- Well, hello everybody, thanks, I'm really honored to be here. We got a great group of speakers. And it's good to be asked to speak to you guys. I'm the orthotist who does the CMTA Center of Excellence up in Boston, Massachusetts at the Mass General Hospital. I've always had a focus on CMT my whole career. But when I first started as an orthotist I was at Mass General Hospital. And I just had way more CMT patients than was more than my share I guess. And I kept asking people about it. And nobody knew much about it. So a friend of mine, I asked her how to do some research. And she was teaching me how to do research. And I made friends with the hospital librarian. And she helped me get articles. And the next thing you know I just got a little expertise. And that's why I'm here where I am today with, sort of, I call it my focus and my practice is on CMT. And I said to myself, you know, if I were attending this lecture, what would I want to know about orthotics? And pretty much the biggest thing I'd want to know is what can I really expect from AFOs? So that's the title of this program is what can I really expect from AFOs? You know, do I already have the best AFO design for me? Or is there something else out there for me that I'm just not aware of that would be better? And what would be those realistic expectations? Well, ideally, we'd like to see AFOs, sorry, move this over here, AFOs restore the basic elements of normal gait. And, also, restore normal balance. It would be great if all CMTers could just walk normally and have normal balance. This is a video of a patient, Chuck. And I chose Chuck because he's sort of an averagely-involved patient. And we can watch him walk, and we can identify some of the specific things that limit normal gait for CMT patients. CMT is progressive. And not everyone's going to have all of these, but may have some of them. If we look at him we can see, okay, first thing we notice is, you know, foot drop. And he's going to try to stand here for us. You're also going to notice his balance is impaired. And when I asked Chuck to stand still he has trouble. He started to stutter his feet and move his feet around, stagger a little bit. And he has trouble standing. A lot of CMT patients and classically, of course, have lateral ankle instability. And that can sometimes turn into a pretty significant deformity of the foot where the ankle rolls laterally and stays there. Fatigue is a big issue for CMT patients. Oftentimes, I'll have patients rate these things, which is most important to them. And I'm always surprised how much fatigue is number one for patients. They say, jeez, I just can't keep up with my peers. We're going to talk a lot about that. Some people complain, of course, of painful high arches and calloused feet. Most CMT patients have a specific cavus of foot called an anterior cavus foot, which happens from just a specific sequence of muscle loss that leads to that high arch. Hammertoes, they can be painful too. A lot of times patients just have a lack of confidence with walking too. And confidence comes from when the foot hits the ground. It needs to be predictable, and it needs to be consistent. And if every time that foot hits the ground it's always a surprise, of course, you're not going to have much confidence. Also, because limited walking speed is another issue that people have. And so, for normal gaits, I have this wonderful nurse who works in a pediatric hospital with me. And when I first got my G-WALK gait analysis system I was doing everybody. And she used to fly around this hospital, and I put her in the machine. And she had some tremendous data, she's got great gait. Now, I could talk about just normal gait, or the basic elements of normal gait for a minute. First of all, you know, she has pretty good walking speed. And she has a lot of

propulsion when she walks. Also, a lot of pelvic motion, pelvic motion is key. It's key to athleticism and the way we move and keeping all our muscles strong. And as she walks, though, her head and shoulders barely move, they're nice and steady. And that's the new definition of stability in gait. When most of the motion takes place in the pelvis, but the head and shoulders stay nice and quiet. She has a very comfortable natural arm swing, which we're going to talk about and see how important that is too. And she also has what we call dynamic balance, not just static balance. But as she's walking she can look all around and not have any problem with balance. Specifically, if we look at her walk, again, were talking about the basic elements of gait. Gait is very complicated. I mean, if you do studies on gait you'll see more information, SSR terms that you won't be able to understand, I'm not familiar anyway. But it gets kind of complicated. We're just going to talk about the basic elements of gait. And we break down gait into two phases, swing face and stance phase. In swing phase, of course, we want her to prevent the toe from dragging, so we need good toe clearance. And if you don't have the strength to dorsiflex, or pick up your foot, then you'll get the toe drag. And stance phase we're looking for three specific "rockers" we call them. Everyone should land heel first. And we call that first rocker. And then when the foot's fixed on the floor you get second rocker with ankle motion. And third rocker is being able to achieve heel rise. Let's talk about that a little more. And we are going to talk about balance. So, balance has, and Stephanie did a nice job covering this too, but I'm just going to reiterate this. There are some basic requirements for balance. The first, of course, is muscle strength. Muscles stabilize our joints. They're the primary stabilizer of our joints, not ligaments, but the muscles are. And we also need them for righting reactions. Everyone knows if you lean forward you sort of push your feet down, and it rights you back up and get your center of gravity back over your base. If you start to lean back you sort of pick your toes up, and that rights you again, sort of like righting a ship. So, those righting reactions are key. You need muscle strength for that. On the sensory side there are three things. There's vision, of course. When we can look and see a stationary object we see how we're moving relative to that object. That helps us with our balance. Vestibular function, of course, is the inner ear stuff. And anybody who's played pin the tail on the donkey knows that happens when you spin somebody around three or 10 times, and you have them try to walk a straight line. They can't do it because they're spinning. The fluid in their semicircular canals and their cochlear, and they lose their balance until it settles down again. Proprioception is the one that CMT patients lose. CMT is called hereditary motor sensory neuropathy because it's not just the muscle strength, of course, it's the sensory part that's involved as well. And proprioception is a part of that. Balance really all comes down to is managing our weight line. Our center of gravity has to be maintained over our base of support, or else we'll fall or lose our balance. So, what exactly is proprioception? Proprioception is knowing where a body part is in space without looking at it and how it's moving relative to the rest of the body. And in our muscles we have these special organelles called muscle spindle fibers. I don't want to get too technical, but those muscle spindle fibers send information about the exact length of a muscle. And that information goes up to our sensory nerves, to our spinal cord and brain, where very single muscle spindle fiber is always working and sending out information. It tells you exactly

