

How Do Advocacy and Awareness Organizations Support our Community?

You can view this presentation at: youtu.be/ZkjCcE6wbVw

[00:00:05] **Leah Campbell:** Hello. Good afternoon, and thank you all for being here and those of you joining virtually. As you said, my name is Leah Campbell. I'm honored to be here and just be able to advocate and be able to speak to this panel. Not quite exactly sure why Chitra, GG, and Lydia asked me to moderate it, but I am honored and grateful that they did, giving me this opportunity and invitation.

[00:00:38] So, I'd like to first connect you to the SRNA for me. I was originally diagnosed with AQP4-positive NMOSD, May 31, 2006. That was 17 years after my symptoms began in May of 1989, when I was just 10 years old.

[00:01:02] I am a Peer Connect Leader with the SRNA and Oklahoma Support Group co-leader with them as well. I think, really, through these roles and my other advocacy involvement through other patient organizations, it's allowed me the privilege to be able to share with individuals and families their diagnostic journeys and navigating life with rare neuroimmune conditions.

[00:01:35] As I said, for this panel, we're going to be discussing how advocacy and awareness organizations support our community, and we have several different types of advocacy: you've got where individuals can share their personal stories to be able to raise awareness, you've got patient and self-advocacy, where patients may advocate to doctors or you may advocate for disability access and being able to travel, you've got legislative when you're more focused on policy changes, or you can have organizational and actually have groups collaborating to be able to share resources and support.

[00:02:21] And for me, I've actually participated in several different types of advocacy, including legislative, for several different organizations and various different causes. So, I guess that's given me a chance to be able to speak to this, and I really have my esteemed foundation people up here, that I'm hoping will be able to give us insights into the vital roles that these organizations can play, the resources and supports they have, and how they can help in raising awareness and helping to get change, and what supports they can give our community.

[00:03:02] So I'd like to begin by having all three of you introduce yourselves, the organizations you're with, and your roles. Whoever wants to, Jacinta, you want to go for it?

[00:03:13] **Jacinta Behne:** Yeah, thank you, Leah. Let's face it, who wants to follow a rock star? She is just amazing. Everybody dearly loves this lady, and I only have 15 seconds left. I better talk faster.

[00:03:26] Hi. I'm Jacinta Behne, Executive Director of The Guthy-Jackson Charitable Foundation. And two things: Chitra, GG, and is Sandy still here? And the rest of your team, it is an incredible honor to be sitting here on this stage today. What a wonderful conference you have, and it's just very humbling. Thank you.

[00:03:55] I'm going to go really even faster. Just wanted you to know just a little tiny bit of history so that you know that in 2008 was the first day that formed our Guthy-Jackson Charitable Foundation. Our foundation charter is research.

[00:04:09] And we started funding big amounts of research -- large, large projects that went across my desk. And then, we soon became aware, a year later, we started working with the patients as well because I loved it. Every clinician on this, up here, has said we learned from our patients.

[00:04:30] We still learn from our patients today. So, again, it's humbling to be in this room with you and the caregivers -- let's not forget them. Okay, to you now. I'm sorry. I took more than 20 seconds.

[00:04:42] **Julia Lefelar:** That's okay. Are you done?

[00:04:43] **Jacinta Behne:** I'm done. That's all I'm going to say.

[00:04:45] **Julia Lefelar:** I love sitting here next to Jacinta because I just have to say I second everything she says, certainly about this conference here. My name is Julia Lefelar. I was just up here and stayed.

[00:04:59] So, you know I'm the Executive Director and co-founder of the MOG Project, and, obviously, I'm a MOGAD patient -- I've talked about that. But it's the reason that I started the organization, and, very similar to what Jacinta said, we started our advocacy because when I got diagnosed, it was with a new rare disease.

[00:05:19] There was no information out there, and we thought it was just going to be some car washes and a bake sale. We realized that we had to develop our own educational resources, and we started with the TMA to do that, which is now, of course, the SRNA.

[00:05:36] And the reason that we did our advocacy was because we, as patients, knew what we needed. We knew that there was -- and by advocacy, you asked us to define that. Should I wait to do that or do that now? I'll wait on that -- but that's how we came to be, and it's very important to us, and we've hit it heavily.

[00:05:57] We were the ones who got the disease code in the CDC with MOG for MOGAD, and we have a big policy area, and I can talk about that a little bit later, but education, education, education is where we needed to start with this disease because it was new. Anyway, thank you.

[00:06:13] **Jasmine Patel:** Hi, everybody. I third what the whole panel said. My name is Jasmine Patel. I'm a Strategic Advisor with The Sumaira Foundation. I am not Sumaira; in case anybody was wondering.

