



Creative Communities: Taking Advantage of Unconventional Resources

Presented by: Dr. Brant Oliver, PhD, MS, MPH, FNP-DC, PMHNP-BC and Cheryl Breton

Kyle Pinion:

Hello and welcome to the Multiple Sclerosis Association of America's live webinar, Creative Communities: Taking Advantage of Unconventional Resources. I'm Kyle Pinion, Senior Director of Education, Healthcare Relations and Advocacy for the Multiple Sclerosis Association of America and your host for today's program. Happy Saturday, everybody. On behalf of MSAA, Impact Education and today's presenters, we greatly appreciate the opportunity to keep you updated on this very important topic. And please know we hope you and your family are always staying safe and healthy in these very uncertain times.

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 nonprofit organization and service for over 50 years dedicated to improving lives today for the MS community. I wanted to take a moment to give a briefer than brief overview of our services. If you've called us before, you've likely already connected with trained and compassionate Helpline specialists who have a social services or counseling background and are familiar with multiple sclerosis. Helpline specialists can assist people living with MS and their care community with identifying helpful MSAA program recommendations, as well as other resources available from the broader MS support community. A very timely thing to talk about right now, actually, given the topic of the program.

I will also note that the MSAA Cooling 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 the symptoms of MS. Examples of products available through these programs include 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 visit the MSAA website, pop us over an email or give us a call, we would love, love, love to hear from you.

Also, a brief reminder that the discussion being presented today is for reference and informational purposes only and does not constitute formal medical recommendations. For any and all personalized recommendations, please be sure to consult with your medical professional.

And we also want to extend a huge, huge thank you to our friends at Biogen, Genentech and Sanofi Genzyme for their vital support of our new virtual display hall. If you haven't had a chance to visit yet, 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, you could join us today, today's program will be archived on our website very soon, probably within the next few weeks. For our Q&A session, please type your questions in the chat box and we'll address them at the very end of the presentation. And if you're having any technical issues at all, please type those concerns in the chat box as well. We'll be happy to address them.

Finally, at the conclusion of today's program, you'll be asked to complete a short survey. We would be so grateful and appreciative if you complete this survey before closing out the meeting 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 really makes them possible.

With that said, I am delighted to introduce you to each of our presenters for today's important discussion on creative communities. First things first, I would like to introduce Dr. Brant Oliver. Now Brant is a Healthcare Improvement and Implementation scientist, educator and ANCC board-certified family and psychiatric nurse practitioner. Dr. Oliver's work focuses on applied healthcare improvement science research with a focus on 3-C, those three C's are complex, costly and chronic, health conditions, including multiple sclerosis. He has been in clinical practice since 2003, working primarily as a certified MS specialist and neurobehavioral nurse practitioner. In 2020, he founded the Chronic Health Improvement Research Program, which applies improvement science research to optimize care experience and outcomes for people with those same 3-C conditions. In 2021, he was appointed as interim Associate Chief Quality Officer for Patient Experience at Dartmouth-Hitchcock.

Now, our other presenter, Cheryl Breton, is a mentor with the Concord Hospital MS Pure Wellness Program. Since being diagnosed with multiple sclerosis over 35 years ago, Cheryl has overcome many obstacles, including regaining her ability to walk free of mobility aids. Cheryl's optimism, curiosity and determination have enabled her to turn a challenging journey into a valuable education in nutrition, fitness, health and wellness. Cheryl now uses her experiences and knowledge to help her mentees work with obstacles relative to MS and challenge them to live a life by design rather than diagnosis.

Really a powerhouse duo, and I can't wait to dive into this topic with them. One of the key things before we begin and I hand this over to both Cheryl and Dr. Oliver, is just the discussion about the design of this program. So when you talk about things like resources and communities, it's important to note that every community has different resources. No community is like another community. and when we start talking about rural communities, the disparate nature of resources that are available is a really sort of key thing to understand and underscore. So before we designed this program, Dr. Oliver and Cheryl had the brilliant idea of actually surveying people out in these communities to have a better understanding of what sort of drives people towards certain resources, what resources are available, and how people are able to overcome any particular obstacles in their community. So you'll find throughout this program a number of these slides are driven by those questions that were asked and the answers that we received.

Secondly, I would like to note, again feedback being key, we would love to get your feedback during the course of this program. Do not be shy. For those who are attending live today,

please, if anything strikes you at a certain point, we would love to hear your thoughts and responses, some of the questions that we receive, and I'll be looking at the chat to make sure that I feed those over to Dr. Oliver and Cheryl after talking within the context of those certain questions. With that, said, Dr. Oliver, I will start with you and turn it over to you.