where your body is in space. So it's how the brain interprets where you are in space. Unfortunately, with CMT, because the sensory nerves stopped working that information never gets there. So the information from, usually, your feet and ankles doesn't get to your brain and spinal cord to tell you where you are in space. And that makes balancing very difficult. Now, there are some strategies how to compensate for that. And CMT patients that are challenged, or balance-challenged with muscle weakness and proprioceptive loss most of the times compensate by maintaining contact with a stationary object. We always think about the finger on the wall strategy. You know, if you're losing your balance you reach for the wall or anything that's stationary. Holding onto your spouse sometimes is the number one. I had one woman that her husband was her brace. She always held onto him all the time. And I had another patient who said all he had to do was back up against a bush, and he could talk to his neighbors for hours. And the other strategy is knee against a coffee table. And there's a scenario I want to propose just for purposes of this discussion. But suppose you're at a dinner party with your boss. And you're in his living room. And he hands you a drink in one hand, and then comes by with a sandwich in the other. And now he wants to talk to you about your raise. And, jeez, you know, with both hands tied up and nothing to hold onto, a lot of people will - a nice strategy might be just sort of just maneuver close enough to the coffee table. You can put your shin against that coffee table. And that knee against the coffee table or shin against the coffee table, that can compensate just like a finger on the wall. A way to get that in a brace is the same way a ski boot does it. Ski boots give us ground reaction too. And anyone who's skied knows, you strap yourself into this boot, and the boot reaches up to the top of your shin. And, of course, it's locked into a ski. And if you try to lean forward you want that feeling at the top of the boot on your shin. That's a ground reaction force that orthotists will talk about a lot. And that's how we control a lot of motion and also help people with sensation loss, especially proprioceptive loss. This is my friend, Mark. This is an old video. I've had this video for several years. But I don't have one that's any better. And I'm going to show you how Mark stands without a brace, and then compare it to the brace on this right side. Here you'll see where a ground reaction AFO is going to help him. So, this is Mark trying to get balance here. Mark's a great guy. And, basically, when he first started to crouch, he crouched like that a little bit, that turns on a lot more muscles, proximal muscles around his hip and around his knee. And that's a strategy patients do too sometimes to get balance back. Because then those muscle spindle fibers will basically give more information back to the brain and spinal cord to help you with your balance. But we don't want to stand in a crouch all day. It's not the best way to stand. So, here's Mark with a simple traditional style polypropylene ground reaction AFO. And it's going up to one knee. He only has it on the one side. And we're going to see how that improves his balance, his proprioception, his static balance. So, finding your balance with the ground reaction of an AFO is a skill you get. It's sort of like driving a car. I always say, the first time I drove a car wasn't very good. But after few weeks I was like Mario Andretti, and I felt a lot better. It's the same thing with ground reaction restoring balance. Even if it doesn't seem amazing when you first get it. Usually, in about two weeks my patients come back. And they say you should see me now, Ken. I can stand now, and I really have my balance. It's a great thing.

Balance I like to talk about because I have one guy, one patient who was very tall, six foot four attorney. And he would be in court litigating, and he would be defending a drunk driver. And he would turn to the jury, turn to his client, and turn to the judge, and lose his balance and stumble. And, of course, there he was embarrassed because he's defending a drunk driver and he looked like he was drunk himself. So he said I don't care what you do about anything else, just give me my balance. I don't ever want to be embarrassed like that in court again. And we could do that, we could give him ground reaction AFOs that made him feel rock solid in court when he was food standing. And that was very important to him. There are all kinds of AFOs out there. And we're going to talk about this. What can you expect from specific types of AFOs? Well, most every AFO you'll see pictured here. And maybe you have some of these yourselves. A simple leaf spring AFO, what we call a solid ankle AFO. This is that ground reaction AFO with that rigid anterior shell. The IDEO from hanger over here, simple silicone SAFO, these really nice ground reaction AFOs from Allard. The DR3 from a woman out in San Diego. And they go on and on. Here's the Double Helix that works really well. Simple exoskeleton AFOs. And, of course, even a custom articulated AFO. All these braces would help in swing phase. There isn't one here that won't. It'll help you with that toe pick up. But that's only 40% of our gait cycle. And we want to do more. Really, helping CMT patients walk better comes down to managing stance phase. And stance phase, we're going to talk about those three stance phase rockers. In a normal gait we're looking for first rocker. And you'll see here how in this illustration in red here, when the heel hits the ground you're supposed to get this slow controlled plantar flexion of the foot as the foot comes down to the ground. If you don't have strong enough muscles to control that lengthening of that muscle you will get a foot slap. And, Chuck, the guy in our first video, he owns a machine shop. And he would have to get onto the floor to talk to his machinists every so often. And they all heard him coming because of the slap, slap, slap. And when he got there, you know, if he didn't have anything to lean onto he was more focused on managing his balance than he was on what they were even talking about. So it was very difficult. But that first rocker prevents that foot slap. I don't want to go too off topic here. Second rocker is when the foot is fixed on the floor. The leg and the body up above advances over the foot to a certain point, when prior to the leading foot making heel strike, we achieve heel rise of the stance phase foot. Heel rise is what's called third rocker. And it is really important. It seems a little insignificant sometimes. But that one simple little action there is responsible for most of our propulsion. Many authors, especially these authors that write about propulsion and far and away, this ability to achieve heel rise, where you can get up on your toe in single limb support, with one foot in the air, is responsible for nearly 70% of your propulsion. Now, that translates directly into gas mileage. And that's where fatigue comes into it. You can get 70% better gas mileage if you can get that heel off the ground when you walk. And some AFOs can help us with that. And that's what we're going to talk about. Here's a simple custom PLS AFO. And you see if we compare this to what these normal rockers require, we can see that it really doesn't give much for ankle instability. But it will give us a controlled first rocker. It'll restore first rocker. It'll also give us second rocker. But it's really not strong enough to give us heel rise, third rocker. And, of course, there's no ground reaction to help us with

