



The Medical Road Trip: Seeking Care and Resources Outside of Your Hometown

Presented by: Alisa Druzba, MA and E. Chandlee Bryan, M.Ed

Marie LeGrande:

Hello and welcome to the Multiple Sclerosis Association of America's live webinar, The Medical Road Trip: Seeking Care and Resources Outside of Your Community. My name is Marie LeGrande, and I'm the Director of Education, Healthcare Relations and Grant Management and your host for the program this evening. On behalf of MSAA, Impact Education, and tonight's presenters, we greatly appreciate the opportunity to keep you updated on this very important topic, and please know that we hope you and your family are staying safe and healthy in these uncertain times. Now, before we begin, we want to take this opportunity to thank Bristol Myers Squibb, Genentech, and Greenwich Biosciences for making this program possible.

As you may know, MSAA is a national non-profit organization dedicated to improving lives today for the entire MS community for over 50 years. If you've called us before, you've likely already connected with a trained and compassionate Helpline specialist who has a social services or counseling background and are familiar with MS. Our Helpline Specialists can assist people living with MS and our care community with identifying helpful MSAA program recommendations, as well as other program resources available from the broader MS support community, which also includes the MSAA Cooling and Equipment programs that are available to individuals who might be experiencing financial or insurance barriers to accessing tangible items that can help to manage some of their MS symptoms. Examples of these products are available through these programs and consist of items such as cooling vests to help those experiencing heat sensitivity and/or seated four-prong walkers for mobility support. We also have the MSAA MRI Access program, also for those who are experiencing financial barriers to accessing their cranial or C-spine MRI for a diagnosis of MS or to track disease activity. For information about eligibility criteria, applications or just more details about these and other MSAA programs, please do visit the MSAA website. You can also send us an email or give us a call.

Please note that the discussion being presented tonight is for reference and informational purposes only and does not constitute as formal recommendations. For any personalized recommendations, please be sure to consult with your medical professional.

We would also like to take this opportunity to extend a huge thank you to our friends at Biogen, Genentech and Sanofi Genzyme for their support of our new virtual display hall. Now, if you haven't had a chance to visit yet, please be sure to click the link in the chat box to take a look at the products and services they have available. For your friends and loved ones who could not

join us this evening, tonight's program will be archived to our website very soon. For our Q&A session, please type your questions into the chat box and we'll address them at the end of the presentation.

Also, if you are having any technical issues, please type those concerns into the chat box as well. Finally, at the conclusion of tonight's program, you'll be asked to complete a short survey. We would be so grateful and appreciative if you completed the survey before closing out of the main window, your honest and open feedback of our programs is vitally important and helps not only shape future programs, but also continues to secure the needed funding that makes them possible.

Now I'm delighted to introduce you to each of our presenters for tonight's important discussion on the medical road trip. I would like to introduce the Director of Rural Health for the New Hampshire Public Health Department, Alisa Druzba, and MS community member, Chandlee Bryan. Alisa collaborates and consults with local, state, regional and national stakeholders and partners, and with the assistance of contractors and other agencies, develops strategies to improve access to quality healthcare. Diagnosed with MS in 2013, Chamblee is co-facilitator of her local MS support group and partners with the Chronic Health Improvement Research Program at Dartmouth on healthcare quality improvement initiatives. Welcome Alisa and Chandlee.

Chandlee Bryan:

Thank you, Marie. First, I'm delighted to be here with all of you tonight, and thank you so very much for the invitation to contribute to this important topic. I wanted to start out by talking a little bit about my connection to rural life. I feel like I'm especially able to speak to this area in some ways because I've also lived in metropolitan areas, including Washington, D.C., Philadelphia and New York. But for the past ten years, I've lived in New Hampshire and I live in a town of approximately 13,000 people. But it should also, I should also mention that I'm within ten miles of Dartmouth-Hitchcock Medical Center, which is one of my state's and Northern New England's premiere medical facilities.

So I have access on paper to wonderful facilities, not only just on paper, but also in practice. But as a person with MS, and I was diagnosed eight years ago after having symptoms for about seven years before that, I feel sometimes that the specialists that I have access to through my local medical center aren't always people that I feel the most comfortable speaking about some of my MS symptoms, especially, quite frankly, urinary and bowel and bladder issues. I know that I've learned that up to 70 to 80% of people with MS experience these challenges at times, but it can be uncomfortable to talk about them. And one of the things that I've found in my own experience having multiple sclerosis is that everyone's form of multiple sclerosis can be a bit different. And it's important to address things that are that are bothering you. In fact, I've heard that, I've read research that suggests that the number one cause for hospital admissions for people with MS sometimes isn't a relapse, it's actually a urinary tract infection. So, it's really important to address, it's been really important to me to address the things that I feel a little bit squeamish talking about and finding the right people to talk to.