Dr. Brant Oliver:

Thank you, Kyle, and it's a pleasure to be working with MSAA this afternoon and with all of you that are attending and especially to be partnering with Cheryl on this really important program. Cheryl and I have collaborated for many years now in the MS Wellness program. And it's a real treat to be able to have a conversation with Cheryl today in response to these questions that we're going to ask you first and then we will have a discussion and follow up to the responses we see. And I see already we're seeing some folks chiming in on the chat already, and hello back to Montana, it's great to have you with us, Grace, and I'll kick us off here with the first of a number of questions that we're going to ask you the audience. And we'd invite you to respond by using the chat feature on your Zoom webinar. So this first question is: What are some situations that people with MS might want or need to identify resources? So what are some things that we might need resources for in the MS community, especially in rural areas?

Kyle Pinion:

I've already seen one very good point - local transportation assistance is a really, I think, key thing for people in rural communities in order to get to the things they need. Here's another good one - mental health resources, things that are local to them as well. Physical therapy, another good addition. And a good question. With those three, perhaps we could tackle those, Brant and Cheryl, in terms of thoughts locally. Let's start with local transportation assistance, perhaps.

Dr. Brant Oliver:

Sure. And, Cheryl, do you want to start or would you like me to jump in?

Cheryl Breton:

I can start. I know for me there have been a number of times that transportation has presented an issue. I know that I've been able to touch base with my physician. The MSAA website can help connect you with organizations that help manage transportation. Volunteer groups and local churches, and the great thing about a church is you don't necessarily have to belong to a specific church. They're just people willing to help. They have good hearts and they want to make a difference in their community. The community I live in, you're a good seven acres before you even have a neighbor. So you're really limited in that regard to what you can do. So you have to do the research to try and manage your way around, period.

Dr. Brant Oliver:

Maybe we can go to the next slide to build on Cheryl's comments by just showing the participants what we saw in our regional survey and what, for the benefit of the audience, as Kyle has previously mentioned, we did a survey a couple of weeks ago with the members of our peer wellness outreach community in New Hampshire. And it's a rural community and it's a group that's been working together for a number of years. And in their combined experience, they have quite a bit of knowledge about the rural community and its barriers, and also its facilitators, what's good about it and also about resources. And interestingly, if you look at what went into the chat, we saw transportation, mental health, physical therapy. The bigger the word is on the word cloud, the more responses came in around those issues. You see that the word

transportation is quite large. So in the rural community, transportation is a big deal and also resource capability is a big deal.

Dr. Brant Oliver:

But we also see a number of other things show up, like access to services. So the comment on physical therapy, how do I get access to physical therapy at home and how do I get access to experts? How do I get help with symptoms? How do I find things? See the word find down in the lower left hand corner. How do I find the things that I need and how do I get the support that I need? Upper left hand corner of the slide. And then how do I get internet based resources? Right in the middle there, pretty large word "internet" there. And in rural communities, sometimes, that's an issue. Sometimes internet access isn't as good as we would hope it would be, or technology access, and that has implications, especially if you're looking to do online activities or virtual activities, including telehealth visits with your providers. Sometimes, certain rehab services can be done virtually. I have a few patients that actually in New Hampshire are doing physical therapy with a provider out in the Midwest doing virtual PT. So getting to Grace's point about any help with physical therapy at home, sometimes it's getting the PT to you in your house. Sometimes it's getting virtual PT to you from providers that aren't located physically with you.

There was also another comment in the chat about, is there an online or Zoom support group that we can access? And I wonder, Cheryl, maybe we'll talk more about this later, but maybe you can give them a little teaser about our MS Wellness Community and what we're doing virtually around that kind of thing.

Cheryl Breton:

The MS wellness community is such a benefit. It's emotional for me, sorry. We work together. We learn each other's strengths, weaknesses. And we're able to work together to find the solutions that work. The majority of our meetings, especially lately, are done either online - Zoom meetings, Google Meet, telephone, email. And you really learn how to communicate clearly, and you learn so many new ways of just getting solutions and living your best life possible.

Dr. Brant Oliver:

Thank you, Cheryl, and I know that we've got to move to our next question, but we'll talk a little bit more about how that community works and how it was in response to resource needs of the rural community. We had a barrier to access for peer support and networking and a number of other things. And what was really unique about it is that this was not a professional driven thing. It was started by a professional, me, who got some grant funding and then got some really interested people with MS to co-lead it with me. And the rest is history. The program's been around for almost a decade now. We'll talk to you more about that as we move forward.

And I saw that there was another chat comment about how can I find employment or working at home? That's one we'll definitely touch upon as we move into the next question. And question two, and again, we would invite your comments here in the chat - Where can someone start looking for resources? What should they look for? What do you do and what do you think is helpful?

Kyle Pinion:

One person has mentioned MSAA asking about local resources. So I guess, yeah, I think that point is that approaching organizations like MSAA perhaps?