[00:06:25] The Sumaira Foundation has been around for 10 years, and I'm not the best person to tell Sumaira's story. If you've met Sumaira, and you know why her organization was formed. When she was diagnosed with her condition over 10 years ago, she was lost as a patient, who just didn't know where to turn or where to go. The information that was available on the Internet was very complex, a lot of jargon. And she started the organization to build community and support for people like her who are living with NMOSD, and now she is doing work in MOGAD.

[00:06:58] I think all of these organizations on stage have very specific, unique missions. And personally, I've been in patient advocacy for a very long time. I've worked for many different disease organizations. So, I'm excited to share my perspectives on the value that patient organizations bring to the community. Thank you.

[00:07:17] **Jacinta Behne:** Back to you, missy.

[00:07:19] **Leah Campbell:** All right. Well, first question is basically to define what we mean by patient advocacy in the context of each of your organizations. So, we are going to start with Jacinta then we're going to start with Julia, and then rotate.

[00:07:32] **Jacinta Behne:** Yeah, okay. And I think I get one minute this time?

[00:07:34] **Leah Campbell:** Yes. One minute.

[00:07:35] **Jacinta Behne:** Okay. I could talk a little slower. So, I'm just going to give you a quick nugget of how patient advocacy became really important to us because it was August 1, 2008, that we formed.

[00:07:48] Three months later, we brought researchers together for our first roundtable. At the end of that day, Victoria Jackson, one of our founders said, "Jacinta, next year we need to do this again, but we need to get patients together. They're a big part of the research, and they have been forever."

[00:08:05] So, it's you all, as well as your caregivers -- we can never forget them -- are the reason why we knew we needed to begin pulling patients together. And advocacy can be something that it's really double-sided.

[00:08:23] Yes, we advocate for patients, only because we listen to them a lot, and we learn from them a lot. And what's on patient's minds is really at the heart of who we are. We're very patient-forward and we take that patient-forward approach to program.

[00:08:41] So, patient advocacy is an umbrella for us because it really is what leads us to offer eight, nine different programs actually. So, that's the short answer, and I left a lot for you to say. Okay?

[00:08:58] **Julia Lefelar:** Well, I will start by saying again that I second what Jacinta said. And as far as our organization, we were in a unique situation where we were to advocate for a brand-new disease. And so, to us, in the beginning, what that meant was education, education, education.

[00:09:20] And we spent a lot of time really focusing and building up on that, and we continue to do that because the disease is ever changing. It's one of the reasons why we work with the SRNA who does a fabulous job at that very thing.

[00:09:35] And there are other reasons we work with the SRNA -- I didn't mean to, Chitra's laughing out there. And I think that it evolved also into realizing that we needed patient support, we needed to have policy. And I mentioned a little bit about the ICD-10 codes for MOGAD, there was no insurance code there.

[00:09:58] I actually did it myself. We put in the first proposals with the World Health Organization of the CDC. I had help from some pretty amazing doctors to do that, and also UCB was part of helping us advocate there. And we were very successful, and we're still pushing the World Health Organization, but we'll be there soon.

[00:10:18] Also, our policy efforts go on. We're trying to get better language in some of the Senate appropriations and things like that for MOGAD research, and we can expand that to the other countries we're connected to.

[00:10:36] That policy piece came into play, support came into play, and we started support groups. Then, as far as our own governance and the way that we built this patient-led organization, that became really important.

[00:10:49] And I'm going to expand because The Guthy-Jackson Charitable Foundation has done that very well, the Sumaira Foundation as well, the SRNA, is to create an organization, a culture where patients really inform researchers, clinicians, and pharma companies, and we become their teachers, and it's especially important with MOGAD because of the fact that it's a new disease.

[00:11:15] There are some idiosyncrasies. There are some special things about MOGAD that are very different from other neuroimmune disorders, and those things need to be known. And so, we spend a lot of time on that, and I think that's something that we'll always be spending good amount of time on. So, that's what we define as advocacy, I think. And I'll let you go.

[00:11:37] **Jasmine Patel:** I think advocacy itself is a very, very broad term. When you take a step back, people think advocacy is driving policy change. And, yeah, there is an element of that. But I think organizations like all of ours, our responsibility is to be the voice on behalf of our community. And who's in our community? It's patients, it's caregivers, it's the medical experts, and it's also industry.

[00:11:58] Industry is part of our community. They're the ones who are driving the way forward for innovation, bringing treatments to market that are serving the patients that need more options. And so, for us, advocacy means bringing all of those voices together in a conversation while making sure patients and caregivers have an equal seat at the table in those decision-making conversations.

[00:12:21] Whether it's designing a clinical trial, whether it's determining what educational materials are best served and suited for patients. And then, when a potential treatment is coming to the market, how are we going to make sure that those treatments actually get in the hands of patients who need them the most? And so, for us, advocacy is making sure all of those components come together in the best interest of the people we are serving, which are patients and their caregivers.