In terms of having connections to the MS community locally, as Marie mentioned, I am very actively involved with the support group and have been since I was diagnosed. I was very fortunate right after I got diagnosed and on my first visit to see a neurologist to run into someone I knew loosely from the gym, in the waiting room of my neurologist office, and I confided in her that I'd been diagnosed, and she said, Me too, you know, I was diagnosed a year ago. And so she basically whipped out her cell phone, insisted on getting my number and basically escorted

me to my first support group meeting and I've been a member ever since. Regionally, she also got me involved with a group called Outdoor Mindset, which exists in some communities across the US, which is an outdoor activity group just for people with neurological issues, you have to have a neurological condition or be the partner of someone with a neurological condition in order to participate. So I've been lucky to be part of that, as well as a peer wellness group that I got connected with through a medical roadtrip.

So I would describe a medical road trip as any time you need to drive at least 20 miles away from home just to see a care provider. And for me, part of my experience having MS has been about identifying a community of providers or a network of providers that I can work with to address all of the issues of my MS. So, in some ways, that includes not only my neurologist and my primary care provider, but also a urologist, a podiatrist, who I see occasionally, dermatologists, who I don't really see for MS, but still is necessary, but just all of the different types of providers that I need to see. And also a neuro-psychiatry nurse who specializes in sleep. So, those are some of my care providers, and the urologist and a female neurologist are on my short list of people that I take medical road trips to see. And now I'll turn it over to Alisa.

Alisa Druzba:

Thank you, Chandlee. So, my connection to rural life is primarily having been the Director of the Office of Rural Health for the State of New Hampshire for the past 17 years, and all of our projects involve working with communities and learning about their experiences and hearing from them what they need and then trying to align our resources on a state or federal level to meet those needs. So I am fortunate to get to go to rural communities and meet with folks and see facilities and see home towns and sometimes try the raspberry pie, or whatever the local specialty is, and also work with them and partner with them to create programs that are meaningful, that really take in mind both the culture and the resources available in a rural community. And because there's one of me in every state, a State Office of Rural Health in every state, of varying sizes, I get to do a lot on a national level. So I also get to learn a lot about rural communities across the United States and the different approaches that they have used to meet the needs of those communities and the ways that their communities have come together. So even though I don't live rural, I live small. It's a pretty small city that I live in here in New Hampshire. It's not rural, but I do feel like I've learned a lot about rural life, and I'm always looking for stories to hear about people's experiences.

My connection to the MS community is actually through my mother. My mother was diagnosed with MS in 1992. I think I was a couple of years away from graduating from college. I had to go to the library to look things up. Now it's a lot easier, fortunately, like webinars like this, for example, to get information. But so really my role has been to be a daughter and also to be supportive and to learn about research and available resources and share them with my mom and support her. And, you know, really sort of do a lot of planning and thinking.

So whenever they've moved, we've talked a lot about available resources and support and things they might need, and even, you know, even to sort of looking at their home and making sure that, should my mother's condition worsen, you know, they can adapt their home and their environment and things like that. So I don't think there's really a lot that happens that we don't talk about those things and just really kind of consider them. But after all this time, they really have been integrated in the way that we have a relationship and we think about the future together. And because of that, of course, I really tuned in particularly to issues to the MS community when I am out and about and doing my thing for rural health.

So I would describe a medical road trip as an opportunity to access care and gain information that's perhaps not available in your own community. And the hope is that you don't have to take them often, but when you do, you get the most out of that experience. And I think that's really what Chandlee and I and MSAA are hoping you get out of tonight, a little bit of prep and planning, so that if you do need to take a medical road trip, you get the most out of that experience because you're prepared. You know, the healthcare system is incredibly overwhelming. It is extra overwhelming when you are dealing with a diagnosis that might be very emotional for you and your family. And then add on top of that living in a rural area, where access can be radically different from state to state, county to county. And so really hoping that we can help you think about things like that and how to access, and some tips, definitely from Chandlee as a patient, and me as kind of a bureaucrat and a systems person, to try and figure out if we can help you manage a little bit better, be a little bit more prepared.