proprioceptive loss and balance. So, for those brace here, if your CMT only involves your weakness of dorsiflexions this should be a great design for you. Because that's just going to do that. It's going to keep the foot up in swing phase, restore first and second rocker, no more foot slap. But it's not going to help you with the propulsive piece or the balance. So that's what you can expect from this design type of AFO. Now, an articulated AFO. Articulated simply means it's got a joint to it. So it has a joint here and some limited motion. This articulated AFO usually doesn't allow the foot to drop down, so have a stop in the back, it can't drop down. And when you step on it it holds your foot up. Now, let's talk about it. It will give good ankle stability. Oh, my God, we can strap it, we can hold it. We can keep the ankle from rolling laterally or medially. But it really won't give us first rocker because it doesn't allow the foot to drop down. It also doesn't give us second rocker because it's such a small percentage it doesn't count. And it's free dorsiflexion, so it won't give us any heel rise. It also won't - has no ground reaction, so it won't help us with proprioception. And I don't know if I mentioned now, but this is the most commonly prescribed brace in the country right now for not just CMT, but every disorder. And, unfortunately, it doesn't help us with any of our stance phase rockers, it helps us with our balance. So it's not a good design in general for CMT patients. So, there are carbon AFOs. And I call myself, that I'm a carbon enthusiast. It's the only bracing design that really restores everything we need for a CMT patient, which is ankle instability, ankle stability yes. It'll certainly give us first rocker, second rocker, and is strong enough with this ground reactive piece in the front to give us third rocker. And, also, because it's a ground reaction brace it helps us with our static balance and even our dynamic balance. So we have a lot of good success with this. Actually, I take these braces with me to the clinic. And we're able to try them on patients then and there and see if that's going to be beneficial for that particular patient. Oops, going to go back. In general, and we're going to talk about this a little later, you know, there are all kinds of carbon braces. They're not all created equal certainly. If the AFO is in the front of your leg, like over here, it's going to be different than if it's a simple cuff and a strut in the back of your leg. If it's in the front of your leg it's going to be able to offer this ground reaction for heel rise and help us with balance. And, of course, we start all three of these stance phase rockers. Yay for the ground reaction style brace. Now, if you don't need that much, if you're minimally involved with CMT, and you simply have foot drop problem and maybe some mild instability, then this would be a better design for you. And this the cuff will be on the back. And it'll help us with first and second rocker. So, if your carbon brace looks more like this you know what to expect. And if it looks more like this you know what to expect. And a great question I get all the time, and many people are just fearful to want to wear a brace even to begin with. A lot of times it's because a parent or somebody that they know had a bad experience with AFOs. But often too they're obviously concerned about will this AFO make me weaker? Will I become dependent on it? I want to keep what strength I have. And there was a study done six years ago now in Lower Extremity Review. It was based on this one woman. Her name was Beth DeLorean, and she was a marathon runner. Now, she didn't have CMT, she had a spinal cord injury. But she kept going into reusing different style braces when she was running. And she kept saying, you know, when I have a plastic brace it