[00:12:48] **Jacinta Behne:** Great.

[00:12:49] **Leah Campbell:** All right. So, all of your organizations have impactful initiatives. What do you think is the most impactful initiative that you're doing? And a little bit of a pop question, do you have anything that's upcoming, new, or other advocacy things that you're going to be getting into?

[00:13:10] **Jacinta Behne:** Pop question, that wasn't on the list. Oh, my, I love this lady. There is, without a doubt, the most important patient program, and we had no idea when we had that first patient day in 2009 that it was actually going to become an ongoing program. And we learned that day, and it was one of those, "If you build it, will they come?" But we went ahead and announced that we were hosting a patient day.

[00:13:39] It was in a small boutique hotel in Los Angeles because we didn't know if anybody would be there. And we scheduled it, and the elevator doors opened, and those patients and caregivers started streaming off. I still get choked up today because it was the first time that any of them had ever met anyone who had that same diagnosis that they did. And there were tears, somebody ran for Kleenex -- happy tears.

[00:14:11] But I'll never forget that day, and every time we have a patient day since then, I think about that very first day because everybody left knowing that they are part of an NMO family and they're not alone. "You are not alone" is the most important thing to take away, in our opinion, because it's a rare disease, right? So, what was that pop question?

[00:14:38] **Leah Campbell:** Pop question, what in new advocacy things, working things?

[00:14:43] **Jacinta Behne:** Yeah. We work closely and have for many years with industry. The three industry organizations that have the FDA-approved therapeutics: one of them is here, Amgen, with Bea McLucas, who we love dearly, and I'm looking for Shervin from Genentech -- he must have stepped -- well, there's a Barista in the hall, right? -- and then, I think Christine Rowe, are you here? She told me her plane was out. So, it's Amgen, Alexion, and Genentech, and early on, we knew that we needed to get to know them.

[00:15:23] So, the pop question would be, were it not for those three patient-forward organizations, and remember, for many years, pharma has had a bad rap as being in it for the money only. Well, that is not true in a rare disease. All three of those organizations spent \$150,000,000, \$450,000,000 went toward finding therapeutics for the rare disease of NMO.

[00:15:51] So, we learned very quickly that the Bea McLucas' of industry are our most wonderful friend. And that's how we could begin to offer all the patient days that we did. So, grateful to you. How did I do?

[00:16:05] **Leah Campbell:** Good.

[00:16:07] **Jacinta Behne:** Okay. Onward..

[00:16:09] **Julia Lefelar:** I have to second that. And I will say that these pharma organizations, especially Bea -- we know very well -- and Danielle Hardick from UCB has been wonderful to us and backed us through the programs that we are very much excited about.

[00:16:30] And again, the programs that we feel that are most impactful, and we could never do without, are the building of educational resources. Anywhere from our MOG casts to our patient brochures and things that -- We also have a great MOG glossary now on our website that's fully integrated into our website and our disease information page, which is coming, that allows for on demand pop-ups of information when a term needs to be defined that patients are looking for.

[00:17:06] And so, those improvements to reach -- that's probably the one thing, the one program that helps patients the most, even aside from our support groups and things like that. Our policy work, that's so important to us. I really have a hard time identifying which one of them is the most important.

[00:17:29] But Jacinta's right. The pharma companies have been -- it's a whole new ballgame with rare disease -- and they do care. And our clinical trial education reflects that. They help us help patients understand what it is to be in a clinical trial, what you can expect, and that it's not necessarily a scary thing, it's something that's an option.

[00:17:54] And without any FDA-approved medications, we absolutely need options. And I think a lot of your MOGAD patients out there know that. And the last question is, what was the --

[00:18:08] **Leah Campbell:** New thing.

[00:18:09] **Julia Lefelar:** The new thing. Oh, my gosh. We've got so many balls in there. One of the new things for us is we've always been a global organization as far as our patient connections, but we're making that more official with our new regional delegates that we're identifying in the 20 countries -- slowly but surely -- that we have been involved with, and we're just making it more official. That's one thing. And you said just one thing, but I'm going to go for two. It looks like a --

[00:18:39] **Audience Member:** Blind resources.

[00:18:40] **Julia Lefelar:** What's that?

[00:18:42] **Audience member:** Blind resources.

[00:18:43] **Julia Lefelar:** Oh, yes. That's one thing. We do have a great area on our website for blind resources, and one of the programs that we actually recently -- and I think this is a great thing to bring up because Jacinta's sitting here, and Chitra's out there -- but we've been doing what we call the adaptability program.