Dr. Brant Oliver:

And it could be that using something like the Helpline to get some initial advisement on what local resources might be available and, you know, just because we're talking about rural situations, it doesn't mean you can't access national organizations to help you. MSAA, the National MS Society, and others are critically important. And it doesn't matter if you're in an inner city or a rural community. The value of those organizations is equally important in both situations. So using MSAA's resources, getting help from the Helpline, et cetera. Really good idea. Really good idea.

Kyle Pinion:

Great. We've also got - identifying local MS organizations, which, you know, I feel like that's probably something that's kind of few and far between, sometimes. It is particularly hard in rural areas, as this person points out. She said they liked Cheryl's suggestion about connecting with other groups like church groups, and they feel like building a support network is obviously very important. So I don't know, Cheryl, if there's some thoughts you might have about building that support network further or anything that toward your experience that might be able to add to that thought.

Cheryl Breton:

No, I do believe that building a support network is very important. One of the biggest issues with having MS is more often than not, you feel alone. So, developing that support network for yourself can be vital. And, through organizations like MSAA, there are groups, they can direct you towards groups, you can do Google searches, which I can't say I am the biggest fan of, but I have had success with them.

Now, in the age of Facebook, there are a number of virtual support groups on Facebook, and they meet daily, weekly, monthly. There's a large variety to mix with any person with any mobility level.

Dr. Brant Oliver:

To build on that, there can be multiple pathways to get advisement on how to find resources and where they are. One is, as Cheryl mentioned, through your own knowledge of local resources, through online support communities, and also, as we previously discussed, through accessing national organizations like the MSAA. Another way can be through leveraging and getting involved with a local support community, and it's through the people in that community that know the local area that suddenly identify all these things you never knew existed. Like, Wow, you know, there is a wonderful yoga program over here, and there's a place that does modifications to bicycles over here to make them power assisted. And oh, there's something over here that does tai chi, and that they're not they're not known or publicly broadcast on websites that you might search, or in other online communities, and the national organizations may not even know about them, but these support communities do because they live there. And once these support communities start talking to each other, the people in them, suddenly, as a group, that whole community starts learning about all of this extra stuff they didn't know about. So that's another pathway. National organizations, online communities and peer support groups.

Let's move to what our survey said. Let's see how on target we were. What the survey said. Where can someone start to look for resources? National organizations, we mentioned that and also local organizations - United Way, YMCA, local chapters, churches. Social and online groups such as Facebook. Resources identified by providers and your MS Center. We didn't talk

about that too much, but that's another area, too. Your providers are seeing people from the community, so they're gaining some cumulative knowledge of what's going on throughout the community that they serve and they have some guidance as well. What's kind of cool is when the providers and the support groups start working together very closely, like we have in the wellness program, that Cheryl and I work on, we start sharing knowledge about those resources, so suddenly what the providers know the support community knows, and vice versa. And we start to be able to get much more aware of our local resources.

And the question about what they should look for, this is interesting because it hits on a number of the comments in the chat from before. Accessibility - finding the resources is one thing, can I get into the building? How do I get access to the thing once I find it? Are there travel considerations? Are there technology considerations? Wow, I found this wonderful online thing, but I don't have the internet speed needed or the computer I need to get to use that internet service. And the bottom bullet, boy, Cheryl, we could speak to this one, huh? I'm seeing information, is it reliable? Can I trust it? What do I do with what I'm seeing when I learn things from these online communities? And how do I protect myself against scams? What are your thoughts on some of this stuff, Cheryl?

Cheryl Breton:

Well, as far as the reliable information, in doing research for the wellness program, because there's a variety of issues that you're trying to work with, and I keep notebooks and I bullet point the initial resource that I found, a possibility, and then they narrow down to the actual resources and how good they are with feedback that other people have used. I've been surprised that there is so much out there that you're just not aware of. The reliability of the issue, it takes time and research, and unfortunately, sometimes it's trial and error, which you don't want to have to do.

Dr. Brant Oliver:

You know, to build on that comment, one other protective mechanism we found that comes out of our wellness community is that we meet monthly online and we talk about this stuff. And that's a place for us to pressure test the things that we're learning. Hey, did you read this? What do you think of it? You know, is it reliable? How good is that information? Has anybody talked to a provider about this? et cetera. Where did this come from? Oh, it came from the MSAA, you can probably trust it. You know, that kind of thing. That conversation helps us to pressure test what's out there and also not feel so alone when we're looking into all this stuff.

And I was going to ask Kyle for a minute to summarize what he's seeing in the chat. Well, one comment that I saw was, sometimes the doctors don't keep up with us, that they don't quite understand our needs? Having this interaction between support groups and professionals can actually help the providers keep up with you and make sure that they can hear what your needs are. Kyle, what are you seeing in the chat?