Chandlee Bryan:

So I think one of the first things to think about is knowing when to stay. And as Alisa mentioned, you don't always need to take a trip to get help for your MS, especially now. Some things are better left local. And I think one of the most critical pieces of that that I would really recommend, if you can, is finding a local primary care provider that you trust. I know that for many, it takes a long time. I think I've heard that... I was surprised when I got diagnosed to learn that sometimes it does take, on average, five to seven years to get diagnosed with MS because it's such a complex disease and nothing presents the same. And for me, ultimately, it took me three visits within three weeks to see a primary care provider to get the tests that I needed to start on the way towards my MS diagnosis. And my last appointment was actually the first appointment of a physician's assistant in her brand new job. And I have used a physician's assistant as my primary care provider ever since because one of the things that I learned, at least within our system, is sometimes physicians' assistants are able to spend a little bit more time with patients, or at least that's been my experience, and they also have all their work signed off on by a supervising physician as well. So it's been kind of a great check in system for me.

So I have my primary care facility local. But one thing that I've learned from some of my research work within my local system is that a lot of the people with MS who were seen by our clinic at Dartmouth-Hitchcock don't have a primary care provider within the Dartmouth system. So people are traveling up to four to five hours for an appointment, which can happen when you're in a rural area. And so the communication is really important between your primary care and your neurologist or your specialists. And so we can talk a little bit about that further. But it's important in terms of things, in terms of thinking about services that you need to have local.

Again, this is from my personal perspective as someone with MS. It's been really helpful for me to have a strong primary care relationship where I am, and to also have a relationship with the neurology practice that I know that if I were to have a relapse, I could get treatment fairly quickly. But I also have been able, through my insurance, to see another neurology practice that has a slightly more holistic approach than my local clinic. So figuring out what is important to leave local is, I think, a critical step and recognizing at the same time that some of the resources and expertise that you need may be where you are.

One of the things that I routinely work to do is to share notes from my neurologist or to make sure that my primary care person has the notes from the neurologist in the system, and that she is aware of the issues that need to be coordinated with my specialists. So I think that's an important piece.

I also routinely do phone check-ins with providers, when I need to, and send messages through our electronic messaging system. And one of the things that I think for me has been really important is, just in my overall approach, has been not... trying never to assume that a message gets delivered. So, you know, if I'm sending something over the electronic health system and I don't get a response in two days, I try to call and follow up and see if there's a case management program that can help me with that process.

Telehealth has also been really helpful, especially where I live in New England. From November to March it's really tricky. It's also, in fact, one of the benefits of COVID is we're now able to have our support group meetings over Zoom, and we're going to be doing that now through March. All of our future meetings until the winter snow season is over will be remote. And that is kind of a blessing thanks to COVID. But figuring out when to stay put is also an important part of this overall process. Alisa, any thoughts on that?

Alisa Druzba:

Yeah, so I just wanted to add a couple more things to that, and one of them is when you create that strong relationship with your primary care provider, I think it's really, it's OK and it's super helpful to say to them, this is the way that I like to take information and I see this as a partnership. So when we're talking about next steps, when we're talking about medication, whether or not I need to see a specialist, whether I need another test or something like that, you know, I really want to have a partnership with this, so I'd love it if you could just sort of tell me what my options are and then we can talk about how they fit into my lifestyle. A lot of primary care providers are trained that way. They're trained to listen and have a partnership with their patients because they know that it doesn't do anyone good, right, if they line up a bunch of things that you are not going to be able to access, that don't fit your lifestyle, that are cost prohibitive for you. So it's OK to have a conversation with them about the things that are going on and what works for you and to really make those decisions together.

There are often multiple options for things that you can talk about and figure out which one works best for you and then come to that decision together. That way, you don't sort of walk out of the office with a list of things, and you're kind of like, there's ten things on here. And I can tell you right now, six of them are not going to happen based on, you know, my resources, my life, what I know, what works for me. So it is really it is helpful to know that they also want to hear from you.

And then the other thing is a lot of insurance companies, including federal programs like Medicare or state programs like Medicaid, they have a specialty case or care management program. So those folks are... their whole purpose is to be there to help you navigate the system and to understand benefits and what you need to do in order to access things. So you want to reach out to them and just let them know. And what they'll do is they will create a file, a digital file of you as a patient and then you can go directly to them and coordinate and talk through your options with them. And those folks are specially trained to do that work. So if you haven't utilized something like that, I would encourage you to reach out and check in with care management.

Chandlee Bryan:

So, Alisa, those individuals can help you and can be a resource to go to if you're not sure who else can help you, is that right?

Alisa Druzba:

Yeah, it's really... So for example, you might have a visit and after the visit, you walk out there with those aftercare instructions and there are a number of different things -perhaps its lab work, or tests, or a prescription, and you're not sure what's covered or if there are steps such as getting pre-authorization, or perhaps you need a referral in order for things to be paid for by your insurance company. They can help you figure that out so you can call them up and tell them that you just left a visit and that you have a number of items that you need to follow up on. And they can help you figure out which processes you might need to use so that that goes smoothly and that also everything's going to be covered according to your benefits, of your insurance company, and you're not surprised. I mean, you definitely don't want to be surprised by a bill when you're just trying to worry about accessing care.