seems like my leg gets smaller. The study was on calf circumference. And then when she went to the carbon brace she said her leg got bigger. And at first everyone said, no, that's impossible. But she said it enough that it prompted a very short trial. It was only eight weeks, and only 19 patients. Right now there's a multi-year bigger study going on. But everyone had the same result. They said when they went with carbon braces their legs got bigger. And when they were in limiting, thermoplastic AFOs or braces that limited motion, they got smaller. And what we can deduce from this is that, certainly, the carbon AFO doesn't reverse the disease process. No one's going to get their nerve back or their muscle back that they've lost. But it's not those muscles that are making the change. We assume now it's all those other muscle groups, those synergistic muscle groups that work with the muscles involved with CMT and antagonistic groups that work with them at the same time. They got bigger and stronger because the muscles were working more normally. And by normally what I mean by that is they were lengthening all the way and shortening all the way. And I like to use this example. If I wanted to have big biceps, you know, for the beach I would probably go to the gym and get a dumbbell. And I would lengthen my arm all the way under load, and then I would shorten it all the way. You lengthen it and shorten it. That's what makes the muscle get stronger, when it goes to its normal range under load. And I didn't mention that earlier, but most CMT patients when they don't wear braces, and they're getting weaker and losing sensation, they tend to guard their pelvis. And I talked about pelvic motion earlier. We're going to talk about it more. But when you guard that pelvis, and you're walking kind of stiff, your muscles aren't lengthening and shortening. And that's when you get weaker. So you can get weakness of muscles that really aren't even involved with the CMT process. It's just they're getting weaker from what we call disuse atrophy. This is a picture of me on the right. I am an identical twin. I have a genetically identical twin brother. And I always thought to myself wouldn't it be nice to compare truly identical patients with different AFOs and sort of see the results? And just a year and a half ago it happened at our clinic in Boston. In came these two brothers that were identical twins. And I was treating one with a brace, and then his brother came in, and we got to compare the two. And here they are. This is Fred on the left and his brother on the right. I forget his name now. But we're going to watch them walk. And you'll see that they are pretty much identical. And we're going to talk about this as we watch them walk. Now, they're pretty involved. They've got pretty much weakness in all three compartments of the leg. Meaning that they can't walk on their heels. They can't walk on their toes. They've also got enough sensory loss that their balance is greatly involved. They can't maintain static balance. Your neurologist and people will do what they call a Romberg test. They'll have you stand with your hands on your hips, eyes open, then eyes closed, and see if you can maintain your balance. Both of these guys would fail that test. And then you see the side view as they walk. Same speed, just nice and slow. They look really identical without wearing AFOs. Now we're going to look at them over here with AFOs. I'll pause this. And you'll notice this brace that I fit Fred with on the left is a ground reaction dynamic carbon AFO. And his brother over here just had the regular ones around the back. But he had a dynamic carbon AFO as well. But it wasn't a ground reaction AFO. And here I'm just asking them to walk together. And Fred in the blue shirt is slowing down a little bit for his brother. Because Fred has more

confidence when he's walking. Fred's confidence is better because of the ground reaction piece. And you'll watch him walk. And coming back I'm going to ask them to, I'm going to ask them to walk more quickly. And you'll get to see the side view. Now, his brother certainly has no more foot drop. That's all being taken care of. But his confidence isn't there without that ground reactive piece. Now I'm going to ask them to walk quickly. And here Fred likes to show off and show how fast he can walk. So, walking speed. Now I'm asking them to stand in open space. And Fred can stand in open space nicely because he has ground reaction on the front. And his brother has to hold onto the wall. So, what can you expect from different bracing designs? It can be quite a bit. Expectations can be much more for a ground reaction AFO than one behind. Sorry, my next one here, there we go. Go back again, yep. A question that comes up, do I need any special training with AFOs? Or is the AFO the magic, or is their training involved too? And the answer is very much, training is involved with the AFO. And I use this as an example. I say, if I gave you all Apache helicopters fully armed it'd be wonderful. But without the training to use it, it wouldn't have much value. Most patients walk the same way with with the new AFO as they did before. And the reason is is because the gait compensations that CMT patients learn just to be as functional as they can be considering all the doubts they have is just amazing. And, also, those gait compensations, the way they're walking with those gait compensations it's familiar, it's habit, and it's safe. And moving your pelvis, your center of gravity forward is terrifying for patients with CMT because they're not sure what's going to happen, usually going to end up with a fall. So, with a new AFO patients need to experience that corrected gait with the AFOs in order to really know what's possible. And that has to happen in a very safe environment. And that's why we do that initial training in our office when we're fitting these braces. And that gait training, usually I have a couple of military analogies that I use. First of all, when you stand you stand at parade rest, nice, and tall, and straight. And if you look at the soldier to your left, he's at parade rest. His pelvis is forward, his shoulders and head are over his base. And if was wearing AFOs he's be leaning against the front of ground reaction AFO. If you compare that to a gorilla who is much stronger than a man. He sort of stands with his butt in the back seat there. All these muscle are turned on trying to stabilize him right now. His hip extensions, his knee extensions, his low back muscles, they're all working because he's not managing his weight line. If you look at the soldier on the left again, he manages his weight line very well. And it takes almost no muscle activity to stand like that. Very little muscle activity, which is why I always say there's a general, a Roman general who I invented for purposes of this discussion too. And I say he taught his soldiers how to do two things, how to stand and how to walk. And when you're taught how to stand you stand at parade rest. Because you can stand like this for a long, long time and not get tired. Because there's so little muscle activity required. So it's a wonderful thing to stand up nice and tall, hands behind your back. And it takes very little muscle activity. The other thing, when you're walking, as seen [?], and on the right you'll see is she introduced contralateral arm swing. Contralateral arm swing is key to powering your legs. And it's complicated how it happens. And I won't go into it here. But it's the way all the muscles need to lengthen in order to have the power to contract more powerfully. So, soldiers are taught to walk. And this is an

exaggeration here, but you know, with their hands 12 inches in front and 12 inches behind. And that gives them more power. These soldiers could then walk longer carrying longer loads and not get so tired. Because their muscles were more efficient at doing it. And if anyone's ever tried to run and not swing your arms you'd see it's kind of difficult. But this is an exaggeration of somebody who's running, obviously. But when we run we swing our arms. Because that's what gives out legs the power. If you try to move your arms in the wrong direction you can't run. So contralateral arm swing is really key to getting more power. And when you have an AFO, that puts your feet basically on automatic pilot. So, you're going to have restoration of all three stance phases rockers, and it's going to be predictable. And it's going to be consistent. You will then have the confidence to move your pelvis and move your arms and walk more confidently. But without those pieces you won't do it. You can't do it. Pelvic motion is key. And anyone that gets fit with a brace at my office, we'll be talking about pelvic motion a lot. You know, it's instinctively attractive to us. I always say there's a reason why men like to watch women walk away. And it's not just men, yes, women too. And I use John Travolta because when John Travolta's walking down the street and his pelvis is moving it looks good to girls too. I think it's instinctively attractive because it tells us there's a good, strong, healthy possible mate for us there. So, pelvic motion is key, especially side to side pelvic motion. The pelvis should follow the leading foot, not the shoulders. And, unfortunately, too many times with CMT patients, their shoulders follow instead, instead of the pelvis. And their head is moving too much. And their pelvis isn't moving enough or going the wrong direction. So, here's our friend.