Kyle Pinion:

Well, I just wanted to add to what you were saying that I completely agree. I feel like support groups, self-help groups, whatever term you want to use, those tend to be sort of like front lines in terms of keeping people connected in the community. And I do want to add, and I'm about to put this in the chat for everybody, a link to myMSAA Virtual Community, which is a really wonderful forum as well, not to upstage anything that Dartmouth provides as well. But I also would be remiss if I didn't mention MSAA's community forum that you can absolutely join at any

time and there's wonderful conversations that are available. So at that link that I just sent to everybody.

But secondly, in terms of what I'm seeing, I just see a big underscoring, I would say, in terms of if you are looking for resources in your community, the first thing to do is to get connected with all the local nonprofit organizations, as well as the MS organizations. And I think Mary has a really great comment about that, where she says that there are several good support groups on Facebook, Twitter and you can find good bloggers around MS, that, I think, have a lot of great information as well. And the virtual chat groups, which includes both the wellness virtual group, that you guys are referring to, and myMSAA community forum, among others. So really, I think it's just a an amplifying of the message that we're already kind of sharing here.

Dr. Brant Oliver:

Kyle, here's a great question from Grace, saying is there such a thing as a book that includes resources state by state? And boy, would it be nice if we had a centralized resource for that. I imagine that's on everybody's To-Do list. And I almost wonder if there's an opportunity to, as you know, we're starting to delve into understanding rural health needs more, to actually doing a needs assessment survey from the MSAA about local resource needs and also which resources people in the communities are finding most helpful. And from that, we might actually be able to put together something like that - a recommended resource guide for rural communities.

Kyle Pinion:

I think it's a great opportunity, Dr. Oliver, for sure, and bless you, Grace, for not using social media, I wish I had your strength. But I definitely understand your security concerns.

Dr. Brant Oliver:

Let's go to question three. And this one here asks, what are the resources you share with those living in your rural community? Are there any in-person resources you turn to? Are there virtual resources that are your "go-tos"? This actually gets at just what Kyle and I were talking about. We're doing a little mini survey of you. What are the things that you go to? What are the things you trust? What national organizations do you turn to and what local resources and organizations are your first point of contact? So if someone you just met and who's newly diagnosed just came into your support group or into your circle and you say, Well, you got to go to X, check this out. What are those things?

Kyle Pinion:

Well, it looks like one of the first bits of feedback we've gotten is again, getting back to social media, Facebook groups through my support group seems to be a pretty popular answer. Also, my support group, somewhat as mentioned, has started a text chain so that we can connect and support each other between meetings. It's a nice way to connect. You know, Cheryl, that does make me wonder, in terms of the facilitation of these groups and sort of staying in touch in between meetings, have there been any tried and true methods that you've seen in your experience?

Cheryl Breton:

Basically, you... Because it's a topic that is so personal to each of us, there may be one comment or a subject matter that isn't my strong suit, so I might not delve into that, but the next person will. And because with MS there are so many different symptoms and issues and ailments, everybody is always checking it out. You're always following it through, so it kind of facilitates itself, almost. Every time there's a new question, you have some people that are

going to delve right in and start trying to research it to look for information and want to share that information. And then you're going to have others that have had it, found it and are willing to share. So it's an easy, relatively easy, facilitation project.

Dr. Brant Oliver:

And Cheryl, you know, I'm thinking back about our collaboration in the wellness program, and I think other support programs may have a similar experience and that there's no one way to always do it. It depends on the needs of the people in the group, in the community. Some prefer high tech like social media, especially if it's a secure social media approach. Others, like a "less touch", they like to come every month on a webinar and just hang out or go to an in-person meeting if that's safe to do so. And others really like the more consistent contacts, like this text chain idea is really cool, because it's a highly accessible option. Most people have cell phones with text service enabled. Not everybody, so we have to make sure we don't forget those who don't have that. But that's a really creative option. In our program, we use a secure online Facebook group, but it's the same idea. And that others really like a personal approach, to work one on one with another person with MS, to talk that way - Go for a cup of coffee. Talk on the phone. And there's a number of different ways to do it. And it seems to me, Cheryl, that our success in our program has been because we've tried to do multiple ways. We haven't forced everybody to do just one way. We've tried to create multiple options for people.

Cheryl Breton:

I think our success is in that we don't want anyone to feel neglected or we want everybody to be part of the group. We want everybody to be part of the solution. And so whatever it's going to take to get that done, we do. The Facebook group, there's always some sort of conversation going on in Messenger, with Facebook, with that group. And it's, at times, it's enlightening, it's educational. It's a great break from the day. And although it's an MS community, it kind of helps you not have MS, or the fact that you have MS, on the forefront of your brain every day.

Dr. Brant Oliver:

Really appreciate that comment, Cheryl, and also Mary's comment, talking about, well, you know, really the power of networking and that there's a number of resources out there like WEGO Health and HealthVoices and others that could be considered in conjunction with local things that you're doing in this idea of reaching out and getting actively involved. And, you know, Cheryl, you started off in our work as a mentee and then became a mentor. Can you talk a little bit about what effect that's had on you being a mentor, helping other people?