Chandlee Bryan:

Especially. Great points. One of the things that I've found very helpful in terms of navigating my MS here is really trying to envision myself in the driver's seat when I seek care, and really thinking of my providers as partners. I know that in the academic world, there's this term that's being bandied about a lot right now called "co-production", which is the idea that healthcare should really feel like an ongoing service and not a transaction and in some ways that there is some continuity of care. So just like Alisa talked about in terms of of working with your insurance companies and with organizations to make sure that you know the providers who are working with you and can see the communication between parties, or that you are helping that process, helping to facilitate that process.

One of the things that I found was challenging for me is at one of my neurologists, every time I go in, I'm asked to fill out a questionnaire before I meet for my appointment. And so if I don't do it in advance, I'll get it on an iPad, when I first go in and there's a series of questions that ask me about multiple functional areas, such as, like, have I recently fallen over the last three weeks or what is my, again, urinary habits and other aspects. And I had always assumed that that was the basis, that that was going to kick start the conversation with my neurologist. And what I learned later was that all that those results contributed to was a basic score, and it was a numerical score. It was stored in my records, but it wasn't something that even corresponded to the individual questions that I'd answered in the waiting room. And so I think understanding how the information that you're asked is used is really important.

I know whenever I go to the neurologist, I have a 25 foot walking test. What is my walking speed look like. That's often reported, or it's always reported, and sometimes if I look in my after visit summary, I can see it. But unless I ask, the neurologist doesn't say to me, Hey, your time has improved by 0.7 seconds or you're a little bit slower this time. And I feel like, sometimes, figuring out when to ask for feedback and what to monitor is really important. And one of the things that has been really empowering for me, but also something that I really had to learn was how to talk to my providers as people rather than just as people in power and how to feel comfortable saying, This is what I'm looking for out of this appointment. And I think it's really important to prepare for appointments in such a way that you know that you have a defined goal going in. In my experience, it's really helpful to have that written down, to say, you know, here is a specific question that I am looking to have answered in this particular appointment.

Alisa Druzba:

That's great tips. I do that, actually, I have a little note thing that's an app on my phone because I never know when an idea is going to come to me and I have a little note that's called "medical", and I'll write down all my little questions and things like that. And then I figure out, is this

something that I can just send as a note through the electronic health system? Or is this something that requires an appointment? Do I save this up for my next visit anyway? And then that way I feel like, yeah, like you're a little bit more in control, almost like setting an agenda for your own appointment, which is great. And then, you know, beyond that sort of learning how your team communicates with each other, I think is really helpful as well. What you shared about not making assumptions about how things are communicated, how screenings, how aggregate scores are conveyed, its always fine to ask questions and things like that. The other thing that we can do is you could ask your primary care provider or even if you're working with a neurologist who's not a specialist in multiple sclerosis, you can suggest to them this opportunity called Project ECHO, and "ECHO" stands for "Extension for Community Healthcare Outcomes", and this is a program that was started in very, very rural New Mexico, specifically because there was a recognition that there were rural patients in areas who had chronic diseases, who by the time they access specialty care, were suffering from very, very extreme outcomes. And it was really because their primary care providers just didn't have the expertize to help them manage, or even if they did get to a specialist that perhaps that specialist didn't have the most up to date information on that.

So what they created it was Project ECHO, and it's not like telehealth, where telehealth you would have a patient visit through that modality. This is actually for providers to learn from each other. So they participate in like a set series of seminars, if you will, where they learn from a specialist in a particular area. So in this case, it would be multiple sclerosis. And then what they do is they also learn from each other. So different rural providers will talk with each other about patients that they have, always kept private, but as a case study, and they really talk to each other about ideas and accessing different resources. And because a lot of times they're rural folks, they are very aware of what their patients are up against, and they're very creative and very innovative with what they're suggesting and working with each other. So that's one of the things that you could talk to your primary care provider about, for example, would be engaging in an ECHO project, a relatively short term commitment for busy, busy doctors where they could get some support and education around MS. And then that will help you both work together as a team as well as any other patients that happen to come along.

And then another good note on this would be making sure you verify if you do get a referral out, who takes your insurance, what it covers, including medications and what your co-pay amounts are going to be. And it's OK, if a provider refers you to somewhere, it's OK to say, I need to make sure that that's covered by my insurance first, or, I know for a fact that that particular office is not covered, could I go somewhere else? And to have that conversation before you even leave the office.

