RARE-Xtra DEI Podcast Transcript – recorded March 18, 2022

Daniel Levine: I'm Daniel Levine and this is RARE-Xtra. Ensuring diversity, equity, and inclusion in rare disease organizations requires focus programs that engage all stakeholders. According to a nine-month project just completed by RARE-X, the project was undertaken to provide a general overview of the rare disease landscape regarding DEI issues, and offer recommendations to support RARE-X's efforts to ensure the long-term development of an inclusive rare disease data platform.

We spoke to Teneasha Washington, Diversity, Equity and Inclusion lead for RARE-X, J.P. Sacksteder, senior director of Patient Advocacy Relations for Genentech, and Nancy O'Donnell, director of Outreach for the Usher Syndrome Coalition. The three discuss the RARE-X report, their own experiences around DEI issues, and how to best address the challenges they've encountered. Teneasha, J.P., Nancy, thanks for joining us.

Teneasha Washington: Thanks for having us.

J.P. Sacksteder: Yeah, thank you.

Daniel Levine: We're going to discuss diversity, equity, and inclusion in the world of rare disease, and a recent DEI Scoping Report from RARE-X. Teneasha, perhaps we can begin there with the scoping report that you wrote. Why did RARE-X undertake this work?

Teneasha Washington: Yes. This work was just coming out of the importance of us understanding in the rare disease space how important it is for us to be diverse in everything that we do, and as a part of that, we were really engaged with a lot of different organizations just understanding their thoughts about diversity, equity, and inclusion, and some of that included making sure from the beginning that our advisory council was very inclusive so that everything that we planned was around their thoughts. So, we were starting that project with an open mindset of what we were going to be doing and I'm sure we'll talk more about everything that that consisted of, but the final report also lists some things as far as participating in individual interviews, focus groups, as well as a survey that we put out for everyone to complete.

Daniel Levine: And how is the report expected to be used?

Teneasha Washington: So, that's the great part, Danny—the idea that really we want organizations to be able to use the report however it's fitting for them—whether that's something that works as far as at departmental level, that's great. If it's more of an individual level for patient advocacy organizations, that's great for them. So, really, whatever works best for the particular organization that plans to use it.

Daniel Levine: What did the report find?

Teneasha Washington: Well, for the most part, something that I think we anticipated was the idea that first off, just a sure definition of diversity and what that means, thinking from a perspective of an individual base as far as race, ethnicity, but even thinking geographically, also thinking about gender and how people identify themselves. In addition, thinking through disability status, which is also very important. Other things that we found was the education that's necessary, so oftentimes, people think, "Oh, everybody just knows about rare disease, or can identify them within their community," and that

doesn't seem to be the case. There are misconceptions about rare disease and what that looks like, particularly demographic groups, and how to engage people. Oftentimes people that identify with having a rare disease, they're already overburdened with caregiving and things of that nature. So, just how do we keep them engaged in the work that we're doing so that we can attract an inclusive group of individuals?

Daniel Levine: Any surprises in your findings?

Teneasha Washington: I would say, I think that just how we'd look at data. We did ask some questions specifically related to RARE-X's platform that they're building and how people want to participate in that. So, thinking through what are the best ways to organize a website? What are some resources to provide so that people understand how to complete surveys? How to make sure that the language is even inclusive? So, things like that that I think we don't just really think about when we're creating just different platforms as well as just different resources. Just being a lot more open-minded in our practices.

Daniel Levine: As you mentioned, there were surveys, you surveyed not only patient organizations, but, a broad set of representatives across the rare disease ecosystem. Were there any differences in the way patient advocates view DEI issues relative to other stakeholders?

Teneasha Washington: Oh, yeah. I think from a patient advocacy perspective, there was a lot of just the empathy factor, like understanding a rare disease and what that entails. Also making sure that they have access to the care that they need and that they're even given the opportunity within their health care setting to have a referral to where they need to go rather than just putting out, "You may have a rare disease," and not necessarily following up with any necessary resources for them. On the opposite end, thinking about researchers and pharma companies and things of that nature, it was more related to making the data accessible and when I say accessible for those particular stakeholders, it was more so related to how do we easily manage that data and pull the data from the platform in the future, as far as how they're going to be able to see those results and being able to tangibly use those results for the activities that they have, geared towards their research and their biopharma company. So, what you'll see in the report is that those responses were very unique based on the particular stakeholder.