[00:19:03] That is hopefully going to be an ongoing thing, but it's a collaborative effort between our three organizations to have patients come through and talk about, in a short video, their methods for adapting to their new normal and to regain their independence and abilities through, whether it be tools, adaptable devices, or even just lifestyle changes that they've come up with. We're very proud of it. It was launched, and I think we're on our 4th one -- and beautiful videos. Thank you for doing that video.

[00:19:44] **Jacinta Behne:** We're going to see GG later.

[00:19:44] **Julia Lefelar:** GG's will be showing later. I just found out, so I'm excited about that. Anyway, please.

[00:19:53] **Jasmine Patel:** Thank you. So, I think The Sumaira Foundation, we have also done quite a few patient days, and I think the beauty of patient days is that there's no shortage of destinations as to where you can have a patient day because the thing about the conditions that we're focused on it does not see race, ethnicity, gender, region around the world.

[00:20:14] Patients are everywhere, and different communities have different needs. And so, we've done about 15 patient days in the last year and a half around the world. Recently, there was one hosted in China, and it was tremendous.

[00:20:29] I think the beauty about patient days, as Jacinta mentions, is no matter how long this disease has been known, there are always patients who come to these events who have never met another patient. And I think the best thing, for especially a young patient to see, is an older patient who's thriving because they're able to see what good looks like.

[00:20:49] And the nice thing about these patient days is it's a platform for those interactive conversations to say, "How did you get there? Tell me what I should be doing. How can I have these kinds of conversations with my healthcare provider?" And that's what I love the most about these patient days.

[00:21:06] In addition, similar to what you have going on, The Sumaira Foundation has ambassadors around the world. So, they have about 80 ambassadors across 30 countries. Each of these individuals are representing their own unique needs based on what's going on in their own countries. And so, again, it brings more diversity to the conversation around what a patient living with these conditions look like. It is not a one-size-fits-all all journey. And as we're progressing through research, we have to also make sure that we're thinking about the needs of all patients, and that's the benefit of these programs.

[00:21:38] **Julia Lefelar:** Yeah. Very nice.

[00:21:40] **Leah Campbell:** All right. So, we basically touched on already the groups and organizations that we've all worked with. And my last thing was just summarizing, just focus on the last 30 years as the

anniversary of the SRNA, and where do we see any gaps and things of that nature in our organizations, and things that we could work together collaboratively and working with others on trying to help the needs of our community. I just want to thank you all for your insightful comments, and everything, and your participation. Just if you want to one more thing of what we can work towards, that would be great.

[00:22:27] **Jacinta Behne:** This is going to be short. I hope that in the next 30 years, no matter what technologies happen, if we're in holograms sitting around a table together, or whatever is going on, never, never, never forget the power of coming together. I think 30 years from now, we still need to be sitting in this room with Chitra, and GG and Sandy, and the team, and that, to me, is critical more than anything.

[00:22:54] **Julia Lefelar:** I'm sure this is getting old but I second what Jacinta said. I have to say that she's absolutely right. I think, in addition to that, policy changes need to be made. There needs to be the organizations, of course, we do collaborate, we want to continue that, build upon that. And those policy changes should include the ability for a team to be created for patients that focuses on holistic brain health. That's one thing that I think is, and by brain, I mean, brain and central nervous system health.

[00:23:35] And that can be something that is a policy changer for insurance -- patients being able to see more than their neurologist, and for a team to be formed to ensure that they are wholly treated, not just for their neurological symptoms, not just for their PT, OT, but also for their soul.

[00:23:59] We have depression, we have anxiety, and there's a lot of that brain health. We've talked a lot about fatigue and a lot about psych. Those things need to be part of the equation, and the ability to get that help worldwide, like you said, no matter who it is, needs to be able to achieve those goals. Thank you.

[00:24:22] **Jasmine Patel:** I think I'm going to speak to what both of you said. So, when it comes to access, for example, as more treatments come to the market, there's going to be more confusion by these decision-makers as to what treatment is actually going to get into the patient's hand.

[00:24:40] And we have to take a step back and make sure we're all working together to make sure that these decisions don't come in between a patient and a provider. And so, the role of advocacy organizations is to make sure that stands true today, tomorrow, and 30 years from now.

[00:25:00] And I'll leave with an analogy. I learned something when I went to Maui a couple years ago. I was there during whale season, and what I learned is that all the whales are singing the same song every single year. It's a different song each year, but they're all singing the same song.

[00:25:18] And all of us in the community who are, it's our own responsibility to do what we're supposed to be doing, whether a doctor, a patient advocacy organization, whether we're an individual patient ourselves, we all need to be singing the same song to make sure that the patients that we represent are getting what they need. And that's what I'll leave with.

[00:25:37] **Julia Lefelar:** That's good.

[00:25:37] **Jacinta Behne:** Thank you.

[00:25:38] **Julia Lefelar:** Thank you.