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### The Evolution of Multiple Sclerosis Patient Needs: Perspectives From Patient Advocacy Groups

**Announcer:** Welcome to ReachMD. The following program titled, The Evolution of Multiple Sclerosis Patient Needs: Perspectives From Patient Advocacy Groups, is sponsored by Novartis Pharmaceuticals Corporation.

**Yousuf Ali:** Good evening, everyone. I'm Dr. Yousuf Ali, medical director with Novartis Pharmaceuticals.

**Jessica Di Paolo:** And I'm Jessica DiPaolo, Director of Patient Advocacy at Novartis.

**Yousuf Ali:** We're happy you can join us for today's discussion, which is sponsored by Novartis Pharmaceuticals Corporation. The COVID pandemic has rapidly changed how we live, work, and learn. The new normal of this public health emergency coupled with guidance around physical distancing has made this a very trying and uncertain time for both clinicians and patients struggling with multiple sclerosis. Fortunately, MS patient advocacy societies have been here at the forefront of the pandemic, responding to the unmet needs of patients throughout this crisis

**Jessica Di Paolo:** And to help us better understand the positive impacts, new insights, and lessons learned from their efforts, we'll be joined by members of five different patient advocacy organizations for this discussion.

**Jessica Di Paolo:** With us today are Natalie Blake from the Multiple Sclerosis Foundation, Amanda Montague from Multiple Sclerosis Association of America, Stuart Schlossman from MS Views and News, Dr. Rosalind Kalb from Can Do Multiple Sclerosis.

**Rosalind Kalb:** Hello.

**Jessica Di Paolo:** And Darren, and Darren Ball from the National Multiple Sclerosis Society. Thank you all for joining us today.

**Jessica Di Paolo:** Before we begin, I'd like to remind the audience that this presentation is sponsored by Novartis Pharmaceuticals Corporation and that the views expressed here are those of the participants and do not constitute the views of Novartis.

So, Amanda, let me start with you. What do you think are the most prioritized patient needs during this pandemic?

**Amanda Montague:** I think it's a really great question and one that's challenging because there are so many needs. As we've all probably seen, I think the needs are changing over the length of the pandemic, but certainly what we've experienced as probably the most critical need is the need for connection to others and mental health services. There has been a lot, I think for all of us with or without MS, right, that has made this a very challenging time, but for people living with MS, this has become much more pronounced in terms of, some of the ways in which this is impacting their mental health and their feeling connected to others, so that's something we're really focused on in, is trying to make sure that people have the resources they need in order to really adequately deal with some of those emotional mental health issues.

**Jessica Di Paolo:** Great. Thank you, Amanda. Now Stuart, let's move on to you. What do you think about this?

**Stuart Schlossman:** So, the most trying that we have seen is that most MS patients do not understand how their MS could be affected by COVID, and they don't have enough resources available to them or that even their local community support group leaders don't know where to properly, send them to learn more information or to be able to provide. They don't even know that, like, the key MS organizations which we are all part of, you know, are, all list something about, you know, their MS medications as well as, you know, what could be, you know, where they might need to have concern or not have concern. The second largest issue that I see, though, is their emotional support. They're just not getting enough of it, and they don't know where to turn, and for those that are, living alone, it makes it that much more difficult.

**Jessica Di Paolo:** Great, and thank you, Stuart, and turning to you, Darren, what are your thoughts about the greatest challenges right now?

**Darren Ball:** So, I would echo Amanda and Stuart with, regarding emotional issues and mental health issues, and in addition to that, there are some really unique challenges of those people who are dealing with, with unknown symptoms related to a diagnosis that they haven't had yet, and the second one is wellness and physical exercise. So, we find that, as folks have, have been quarantined, if you will, that exercise and physical activity has declined and that's also related to some of the emotional challenges that people are experiencing as well, and so it's increasing the difficulty that people have to live their fullest, highest quality of life.

**Yousuf Ali:** That's an excellent insight, Darren. Thank you so much. So, moving on to Natalie, what patient needs come to mind for you?

**Natalie Blake:** You know, we hear so much about individuals who feel more isolated than normal. I mean, MS is a debilitating disease, and because it affects your life in so many ways, people feel isolated anyway, and due to the COVID-19 pandemic, individuals can no longer get with family members in person or, you know, meet their friends. Many of the support groups that many of us, our organizations have, have had to go virtual or they've stopped altogether because individuals can no longer attend group meetings, so it's really affected every aspect of their lives in terms of mental health, isolation, access to care, it adds stress to an already stressful diagnosis, and the uncertainty is heightened as well.