Daniel Levine: Okay, let's bring J.P. and Nancy in. All patient organizations and companies are different. Do you think the industry and patient organizations are taking DEI issues seriously? And, in particular, as you think about the realm of rare diseases, what's the case for why companies and patient advocates should be concerned about these? J.P., do you want to start?

J.P. Sacksteder: Yeah, sure. First, thanks so much for welcoming me on and really hearing from industry as well, and hopefully I can be somewhat of a proxy for it. So, to your question about is industry taking DEI seriously? I would say, yes. And I really do believe that, and it's been an evolution, but I believe it's the case, and I think you can start by looking at it in a couple of different ways: internally, meaning, what what is the pharmaceutical industry and companies like that doing within their ranks? And then how does that project externally in the partnerships and activities that they take? So, I can speak on behalf of one company, the company that I have the pleasure to work for, and that's Genentech. Genentech's approach to DEI really has kind of a three-pronged approach, and it starts internally with the first prong of fostering belonging. That's about creating a culture where great ideas thrive, where there are diverse opinions of people who bring their whole selves. And so, kind of based on this foundation, that projects externally in focusing on two areas: advancing inclusive research and addressing health equity, and then

transforming society. And that third external-focused pillar of our diversity, equity, and inclusion approach is aspirational, but really shows up in how we partner with groups like RARE-X, partner with the broader patient advocacy community, but also partner with education providers, HPCUs, partnering with other areas where members have historically been left out. I think it's one thing to say all these things. It's another to look in the mirror and see if you're actually measuring up to that. And so, our company's taken an approach where we publish a report on how we're doing. We've put these things out there and then we asked and saw if we're doing it. And we put that out publicly—warts and all. And I'm really proud of that. It's easy to put a glossy "we did great" report out there, and we have made some great progress, but we've also shown that we've got some areas to grow and we're putting that out there as well, and hopefully encouraging others to do something similarly. So, to bring it back to the last part of your question of how does that focus on the rare community? Our overall vision is to deliver three to five times more patient benefit at half the cost to society. So where do we find three to five times more patient benefit? It's looking for scientific innovation in areas of the most unmet need, and we know that is so often within the rare community. Our company is undertaking dozens, perhaps close to 50, clinical studies focusing in the rare community on rare diseases and disorders and diagnostics.

That's all about finding that benefit. But you can't have benefit and have a system that is unsustainable for it, and that's really thinking about the overall cost to society. And so, when we think about the cost to society we can't have a system of haves and have-nots, access and no access. It's about reducing the overall burden on society as it relates to the rare community, by thinking about things like access, care, and continuity of care to access and to treatments. So, it's really a broad approach, but the rare community and all the things that we're learning from Teneasha and RARE-X's research really fit in nicely with this broad approach.

Daniel Levine: Nancy, how about from a patient perspective?

Nancy O'Donnell: Yeah, glad that you're zooming in on the very local level. The community that we serve and that we work with happens to be individuals who are deaf and have a progressive vision loss. So, when you think about access and accessibility in general, you're dealing with many, many forms of communication. You want to make sure that your websites are accessible for health literacy and an understanding of where each person's disease progression is at. You want to make sure that any forms for surveys are accessible. You want to make sure that if people use sign language or tactile sign language or braille, or electronic forms, that they're all accessible. So, we love to partner with other organizations that are providing services to the Usher Syndrome community specifically, but we find that if information is accessible to our community, it's pretty well going to be accessible to other rare disease communities as well. And because we work with the deaf community who are culturally Deaf, and that's with a capital D, and who use American sign language as their primary method of communication, then English would be a second language for many in this community. And that goes along with, as Teneasha mentioned, that we make sure that our language in surveys or even reports, is accessible. They fall between maybe a sixth and eighth grade reading level, and that not only benefits individuals who are deaf, but if we have individuals from other language bases, Spanish, French, whatever, that it makes it accessible to all. So, we really work with it on a one-to-one and a local community level.

Daniel Levine: All three of you engage with various stakeholders in the rare disease community. I'm wondering, what's your sense of how seriously people are taking DEI issues and what's driving that? Whether it's a cultural issue or a science issue?

Teneasha Washington: I think that's a great question and I say that because I think that really determines... It's really based on [the] organization and I feel like more and more what I'm seeing out in the scope of the work that I do is that more and more organizations are genuinely worried about diversity, equity, and inclusion. The levels that we're there trying to attack, each of those areas depends on their focus. I've seen a lot of thinking about diversity in the sense of making sure in the development of an organization from the board of directors to any people that volunteer with the organization--even contractors. They're thinking about diversity and from that side of diversity, and then in addition to that, also thinking about other organizations that are really kind of attacking their thinking through the inclusion aspect, and really trying to develop novel ideas and approaches to actually communicating with people whether that's in different languages, as well as thinking about Nancy's organization and who she works with; identifying ways to communicate that may not necessarily be what we're accustomed to thinking through; being very strategic about [it], even if it's sign language and other ways of communicating that they are really kind of pushing that to the top of their priority list.