- [Moderator] Ken, you're at 30 minutes, you're halfway through.

- Okay, thank you. Here's our friend Chuck again. And he's going to be walking here. And you notice he's quite happy in his AFOs. He smiles a lot. But look what we've done. He's going to balance here for us. I asked him to stop short. And it's easy for him stopping short. And I'm going to ask him to look up at the ceiling. Hands on his hips, look at the ceiling, tiles over his head, or left and right. And he feels very confident standing there in those AFOs, as opposed he was before. You know, the AFOs also, of course, take care of that foot drop and swing phase. They eliminate any ankle instability. And they're not for everybody. I'm going to talk about that in a minute. But his balance is greatly improved. And not just his static standing balance, but his dynamic balance as he's walking. With the restoration of heel rise at third rocker we talked about, he gets much less fatigue. And he gets that normal propulsion when he walks. And the confidence comes, again, from when the foot hits the ground, if every time it's predictable, and it's consistent, and you notice he doesn't have that downward gaze. He lost that habit a while ago. And he has that great pelvic motion too as he walks. So, that's what you can expect from a carbon AFO, and with that dynamic ground reaction carbon AFO. I forgot to include, and I'm sorry about this, what happens if someone's not a candidate for a carbon AFO? And who would those patients be? When would a carbon AFO not be appropriate for me? And the the answer is if you can't manage the weight line, if you can't correct the heel and the forefoot, and line it up underneath the foot, if you have too much deformity that the weight line

is going to fall one way or the other, then you're really not going to be able to use a carbon brace like this. You're going to have to either have a very elaborate carbon brace or more of a traditional thermoplastic type of AFO. And that's about it, Jonah.

- Thank you Ken, that was a great presentation today. And we have a number of questions in the chat function. So I'll just start with the first question that came in. And we'll do our best to work our way through them. And if anyone else has questions please feel free to type them in the chat function now. Some of the questions are a little more specific in nature, but we'll, you know, we'll ask them. And we can certainly help provide any follow-up as well. The first question that came in was about Ottobock braces. We have a community member asking about them. Their child has CMT 4A, 13 years old. And they're really severely affected. And they're questioning whether they should get this type of brace.

- Ottobock makes several different types of braces. And I don't know what specific type they're talking about. But they make carbon braces. They make the C-Brace, which is a microprocessor control for, you know, when people don't have any knee stability. The most common one I use from Ottobock is called the Ottobock Reaction plus. It's a very good dynamic carbon ground reaction AFO. The neat thing about it is it has a medial strut instead of a lateral strut. Meaning that the strut comes down on the inside of your foot, the big toe side, as opposed to the little toe side. And for patients who have too much varus instability and their ankle goes out to the side, you can sometimes put a strap to that and do some posting. And the strut is never a problem. It works very well, so I do like those Ottobock Reaction plus AFOs. I think they help a lot of patients who, you know, have a lot of weakness in the foot, but not too much deformity.

- Then, we have another question from a community member who says they fall a lot and they have weak thigh muscles. So they're wondering what some of the better options may be for them in terms of braces and the such.

- Great question, so again, most people don't get too much weakness above the thigh, but it does happen. And when that happens you can certainly use a ground reaction AFO to help stabilize the knee to a point. But if that doesn't work you're really looking at probably what we call a stance control KAFO, which would be a brace that would go above your knee. Ottobock makes probably the most sophisticated one out there, that's called the C-Brace. And it's very expensive. And it's not covered by insurance at this point. And they're about $90,000 a piece. But it works the same as their prosthetic knee joints do to help stabilize amputees with the same technology. So, unfortunately, if a carbon - if a ground reaction AFO, a brace below the knee doesn't work, then you're probably looking at a KAFO with either some sort of locking mechanism to support the knee and keep it from buckling.

- Then, we have another question from a community member about 3D printing of shoes, options for that for patients living with CMT with foot deformities.

- I don't know anything about that unfortunately. 3D printing, we're using it very little just for some cosmetic things and prosthetics. We're not using it to make shoes. And I don't know anyone who does have any experience with it anyway, but I can say this. If you can 3D print a shoe, or even an insert, or something that can help manage the weight line, what that means is that your ankle's rolling outside, or your foot has deformity with their first ray of plantar flex, you can make a nice custom base that can help correct the hindfoot to manage the weight line a lot better. And that can be done the traditional way, with 3D printing, CAD/CAM, however you get there. The idea is to manage the weight line as you walk, as you stand, okay?

- Also, make sure to, I don't know if you're already aware of this, but there are shoes with extra depth, which I know your original question was about, you know, shoes for the CMT foot, and I only wear shoes with extra depth. It's not always perfectly easy to find them, but there are a lot of options out there. New Balance has extra depth. There's a lot of companies. So, just make sure to make sure your shoes are extra depth.