**Yousuf Ali:** Well, thank you for that, and finally, Roz, can you give us your thoughts on this as well?

**Rosalind Kalb:** Sure. So, I have to agree with what everybody else has said. We're pretty much all hearing similar things, but to those issues, I would add a real high level of anxiety, about what's going to happen, how COVID might affect, their MS, and how they can get their healthcare back on track. So, a lot of people aren't used to virtual visits, or they don't know how to make the best use of virtual visits, so they have a lot of concerns about their MS care. I think also we see different levels of risk tolerance, between people with MS, sometimes their other family members, their extended family members, which just contributes to the anxiety because they don't know how safe is safe enough, and so they're always feeling very, very vulnerable, and sort of under threat, and I want to call attention to the needs of support partners as well because I think they're often ignored and neglected as we have these conversations about needs, but in many families we're working with, the support partners are having to go out to work, go out to shop, go out to just take care of everyday business, and then just the thought of coming home and worrying that they're bringing something back in with them so that they go through these elaborate rituals to come into the house, take off their clothes, get them into the washing machine, some even take a shower before they come into the house, so I think support partners are always, a little overwhelmed and anxious about their role as support partners, but during COVID I think they also are experiencing a high level of depression and anxiety, that we need to pay real close attention to.

**Yousuf Ali:** Well, thank you, thank you so much, Roz. So, turning back to you, Darren, what are, the key lessons that we can learn, from our experience with the COVID-19 situation which can be implemented in the future?

**Darren Ball:** One thing that the society has recognized is the importance of delivering educational opportunities both for healthcare professionals and patients in a timely way that is relevant to the needs of both providers, that care for patients with MS and for people living with MS as well as for the caregivers that Roz mentioned, and so what I have noticed across all of the organizations represented here tonight is a, quick and noble response to meet the needs that this population really has, and I've seen a lot of creativity in program delivery.

**Jessica Di Paolo:** Thanks so much, Darren. Moving to you, Stuart, what are your thoughts on this and what the key lessons are that we can learn?

**Stuart Schlossman:** Well, the key lesson I think mostly, and, again, everybody's involved like Darren was saying, is that the virtual learning that, so many needed to learn how to do and have taken of advantage of it because while they are home, that is basically what they have learned to do is go from program to program and make sure that they're in a key learning basis, and they're using social media more. They may not have even used social media in the past, but now they're using it. Others have learned that being home really is not such a bad thing. I mean, you know, they were out and about all the time, and they were running from meeting to meeting, and they found that they could do all these online now and, and be at the safety of home. So, you know, this can be used going forward as well. I mean, it could be a year from now, it could be six months, it could be two years before everybody can actually get out and do as they once did, and so, you know, they've learned to make the best of it, I believe, for right now.

**Yousuf Ali:** That's very interesting, and now, Amanda, can you give us some, key lessons based off of your experience?

**Amanda Montague:** Sure. So I would have to agree with, with Darren. I mean, I think we all should be proud of the wonderful way in

which we were able to pivot to really meet the increasingly changing needs during this crazy year. That being said, you know, I think we're really focused on trying to continue to meet those needs as they come, and they are ever-evolving, right? So, one of the challenges I know for MSAA has been we have a number of programs that are specifically income-linked, such as our MRI fund where folks can get free MRI if they income-qualify. Because of the large n-numbers of now folks who are unemployed, we're seeing record numbers who now are actually in that pool who can access it, and then we as a nonprofit, of course, have the challenge of making sure that we have enough funding to support that extra need. So, that's one piece just from the nonprofit side that I think we all are probably experiencing some, in some ways that the demands are significantly increased, and it can be a struggle to meet those demands. The other piece is that we've been really trying to think outside of the box in terms of some interesting third-party partnerships, on some of these issues, including mental health issues and virtual opportunities, to really make things slightly more dynamic and pilot some programs that might be able to work for the longer period of time. As, as Stu mentioned, who knows how long this is going to go on, but certainly it's going to be here for a while. Lastly, I think we are really concerned, too, and recognize that there are a large number of people who r-really don't have access to this new virtual world, and so for those folks, too, what can we develop or how can we ensure that they continue to be able to link in to the wonderful educational resources and sense of community that we're all trying to, establish in a virtual environment.