Daniel Levine: Nancy, what's your experience?

Nancy O'Donnell: I think that organizations in general want to be more inclusive, but I don't know if they know how, and you really have to have experience with your consumer-base, with your community in order to understand what their needs are, and in order to respond to their needs. Basically, let the community tell us what they need, and that's what we have done for years as technology has changed. My goodness, it's made such a difference in the lives of people who are deaf and blind, deaf-blind, people with disabilities, internet accessibility, various adaptive equipment, et cetera. But for the mainstream community, or for an organization or a company or a corporation that does not interact very often or doesn't have the opportunity to interact, they might not know where to start. And that's where we kind of shine. We, as a service provider, as a consumer-based organization, we are the bridge between those communities and I think you really have to go back to the community itself and always touch base there because things are constantly changing.

Daniel Levine: J.P. do you find, when you engage with others in the rare disease world that there is this focus? Is this something Genentech is bringing to patient organizations or its partners?

J.P. Sacksteder: Yeah, absolutely. I think one of the really encouraging signs that we've seen over the last, I'd say five or six years is the focus, especially on the science, of recognizing the shortfalls and the opportunities to be more inclusive. And when I think about the science, it's really two areas. One, it's who is doing the research? So, bringing in unique diverse researchers that have a different perspective on how to conduct research, and then the second piece on the science side of being more diverse and inclusive, is who are the subjects of the research? And I think the first of bringing in diverse researchers has made such a tremendous benefit in how we think about going out and engaging diverse and more representative communities for the science. And we know right now that roughly 90 percent of genetic material that is being used in basic and translational research is of European descent. That is a symptom of when this information was captured that many of the folks doing the research were of European descent. So kind of changing that paradigm now while those who are doing research are more diverse will ultimately lead to better genetic material, and therefore better research that is more diverse. So it's really heartening, there's a lot that's happening, plenty more to be done. But the steps, and it feels like the wheels of this are- are really in motion.

Daniel Levine: You mentioned genetic material. RARE-X is focused on data gathering and data sharing. From a data point of view, particularly with regards to rare diseases that tend to be genetic and

heterogenous, why is it important to think about DEI issues with regards to things like natural history studies or patient recruitment for clinical trials?

Nancy O'Donnell: A recent initiative that we have started is to develop a volunteer base worldwide. In our rare disease community it's estimated that there are approximately 400,000 people worldwide living with Usher Syndrome, and we've recently started to reach out and train volunteers in countries where we've really never had an impact or a contact person. For example, in Nepal, I'm training a team of volunteers there about Usher Syndrome, and these are individuals who themselves have Usher Syndrome. They use a different sign language system. Their sign language is interpreted into spoken Nepalese, and then into English. We would love to build our community there and find out, are there other genes that could be identified that are just unique to Nepal? We just created a team in India as well, and we know a large population in India has basically been untapped, not organized, and we're excited to see if there are unique genes there, and our other country is Greece that we're starting to work with. So, prior to the onset of platforms that are virtual, we would not have been able to do this type of work, and it's very exciting to think that not only on the research side but on the education side and on the recruitment for clinical trials, all of these are elevated to a whole new level now.

Daniel Levine: J.P., on the drug developer side, are you finding regulators are scrutinizing data for diverse populations? Is that something that drug developers do on their own as they look for finding, perhaps, sub-populations where a drug may have efficacy? What's the pressure internally to be inclusive with regards to the data you're gathering and the clinical trials you conduct?