- Thanks Jonah, yeah. And I always have to have the shoe talk with people that come in because not every shoe is going to work with an AFO. You really need a lot of extra room. Shoes are designed to fit foot in a sock, you know? And we're putting a lot more stuff in there. So you got to get the volume to do it, yeah.

- All right, we had another question come in. A member had to quit golfing. And they were wondering if AFOs could help get them back on the course.

- Great question, and I do have a guy who says he got two strokes taken off his game wearing carbon AFOs. And I had another guy who just came in recently who said he wasn't even going to try it. He didn't want to. But it's very, you know, unique, but these carbon AFOs work really well on level surfaces. If you're on a slope it's less so. But if you're on the greens or teeing off, an AFO can give you much better balance. It's not going to really restrict your motion. And you should be able to move nicely with it. So, yeah, I would definitely start at the driving range and and see how you do with it.

- All right, and then we have two questions that are kind of related. One was about when to get evaluated for AFOs, at what point of the progression of the disease would you recommend that. And then related to that was a community member was told by a PT that if they get AFOs that the progression could get worse and worse. And it'll do work for, you know, for their muscles essentially, and the progression of the disease will get worse. So, is there truth to that?

- I'm going to go back to what I alluded to earlier when I was showing that study, that 2014 study on calf circumference. This is what it's all about. And the truth is if you're in an AFO that's immobilizing your foot you will get more disuse atrophy. So the nice thing about the carbon AFOs is they only limit the motion to a normal amount. But if you're in a brace that's going to immobilize the foot somehow, we think about solid

ankles or even jointed AFOs that are limiting motion, limiting heel motion. Yeah, you can get weaker from wearing those braces. That's what that study was all about. The thing is when does the functional improvement outweigh, you know, the getting weaker. And some patients that come to me, they said they didn't want to get weaker, but they are already were graded at one or two over five in strength anyway. So it really was a negligent amount of more weakness they could get. That's the time where they went to a brace. When I think of my pediatric population, I think about two things. I think of function - stop them from falling and being so clumsy. That's typically the first complaint you hear. Well, my child is a little more clumsier than their peers. They're falling, they're losing their balance a little bit more. And if their parents - if their parent they inherited it from is a person who has some equinovarus deformities, some plantar flexion of the first rays, really high arch, there are some things you can do as an orthotist to put forces in place as the child's growing to limit the amount of deformity that the foot will have. So, even if it's a simple thing like a little just an insert that goes inside someone's shoe, if we can put something in there that creates a force to counteract what we can predict is going to happen, then it's worthwhile to brace kids early that way. Now, I'm not saying immobilizing anything. But if the ankle is starting to turn to the side, and you're going to get a lot of fixed deformity, it's good to treat that orthotically as early as you can. And try to stop that deformity from progressing.

- Thank you, and we have a couple questions about specific types of braces. One community member was asking about the Arizona brace and when that is appropriate. And then another community member was asking for your opinion on the TurboMed type.

- Great questions. The Arizona brace, was originally, it's an ankle gauntlet. It's basically a plastic and leather sandwich. What it is is it's leather on the inside, leather on the outside, but it has plastic on the inside. It was originally designed for patients with arthritis or some varus or valgus instability at the ankle. The thing is does kind of immobilize the foot. And it's heavy, and it's kind of bulky. I would think there are more dynamic versions of a brace that I would prefer for patients with Charcot-Marie-Tooth disease. The other one, the TurboMed is a great option for some patients. It was invented by a guy in Canada who had a complete foot drop. And this is a really active guy. He was up in Canada, he liked to run up mountains over boulders and stuff like that. And most braces didn't have enough dorsi assist, toe pick up assist, to get him up over those rocks. And they kept breaking too. So he invented this brace made out of a very durable, very compliant plastic that attached to the outside of his shoe. It's the only, really, what we call exoskeletal AFO that we use on a regular basis. And that's great for someone who just has the foot drop piece. If you just have some foot drop and some mild medial and lateral instability it can be a fabulous brace. One guy I have in it, he works for the Army Corps of Engineers. When he's not, you know, in a quarry somewhere, or walking on a jetty, or walking on even terrain like that he's in a business meeting, and he has to wear a dress shoes. So he needs a brace that can go on a lot of different types of shoes from boots, to dress shoes, and casual shoes. It works really well for him. The thing about that brace is it doesn't do - is

it's not going to help anybody with plantar flexion weakness. If you can't walk on your toes that's not going to give you much help for propulsion. It also won't help you much with balance. Because there's no ground reaction piece to help you with the balance piece. So, for certain patients, they call it the XTERN now, is a great brace that works really well.

- And then a question came in. If you can still walk well with the more minimal AFO, is that a better design? Or is the ground reaction always better?

- The ground reaction is better I say if the disease has progressed to the point where you can't walk on your toes, or you just plain need better balance. If your static balance is so poor that it's embarrassing for you to be in court, for example, or something like that, then yeah, you need to go to the ground reaction. But if you just have, you know, foot drop and very little mild varus valgus instabilities, then you don't need the ground reaction piece.

- All right, thank you. And then we have a question on the Allard BlueROCKERs. There's a community member that has them. And they keep cracking every one and a half years. They're very active, they hike. But they're looking for something that, you know, they love the carbon fiber design, but they're looking for a new AFO with the flexibility in the footplate, but also with a carbon fiber design that will last longer.