**Jessica Di Paolo:** Great, wonderful, thank you so much, and I'll, I'll pose a question to the group now, to see if any of you have any thoughts on what we could do, differently as partnering with, with pharmaceutical industries and other organizations. What do you think is most important to be focusing on and prioritizing right now? And if anyone wants to take a stab at that, or I can ask-

**Rosalind Kalb:** So, let me take a stab at that. I think what everybody has been saying that we've learned is, is critically important, and I think we need to find ways to help people who don't have access to technology get access to technology. Pandemic or no pandemic, learning is going to increasingly happen for all of us online, and we need to make sure that, families that are affected by MS have equal access to the information they need and it's gonna be online. A second thing is that I think in the past we've thought in smaller ways about how people support one another, you know, with in-person support groups or, small group chats. I think one of the things we've learned is that you can get very large numbers of people, 100 people, 150 people online, use Zoom, get them into Zoom breakout rooms, give them opportunities to problem-solve, to support one another, to provide resources to one another, and it brings them to life. They love to teach and support one another, and they love to learn from one another. So, I think you could help us, expand our ability to use these technologies not only to help us reach individuals and families living with MS but to help us help them connect with each other with some oversight or guidance or facilitation from us to make sure that the information they're exchanging is actually accurate, and up to date, but I think there are wonderful partnership opportunities there that we could all really, make good use of.

**Jessica Di Paolo:** Great, thank you so much, Roz. Anyone else have anything to, to add to that before we, we move on?

**Amanda Montague:** Yeah. Well, I was like, amen to Roz. I think that that's absolutely spot on. The other piece, I think, which is very helpful and you all are in a unique position to be able to do so, n-now more than ever obviously, people living with MS, their care partners and their families, need all of the support they can get, and represented here is a good subsection of, of those organizations that can provide needed support, and we all do slightly different things and have different supports, and oftentimes it's always a puzzle to me, but people don't walk through all of the doors at the same time, right? So, they might know about one of us but not know about what the rest of us offer, and that's something I think Novartis could really help with is by making sure that when people living with MS are contacting you or reaching out to you or even physicians, healthcare professionals, that you're able to provide them with the resources that we all have available to the MS community so that they're all being taken advantage of.

**Jessica Di Paolo:** Right. Thank you, Amanda, and I, I appreciate that, and before we close our roundtable discussion, I'll, I'll turn to each of our panelists now to describe one of the initiatives they would like to spotlight from their respective organizations and how it addresses unmet needs for MS patients.

Natalie, starting with you, what can you share with us from the MS Foundation?

**Natalie Blake:** Well, the Multiple Sclerosis Foundation, which is also known as MS Focus in the community, has 18 ongoing programs and services which provide assistance to those with MS free of charge. The newest program is our transportation assistance grant. This transportation assistance program provides free rides through Uber and Lyft to individuals with MS to MS centers, neurologist appointments, and infusion center appointments. This program meets a critical need in the MS community and helps those with MS remain independent. People with MS who cannot drive often depend on family members and friends to drive them to and from these appointments. Often they don't go to doctors' appointments because they're reluctant to ask for assistance from others, and the lack of transportation is also a major barrier to care. MS Focus has funded paratransit fees for many years. However, paratransit services are locally run through county governments, and they don't cross county lines. You may live in one county, and your infusion center or neurologist is in another county, so, therefore, you wouldn't be eligible to use paratransit. Rides through our program are available

anywhere that Uber and Lyft are in operation. In addition, accessible rides are available in many locations through Uber. In order to qualify for assistance, individuals with MS are required to fill out an application, and the applications are available on our website, [msfocus.org](https://msfocus.org), or they can be requested by email or telephone. We require a confirmed diagnosis of MS for assistance. Once a person's application is accepted, they need to call us at least 24 hours prior to the time they need the ride so that it can be scheduled through a concierge system that we use for these ridesharing programs. Person must also have a cellphone which is capable of receiving texts to alert them that the transportation is on the way, and unless it is an accessible ride, any equipment that they require such as an aid for walking must be able to fit in a standard-size trunk. They also have to be able to transfer on their own or have another person with them who can assist them if they can't. Because of the high demand for assistance through the transportation program, we've had to limit the help to six round-trip rides per year or a total of 12 rides per year per individual.

**Jessica Di Paolo:** Great, wonderful, thank you for sharing that, Natalie. And now turning to you, Amanda, what would you like to spotlight on behalf of, behalf of MSAA?