J.P. Sacksteder: Yeah, One of the unique things about the rare community, as we all know, is just in that name. It's in the rarity of it. And so, as much breadth as we can find across these rare communities gives us more robust data and therefore, more information to potential participants in clinical research. So, given the heterogeneity of rare diseases, expanding the pool, and Nancy brings up a great point and one that we've been trying to work with as well, is to reach out to those areas where we know there are communities that are impacted by these conditions, that have been either disenfranchised or inaccessible to certain research. And so, by broadening that funnel we're able to welcome more folks in who may be eligible to participate in research and therefore have a broader understanding of the disease itself. I'll take one example that we worked on a number of years ago here at Genentech, and it's for a condition called spinal muscular atrophy. In our study, we were able to expand that to areas that had previously not been able to participate in clinical research. Areas like China, areas like Turkey, or Eastern Europe, or the Middle East. Areas that had historically been not included in much of this research. And in doing so we were able to learn a tremendous amount. Also, when it became a medicine, to be able to go back to those same communities and go to their regulatory authorities and say, "This wasn't something that was done over here in the U.S., or in the EU. This was something that was done in your country, with your communities," therefore access to this medicine was much more favorably viewed. So I think there's a reciprocal benefit to expanding outreach and engagement that can ultimately lead to better research and, ideally, better outcomes for those communities.

Daniel Levine: Nancy, you spoke about language challenges, but I'm wondering more broadly as you think about efforts your organizations have been engaged with, where have the challenges been as you've sought to address DEI concerns?

Nancy O'Donnell: I would say language, or access to language and information, is probably our number one challenge, and also transportation in our particular community because it's combined vision and hearing loss, individuals may be interested or willing to travel but may need someone to travel with

them if they have a recent and severe loss of vision. In terms of communication, as someone loses their vision, they go from visual sign language to tactile sign language, and also touch cues on their body, so you're looking for a very specific group of people who can facilitate communication there. I would also say that, in terms of what I've learned in working with the international community, language that we use here, our vocabulary, especially when I'm doing some of the training, doesn't translate into another culture, into another language, or into the consciousness if you will. When we talk about, for example, in working with our group in India, they say, "Why do I even want to bring my child to get genetic testing to see if they have Usher Syndrome? If you can't cure it, what's the point?" So, we're learning about the- the various cultures and values of communities around the world that still fall under the umbrella of Usher Syndrome, and of course, honoring that, providing information, and leaving that information there for each person to make their own decision as to what works for them.

Daniel Levine: J.P.?

J.P. Sacksteder: Yeah, I think the biggest challenge is reconciling the enormity of the problem, versus what a company like ours can effect, albeit a big and multinational company. Sometimes the problem feels so daunting and our piece of it so small that reconciling those two things can be a challenge. And in response to that, it has been all about partnership, about really leaning into partners like RARE-X, to others in the community, but also policy and advocacy organizations that are focused on issues on the Hill, or issues in the states. Working with academic and research partners, instead of trying to devour that elephant just one bite at a time, but in partnership with others has really helped ameliorate that challenge of looking at this huge systemic issue and being paralyzed by the complexity and enormity of the challenge.

Daniel Levine: Teneasha, as you conducted your interviews and surveys, did you find any pattern of challenges stakeholders faced in their efforts to address DEI issues?

Teneasha Washington: Yes, and I'm going to go back to something Nancy said, because I think this is so important. One of the things that we found out was that, yes, everybody wants to focus on diversity, equity, and inclusion, but many people don't know how. That was why we created this report, the idea being to show them the how so that no matter where you are on that spectrum, maybe you're almost at the end. You feel like you're almost there, you're doing great work. What else can you do? And then those that haven't necessarily started but don't really know where to begin, and what you pull from the report for your particular organization that will be helpful? And maybe start small and then kind of start out some type of strategic plan of how you want to focus on diversity, equity, and inclusion. In addition to that, I would have to go back again to Nancy and say, language. The language is such a barrier in the sense of how do people look at language? How do we identify a language that works best for us? And, again, those cultural aspects. So what does that look like in different settings? And for this particular project we did have this national approach, and more so in the future thinking about the international scope. RARE-X has already done some international scoping work, but continuing to engage our international partners as well.

Daniel Levine: I remember attending a recent DEI event and one of the things that I found interesting was when people in communities that necessarily weren't participating in clinical trials or other types of research, one thing that became apparent had a lot to do with people just asking, and I'm wondering, how much of getting an effort like this started just has to do with organizations being very conscious about reaching out to places they're not, and making that ask?

Teneasha Washington: I think that's a very important point. I think it's being transparent about what's missing and in the sense of outreach, what does that look like? And J.P. mentioned this earlier, a lot of our work, even previous efforts, have really focused on the idea from that Caucasian white perspective, because that's predominantly who's been in the field. So, a lot of organizations were really like, "How do we do this?" And J.P. hit it on the head, the idea of thinking about outreach differently, thinking about engaging communities authentically, and oftentimes that may mean that you're going to have to be transparent about being honest about the history behind a lot of the work that we do and how it has disenfranchised communities. But also, thinking through just being innovative in your efforts, reaching out to HPCUs, trying our best to continue to kind of navigate rare disease and creating, I would say, people that are interested in rare disease research, that doesn't look like what we're used to seeing in this particular field. So, I think that's where we've been working and thinking through how to actively engage communities. Once we learn that process and what that looks like, people are more willing to actually do the work and are actually willing to help. It's just finding the best way to approach them.