Cheryl Breton:

For me, when I, for a number of years I had lost my ability to walk on my own, and when I was told that I would permanently be in a wheelchair, I was like, OK, this is not going to happen. And I realized at that point that there weren't many solutions or, even, there weren't many resources that would say, give it a try. Maybe you can get past this. Everybody, the majority were like, Nope, this is it. You're, you know, live with it. Being part of the wellness program you get to try different things, see what works, see those challenges be overcome by mentees that you work with. And in our group, you get to see the progression of people that isn't your specific mentee because you're part of the the Facebook group and you see the conversation, you see the pictures. It's like, you're really a connected group, you're each other's strengths.

Dr. Brant Oliver:

You know, the thing that's really impressed me, and before we go to the next question, I'll just mention, just watching this group, it was a group that I started with a small grant, but over time it

is the mentors that now lead it. I just get them grant money and the mentors run it. But what's been interesting is we were worried that the mentors might get tired of being mentors and stop being mentors. And for the most part, they have stayed on because of how good it makes them feel and how important their role is. So the idea that Mary shared to get out there, get involved, get active and not only in terms of benefiting from the supports, but also you have wisdom of your own, that you can contribute to others, regardless of which group you're participating in. It could be MSAA's group, it could be our group, it could be another group in another state somewhere else. Same principles. Think of yourself, both as someone who has needs but also can help others. You probably know the answer to somebody's question.

Let's go to a question four. Oh, this was our survey responses to question three. Let's see how well we did here. National organizations came up, we mentioned that. Direction from healthcare providers, we talked about that. Local patient chapters, we touched upon that a little bit in connection with the national piece. Internet searches, local resources, webinars, Zoom meetings. And then we didn't talk about YMCA too much. In many communities, YMCA offers quite a lot of stuff. And then finding... we didn't really talk about exercise. Maybe we should talk about that in the next section. But finding the right exercise locations or resources, and they may be a gym and they may not be, you know, if you're into tai chi, you might be looking for a dojo instead of a gym. But those were some things that came out of our regional group, many of which came up in your community.

Let's go to the next question. What do you do when the resource you need doesn't exist?

Kyle Pinion:

All right, the first comment we've gotten in - Sometimes I talk to my support network about it and we brainstorm solutions. You know, two heads are certainly better than one. Sometimes ten are better than two. So I think that's potentially a very good place to go. And Grace thinks this is a great question about resources that don't exist. For example - my sister has better internet than I do. So I go to her house for my virtual support group meetings. And Mary says that when a resource does not exist, speak up about it, express the issue and get people to hear you, be your own advocate, basically.

Dr. Brant Oliver:

I like Mary's point there, and Mary's had a lot of great points throughout this program. Our regional program came about because a number of people with MS that we were helping as part of our MS clinic brought up that basic thing. They said, We need a regional network, we need X, Y, and Z, and we don't have it. What can you do to work with us to make it happen? So people speaking up, you may think that no one's going to listen or that they don't have time, but they will. They will listen. Your providers really do care about what's happening and also your MS associations - the MSAA, National MS Society. When Kyle was saying, Please contact us, please call us, he wasn't kidding. He was saying, Hey, get on a call, call the Helpline. Tell us what you need. That's why we're here.

Kyle Pinion:

Yeah, agreed. It's a really key thing in order to get feedback, to know what's not available in a community, we sometimes won't know that until someone tells us. Sometimes there are things that are obvious, but then there are the occasional issues that we're just not aware of. So I certainly encourage anyone to get in touch with us and let us know about inequities in your community. And at least we can kind of talk about what may be potential solutions to the issues you're facing, if at all possible.

Cheryl Breton:

I will say I have used MSAA a number of times. I have their app on my phone and one of the first things that made me really rely and appreciate how strong of an organization it is, is one of the times that I called looking for some sort of, like, personal trainer. There wasn't anyone in my area. But they worked with me, gave me some ideas to try. And it was probably a month later I got a phone call from the gentleman that had been helping me with MSAA and just wanted to touch base and see how things worked out. And I was like, Wow, with all of the people, you know, it's not just a robotic phone call. They care. It is the mission, it's a project.

Kyle Pinion:

Thank you, Cheryl. I really appreciate you saying that.

Dr. Brant Oliver:

Grace has a great question about financial impact, and I think we'll try to address that one after question five. Just so we can keep us on on task, but this is a really important one, financial impact, especially right now. Here's what our survey respondents said about question four. And they had a number of ideas and then what we tried to do is put them into some type of flow diagram that might be practically helpful. Many people started with internet or reaching out to healthcare providers, traditional searching approaches and then adapting their search, perhaps based on what they're learning in their local communities. And MSAA and other national organizations were listed as a part of this process. And then this idea of sort of refining and adapting your plan based on what you're learning and then perhaps a final pressure test in the peer to peer connections, a local area.