- I am too. Allard is my go-to brace. And the BlueROCKER for my patients who have these problems is my go-to at that point. But I do have a lot of what we call BlueROCKER breakers. And some people, they break them in a matter of months. And they need a new replacement. Allard has a wonderful warranty. They will replace it twice within one year if necessary. But for patients who have what we call a five year rule from Medicare and Tufts, and other insurance companies that have a five year rule it's a real problem. Unfortunately, what I do with my patients is I just whatever it costs me I'll pass it onto them to get a replacement at that point. But there's nothing that really walks as well as that BlueROCKER right now that I can find. There are a couple of things that are working pretty well. They're just a little bit more involved. One is called the NEURO SWING AFO. And my colleague, David Misener, who I know you know well Amy. He wears it himself, and he has CMT. Unfortunately, with this brace, it's a wonderful brace, it works with an ankle joint. That can have the same effect as the BlueROCKER because you'll be able to control both of those rockers nicely. But there's a breaking problem with that as well. Hence, unfortunately, from what David tells me it's hard to get covered. Probably around a $2500 amount that does not get covered by insurance. So if you needed two of them you're looking at $5,000 on top of what would be your insurance to get it covered. The other brace, another bracing design that uses a carbon strut. Hanger uses a brace called IDEO. And it works really well to function like a ground reaction BlueROCKER. It's much more durable, much more expensive, but it works really well. Another one is from a company called Fabtech. And they make a brace, what they call a PDE, I forgot what it's called, Dynamic Element. And it uses a carbon a strut in the back. And it has to be incorporated into a plastic footplate in another shell. So you it can be

a little bulky, but they're quite durable, and they work really well. So, Fabtech, their PDE, or the Hanger IDEO is a good option for these patients who keep on breaking BlueROCKER.

- [Amy] Thank you.

- I wear those last ones you just talked about. And they have changed the game for me. They're the strongest I've ever been in.

- Oh, the Hanger IDEO? Hey, that's a great brace, wonderful, the PDE. Yeah, that's terrific, yeah. I'm having good luck with it myself. Yeah, thank you Jonah. I like the demonstration.

- That was not planned by the way. We have a community member that wrote in. They have CMTX, and they just had ankle fusion. So, they're asking what will that do to the second phase, next phase?

- Second rocker, yeah.

- Yeah.

- Well, it depends on what was fused. We like to avoid fusions with CMT. Sorry. We like to avoid fusions with CMT. But if they had a fusion, if it's a subtalar fusion - fusions are great, realignments are great, osteotomies are great. They can realign the foot and help improve the weight-bearing line but often it won't help much with that proprioceptive piece, that balance piece. Or the strength piece if they can't get plantar flexion, it won't help with that either. So, sometimes you need a carbon AFO just to augment the correction of your fusion. Unless of course you've had a complete ankle fusion, in which case there's not much you can do. If the entire ankle and foot is fused, you're just going to walk with a sock and shoe. Because it's taking the place of a brace.

- All right, then we have a couple more questions here. One is asking about your favorite brand of AFO or brands of AFO that you recommend patients. This particular person said they have fairly severe supination. So that's great - supination. Well, a question that I would want to know is can they walk on their toes? And how bad is their balance? If they can't walk on their toes, and they're getting a ground reaction carbon AFO. And the Allard BlueROCKER is my go-to. If they can't tolerate the lateral strut, I will use the the Ottobock Reaction plus. And that can be used with a nice soft comfortable T-strap that helps hold the ankle. And you get the same function out of it. You get the same restoration of all three stance phase rockers. And that's great ground reaction for balance. So, those two work really well. There are some other braces out there too. SpryStep from Thuasne is another good option. So, yeah, it depends on the deficits that you have as to actually which type you would want to go with. But the BlueROCKER is my go-to.

- Now you have another question about your opinion on the NEURO SWING AFO and if you use those.

- I was talking about that earlier. And, again, David Misener up in Albany, New York has the most experience that I know with it up there.

The NEURO SWING is a wonderful concept. It's a great brace. But what I'm told is it's having a breakage problem as well, which they're working on. It works by using a big ankle joint on the side. And you can adjust how much resistance in the dorsiflexion and plantar flexion you get. It's very strong in the transverse plane, so it's a wonderful design. But it is breaking, and it's more expensive. It's not all the way covered by insurance because of that non-covered piece that costs about $2500 per side. So you're looking at about five grand on top of what they would bill your insurance to get it covered. But I think just things are going to have to change, and it could become more of a mainstay in our arsenal so to speak.

- We have a number of comments coming in thanking you. We still have questions to go through, but I don't want to miss the opportunity just pass those along how people are really appreciating your expertise, you spending your time with us today, coming directly from our community members. We do have a question, again, about BlueROCKERs. A community member wears the BlueROCKERs, but their right ankle rolls out. And the bar really bothers them. And they're super active, so they're asking what other types you might suggest. They don't wear everyday. This is really only for long hikes and walks.

- Yeah, so to avoid that pressure on that lateral strut, I have employed a lot of strategies to alleviate that problem. The BlueROCKER really should be provided with a custom foot orthotic. I do it every time. And if you can wedge the foot over you can manage the weight line better, so it won't roll and hit that strut so much. If the foot orthotic also has a strong enough lateral wall to it, you can actually hold the foot away. Because we take that foot orthotic, and we will fix it to the footplate, so that you literally can't hit the lateral strut. If all those options are exhausted and you're still hitting the strut, then you need to go to a medial strut. And for that I'd recommend that Ottobock Reaction plus. It gives very similar effect to it, very similar function out of it. And it can work really well to avoid that lateral strut issue.