**Amanda Montague:** Thanks, Jess. So, I'm gonna spend just a couple minutes talking about a new tool we have on our website, and it's also available, on our app, My MS Manager. We partnered with Wondros which is this wonderful, company that's very, involved in social justice and education and access to information, to develop, a tool that is really to date in terms of the latest we know about COVID-19 and is specific to the MS patient community. But all of the data is coming from well-sourced sites, New York Times, World Health Organization, Johns Hopkins, NIH, CDC. I think it's fair to say that we are living in a time of enormous misinformation, and, it can be challenging to find reliable sources, and our goal here was to try to create a space where specific information about COVID-19 and MS could be located, and it would provide both healthcare professionals and, people living with MS, an opportunity to also interact with the tool and let us know what's missing, what additional information is needed, so the tool's being updated, on a weekly basis with new information as it comes out. It's also easily, translated into Spanish. We are looking at translating into other languages, but at this point you can access it either in English or in Spanish. It's interesting cause it looks right there like there might just be five pods, but you can go down a rabbit hole with this, and I will tell you, I have done it many a times. You click on one of the pods, and all of a sudden it brings you to another six pods. You click on one of those pods, and it brings you to a whole nother five pods, and it really is something that we're, we're very proud of. We've gotten enormous feedback from it, but I think it's a solid place for people to find reliable information, about what's happening in the age of COVID-19, and MS.

**Amanda Montague:** Thanks. The branching, as I said, it opens with basic questions, so it starts out very simple, but then it goes into more detail. So, the more that you want to find out about a particular subject, you can keep going down that lane. You can also, go back to find out more information about other areas. It's also set up, as, you know, Roz mentioned earlier and we talked about for care partners and family members, there are so many concerns, and, again, there's so many unknowns, but there's also a lot of unfortunate misinformation, and so this is a space where we are hoping that people feel comfortable really, being able to feel like they're doing the right thing and they're doing all they can to protect themselves and their loved ones. So this is something that will be updated at least, through June of 2021, so it's an ongoing project and partnership, and I would encourage everyone to take a look at it and see if it might be useful and certainly let the patients with MS that you all are working with, know about it as well, and we look forward to feedback on it. So, if you see something that's missing, please let us know. One last thing I will say since we all know I think that, the underserved MS patient communities, especially African-American, Hispanic patient communities are also being hardest hit by COVID-19, and so we have a lot of specific information about what we do know at this point at least about, patient demographic-specific population information as it relates to COVID-19 and MS.

**Jessica Di Paolo:** Great, wonderful, Amanda, thank you. And Stuart, what can you tell us about MS Views and News?

**Stuart Schlossman:** So, MS Views and News developed a series of different programs, one is MS Views NOW, and MS Views NOW was developed as a direct response to COVID-19, to the COVID-19 pandemic, bringing monthly educational updates plus social media connectivity for the MS community, which is now needed more than ever. We launched this in March of 2020 during the peak of the pandemic. The series remains increasingly active with two events per month. Sometimes we get in a third.

**Stuart Schlossman:** ...every month the series addresses a topic that are impacting related to MS and COVID-19 relative to the date. Some examples of topics and discussions include caregiving during the pandemic, access to telehealth and your healthcare team, mental health and wellness, managing anxiety and relationships, diagnostics like how to access MRI during the pandemic concerns, where you can get it safely. These, events promote direct audience engagement with live questions and answers with the audience, so we break up the program so people stay involved or engaged with it as well. We, we let the presenter speak for a little bit, then we take some questions, we do a little bit more from the presenter, take some more questions, and this way it just keeps everybody engaged with the conversation. Also included with every one of the programs is to bringing it up to date whatever stats that are available for the COVID-19 and going, you know, highlighting the COViMS registry as well. So to date, or I should say as of last month, we had 764 nationwide registered participants that are engaging with our programs every single month, and this is just increasing. So, each month