Now this isn't the the only pathway you can take. But what's interesting to me, I'd be interested to see what Cheryl thinks as well, is that a number of the key elements that keep coming up in the conversation, appear to be coming out here - web-based supports, interface with your provider and your MS center, the national organizations like MSAA and National MS Society and others, and the local peer support networks, getting involved with one of those, or even a national peer support network like the one that MSAA has. Having those components, those four things: internet, provider, national organization, local peer to peer support involvement, seem to be critical parts to have on your checklist. Cheryl, what do you say to this?

Cheryl Breton:

I agree. 100%. I know I may only see my provider once every three to six months, but they have a patient portal, and at any point in time, if I have a question or I have an issue that I want to look into, I can just log on to that, send a message and my new research is going to be off and running, right then and there. The peer-to-peer connection, It's a way of reminding you you are not alone. If you have something that you can't find a solution to, great minds think alike, and you're going to have a collaboration of people and you're going to come up with a solution that is probably going to have as good, possibly better, results than if you followed someone else's tried-and-proven way, because it's specific to you, it's your way, you did it.

Dr. Brant Oliver:

Now, that customization of the strategy to fit you is something we've really observed in our program, what we've seen in other programs too. You know, a cookie cutter approach doesn't fit all, for sure. And it looks like we're seeing some questions to learn more about the MSAA peer to peer connection platform. So that's excellent. Maybe we can put some information in the chart for that. Let's go to question five. I think this is our last question here. What steps have you taken to create the resources that you need most in your local community?

Kyle Pinion:

One person said, this is nice to hear, there aren't any additional resources to create in their community, they feel very well supported. I love to hear that.

Dr. Brant Oliver:

That's always a possibility. That's one that we like.

Kyle Pinion:

Oh, yeah - resources for caregivers. You know, as one I can tell you, that's always very close to mind for me. I'm trying to start something for my husband. So, yeah, caregiver resources are a big one, they are often left out. We, and I will tell you, as someone who facilitates a lot of educational programming, I hear a lot from care partners who ask for education directed solely at them. So that's something that's really top of mind.

And you know, Mary, yeah, good. Good for you, Mary. You search and you talk to people, explore everything you can, you know, be the change you want to see and keep yourself as well informed as you can. I can't fault that, that's a really excellent plan. But yeah, caregiver resources, it's an interesting thing.

Dr. Brant Oliver:

And, you know, Cheryl, as I look at Mary's comment, I'm like, Oh, Mary, would be a wonderful mentor, and with 23 years of experience, imagine the wisdom that someone like Mary has. Cheryl will be calling you, Mary, we're going to sign you up. Just think about the more experience that you have with MS and the more knowledge you have in your local community, you actually become part of that wisdom, part of that resource in the community. And sometimes we're so focused on thinking about the problems and the lack of stuff, we sometimes don't realize that within ourselves, we have quite a bit to offer. You're part of the resource. And so especially for many of you who have lived experience with MS, you start working together. It'd be amazing what you find that you know.

Let's see if there's any other comments about what steps you've taken to create the resources you need. Anything that's worked really well? We'll put up what we found in our survey while you think about that. Again, internet-based approaches, local resources and also outreach to providers, those would seem to be the three basic strategies that came out of our group.

Kyle Pinion:

Grace brings up a very significant point, which is just being so overwhelmed with your MS, it's difficult to really be that sort of change in your community. Even if you want to, sometimes MS could be such a challenge for an individual because everyone's MS disease course is, of course, different, that flare ups are an ongoing concern on a daily basis. And I don't know, Cheryl, if you've ever run into that in the community where someone has said, you know, I just I don't know how to get through the day, much less figure out how to plan something that might be able to help the broader community.

Cheryl Breton:

There are so many days that you just, you're not sure you can make it to the end of the day. You can't plan for the future because you're not sure what your abilities are going to be from day to day. And the flip side of that is, for me, the challenge became finding things that I could do that I would want to do if I couldn't walk. I learned to cross stitch. And at the time, I didn't have feeling in my fingers, so there was a lot more stabbing of my fingers with the needle than there

was actually completing a project. But at least it was something that I could attempt to do. And that in and of itself gave me some level of satisfaction. It wasn't something I ever thought of doing before, but it was new and I could do it and I could get better at it. So instead of looking at the challenge, it was just finding ways to redesign what I was, what I wanted. To get to the next step. And it was just coming up with my own individual game plan.

When I wanted to start learning to walk again, there weren't many physical therapists that would take me on. But I had a physical therapist that put me in touch with somebody that was interning in his office. And she worked with me day in, day out at my home. It was a learning exercise for her. It was a learning curve for me. And it just worked wonderfully. So you just, you can't ever give up.