- I have a question really quick. Is there something Hanger could make like the NEURTO SWINGS with that little ankle joint? Could they make their own? Because my orthotist kind of thinks he can. He has his own little mechanism that he thinks he can put together some NEURO SWINGS. Is that something that you recommend or recommend not happening?

- Lacey, that's a great question. You know, I don't know who the orthotist is. He wants to take the NEURO SWING joint and build the brace himself in other words? Yeah, because they're having a lamination problem when they're having it made. The thing about it is if you're willing to gamble and spend the money on it, it may be worthwhile to find out how he can do it. Will he guarantee it? Will he warrantee that it won't break?

- Right, yeah, I don't know, I don't know all that. But I'm the one who asked that question about, oh, I don't even know what I asked now. I have such terrible memory problems. But, see, my knees give out a lot because my thighs are really weak, okay? Right now I'm wearing the basic white propylene whatever it's called brace, okay? And it goes under the knee. I have a flap that goes over my knee. And so, I'm just wondering what would

work best for me. Because I'm tired of falling. I mean, when I fall I go down hard and I always hurt myself. I tried a KAFO that goes all the way up to my hips, but with those I can't even sit on the toilet. I get so many pinch spots. I mean, it's - I don't know, I don't know where to go anymore.

- I hear ya, well, ground reaction it doesn't matter what the mechanism of it is. It can be a solid ankle ground reaction AFO, which is what you have now. Or it can be ground reaction can be limited with the NEURO SWING ankle joint or across a BlueROCKER that's set up just to block dorsiflexion anyway. If you already have a polypropylene brace, that's the regular plastic one that comes all the way up onto your knee, that's probably the best ground reaction you can have. Now, that being said, and my good friend in San Diego, Marmaduke Loke, he makes a custom dynamic carbon AFO that goes up onto the knee a little higher than most. He also extends the footplate out further forward so that the ground reaction force is greater, meaning you have to get a longer shoe. But he can really, I've never seen a brace optimize ground reaction as well as his does. And if that's enough you could avoid going to a KAFO by getting something like that. And even if your orthotist at Hanger could extend that footplate out longer, you know, it doesn't have to be by much. You know, sometimes an inch is all it takes. And that can create a strong enough ground action force that would stabilize that knee while you're walking.

- Okay, yeah, I was thinking about something that comes about mid-calf. But he is so worried about me falling and breaking that bone right there.

- You want to maximize the leverage, so you really got to come all the way up onto really the very top of your tibia, that lower bone in your leg. The taller that is and the longer the foot piece is the stronger the force to hold that knee from buckling forward.

- All right, thank you Ken.

- How's your balance, Lacey?

- My balance is not good at all.

- That ground reaction will help you with that piece too. You should be able to stand in open space, look at the ceiling tiles over your head, things like that. If you can't, then you've got to go further up.

- Okay, cool, yeah I can't do that now. I'm always wall surfing or holding on to somebody, so yeah. All right, well, thank you so much Ken.

- All right, Ken, we have a couple more questions here. One kind of similar in category. Is there an outside the shoe AFO that will help with push off?

- To help with push off, I'm not aware of one, no. That Canadian one that we talked about earlier, the XTERN, that's an external, a real exoskeletal AFO. But, yeah, I don't know any other ones that do that, no, that'll help with push off.

- [Member] That's why I'm asking. I was wondering if there's a TurboMed, like, that helps with push off.

- Yeah, there isn't unfortunately.

- All right, thank you.

- Yeah, you're welcome.

- And then some questions about people that have worn SAFOs, what do you think of those? Do you like calf GRAFOs?

- Ground reaction AFO, what was that first part you said Amy, I'm so sorry, can you repeat that?

- SAFOs?

- Oh, silicone AFOs. Silicone AFOs made by Dorset in England are pretty much an exclusive of Hanger nowadays. But that brace, it was originally touted as a CMT brace. It was very cosmetic, It looked pretty nice around the foot. And it was supposed to help with foot drop, balance, a little bit of everything. And the truth is the word little is the operative term. It does help a little bit with all those things. But if somebody has a lot of proprioceptive loss and poor balance, if they have a lot of ankle instability, and they're always rolling their ankles, it's not going to help with propulsion either. It's just not strong enough to do that. It can be a nice brace for those that are mildly affected with CMT. But if you can't walk on your toes, and you have pretty strong balance, or a pretty significant varus deformity in your foot it's not going to be much help functionally.

- Then, with the ground reaction they're asking specifically with kids.

- Kids for ground reaction. Usually, it's not necessary with children. With kids with CMT, say under 10 years old, usually the disease hasn't progressed to the point where they're going to need ground reaction. Now, I do have some kids in ground reaction AFOs, those Allard calls KiddieGAIT braces, and they're terrific. But those are for patients with more unique issues. A lot of times idiopathic toe walking is - they have idiopathic toe walking, and they also have CMT. And I've seen my patients being referred to as CMT. And, really, it's more the idiopathic toe walking that has to be just broken first. So, for that a ground reaction AFO works great. You can put them into a nice little ground reaction AFO and break up the toe walking habit. And then assess their strength later after that's broken up. But, generally, I find that you don't really need ground reaction AFOs for children under 10.