

- I am Jonah Berger, National Youth Programs Manager. I'm getting there. And I basically get the honor and the joy of helping to develop youth programs and helping to run the youth programs. And I've been a part of the CMTA kind of unofficially for years and years and kind of volunteering to help out from time to time with youth initiatives but then was hired on full time almost one year ago and I just say this all the time. I love my job. I love my job. I have a great, great job. So I want to give you a little bit of an update on what it is that we are doing in the youth program, what we've been up to, and then I'm going to finish by giving you a little dose of my take on CMT, which is all about focusing on the positive which we were just talking about in our last session or lunch break earlier. First, the youth update. It's very important. Hold on. Let's enter into the youth update in a youthful way by singing. ♪ I believe the children are future ♪ ♪ Treat them well and let them lead the way ♪ ♪ Show them all the beauty they possess inside ♪ Sing along with me. ♪ Give them a sense of pride ♪ ♪ To make it easier ♪ ♪ Let the children's laughter ♪ ♪ Remind us how we used to be. ♪ Okay, that's it. I won't sing anymore 'cause I only have 19 minutes. I have to stay focused. In the youth program, we started years ago, when we would have these very conferences, when they were in person pre-COVID. We would take the youth out for the day. So I would come to whatever town or city the conference was happening in and take a group of the youth out. So the adults were learning all of the neurological updates and the youth were out having fun and getting to know each other. And at first it was just about social but every time I took a group out, I started to realize what was happening at those outings, and it was amazing what was happening. These kids who didn't know each other, usually about 10 to 15 of them, were connecting like old friends. At first, it was extremely awkward and quiet, but then they were really connecting because they understood a part of each other that was the most personal and the most challenging without anyone having to speak a word. And the more they started to understand that, the more they connected, and over time, I think the leadership of the CMTA and all of us who were involved in it were seeing that there was room for something bigger here. Something was going on and that it behooved us all to get a large group of these kids together and so welcome Camp Footprint, started five and a half years ago now. This summer will be our sixth summer. In 2016, we started it. There were 38 kids our first session and 18 staff. Second session, second year there were 60 kids and 40 staff. Third year, there were 80 kids and 60 staff. Third year. And fourth year there were 92 kids. And last year we had 115 kids who were signed up for camp and then we ended up moving to virtual, which was its own wonderful experience. But there's just something really magical that happens with these kids. Most of the staff have CMT, some don't, and I've directed eight camps in my life and I have never had an easier time getting everyone to gel. There's just an energy that goes on there that is the most magic thing to be a part of and it really helps the kids to see. A lot of these kids are the only one in their friend group who have a disability. Some of them are the only one in their family who have a disability, and so to suddenly be surrounded by 99 other kids and a bunch of adults who get it, who just get it, it's pretty magical. Once we saw what was happening with Camp Footprint, we decided it was time to launch a full blown youth program, and we started with a youth council to create some leadership for organizing and running things with me, and that is 11 kids who came together in Colorado for a weekend.

I used to live in Colorado, and by the end of the weekend, we had a logo. We had our mission. We had our marching orders. We had committees that we had broken them into, and there's a social media committee that works on creating and then growing our social media presence with the youth that's been unbelievably successful. We have a fundraising committee that is doing more and more work all the time and working with Jeana and all of us at the CMTA to begin to develop some fundraising grassroots for the youth specifically. We have the "Book of Dreams," which is a secretive project, that that committee has been working on and the results of that secretive project are going to be launched in the first week of December. That's all I can tell you. I might be able to tell you that it's a book. I might be able to tell you that it's a book with kids from all over the country and a few from all over the world. We've written about their experiences with CMT but that's it. That is all I'm telling you. The rest you will have to find out for yourselves when you order many, many copies of this surprise, perfect for the holidays' gift. We'll see you on December 4th. Keep your eyes open on our postings. The youth database was a project that we wanted to start getting a little bit more organized about who are the youth of the CMTA. Who are the youth in our community? And let's have their contact information and start to keep in better touch with them. We are at 175 names on the youth database and growing day by day. I get about one a day, sometimes every other day, sometimes I get two or three in a day. It's wonderful to see. And then this year, feeding off of the success of virtual Camp Footprint this past summer, we decided to create quarterly hangouts where we do kind of a mini hour and a half to two hour this. We jump on Zoom and we hang out and we talk and we have fun. And there's very little planning that has to be done with it because you get these kids together and they just flow and it's so wonderful. We're also creating a newsletter, an E-newsletter, that's going to go out quarterly to the youth as well that's designed and geared directly to the youth. And there's lots of future goals. We have in the works a second Camp Footprint, a West Coast Camp Footprint that we're hoping to launch in the summer of 2022. We are talking with youth leaders in the CMT community around the world. I had a conference call last week with the youth leadership from Australia and from London, and we were talking all about camp 'cause they do their own camps as well, camp exchanges. We were talking about someday in the future a global camp and starting to talk about ways that we can get the youth from all over the world to start communicating online in a more cohesive way. So the current and the future is extremely bright. I have 10 minutes to go. Look at me, all right. Is extremely bright and there's just so much support from the staff at the CMTA, from the board of directors, from the community around everything that the youth movement is trying to accomplish and as the manager of this program, I just couldn't be prouder of the kids that we're associated with. It is wonderful. It really is to see what these kids have as part of their hearts and spirits. If anyone ever wants to communicate with me around youth topics or programs or ideas or just want to know more, you can holler at me anytime. Sarah, do you mind putting my email address in the chat box? And just reach out to me. I'm always, always happy to chat with anyone about the work that we're up to. So let's shift a little bit and I won't sing this time I promise, to my own take on positivity and purpose. I was taught very specifically by my mom the ways of how to manage life with a disability and not necessarily physically, it was more along the lines of

