

- Going to dive right in, everyone. I want to welcome you to the Fireside Chat with Laurel and Jeana. We are super excited to be here with you. I'm going to go kind of fast because we have a break at 11:25. And so I just want to dive right in. I first and foremost, want to thank you for sharing your time with us today on a Saturday. As a person living with CMT1A, I know how important it is to find community, and to find the resources that you need. And it's a little bit hard with CMT. It's not as well-known as some of the other diseases and disorders. And so you have to do a little bit of digging, but we want to help you with that. We want to be your go-to resource when you're looking for information, education, and community for dealing with CMT. This is really part of our mission at the CMTA. In addition to supporting the development of new drugs to treat CMT, we want to make sure we're helping to improve your quality of life for all patients. And we do that through a variety of resources, education, and events to bring people together, and to make sure you're being seen by people who really understand CMT. So what are those most important resources that you should know about? And those would be the CMTA Centers of Excellence around the country and four overseas. And let me first and foremost say, that all of this information is available on our website, but we've also taken this information and put it into the digital agenda guide that we sent to you. And one of the last pages in that digital agenda guide is the resources page, and so all of this information is in there as well. So I just invite you to listen and enjoy the chat, and then go back and reference those resources as you need it. And of course always reach out with questions. So the really the most important resources we want you to know about are the CMTA Centers of Excellence. And that means you're being seen by a neurologist whose subspecialty is in neuromuscular disorders, and they've received this, they've applied for and received this distinction to be part of our CMTA Center of Excellence family. Also finding a branch near you. Well, what is a branch? Why do you call them branches? Well branches are the term that we use to describe our support and education groups that are around the country. So if you want to get involved on a local level, this year it is virtual, we invite you to find a branch near you, or start a branch if there isn't a branch near you, and find and build that community in your area. Very important resources also would be managing CMT, those therapeutic interventions, excuse me, like physical therapy, occupational therapy, bracing. So really you're getting great information about those therapeutic interventions. And then also youth programs and camp. And you'll hear about this later when Jonah speaks. He's going to talk about how important that is to hear about what's going on with the youth, and to hear about a very special camp that is just for kids with CMT. So how can you stay connected with the CMTA and with the CMT community, and learn about resources that are available to you? As you'll see on that resource page in your digital agenda guide, there are many ways to be in communication. It depends how you like to receive your news. So do you like to read news online, in an email? Really encourage you to go to our website and sign up for e-news. There's a button on our homepage. Looks like someone's sharing their screen. Well, I'll just keep going. So also following us on social media, that's a great way to receive information and be in communication. We put out much information on our social media platforms to include Facebook, Instagram, Twitter, LinkedIn, and that is for adults and for the youth program. So really have a lot going on there. I would also encourage you to join the CMTA's discussion group or

the CMTA's parents group on Facebook. So you can connect with other CMTers or other parents with CMT. And also joining us for virtual events. So for the foreseeable future, we will be meeting virtually until we know it is safe to meet in person. And it's really worked well for us this year to put together these type of virtual platforms and bring everyone together. It's nice that you don't have to deal with parking and walking into buildings, and it's nice to join from the comfort of your own home. So we will continue all this virtually until it's safe to meet in person. And then when it is safe to meet in person, we'll probably still continue with in-person meetings, as well as virtual. So it's really important to have connection and to find people who understand what you're going through. On our website is an events listing page, and that lists all the events that you can participate in that are coming up. So I would encourage you to check that out, and you can join as many events or as few, whatever interests you. So we would love for you to be part of our community and part of our CMT family. The majority of meetings and events being held around the country are organized and planned by our amazing army of volunteers and community members. We really are community powered. And who better to talk to about the challenges of living with a progressive disorder than the people who go through it everyday? And that's one of the reasons I got involved with the CMTA is because I wanted to talk to other people who had CMT. And I got so much out of going to those branch meetings and meeting other people, so it's really meaningful time. So we would love to see you there. Before I turn it over to Jeana, I want to leave you with a quote by Coretta Scott King. And she said, "The greatness of a community is most accurately measured by the compassionate actions of its members." And I think we have the best community out there, and we invite you to join us. So I'm going to turn it over to my fireside buddy, Jeana Sweeney.

- Thank you, Laurel, thank you. Aren't our backgrounds just so cosy? I can feel the love, I can feel the love. So I'm going to move this 'cause I don't like looking at myself when I talk. So I'm going to I look this way, but my camera's, my Zoom is this way. But thank you, Laurel, ever so much. And I really want to recognize you for all of the efforts that you've put into this virtual conference. I know that it took you a lot of planning and a lot of organizing. So, truly, kudos to you on an excellent job, really.

- It's a team effort.