Chandlee Bryan:

I would say, finally, that one thing to think about when you do determine when it might be necessary to do a road trip is, sometimes if you can't find something in your local area or if you aren't going to have access to a service for a set period of time. So for example, when I got diagnosed, I remember feeling absolutely panicked because I had learned that it was important or it was recommended that I get on a disease modifying therapy relatively quickly. But at first, I wasn't offered an appointment for three months and it was May and I was offered an appointment in August. And I was able to speed that time up through a lot of advocating for myself and for an earlier appointment. But in that particular time, I basically panicked and I didn't feel like there were other options. And I think it's important to realize there are almost always other options, sometimes for care and for help, and reaching to the individuals and the organizations that Alisa mentioned earlier. And I think you also shared with me that 211 can be

a great resource as well for just finding out about potential available partners or organizations that can potentially help is important too.

So one of the things that I have done a fair amount in terms of preparing for a trip is really planning as much as I can in advance. I know one of the things that I always try to do is plan trips for a particular part of the day so that I can limit surprises as much as I possibly can. And personally, I find that timing is everything, both in terms of getting appointments on the books early, making sure that I have the insurance authorizations that I need, that I have a sense of paperwork that's going to be required, information from my other health providers that may be helpful. One of the things that I've found is if I'm missing data, for example, a CD with my MRI results, a great time to get that information is on a snowstorm because New Hampshire, here they'll have an average of 1000 cancelations at our medical center on a snow day. But if the roads are still pretty good, there are people who have more free time on their hands to make me a copy of my image results if there's a light snowstorm going on. But making sure that I have the information that I need and again having what I need to cover prepared and allowing extra time.

And one of the things I've been known to do is to try to coordinate multiple appointments in one day. So I have a neurologist and a urologist who are about an hour away from me who are only, I think, they're actually in the same medical complex. So it takes me about ten minutes to travel between their offices, but I'll always allow myself at least an hour and a half between appointments so that there's plenty of time in case something runs over.

Alisa Druzba:

And the only other thing I would add to your experience, Chandlee, would be to remember to have extra time because there are a lot of different COVID screenings that are still happening. So there may be a little bit more steps that you have to take, even just to access the building or to get into your appointments. So you'll want to add that time in as well.

Chandlee Bryan:

Absolutely. One thing that I think is really important with MS is managing your energy and anticipating difficult days. I know sometimes I have a lot of energy, and I feel almost unstoppable, and sometimes I feel completely stoppable. And I know for me it's important to know that how I feel today might not be the way that I feel the day of an appointment, so really to plan my energy accordingly. So for example, if I'm traveling anywhere that requires a lot of walking and a lot of travel, really thinking about what I need, how I pack and how I provide for myself and knowing that you don't have to take the trip alone. One of my friends who has MS and is in my support group, is single and regularly looks... She tells a wonderful story about traveling to a health appointment with a basketball team, essentially, because they were at a game in the same area that she needed to see a doctor. And so they arranged for it. She arranged to go on the same day they had a game. So, you know, really being creative with transportation. And again, that's a place where Alisa's 211 can come in handy, also.

Alisa Druzba:

Yeah, you can access 211, which every state has that and it's, you know, they have a website as well as a phone number in each state, and they are really there to help you access different services. So you can let them know that you have a transportation need or you anticipate a transportation need and you're trying to plan ahead and they'll let you know what's available in your town. Tell them where you're starting from, where you need to go, all the information they need for that and they'll let you know. And one of the things that I've found in rural communities

is that there's a tremendous amount of transportation options that are volunteer driver programs. So the people in the community who sign up for shifts so that they can make sure that people that they know or don't know, people that they feel are neighbors can get where they need to go. And so that can be a great way too, you're not alone and you've got a person who literally would rather be doing nothing else but getting you where you need to be. So I would encourage you to look into transportation even if you don't think you're going to need it, but just as a backup, depending on how you end up feeling that day.

Chandlee Bryan:

Really, I would just say it's really important to realize that you are not alone. I know for myself, when I first got diagnosed, I thought about the the types of individuals that I needed on my team and I thought about it in terms of who do I need mental support from? And that included coworkers, I'm fortunate enough to still be able to work, that included, at first, an occupational and physical therapist, my support group, spiritual connections. I think really thinking about the patients and care partners that you can turn to for support and also not just thinking of yourself, but I think about people like Alisa who are also, in addition to your job, you're helping to support your mother and you are your provider. So it's important for care providers to have supporters as well, and just sort of think about these circles of support and how we can both support one another and ourselves and to really be willing to ask for help.