Dr. Brant Oliver:

Patricia is echoing your comment, Cheryl, in the chat. She's saying, Hey, you know, it costs a little bit more, but I'm bringing people to me and I'm worth it. I think that's awesome. That's, you know, that's a tailored approach. You know, the other thing I wanted to say to, I think it was Grace's comment, thank you for being brave to share that, number one. And number two, there's so many people that are in the same situation feeling the same way, and just as Cheryl was saying, you may not need to have the answer. And in what we see in a number of support group settings, including ours and others, is that you do as much as you can when you can. It may just be getting to the webinar. You know, just being on the webinar once a month is all you can do. And later on, you want to do something else, you learn something else. And so, if you don't have the answer, if you feel overwhelmed, as my soccer coach used to say, just show up to the game; just show up to the group and be part of the group and worry about winning the game later. But if you don't show up, you can't win. So you could find an activity or some group or some support or some activity that makes sense to you and you can start there, even if you don't know if it's the right step.

And Mary's saying, yes, reinvent yourself. Explore new ideas. You know,

Kyle Pinion:

Dottie brought up another good point, too, about mental health resources and I think in relation to this pandemic, and we talked about this in previous iterations of this program over the last couple of days, last week, where we've talked about how the pandemic has had a doubly strong impact on people who are already potentially feeling isolated - I have MS,. I'm the only person in my community who has MS potentially, I'm the only person I know that has MS. And now, because of the pandemic, I feel even more housebound. I feel even more isolated. So I am kind of curious about the mental health resources that you both potentially access that may fall in line with some of the things we talked about today.

Cheryl Breton:

I know that for me, there are a couple of online organizations that are geared towards health and wellness. And they always have unique, entertaining, and successful ways to at least get you through the day, to get you through. Or to get you to start accepting the difficulties that you're handling at the current time. The area that I live in, it's anywhere from 45 minutes to an hour commute to get, like, a formal mental health provider. So the virtual thing comes in handy at that point. I, at times, me personally, I feel like I am so committed to looking at the glass half full that I don't even contemplate it going below half. At this point, there is so much for me to be grateful for, the best thing that I can do is to share my strengths with others within the community. So, and in that regard, there are probably eight or nine of us that are expanding

within this area, to do what we can to get people to find the resources that best suit them. And in some cases, it is finding a friend to get someone to a provider's office so that they can have the one-on-one time and then go to a virtual-type setting.

Dr. Brant Oliver:

There's been a lot of comments that've come in about the virtual aspect, and I know we have to go to Q&A, but I'll add just a 15 second comment to build on what Cheryl said about what's happening on the provider side. A lot of MS centers are embedding mental health practitioners. I'm an embedded mental health specialist within a MS center. That's one approach. And then we collaborate with your primary care providers and your MS specialists to improve access to specialty care. Virtual telehealth has been a godsend, especially in COVID. Health systems finally had to get with it and use more telehealth than they have used in the past.

And many of the folks I worked with as a mental health specialist loved it. Mary added a comment about - so helpful, I can be at home and do therapy. And also, imagine if you're in crisis, wouldn't you rather hear from your own provider by telehealth in your own home than having to call a crisis line and explain your crisis to somebody you don't know? So there's really a lot of options with this virtual capability that could increase mental health. And there's also a lot that can be done on prevention - being part of a support group, being part of a community, even if it's a local church, it doesn't have to be an MS support group, if you're part of a church or a YMCA, if it's national or local. But that sense of belonging and reducing isolation and interacting with others actually has a mental health boosting effect. It's not a mental health formal treatment per se, but it really is a big deal. To be networked and connected can be protective from a mental health perspective. So I greatly encourage you to do that.

So, Kyle, I know we're getting into question and answer. Cheryl and I talk too much, but we love talking about what we're talking about. So, sorry that we went into the question and answer period a little bit. We'll hand off to you for question and answer.

Kyle Pinion:

Sure, sure. So I've got a number of questions that have come through and thank you, everyone, for your comments throughout the course of this program. I think we had some really wonderful, engaging discussion here, that really was the whole point of this program in the first place. But I think the first thing that came through, and this is a question I can answer, the question was who at MSAA should we contact if we live in a rural area and want to seek out support. That is very easy. So I will say that you should get in touch with our Helpline and we are happy to try and find what resources there are in your area and if there are any direct programs that may be able to assist you, like our MRI Access Fund or our cooling vest or equipment distribution programs. But the last slide in this will have our number, but I'm going to put it in the chat too, so you can directly get in touch with client services and we can kind of help you from there.

Additionally, let's take a look at some of the other questions we've got. I'm going to wrap this all up into one big question just in the interest of time. So this is going to be a question for both Dr. Oliver and Cheryl. What do you wish you would have known about living in a rural community and or supporting others before you started working with those living with MS? So that's that's part of it. Cheryl, for example, when you started working with your support group, and Dr. Oliver, when you started working with rural communities, so kind of a two-faceted question, what have been the lessons learned along the way?