Daniel Levine: I'm wondering if any of you can offer creative solutions you've either found for yourselves, or seen others apply that you think might be worth considering?

J.P. Sacksteder: If I could, piggyback on Teneasha and perhaps offer one. I think the question, especially as it pertains to research, is not just how but where? What so often happens are sites and locations where research has taken place, they're largely academic medical institutions, and it's that way for a lot of different reasons, but that's also self-selecting for the types of patients and individuals who are able to participate in that research, and it leaves a lot of folks behind, folks who are not seen or don't have access to those sites. Genentech has started an initiative. It's called the Advancing Inclusive Research Site Alliance, and it's partnered with quite a number of reputable research organizations across the country here in the U.S., sites that do those types of research. But they're partnering with them to have outreach to other community sites in their proximity to bring them on board, to be part of the research, and to have their constituents, constituents who might not otherwise be given access to research, the ability to participate. And so, it opens the door for more folks to participate, and that's part of it. But there's more that goes into it. These are communities that have a less traditional experience of participating in clinical research and therefore need more resources. So in addition to the outreach and engagement of these community-based sites, is putting together an ecosystem to support potential research participants. That includes things like logistics support, things like case management, things like differentiated education about clinical trials and what to expect in appropriate language, back to what you were mentioning Nancy. That is something I'm definitely going to take away from this conversation, is the importance of language, but really putting that in a way that's the most applicable. So, through this alliance we're hopeful to really expand into many rare disease areas and make that accessible to communities to participate in research that might not otherwise have had the ability to do so.

Nancy O'Donnell: This is really helpful to listen to everyone else talking about ways that we can better serve our communities. I have three things that I've written down. The first one is trust, and in working with the deaf-blind community for many years, and with any community that's been marginalized or overlooked, I think trust is the first thing that we need to make sure that we build and create. In fact, we went so far as to call our international registry the USH Trust, because not only is it secure and we don't share information, but we want the community to know that when you trust us with your information with the knowledge that you have Usher Syndrome, we are not going to go and share that without your permission. The second thing is time. It takes time to make information accessible. It may slow down the pace of a conversation. A podcast such as this, for example, it would take time to change this into a text document so that this is fully accessible to, for example, our community who they don't hear so they

won't have access to this. So, it takes time to make sure that all communities are included. And then, translation has a couple of meanings. Number one for me, I didn't come into this with a background in science, so translating those big words and those huge concepts to the level that a lay person can understand so that when they sign up for either a natural history study or some type of clinical trial, they truly know when they're signing the consent forms what they're getting themselves into and how they can get themselves out of it and understanding what the process will be, what the commitment will be, et cetera. So, understanding the science that they are interacting with. And then, translation of the language as we mentioned, so that it's in a sixth to eighth grade reading level that is accessible to all. And then making that information available through a text transcript, and making sure that captions are available on any information that goes out, making sure that PDFs or Word documents are accessible. That all builds trust in the community that we really are listening to individuals and that enhances the relationship, it makes people feel heard, it is making people feel heard, and is also inclusive, and then people can make informed decisions.

Daniel Levine: Well, Nancy, how does a report like the RARE-X Scoping Report help you in what you're trying to do?

Nancy O'Donnell: Well, first of all, it lets the community know that we are not just an isolated community looking at our own segment of the disability world, if you will—that we are working together and collaboratively to get the big picture. And that information that comes in through the report can go out. I would say that for 105 pages of the report, that's a lot to read, so hopefully there's an executive summary or we can make that information accessible to individuals, and to come up with a version that isn't going to cause mental exhaustion, visual exhaustion, tactile exhaustion from reading it in braille. But, I think there are many levels that are comforting to a community to know that they are not alone, that the whole rare disease community is working together to improve the quality of life for all.

Daniel Levine: And J.P., how are you using the report?