Alisa Druzba:

And I think about also that there may be, at different points in your, sort of, progress with your disease, that you might need more or less or different things. I know I chatted with my mom about this webinar and, you know, I sort of talked to her about things she thought might be interesting. And she said, you know, she never necessarily needed a formal peer support. But she does go to MS Yoga, which I know she does on Saturday mornings, and she really enjoys that. She loves yoga, and she loves being with people who understand that she might seem different from week to week and they might be too. And it's a great program for them. And in fact, she told me about a woman who has a Great Dane that helps her up and down off the floor for yoga. And she described this Great Dane so well that I saw this Great Dane out and about in town, and I called it by its name, and then had to explain to this woman how I knew her famous dog. And my mom is very, very keyed in, for a very long time, into any sort of research and things that she could learn so that she could have very, what she felt, she could have empowered conversations with her providers about what works for her and what doesn't work for her and what's available and what they think about it.

And so I know that that was really, really important to her. And now she's almost 76 years old, so her needs and the things that she's interested in are a little bit different. And so she shifted and she's doing, you know, she's utilizing different resources from her MS support network. So it really is one of those things that might change along the way, but just knowing that they exist. And I think that your family, the people who love you, they always want to be there for you, and so it's great if they have a tangible thing that they know they can do for you. I know it's not about them, but sometimes it can be really, really fulfilling to say to someone, this is what I need and then be able to deliver that for that person and feel like you're in it together.

All right, so now we'll pass it to Marie for... Oh, I'm sorry, Chandlee, I skipped ahead.

Chandlee Bryan:

Oh, I just wanted to share that, you know, to also think... sometimes one of the things that I've found really helpful, both in terms of thinking about things that I can do for myself, but also with

other people and for other people is just how we can help one another. And again, participating in a wellness support group has been really meaningful for me, and in my local MS support group. But this is just a survey of ways in which other people can help MS patients in the US in coping and managing stress, emotional support, household chores. We're kind of all in the top three areas identified, but don't be afraid to ask for help.

And sometimes. I think, you know, you may find people who aren't able to do some things because they are limited by their MS may be able to help in other ways. So, for example, one of the members of my support group has trouble really with his energy level. He has primary progressive MS. It's really challenging sometimes, but he loves helping people manage their finances and bills. He volunteers helping people with taxes, and he absolutely adores it, and sometimes he'll say, I can only do two hours of it at a time, but I really enjoy that and that brings me energy. And thinking of the ways that you get energy is really important, and recognizing that you still have a lot to give, just as much as you might need help, too. Or at least that's been my experience with MS. And that there are a lot of people out there who are able to help us and there are also a lot of people who can benefit from your help and your gifts as well.

Alisa Druzba:

It's funny, my mother is a retired CPA, so for many years she would volunteer at the local senior center and help people with their taxes, which to me does not sound fun, but you're absolutely right, she was always really excited to do and always felt really great at the end of the day of doing that. Now we will pass it back to Marie for Q&A.

Marie LeGrande:

Thank you both so very much for the wonderful discussion. So this question is for the both of you, for Alisa and Chandlee, I don't have the ability to take a full day off of work to go to medical appointments. I could probably take a half day, but that would impact my income. Do you have any recommendations on how to make time to travel to my specialists with this in mind? I'm about two hours away, each way from this physician. Chandlee, would you like to go first?

Chandlee Bryan:

Sure. One of the first things that I might also do is look into 211 for that situation and also the local United Way and see if there are possibly any programs that can provide assistance, with financial support as well. One thing that comes to mind quickly is just looking at telehealth possibilities also. I think one of the things that we're more likely to see coming up is flexibility. I know, for example, at my local primary care provider, they now do weekend appointments. And one of the clinics that I see with a medical roadtrip, I've made actually a medical road trip on a Saturday morning, to a clinic that was opened on Saturday morning. So don't necessarily assume that they're not open. And this gets into a whole other territory that isn't necessarily our topic for tonight, but just in terms of the power of disclosing a disability sometimes means that you have rights for some accommodations, and one reasonable accommodation may be making the time to see a specialist and figuring out a way to make up hours later.

Marie LeGrande:

You do bring up some really good points, Chandlee. I've seen that there are a number of physicians who are opening on weekends as well as providing evening appointments as well to accommodate those who cannot necessarily make it during the day before five or 6:00 p.m. Alisa, did you have any thoughts?

Alisa Druzba:

Yeah, I don't have a lot to add to what Chandlee said, except for where it is possible, try and make your appointments in advance so that maybe there's a little more flexibility on the schedule, so that you can get the first appointment of the day or the last appointment of the day, wherever you're heading to. And then, also working with your employer and explaining that you want to work and you're a great worker, is there flexibility for you to get your hours in another way or to change your shifts or things like that for the occasion that you need to do that? I mean, they should care about you as a human being, but they should also care about you as a good worker. And if you're able to access healthcare and keep yourself as healthy as possible, then that means you're also going to be at work and productive too. So it really is a benefit to them to enable you to access your care.