they go to the, GoToWebinar platform that we're using, and they get signed up for the program. Right after one program ends, we already have people clicking in and just signing up for the next program. MS Views and News is now, or I should say the program MS Views NOW, is featured on the Instagram TV, reaching, engaging even a younger demographic of people as well, and 1426 views featuring interviews with patient leaders, which is what Damien is doing, he's speaking with the patient leaders and this is just, you know, who he's interacting with around the country. Most of them are younger, so we're drawing a younger audience to what we're doing, and they're taking the information back, and they're able to even speak with, you know, others that are older than they are in the, area with what's going on. Some of those topics include the movement from home, relationships and intimacy, advocacy during a pandemic. Our YouTube channel for all the MS Views and News series, events are archived and remain on the MS Views and News Learning Channel as an enduring educational material. To date, for the first four interviews, we've received over 1426 views. Again, this was as of last month when we put all these numbers together, and the four recorded program webinars, are now exceeding over 2,000, you know, as of just a few days ago. On Facebook through our Facebook posts for those first four events, our reach was over 2700 with 223 of those actively asking us questions about the different topics and where they could get more information from the presenters or how they can further reach those presenters. So, the audience feedback with the goal to connect with people to resources and to help reduce anxiety during these uncertain times, we can see the impact the series has had through the series, through all the different feedback, and I'm not gonna go and read all the different feedback from you, but it is pretty incredible to see how many people are enjoying and learning from these webinars. So in closing, we at MS Views and News feel grateful that we're able to provide this resource for so many during this uncertain time utilizing these different platforms, and we are excited to continue to bring engaging and resourceful information to the multiple sclerosis community through this educational series, and as we go further along, we have set to do another 12 going into next year. So, that's what MS Views and News is doing.

**Jessica Di Paolo:** That's terrific, Stuart, thank you. Roz, what can you share with us from Can Do MS?

**Rosalind Kalb:** Sure, happy to. Well, as a health and wellness organization, Can Do MS has always had a really strong focus on mental health, including emotional and cognitive health, as a key component of overall wellness, so we feel that this is an under-met need for both people living with MS and their support partners, so we have always had a heavy focus on the entire family, not just the people living with MS.

**Rosalind Kalb:** ...we offer interdisciplinary webinars on a wide range of topics, so frequently it might be, a nurse practitioner, a psychologist, and a rehab professional presenting together different aspects of a particular topic, including those related to mental health. We have downloadable toolkits for people with MS and support partners on topics such as in-, how to increase your resilience, how to strengthen your partnerships and find ways to remain as active and independent as possible as individuals and as couples. We have conversation guides that give individuals and families conversation starters to help with those difficult conversations. Whether it's topics they're struggling to talk about with one another, with their extended family, with their healthcare providers, they really need those jumpstart conversation, and we have guides for proactive problem-solving, so how to help people plan the steps they need to take in order to, address a problem or a challenge rather than just working, worrying about it because with so much depression and anxiety, just putting steps together to solve a problem becomes a problem in itself, so we want to help them do that problem-solving. In the face of COVID, Can Do has converted all of its programming through 2021 into virtual programs, and the results have really been astounding for us, triple, quadruple the numbers that we have typically had registrations for and participation in these programs have just taken off, much to our delight and surprise. Our COVID-specific programs have included, a multidisciplinary panel update on COVID so that, people living with MS and their support partners hear from a nurse practitioner, a rehab professional, mental health professional, updated information about COVID but also how to handle all the different kinds of challenges we've been hearing about tonight from those different experts at one time, and that multidisciplinary panel is updated as there, is more news to report. We also offer video tips of the day, so professionals from different, specialties, might talk to people about how to manage their anxiety and depression during this difficult time, how to stay connected with other people, how to talk to your kids about COVID, how to explain what's going on, and how to deal with different levels of risk tolerance, as I mentioned earlier, within the family, and, of course, ways to stay physically active and eat healthy meals even when it's tempting to just sit and eat junk food and watch television all the time, and also how to nourish your spirituality during this difficult time. I think people's spiritual selves are feeling really threatened by all of this. We also help people manage conflict from all that togetherness time at home, navigate the healthcare system that they're finding increasingly challenging during COVID, and figuring out better ways to work from home. In order to focus primarily on wellness strategies, which is our bread and butter at Can Do MS, we refer our constituents to all of these other groups that I'm privileged to be here, with tonight, certainly to the National MS Society website as well as the CDC and other credible sources about day-to-day updates and recommendations, and as always, we refer to our colleagues for these wonderful resources that they've described here tonight cause we don't want to duplicate, our efforts when resources are so tight, among nonprofits, and as always, we refer them to their neurologists and primary care providers for information about their MS care in the face of COVID challenges. Thanks.

**Jessica Di Paolo:** Thank you so much, Roz, for that, and before we wrap up, Darren, you get the final word on behalf of the National MS Society.