J.P. Sacksteder: Yeah, I think in two ways. First, it's admirable how Teneasha and Charlene and Nicole have really included this focus on DEI at the inception. That is not the case for most other ways that data are collected, be they registries or natural history studies. So, the first thing that's really spurred for us is to think about those existing partnerships that we have, many of which are with patient organizations, and really probe on how we might think about gathering more inclusive participants in those, and also, more inclusive data. So, it's given us pause to think about how we might change our existing partnerships and how gather data. And then I think the second thing is it's spurred us internally, within our organization, to think about how we are capturing data. Any big organization like ours is collecting appropriately and compliantly information from members of communities with which we work. We asked ourselves, we're collecting this normal data set, but why aren't we always doing it appropriately and with consent, why aren't we collecting veteran status? Why aren't we collecting SOGI data? Nancy, you have got my head spinning about how we think about individuals that need visual or tactile support. It's really forced us to think about how when we go about collecting data, are we thinking about it as inclusively as the RARE-X team has been? So I think, both in our partnerships and again, looking in the mirror, it's really forced us to take some pause and really think about how we could do things better.

Daniel Levine: Teneasha, what's next steps for RARE-X? What's it planning to do now that it's completed this scoping study?

Teneasha Washington: Yeah, so many things. I think that's the exciting part. So, I would say, for the first part, transparency, and transparency from an organizational standpoint. So, making sure that we think through RARE-X's policies and how we are actively working on diversity, equity, and inclusion, and one of the ways that we plan on doing that is to also provide potentially yearly updates on where we are in regard to the actual report. So, we're not just putting out this report and then not also doing the exact same things that we recommended. In addition to that, something Nancy mentioned, which is creating an executive summary of the report. That's something that's definitely necessary given the length of the report. One of the things that was very hard for me was, hey, Teneasha, it needs to be shortened, but at the same time, making sure that all of the data and everything that we gathered was there for everybody to see. And then for us to adapt that to a smaller version for those individuals that just want, "Hey, you know, what are the recommendations? How do I implement them into my organization?" And then, really adapting our platform. One of the main goals of this was to make sure that the RARE-X platform was going to be developed in a very inclusive way, and a lot of the questions, a lot of individuals mentioned different share recommendations of what they would like to see on that end. So, we are making sure, as a part of that, that we're actually gathering demographic data. One of the things that I found out was that a lot of organizations didn't even realize that they needed to collect this type of data, and making sure that in that collection of data that we can see who are we actually engaging with this particular platform. Another thing that we're doing is really thinking about identifying rare diseases that predominantly impact minorities, and using our platform to pilot with those different organizations. What I mean by that is making sure that they see the platform and that they can provide us very strategic recommendations on what we can do to continue to improve our efforts of working with inclusive organizations. In addition to that, really taking those recommendations and utilizing them. And one of the ways that we're doing that actively is thinking through a program that we're working on that involves community liaisons and training liaisons to be able to serve as the connectors between academia and all of these different rare disease stakeholders and then the actual people in communities. It goes back to that language barrier. As a researcher myself, I know how I can speak in certain terms that may not necessarily translate to the community So, really thinking through how we engage community liaisons to serve as that intermediary to fill in to that trust level, and then also to help us with really breaking down our language to a level that's understandable, that allows people to access all of the resources that they need to. And lastly, I would say, engagement, engagement, engagement. By that, I mean, authentic engagement. Oftentimes I think that's a lot, thinking about even from a research perspective. We do all of the work that we do because of people, not for numbers, not for data. That's how I think we should think about the work that we do, and I think that if we put people at the center of everything that we do, the ways of thinking through that is really engaging them authentically and really putting what their interests are at the foremost of the organization and then kind of modifying the other areas in a way that is conducive to what they're asking us—but really to formulate those relationships and think about them genuinely as people, and not necessarily what we can get out of them, building those relationships authentically.

Daniel Levine: Teneasha Washington, Diversity, Equity and Inclusion lead for RARE-X, J.P. Sacksteder, senior director of Patient Advocacy Relations for Genentech, and Nancy O'Donnell, director of Outreach for the Usher Syndrome Coalition. Teneasha, J.P., Nancy, thank you all for your time today.

J.P. Sacksteder: Thank you, Dan.

Nancy O'Donnell: Thanks so much, Danny.

Teneasha Washington: Thank you, Danny.

Daniel Levine: Thanks for listening. RARE-X is a collaborative platform for global data sharing and analysis to accelerate treatments for rare disease. RARE-X is adapting proven technologies and partnering with leading experts to create a federated data analysis platform, specifically designed by RARE community leaders scaled to support the diverse and expanding needs of rare disease research, development, and care. To learn more about RARE-X, go to rare-x.org. This podcast is produced for RARE-X by the Levine Media Group. Music is courtesy of the Jonah Levine Collective.

This transcript has been edited for clarity and readability.