Marie LeGrande:

Very good points, thank you, both. So the next question that we have, sometimes I build my road trip around multiple appointments, the last couple of trips a couple of days before one of my doctors canceled. I know that's unavoidable, but it's quite frustrating. I'm sure I'm not the only one out there that has experienced this, but wanted to get your thoughts. We'll start with you Chandlee.

Chandlee Bryan:

One thing I would recommend is making friends with the staff in the office of the medical worker. So, for example, really early on, there was one nurse in particular, in my neurologist's office, Rebecca, who was just as helpful to me as my neurologist was. And so, one thing I could imagine potentially doing, and I'm not saying that it would always be accepted, is when that appointment request, or say the doctor or physician's office pushes back and says, we can't make it that day, is be transparent about the problem, the situation they put you in. And just to share with them, you know, I have made this arrangement to see these two providers on this day. This is how I've set up this appointment. You know, I've done this, this far in advance. Is there anyone else on your staff I can meet with? Or could we potentially do this, and the telehealth way, or could I come in and meet with one of your paraprofessionals and get some of the diagnostic piece done? And could we get the other piece of it through telehealth?

But sort of not accepting just no for an answer at first. I think it's something that I would do. I mean, and I know that sounds a little forward, but about a year ago, I was at the dermatologist and I had an appointment in my office coming up in 45 minutes. They were over an hour late and finally I stuck my head outside the window and I said, Listen, I only have about ten more minutes before I have to go. I need to reschedule. I have a really quick question. And they had somebody in the office to see me in two minutes, but that was me speaking up. And I think it's sometimes about figuring out when you need to speak up, too.

Marie LeGrande:

Exactly, advocating for yourself. That's always very important. Alisa, what are your thoughts?

Alisa Druzba:

I mean, I think Chandlee did a great job covering that. Absolutely, you know, tell them what the situation is. Explain it to them. Make yourself a person and explain what's going on. Or you may end up having to switch if you do get that in advance and one of your appointments has been rescheduled, you can call up and maybe try and slide the other one over to the new day. If you feel like you feel comfortable doing that and you feel confident that one will actually be followed through with. But, you know, just sort of explaining to people in a really reasonable way why you

just want to make sure there's no other opportunities because it's taking you a lot to kind of create your road trip and make your plan and get all of your ducks in a row. And we recognize that things happen, but just really seeing if they can accommodate you in a different way.

Marie LeGrande:

That's very true. And I know sometimes I've had experience where nurse practitioners have stepped in if the physician isn't available as well. Thank you both. So, next question - I live in a very rural town where getting around town is quite difficult. My MS is advanced and I have a hard time getting around my home, let alone being able to go to the grocery store and medical appointments. I tried to find a service that can help me get to my appointments, but it didn't work, so I rely on my daughter for help. I'm just worried that I'm overburdening her. And no, she's not always available to help. Who could I reach out to for assistance? We'll go with you, Chandlee.

Chandlee Bryan:

One of my favorite organizations is always the United Way, because they are in so many different communities and because they screen organizations for fundraising purposes, so I always recommend the local United Way as a place to look for potential healthcare providers. I know if you're in New Hampshire, the visiting nurses associations are fantastic and they have provided a lot of services to people. But I think figuring out who can be helpful, I think also identifying a community of support, and sharing with people what could be helpful to you and where you have need of it. I know, for example, right now I have a cousin who has a spouse who is in a hospice. And so one of the things that she's been really great about doing with me recently is saying, These are tasks that I need specific help with. And she's got me on a list of about five people, and she rotates sort of the areas that she needs help with.

Marie LeGrande:

So, Alisa, are there any resources that you can think of that could perhaps assist someone in that situation?

Alisa Druzba:

So I would again recommend 211. I would also, if you have a local hospital, local hospitals have social work departments and they're very connected with community resources. You don't have to be a patient being discharged in order to access that. So you can reach out to them as well and see what they're aware of. There are tremendous amounts of faith based or other kinds of organizations that run volunteer programs and may not get all of your needs met, but they might specialize. So, for example, you could supplement having to go to the grocery store with perhaps accessing a service that delivers meals to you. So you could kind of work a couple of different angles there with access to food and also with transportation.