**Darren Ball:** Well, thank you. So, the National MS Society issued a three-part rapid and comprehensive response to the pandemic. The first of these three programs was a weekly patient educational webinar titled “Ask the Expert” that continues to occur every Friday afternoon and often draws more than 1000 participants. The second was a series of webinars for healthcare providers, and the third was a series of 12 ECHO MS sessions designed to support healthcare professionals with COVID-19 response. COVID-19 ECHO response programs were possible because of a new innovative partnership the society has developed with Project ECHO. Today I will discuss the work that we’re doing with Project ECHO. ECHO stands for Extension for Community Healthcare Outcomes. Founded in 2003 at the University of New Mexico, Project ECHO is now a global movement engaging healthcare professionals in 40 countries through over 800 programs. Using video conferencing technology, the objective is to increase access to care by improving the knowledge and capacity of community providers. Using the teleECHO model, the society is serving as a shared services hub providing all necessary publicity, data collection, IT services, and ECHO program coordination for three ECHO MS hub sites. The hubs are comprised of multidisciplinary MS specialty care teams located at the University of Washington in Seattle, Washington University in St. Louis, and Duke University.

**Darren Ball:** ECHO is a collaborative model of medical education and care management that empowers clinicians everywhere to provide better care to more people right where they live. The ECHO model does not actually provide care to patients. Instead, it dramatically increases knowledge of specialty care by engaging clinicians in virtual grand round style clinics over a six month cohort. A patient goes to a local provider and presents with symptoms or a challenge. That local provider may be unsure of what that diagnosis might be or how to manage the symptoms that the patient is sharing with the provider or how to make treatment decisions, but the local provider happens to be a participant in ECHO MS, so the local provider presents that patient’s case during a teleECHO session. All the participants, providers across multiple disciplines that join every or twice a month to ECHO MS clinics and the hub team that facilitates the discussion and provides specialty knowledge give that local provider feedback and recommendations on the case. The local provider then can bring that knowledge back to the original patient and to other patients throughout the community, increasing their capacity. Ultimately, the professional workforce is expanded, and access to high quality MS healthcare increases, and transportation and other costs decrease.

**Darren Ball:** I can show you how the society is using a comprehensive pre/post survey and an exit interview to report on outcomes related to knowledge of MS management, accuracy and timeliness of diagnosis, confidence in managing all approved disease-modifying therapies, and knowledge of resources available to patients from the MS Society and other organizations as you see represented tonight. The first ECHO MS cohort begins this month and lasts for six months. The next cohort will begin in the fall of 2021. As medical knowledge increases, the knowledge gap among providers also increases, and therefore the need for specialty care rises. ECHO disrupts this pattern by de-monopolizing knowledge, leveraging scarce resources, reducing disparity, and extending community health outcomes. Thank you for the opportunity to share this evening.

**Jessica Di Paolo:** Thank you very much, Darren. Thank you everybody. So, now we have a few minutes to take some questions submitted from our audience through the chat box, and so I’m gonna take a look at some of them now, and, Stuart, this first question is for you. How has the MS community reacted to telemedicine during this new normal? What are the advantages and challenges of telemedicine for the patient community?

**Stuart Schlossman:** So, that’s actually a great subject for us because at the very beginning when this all began and we saw how people were not able to connect with their physicians, I had gotten together with one of the top MS doctors in the country, and most of you all know him, Aaron Boster, and we put together a telehealth call as if I played the patient, which I am, he played the doctor which he is, and we put together a real call based on what I was going through when this whole thing began, and we made it so that way patients got to understand what this telehealth call is all about and the importance of what it is and how they can use it with their own neuro team. So, this was something that they needed to learn, and I was glad that they were able to pick up from it. In fact, we still have people contacting us all the time to find out – again, they want to see what it was cause they have not had a good appointment with their doctor – so they want to see, they want to review the video that we did months ago, and, it’s just a good thing, you know. It’s, it was a great way to share this important tool that they need to use for their own healthcare services and, and, I don’t know what else to say about it other than it was a great way to help people get accustomed to what they’re gonna need to do with their doctor.

**Jessica Di Paolo:** Wonderful. Thanks so much for that insight, Stuart, and the next question is for Roz. Roz, what kinds of questions and concerns are you hearing from patients regarding their clinical care during the COVID-19 pandemic?

