definitely not created equal as far as the knowledge behind the diagnosis.

- Okay that's great to know. So we really want to, when we need to go to physical therapy, we really need to find that PT in clinic then muscular.

- And that's where too, I say, once you find that PT, and even if you're the one who educates them all about it, once you guys get on a good page, or if you find that one that you just click with, hang on to them for life and just keep following them and they will follow you and you guys will learn and grow together.

- Okay that's fantastic. So one person commented that weight training is discouraged for kids until their late teens, probably their body develops. But is this advice any different for kids with CMT?

- I think there's other ways we can work on strengthening with kids that doesn't have to include strength training. There's a lot of body weight type activities. I typically would just keep it as, you know, don't focus on that resistance training, weight training with using dumbbells, things like that, but focus more on that body weight, like activity-based exercise and strength training.

- Okay, great to know. All Right. "Do you need a doctor's prescription for physical therapy?"

- That depends on the state. There are some states that now have direct access, which means you do not need a physical or a provider's script to come see a physical therapist, but more often than not, I would say usually you want to get a referral from your doctor in order to go see a PT. Usually a neurologist is very quick give that script out too.

- Yeah, absolutely. And someone asked, "What do you think about BCAA?" I don't know what that is. Maybe they can, if they want to unmute themselves. It says Stanislav. I don't know if they can.

- Yeah, I'm not familiar with that.

- I don't know what BCAA is either. Well, if you hear this and want to expand on your question, feel free to unmute. I'm going to keep moving.

- I think it's a sort of a protein powder.

- [Stephanie] Oh, branched chain amino acids. Someone just commented. I'm not familiar with that, I apologize.

- No worries. Okay.

- What about protein powders in general? Or is there a thought about using protein powders? You know, I've talked with other patients with different circumstances on using protein powders, but I haven't had anyone with CMT that I, you know, had the thought about it. So again, I don't have much on that, so I apologize, but that would be something I'd almost want to talk to your neurologist about too, because protein impacts your whole system, not just your building muscles. So it might be something to talk and collaborate with both your PT and your neurologist on.

- That sounds great. All right, someone's asking about, Oh, someone was sharing some information. Some of this is just sharing information. Someone asked, "Is systemic scleroderma" - I don't know if I'm saying that right - "Associated with CMT?" I don't know if you can answer that. That sounds more of a medical question. Stephanie, are you familiar?

- I can't think of any patients that I've seen that also had it in combination with their CMT. But yeah, I don't have much that I wouldn't talk to your provider about that one.

- A lot of what I've heard the docs say over the years is just because you have CMT doesn't mean you can't have all these other conditions that everyone else in the world can have.

- So luck of the draw sometimes.

- Yes, absolutely. Okay, I'm just scrolling through. Oh, "Paraquad, what are they and where are they located?" And I think you touched on what they are, but if you want to answer that real quickly.

- Yeah, so Paraquad is a super awesome facility that we have at least here in St. Louis. I think they may have a location over on the Illinois side as well, but it's an adaptive gym where there are actually actually occupational therapists from Washington University, who help with assisting people complete their exercise routines. Their equipment is all made to be adaptive to where like, instead of having to grab onto a bar, you can have a strap on your hands to still pull down without having any grip. So it's a lot of adaptive equipment. The one in St. Louis, if it's

someone from the area who asked it's right by Barnes Jewish hospital, right by the Washington University Campus off of 40, I'd have to go onto their website and see where their other location is. But it's something I think other cities will probably have something similar. It just might not be called Parquad, but your provider or your physical therapist may be aware of some adaptive gyms available to you.

- Okay, awesome I'd love that concept.

- Yeah.

- So someone asked, "Can PT exercise actually be more harmful than helpful for certain types of CMT and neuromuscular diseases?" And I think that, in the olden days there was that thinking that, Oh my gosh, you have to be careful with the CMT patient. You can't exercise too much, But tell us your take on this, please.

- It's definitely something that is continuing to evolve and change. There's more research coming out saying that it is actually safer than they used to say. They used to be very, like you said, they were very cautious on don't overwork. Don't overdo it. I still tell people because everyone is different. Your CMT looks different from another person with CMT. And so I still tell people to use that caution of just knowing your own red flags, knowing when you feel a muscle burnout occurring, knowing if you're feeling more pain than you should be feeling - but really there's more benefit that can come from those physical therapy exercises. Than there is harm. I do still say, don't go for that heavy lifting. Don't overdo it with those exercises, but you know, just trying to keep it small, start with those light weights and make it a gradual ease into.

- And this is a really important question that I hear often as well. And also everyone who's putting questions in the chat. Thank you so much. If we don't get to all of them, we do get a printout of these questions. And now we'll get back to you trying to answer your questions. So we do have a hard stop at 12:28, so we can get to the next session. So can you talk to Stephanie about balance? Someone asked if balance can be improved. How do you address the compromised balance situations?

- Yes and so that's where usually we'll focus on teaching compensation strategies. So once you lose your sensation or your proprioception of, like around your ankle joints, you can't get that back, but just like we do for an atrophied muscle, we strengthen around it. So we teach you different strategies. We work on strengthening those other senses and those other systems to help maintain your balance. And then if it's so severe that we need to start using some equipment and devices, that's when we can introduce that too, but we can still work on improving your balance. It's just a matter of retraining some of those neuromuscular connections, retraining your technique, things of that nature too.

- Okay, and how do we know? What would fatigue look like? One person asked, "Are arm tremors, if you're seeing a tremor on your body, your arm, your legs, and in a muscle, is that a sign of fatigue or is that a sign of something else? How do we sort of recognize that fatigue? Or is it just how we're feeling?"

- Tremors can be caused by different things, but if it's like, within 30 minutes or so of when you did your exercises, it may well often could probably be that muscle fatigue. So I tell people to watch for that tremor, that shakiness after doing their exercises, that's usually a sign of fatigue.

- Okay, that is a great answer. I don't know. "Do you guys do any acupuncture or dry needling?" Stephanie, what are your thoughts there?

- PTs can do dry needling. I am not as familiar with it. It's not something that I've done yet. It was approved after I got out of school, but I know that it's out there. I just don't know a whole lot about it related to CMT, unfortunately.

- Oh no, that's okay. I get a lot of questions about this and there's no research on it to know if acupuncture is contra-indicated for CMT. But what I can tell you is that I speak to many people in the community who use acupuncture, obviously not as a treatment or a cure for CMT, but to help treat the symptoms associated with CMT. People who use it to help with energy and fatigue and some pain and have had success. But I have not heard of any negative effects of acupuncture. So I'll just share with you not being a physician, but what I've learned from the community, speaking to them about that and...

- Can I have one second please, I apologize. Oh no, go right ahead.

- Laurel, there's a question that came in and I think you could probably answer about an exercise plan for CMT. Maybe you want to speak to some of the exercise videos we have on our website.

- Absolutely, we actually have a wonderful exercise library on our website, but one of our board members produced with a neuromuscular physical therapist, a whole group of videos for people with CMT and depending on your level, which exercises you should do. It's absolutely fantastic. It is on our website under managing CMT. So when you go to our website, [cmtausa.org](http://cmtausa.org), at the top you will see a menu for living with CMT and under that is managing CMT where we house the videos. So it's wonderful choices there. And also you can hear from other people in the community, the CMT active community on Facebook and Instagram, about ways that they incorporate exercise in CMT.