The other thing that a lot of primary care practices, the ones that are what we consider to be safety net, which are the ones that are looking out for those folks who are particularly vulnerable populations, they will have what they call our enabling services, and they have another whole person who sits in that office really trying to figure that out because what we know is that there's so much more going on with patients, MS or not, than just accessing healthcare. There are educational needs, there are heating costs needs, electrical needs, work, transportation, all kinds of things. They're referred to often as the social determinants of health. And there are a number of different factors that impact people's lives outside of accessing healthcare visits. And so what we've seen is people start to staff up with folks who can focus on that and can really be that connector for you and referring you to things and making suggestions. And because they're

based in your town, in both the case of the primary care practice and also the hospital, it's very specific to your community. And often they'll know about things that are not easily searched on Google as a resource as well. So I would try those.

Marie LeGrande:

Wonderful, thank you. And the last question that we have, sometimes I think that I should plan my medical road trips for two full days versus one, for example, my specialist wanted me to get an MRI in our hospital system versus the place I had gone to before back home. They were able to get me an appointment the following day, or I could come back in two weeks. I stayed overnight, but it was a lot. Any thoughts on that? Chandlee, you're up.

Chandlee Bryan:

I think one thing that's important is if you are employed and you have a health savings account or flexible spending account sometimes your expenses can qualify if you need to take a medical trip. So I think it's worth looking into whether there are programs that allow you to get reimbursed for staying overnight. And I think sometimes it can be a good idea.

One of the things that... one of the studies that I was able to work with, the MSCQI study, did in a rural area, was really to look at scheduling in that way, but to coordinate care so that the providers were also looking into it. So, for example, schedule your MRI first thing in the morning and then schedule your follow up with the neurologist later that afternoon, after it had been read. So figuring out if that's a possibility and asking the scheduling team if they can do that as well might be worth it.

But again, I think it's also important to really think about your energy levels knowing what you're able to do. To me, one of the fun things about a medical road trip sometimes is the place that I go, Concord, New Hampshire, is actually also where I have a couple of friends and family. So I have people that I can spend the night with, and I have people that I feel comfortable enough asking if I can stay over with. Sometimes if you are able to get involved with your local community over time, you will develop those types of relationships even if you don't have those networking connections yet.

Marie LeGrande:

Thank you, Chandlee. Alisa?

Alisa Druzba:

Yeah, I mean, you know, piggybacking on what Chandlee said, I think it's really up to you to sort of figure out, you know, what kind of person you are with sort of energy level. So if you're the kind of person who just wants to sort of get it all done in two days and book a bunch of stuff in there, maybe book some fun stuff in there, maybe food in the area that you can't get at home, a favorite pastry, seeing a friend, seeing a movie, whatever it is that kind of makes the most out of your urban visit, if you will. But I think if you're not, you should really ask what your... feel free, like we were saying earlier, to say to your provider, Oh, you want me to have an MRI tomorrow and you want me to have it here? Can you tell me why? Is there something about the visit today that makes you think I need an MRI within the next 24 hours? Is there a reason you're sending me to the MRI facility that's part of your hospital group as opposed to this other place that's actually easier for me to access? And just sort of figure it out because they may just be making referrals because that's their process and it's in place and it's a lot easier to do the easy thing and do that work, and they probably think, Oh, you know, most people want to, you know, a test

sooner rather than later. They're thrilled when we can get them right in. And so they're going to make a lot of assumptions about you.

So I think it's really important to ask them questions about that. And then, you know, feel free to say, I don't think I'm up for that. You know, for some people, travel is fun, and for some people, travel is a lot stress, and some people can't be away from home for more than a certain period of time. So I think it's OK to share some of those concerns.

Chandlee Bryan:

And Alisa, I think you bring up a really great point about the, about questioning. What is it that you need? It's different. So for example, I know one of my neurologists likes to look for very specific slices, and I don't understand what a slice is on MRI's, but she gets very specific in terms of what she needs. But if she can get that information to a local provider and figure out like, who might have that information, that's important as well.

Marie LeGrande:

Wonderful. Well, thank you both so very much for this wonderful and insightful presentation. And I should say more of a discussion between the both of you. I'm sure our audience truly appreciates the discussion around this topic.

So this concludes tonight's webinar. We would like to thank our funding partners, Bristol Myers Squibb, Genentech and Greenwich Biosciences for supporting this series. We would once again like to thank Chandlee Bryan and Alisa Druzba for taking time out of their very busy schedules to provide us with this critically important information.

Thank you to Impact Education for their partnership in delivering this program. As mentioned, tonight's webinar will be archived at MSAA's website, and we ask you to please take a brief survey that is coming up next. Program funding is dependent on our evaluations, so please just take a couple of minutes to answer a few questions for us.

On behalf of MSAA, Impact Education and our panelists, Chandlee and Alisa, we thank you so much for joining us this evening. Please see the next slide for MSAA's website and contact information. Thank you all very much and have a great night.