**Rosalind Kalb:** I think what we’re hearing most is, their concerns about going out and seeing their healthcare providers in person and their concerns about not seeing their healthcare providers in person, so I think this is just one of those sources of anxiety where they don’t know what the right thing to do is, and until they have an experience with telemedicine or they learn from, MS Views and News,

right, it's just an unknown, and they have questions like, "Well, how can a neurologist examine me on by camera? How can the neurologist know what my spasticity is like or what my gait is like?" And, they need to be taught, how the clinician makes those evaluations, virtually and what are the benefits and what are the risks, but I think mostly what we're hearing is that anxiety about what's the right way to proceed.

**Jessica Di Paolo:** Wonderful. Thanks so much for that, Roz. Moving on to Amanda, what kinds of programs is your group running to address the unique needs of diverse MS patients?

**Amanda Montague:** Great question. So we are doing a number of different things and have had to as we all have changed course a bit given, COVID but back in 2019, we formed our African-American advisory board. It's led by Dr. Mitzi Williams and has 14 of the leading MS, health, neurologists and nurses who specialize in African-American MS research, on the board as well as, 15 African-American MS patients and care partners from across the country. The group, is extraordinarily dynamic, and I think it's fair to say that, there are a lot of, a lot of access issues and a lot of systemic problems that we've all known about for a long time but that this group is really aiming at trying to figure out what we can collectively do to improve. So we will be coming out with a white paper this month, that's signed off by all of the participants in the advisory board with some of the key findings both from the HCP perspective of what needs to change and also from the patient and care partner perspective of what needs to change for them, and then we've taken an approach of trying to see, like, what can we bite off with, within one year. What's a goal for two years from now? And where would we like to be in five years so it feels a bit more manageable since there's a lot to do in this area, and it will certainly take a village, so we are looking forward to working with everyone on trying to help, you know, get some of these access issues and some of these barrier issues and some of these systemic problems, out of the way of, of proper MS care for, for all patient populations. Secondly we're also very involved in working on a Latino Hispanic-American, patient initiatives. Just this month we have a, a number of programs that we are doing virtually with Dr. Lilyana Amezcua in Spanish as well as in English and have been really helping in working the folks in Puerto Rico. They've been hit hard, though we all have, but they have been particularly hit hard, and so we've been providing them with cooling vests for all the patients on the island and trying to coordinate better so that we can cover their MRI costs so those are a couple of examples that come to mind initially.

**Jessica Di Paolo:** That's great. Thanks so much, Amanda. Now this next question is for Darren. After experiencing this global pandemic, what are the three lessons you learned that you will implement in any future similar emergencies?

**Darren Ball:** Well, the first lesson is that I think all we see is possibility, and we could not have predicted this situation in any way, shape, or form, and it shows across the healthcare community that providers and patients are willing to, to take a step back and make sure that, that safety is first in their care and to make sure that, that risk management is taken care of and then second I think we will, we will move towards a more personalized and individualized telehealth model going forward, and I think that telehealth will only improve for patients and I think physicians will continue to become more and more comfortable with telehealth and as, as a result, I think that we will be able to break down some of those barriers that we're experiencing this time that make it feel a little bit, or very, impersonal and not individualized, so I think we can prevail.

**Jessica Di Paolo:** Great. Thank you so much for that, Darren. Moving on to Natalie, this next question is for you. Based on your experience, where would you see the biggest need right now when considering an ideal partnership with Pharma?

**Natalie Blake:** You know, Pharma has been wonderful in partnering in issues which concern advocacy for individuals with MS, whether it be access to care issues, and what we're seeing right now is an increase in the disparities in the healthcare system. Obviously, we've known for a long time that individuals that are underinsured or from certain minority groups, you know, have more barriers to healthcare, and that is more apparent now than ever before. Even for telehealth services, individuals who are in low socioeconomic areas don't even have access to smartphones so that they can have a telehealth appointment with their physician. I think that Pharma has been very helpful in addressing access issues, and I think that, you know, through all of the organizations that are represented here today and the help of Pharma, we can come up with some solutions to some of the problems that we're seeing. Also, you know, support for the organizations has become more important than ever before. We're getting a number of requests for housing, for food, for copays with medication, just, you know, needs for daily living, and as an organization, it's very difficult to keep up with the demand for those needs. We, under a normal year, wouldn't be able to possibly fulfill all of the requests we get for assistance. In this new age where so many find themselves unemployed now and you know, behind in their rent and other programs, we really do need more assistance in being able to provide for their needs through unrestricted grants and donations.

**Jessica Di Paolo:** Thanks so much, Natalie, for that. It's excellent insight and going back to Stuart, what would you as advocacy organizations see as important for physicians to understand around MS patients at this time?