Cheryl Breton:

For me, the lesson in working with a support group is it's so rewarding, you learn from each other. There's no right or wrong. It's a learning process, and it's one that I am so grateful for, and even on days when I'm having some sort of impact from having MS, I know that there are people that I can turn to, I know that there are people that will understand. I know that I'm not alone.

Dr. Brant Oliver:

From my perspective, I'll build off of what Cheryl said, I think many providers are trained to provide clinical care and focus on that as their number one mission, and it takes a while for many of them, including... it took me a little while to realize that being effective meant being connected to the community and in a different way than most professionals are trained. I wish I had paid attention to that in my early years of my career because it's more needed than ever in a rural community than in an urban. Urban has a lot more networking capability, more population density, in general. And in a rural community, I wish I had started working with people like Cheryl sooner. It took me a little while to realize that the power and the wisdom is in the people that are in the communities.

And, yes, professional knowledge and professional guidelines and treatment and all of that is really important. However, in a rural community, finding people like Cheryl and the many other gifted folks with MS that are leading this community now, that's where all these discoveries came from. It wasn't from a provider looking something up, it was from these people in our rural community and organizing them together. So I think in rural communities, that's a really critical piece, to organize effective networks that can share a combined wisdom and discover all those resources that are there but may not be known to the community.

Kyle Pinion:

So we are at time. But there's one question I really needed to ask because I just thought it was so good. So I'm, well, I'm going to add a couple more minutes to the clock, if you don't mind. I'm going to do my basketball referee. And this is going to be a question for Cheryl, But Dr. Oliver, you may have some stuff to add here, and I'm certain you will. OK, there's a lot of focus on how to address barriers of living in rural communities, but from your perspective, what are the benefits? I live in a beautiful rural community, and live with MS. I feel grateful to live in such a beautiful area, but do admit it can be a struggle finding a specialist near where I live. So I would love your thoughts, especially on that question of finding a specialist, which I will tell you comes up very, very, very, very often.

Cheryl Breton:

And I will say my provider, I think, is superior, and I, no matter where I live, I would find a way to get to her. And it's not that this is a personal connection between her and I, it's she is such an integral part of my life and the successes I've had that she is a friend, a family member, in that regard.

The benefits of being in a rural community, in an odd way, because I don't have immediate access to resources, it forces me to take the time, take a step back and really think about what it is I need, what I want and what I think will best suit me. The fact that I do live in a rural, beautiful community, I can do a lot more outside. And in the instance of COVID, it didn't impact me as much because of I don't see a lot of people. It was more of an adjustment for me when things started opening up than it was going into seclusion when COVID hit. So I don't feel that living in a rural community... I know that it is kind of a hindrance to getting treatment and care, but I don't

feel like it is anymore. It just... I've learned to just not take no, and if there's something that I need that isn't available, make it happen. Find a way.

Dr. Brant Oliver:

You know, Cheryl, when we were talking about planning for this session, you were sharing with me so many benefits of being in a rural area and one of them, I think you said something like, Oh, you know, I don't have to worry about social distancing. I can go out for a walk. You know, there's much less population density, there's more stuff I can do. And sometimes it's an advantage to be in a rural community and access to natural locations. Again, we talked about mental health, right? We know that access to natural locations can be a very beneficial experience from a mental health perspective. You know, many people in cities yearn to get to natural settings, where in rural communities, you're often right in that rural setting, that natural setting. So there's a lot of beauty in rural communities that sometimes you don't see in big cities.

Kyle Pinion:

Well, with that said, I think that puts like a really nice bow on this entire program. And I feel like we've covered really so much ground today and have gained so much insight into the concept of being a creative community and finding resources in rural communities. I would just like to take a minute to thank not only our funding partners Bristol Myers Squibb, Genentech and Greenwich Biosciences for supporting the series, but I really, really want to take the time to thank our presenters, Dr. Brant Oliver and Cheryl Breton, for taking time out of their extremely busy schedules to provide us with this critically important information. And thank you to our friends at Impact Education for their partnership in delivering this program.

As mentioned, today's webinar will be archived on MSAA's website and we ask that you take a very brief survey that is coming up next. Program funding, as always, is dependent on our evaluation, so please just take a couple of minutes to answer a few questions for us. On behalf of MSAA, Impact Education, and our two amazing panelists, we thank you so much for joining us. And please, as I promised, see the next slide for MSAA's website and contact information in case you need to get touch with our Helpline.

Have a great day. Have a great weekend. And we look forward to seeing you all again soon. Thanks, everybody.

Dr. Brant Oliver:

Thanks Kyle, thanks Cheryl, thanks, everyone.

Cheryl Breton:

Thank you, everyone.