emotionally, because my mom is pretty incredible that way. She, without really doing a lot of talking, showed me the ways of how to go about not just surviving but thriving with CMT. And the first thing, I will tell you a funny thing that happened just the other day, is my bathtub story. I woke up the other morning and I went to pee because that's what I do in the morning time. Don't we all? And before I even got to the toilet, my knee buckled and it's one of those moments that I'm sure a lot of us can understand very clearly. I dropped. I just had ... There was zero ability to affect what was going on. It was instantaneous. When my knee just gives out that way, I go down. Well, our bathtub is right next to our toilet and I was standing right in front of the toilet and I fell right into the bathtub and thank goodness, I was not hurt. My pride was hurt but my body was in general good shape but I lay there for a minute because when I fall, I usually I'm in shock and need a few seconds to kind of get myself together and I laid there for about five minutes and I just stared out the window 'cause we have a window in our bathroom and I realized, you know what? This is my life. Like at first I was really upset 'cause I always hate when I fall down and it frustrates me that I don't even have to slip on something or trip on something. Sometimes I just go down and yet there I was in the bathtub thinking, "This is my perspective on life. I don't have the ability to change that. I don't have the ability to make certain parts go away. What I do have the ability to do is control how I manage it." There was a quote that I always share from an ER episode and Jeanie Boulet was this doctor's assistant who worked there and she contracted HIV and ended up getting fired and fought and kept her job and then she left the show. She left on her own terms. She won the court case and then left on her own terms. And on her last episode, she was walking towards the door of hospital and her friends were at the admin desk and they were like, "Jeanie, goodbye. We love you, we love you." And one of her friends said, "Jeanie, are you going to be okay?" And she turned around and she said, "You know, I'm starting to think it's not about what happens to you in life. It's how you deal with what happens that matters." And I've never ever forgotten and in fact, I wrote it in my book because that's it. That's the ball game you all. We can't change that we have CMT. You can't make it go away but you can do a lot up here on your grip, on the take you have on CMT. And I can tell you from experience and I know you get this. The days where I am feeling like a pity party and letting it run me, I feel like it's this heavy thing I'm carrying throughout my day. And then there are other days where either organically or by intention, I'm just positive and light about it and then it feels light. So, attitude equals experience is the way I would summate that long-winded point. I have a daughter now. Her name's Amelia. She is a beautiful little girl. That's my sweet Amelia with my dad. And because I have CMT1X, we know that every daughter I have will have it because I've passed my X on. Every son I have will not have it 'cause I passed my Y on. So she has it and she comes up to me all the time when I'm putting on my braces and puts her hands on the braces and to her, this is normalcy. When she was a baby, I was carrying her and I tripped. It was my biggest fear my whole life before I got married, before I was a father. "Am I going to fall when I'm carrying my baby?" Sure enough, once so far I have. And I caught the table with my arm and I didn't go all the way to the floor, but she was like definitely jarred and my heart broke instantaneously. And then that night when I kind of got myself together, I realized this is my

daughter's life. In the same way that sometimes I have to look at the morning birds from the bathtub because I've fallen into it, my daughter is going to have a father who trips sometimes. My daughter's going to have a father who trips while he's holding her sometimes. And you know what? She's going to be okay, and in fact she's going to be even better than okay 'cause she's going to understand that this is the human condition. We all have things to deal with. So again, it's all the way you frame it is the way that it ends up being. Four minutes to go, we're on track. My book "He Walks Like a Cowboy," I don't promote this to you because of wanting to make a million dollars on selling books 'cause I'm not going to do that. I sell about two per quarter but if you haven't read it yet, it is everything I'm talking about on steroids, so ... and it only costs \$12 and 30% goes to the Jonah Berger Vacation Fund. So you may want to check that out. And there's a whole chapter in there about my mom and how she was always so open about it. Whenever I was a kid, I saw when someone was looking at her braces or asking her a question, she would instantly tell them everything like they were old friends. And I saw what happened to those people. They relaxed because they understood. We're curious people by nature. That's our nature, is to be curious about that which we don't understand. If you shut it away and try to hide from other people's curiosity, it makes their curiosity grow. If you just give them information and direct honesty in a caring way, it feeds their curiosity and then they move on in better knowledge and less ignorant which I think is good for everyone. My mother is an absolute champion in the greatest sense of the word. So I feel like lead by example. Model the very kind of behavior you wish other people would do for you, do that for them. And more times than not, it comes back to you Boomerang style. I have one and a half minutes left and I'm going to use them to read you a poem I wrote years ago before I spoke at another in-person conference and I call it "The Waves." And it goes a little something like this: "The waves come crashing on the sand. What shall we do? Run for dry land or take our chances and lift our feet and ride the tide our fortunes to meet? We wake up each and every day to work and plan and dream and play and strive not to trip or stumble or fall. Our pride intact, our confidence tall but the truth comes shining through you see. We have challenge to face. We have CMT. Our feet are funky, our balance unsure, our weakened hands are reaching for a cure. And while we wait for the cure to arrive, we must challenge our fears. We must constantly strive to teach those around us with the way we face this challenge with strength and truth and grace. Try not to be normal. Seek not who to blame. Don't add to the weight of your feet with your shame. Walk your own way. Stumble with style. Do more than survive this. Thrive this and smile. Go beyond the boundary where your comfort ends. You'll be strengthened by the wisdom it lends. And when the waves come crashing, do your best to be brave. Lift your feet and ride the wave. Much love you guys.