**Stuart Schlossman:** Wow. More compassion for them I think more than anything. There are a lot of doctors that would have rushed their in-person visits, and, you know, they only had 10-15 minutes to be able to see a patient. Now doing telehealth, I think that they have to

be more compassionate to that patient and give them more time. I do know a couple of doctors and neurologists that are actually giving their patients 45 minutes to an hour each right now, which is great, because even if the patient really has nothing MS wrong with them but, specifically, but maybe more needing an emotional attachment to something, that doctor is the person that is giving that patient what that patient needs at that time. So, I just think that, you know, going forward the doctors have to learn to be a little bit, for those that are not showing the compassion or being able to give more time to their patients, that they need to give a little bit more at this time. They also, as Natalie and everybody else has said, they do need to give more to those that have difficulty with accessing healthcare issues at all or, or even being able to reach their physicians by phone if, you know, as for, you know, Natalie brought up about socially eco-, I don't even remember the word she got stuck on, but what about those that are living in remote rural areas of the country that, you know, they just, they don't have internet, okay, so they're lost on all of that as well, and, and their, yeah, their cellphones, they may be using an old pocket phone that a flip phone that they cannot store everything in, and they cannot look up everything cause they don't have the internet access. Well, how are they getting it? So, their calls to their doctors become extremely important. It is a way for them to connect with everything that is going on.

**Jessica Di Paolo:** That's wonderful. Thanks so much, Stuart. This last question is for Amanda, and what would you as advocacy organizations see as important for physicians to understand around MS patient advocacy at this time?

**Amanda Montague:** Ah, there's so many things. I think, I think the big thing that we're all, and this has been touched upon by all of us, but I think the thing we're all seeing that I think many of the healthcare professionals are, are, are seeing as well this is, there, the, it's more complicated than it's ever been in terms of making sure that the MS patient community and their family members have resources to lots of different types of help. You know, I think we've been fragmented for a very long time, so you might go to your, your neurologist and just talk about disease progression or therapy. That might be that person's only link right now to the outside world, and so it's very important for that healthcare professional to also check in with them about how they are emotionally doing, and even if it might not be something he or she can help them with, direct them to get some help somewhere else, and I feel like we are all doing this as patient advocacy organizations right now. Natalie mentioned it before that, you know, we are getting hit by so many requests for just very basic needs that are impacting people. MSA was fortunate to get a donation from Top Fresh of 1000 food boxes that we were able to send out to families across the country, but that's 1000 food boxes, right? And that's a magnitude of this problem-

**Stuart Schlossman:** That's great.

**Amanda Montague:** - and that we can't help everyone, and I know as much as all of us would like to, none of us have the resources independently or even collectively to do that, and that's where I think we all just need to be very thoughtful about when we have the opportunity to have a conversation with a patient right now, be it healthcare professional or advocacy organization or even a friend or a family member, to really ask some additional questions to make sure there aren't things that we're missing that we might be able to help them with because if there's ever been a time where it's gonna take a village for us all to get through this, it is now and I don't think any of us can do it alone.

**Jessica Di Paolo:** Wonderful. Thanks so much, Amanda. I'm actually, I'm gonna ask Darren the same question about, what would you as advocacy organizations see as important for physicians to understand around MS patient advocacy at this time?

**Darren Ball:** So, I mean, if, our, our advocacy work related to COVID-19 is, is focused on telehealth reimbursement for healthcare providers as well as increased broadband access to the internet in the rural areas that, that Stuart and was discussing earlier, and it's also important that, that as, as time goes on and telehealth becomes more and, and more prevalent that providers are able to access or patients are able to access private spaces to have a healthcare appointment in and not having to go out to their car and, and connect via a mobile network or not having a safe space to sit and answer personal vulnerable questions in an exam and so those kinds of advocacy issues are, are a priority, I think.

**Jessica Di Paolo:** Wonderful, wonderful. Well, thank you so much for that, Darren, and well as we come to the end of our discussion today, we would very much like to thank our esteemed panel members again for their time and participation in this important activity.

**Yousuf Ali:** No, thank you, everyone, thank you, Jess. This has been an inspiring conversation today, and we truly appreciate your efforts on behalf of MS patients. Thank you so much, and everyone have a wonderful evening. Thank you.

**Stuart Schlossman:** Thank you.

**Darren Ball:** Thank you.

**Amanda Montague:** Thank you.

**Natalie Blake:** Thank you.



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12/20 M-NSF-1398044