- It most certainly was. But I do want to hit a little bit on your chat because I really truly cannot stress to everyone enough how important it is for you all to stay connected to the CMTA, regardless as to where you are with your CMT. The world of CMT is just moving at such a fast pace, that things are changing all of the time. The CMTA is always putting out very valuable resources, and there is so much movement in research, you do not want to miss out on the information. And more importantly, you all are your best advocate when it comes to talking about CMT, going to the doctors and speaking for yourself, because always remember that knowledge is power. So I just really wanted to touch on that a little bit. So are you ready for your pep talk? I want to start out just by saying, too, how amazing it was to see the number of people registering for this conference. With every email blast and with every social media post, the

numbers just grew and grew. And we heard it a little bit this morning of the thanks to the CMTA. And people were excited to hear from our experts and from our researchers. But there's one thing that is important for me to mention to all of you, for those of you that may not know this, but behind every email and behind the social media, there are only six employees at the CMTA. Six on our team. So with every new program, with every fundraising campaign, the walks for CMT, camp, awareness month, you name it, it's coming out from only six people. Behind those six people, and it's very important for me to mention this group of people, is there's also an amazing dedicated board of directors, who probably want a treatment and a cure more than we do. They wanted it for us. They wanted it for the patients. They support our efforts. They contribute their time. They even contribute their personal dollars. But what really makes the CMTA tick, and Laurel just mentioned this, is you. It's our community because without the community, really, where would the CMTA be? And if you had the opportunity to see the video, you can see that the CMTA is most certainly treatment driven, but we are powered by our community. So Sarah, could you just pull up that slide? Typically at a patient family conference, I would, you know, when I'm up there speaking about getting involved and finding your CMT mojo, I would pick out a few people in the audience. But because we're in the situation that we are, I wanted you to see the slide and they're every day average folks. But what makes them special is they are faces of patients and families and friends doing their part, and they are being a part of the change of CMT. So please just take that in just for a moment. But these people they're patients, and every single one of them, and this is just a minute, minute part of our community. So thank you, Sarah. You can take that down. So when I was diagnosed with CMT about 33 years ago, that's a really long time, but I literally thought that I was the only one in the world with this crazy thing called Charcot-Marie-Tooth disease. And I'm sure many of you have either felt that or maybe feel that now, and you could be shaking your head like yeah, Jeana, I totally hear you. I feel you. But there was no presence of CMT in my town. I mean heck, like to think back like a fundraiser, like where? 'Cause if there was a fundraiser, I would have totally signed up. If there was a meeting, a branch meeting, I would have totally gone, but there was nothing. Not, absolutely nothing. But as I grew older, I became aware of some events and some of the meetings, but they were happening in far away places in cities and states that I couldn't get to. So what changed that? Or who changed that in my town? I did. I changed that. And it's important for people to know that I wasn't working for the CMTA at the time, I did it for me, and call it selfish if you want. But I did it for me because I wanted to meet others. And I wanted to contribute to the CMTA in the way that I could. And I was able to bring CMT activities and fundraising and awareness to my tiny town of Johnstown, PA. And you know what happened? I started meeting others. And those others said, hey, I want to do more too. And bam, just like that, we had a CMT community within my community. And as I started connecting myself to the CMTA, and working with others, more people were following along, and more and more people were doing the same. And you know why? Because if we don't do it, who will? And today it's unbelievable with what's happening across the country, even internationally folks are doing events and they're always looking for ways to get involved or even donate. And this year, despite COVID, the CMT community still rallied, and they're still rallying now. And you know why? Because they want a

treatment and a cure, and they are recognizing the work the CMTA is doing. They participated in the Walk for CMT, the Cycle for CMT, virtually of course, but nothing stood in their way from doing their part or making their ask. And I'll tell you that the CMTA is so incredibly grateful to our community for not letting COVID get in the way this year, because like I said, where would we be, if it wouldn't be for our community? So just getting back to staying connected, this is another reason why you should sign up for e-news, or join a branch, or follow us on Facebook. Because from the Walks for CMT, the Cycle for CMT, doing your own event, your own ask, or a monthly giving, to giving to a camper, the list can truly go on and on, but I will spare you the details. As Laurel said, see your agenda for all the links, or visit the CMTA's website. But here's the thing. If there's not an event in your area, or if you go to the CMTA site and you're like, oh, I can't find the information to give through my IRA, whatever it may be, don't let that discourage you or stop you. The CMTA has made it incredibly easy for you to do your own event, be it a cycle, a walk, bowling, bingo, whatever it is, we will be by your side. And if you can't find the way that you want to give on the CMTA site, pick up the phone and call us or send us an email. Because even if there's only six of us, we're always there to talk, always. So here's the thing, each of you on this Zoom conference, know that the CMTA association is built for you. We of course work for the quality of lives. We work to better the quality of lives for those living with CMT. And we of course work every single day for a treatment and a cure. But when you hear the STAR update this afternoon, I want you all to know that you all are driving and supporting the success of STAR. There are no large government grants that come into the CMTA. There is no Bill Gates. It is you, the patient, our families, and our friends that are supporting that. You may not be the person looking in the microscope, but you are the person that put that itty teeny tiny cell in that dish. You are the ones that are driving it. This is why we need everybody on board, everybody. These are such exciting times, and the CMTA is moving faster and faster. Just think for one moment. There's 3 million people living with CMT in this world. If 3 million people gave \$20 to the CMTA every single year, that'd be \$60 million. That's a whole lot of dough, and that's a whole lot of research for us. So Laurel, I know I'm a little over, but before I wrap this up, I want to leave you all with one question: Who would inspire you to give to the CMTA? Would it be your daughter, your mother, your friend, or is it you? Since 2000, I have been inspired to give to the CMTA every single year for me, my daughter, and the future generations of my family. And this year there's a bonus. My donation will be matched because the CMTA is now offering a dollar-for-dollar match, up to \$150,000, from now until December 31st. Sarah, will you pull up my slide real quick? And this is why I am inspired to give to the CMTA. So, thank you very much.