

Transcription

Dr. Rochester: Hello, and welcome to Bold Conversations, an immune deficiency foundation podcast series aimed at advancing knowledge and understanding of Health Equity. I'm your host, doctor Nicole Rochester, the immune deficiency foundation's medical advisor for Health Equity and the founder and CEO of your GPS doc, LLC.

Welcome to today's episode of Bold Conversations. I am your host, Dr. Nicole Rochester, the medical advisor for HealthEquity for the immune deficiency foundation.

I am really excited about today's episode because I have guests and it's okay to do solo episodes, but it's so much more fun when I have the opportunity to speak with others and for them to have the opportunity to share with you all. So in today's episode, we are focusing on inclusion in practice. And it's all about the twenty twenty four primary immunodeficiency conference, which I had the honor of attending in June in Chicago, Illinois, It was an amazing conference. And the reason that we're talking about the conference on bold conversations is because the immune deficiency foundation teams did such an amazing job operationalizing the principles of equity. And so I can't think of a better way to express that to you than to have those who were intimately involved with the planning of the conference come and speak.

So before I introduce our guests, I wanna just give a brief introduction and overview of the terms diversity, equity, and and inclusion because certainly not just in today's political climate, but In general, we know that sometimes these terms get misconstrued. So diversity is literally just the presence of differences. And when we talk about an organization, it's the presence of those with multiple identities represented in an organization or a workforce. And to help illustrate these terms, I'm going to use an analogy that I used during a training session with IDF. I think that was last year.

Where we're gonna relate these terms to a party. And so if you think about diversity, it's being invited to the party. And next, we're gonna talk about equity. And equity is really ensuring that Our processes, our policies, our programs provide fair and equal opportunities for everyone to achieve their best outcomes. If we think about this with regard to the party, Diversity again is inviting someone to the party who may be different than you.

And then equity is removing any barriers so that those individuals can attend the party. Inclusion is having a seat at the table. And so think about that with context to the party, it's being asked to dance. So it's one thing to be invited to the party, but we've all been to parties where you or maybe someone you know sat on the sidelines, maybe you were a wallflower, maybe you didn't necessarily feel comfortable. And so not just being there, but

actually being asked to dance is inclusion.

Belonging is something that doesn't always come up in these conversations, but that's the feeling of actually being accepted and being made to feel welcome. So in our party example, it's actually helping to plan the party based on your preferences. Being asked to contribute to the decorations or to the food that's gonna be served or to the music that's going to be played. And so with that, let's delve into today's episode. I am thrilled to have two of the amazing team members at the Immune Deficiency Foundation, Megan Messick and Alissa Creamer.

And I'm gonna ask each of you to introduce yourselves and to share what you do at IDF. So I'm gonna start with you, Megan, and welcome.

Megan Messick: Hi. Thank you so much. As you said, my name is Megan Mesick, and I'm the Director of Education here at the Immune Deficiency Foundation. And I have the honor in tandem with a phenomenal team, a frontline staff, of crafting our digital and our in person learning and engagement opportunities. So together as a group, we really have the opportunity to respond to the core question in, how can we most effectively expand knowledge of PI for those living with PI, but also for their network of loved ones and clinicians who are supporting their journey.

So really incredibly work and work that I feel blessed to be a part of.

Dr. Rochester: Thank you, Megan, and Alissa.

Alissa Creamer: Sure. Hi, everyone. My name is Alissa Creamer. I'm the senior director of education and community services for the Immune Deficiency Foundation. And in this role, I lead the overall strategic vision and development of our core mission work related to community focused priorities.

And this includes education, community services, outreach, and our medical programs. So if it impacts a member of our community no matter your connection, to primary immunodeficiency. My team of six has a hand in the planning and the delivery of it all.

Dr. Rochester: Thank you so much. And again, I'm thrilled to have both of you here. I'm really looking forward to this conversation. So as I said in the intro, we're really focusing on the twenty twenty four PI conference. And there was a lot of excitement around this conference for so many reasons.

For one, it was the first time that everyone would be gathering in person post COVID. And I know that you all and many other members of the IDF team really put a lot of thought into how this particular conference would be different with regard to diversity and equity and inclusion. And so, Alissa, I would love for you to give us some insight regarding the decision to appeal to a broader, more diverse audience. The twenty twenty four conference. And if you can also share how that decision fits in with IDF's strategic plan.

Alissa Creamer: Yeah, sure. So we began to plan our twenty twenty four PI conference at the end of twenty twenty two really still in the midst of the pandemic with a lot of uncertainty about the future of in person events and apprehension regarding whether our community felt comfortable and would embrace an in person event that was still over eighteen months away. However, the way that events and space reservation works means that you really have to think far ahead when you're making these decisions. So we took a risk and committed to this event that was going to be our first in person conference since twenty nineteen. And in the past five years, IDF and our community has changed significantly, and we wanted the conference experience to reflect that.

So we were really cautiously optimistic that our community might respond with enthusiasm to an event like this. And I mentioned a little bit that our community and that IDF has changed a lot. And it really has. We have grown significantly as people have become more aware of the immunocompromised community during the pandemic. And this is not only just general awareness that immunocompromised people exist, but that there is an organization whose mission and vision is to address their education, advocacy, and research related needs.

In this time, we've also embarked on a three year strategic plan that has really kind of been the guiding light for IDF and our path forward. And that has included objectives related to access and accessibility and engagement and innovation and sustainability for IDF as a whole. And we really wanted to weave components of this large signature event into that. So in some ways, this conference was a way for us to introduce IDF to our new community and reintroduce ourselves to those who have been with us for a long time. And knowing that many were new to IDF, we wanted to ensure that anyone who wanted to attend this conference could, and we set out to reduce as many barriers participation as possible. As with many things, a significant barrier is costs, including travel and lodging. So we offered substantial funding to cover the travel and accommodations of those who wanted to attend, but couldn't financially. We provided over four hundred scholarships which accounted for about half of our conference attendees. This is nothing we'd ever done before and it was truly a decision and something we provided that made a huge and positive impact on our community and our event.

Dr. Rochester: Wow. I already knew some of these things, but I'm hearing you say it and being present to witness it. I mean, literally like my mouth is open. That is that is phenomenal. I did not know that these scholarships accounted for about half of the attendees.

How was that received? You know, when you all late made it known that you were gonna be offering these scholarships. What kind of feedback did you get from the community?

Alissa Creamer: People were thrilled. People were really excited about just the opportunity and the potential that this opened for them. IDF has offered conferences many times, many years, every two years for since the nineties, I believe. And has never provided scholarships on this level. For so some individuals, they may have been diagnosed for thirty years, but have never been able to attend the conference because it was out of reach financially or distance wise for them.

So this really opened up the door or the window or just the opportunity for so many people to come and see what our community is all about when it may have been out of reach for them in the past. And it has made a significant significant difference. We heard from individuals who again have been part of IDF for decades and have never attended, but we also heard from people who were just diagnosed through the pandemic and have only been a member of the IDF community for a year, and they saw this as an opportunity that they had to jump on and couldn't let go by.

Dr. Rochester: That's that's incredible. And it really just speaks to this principle of equity that we talked about in the in the beginning, this idea of removing barriers. You know, when when you have a focus on diversifying your community, it's more than just saying it. Like, we wanna have a diverse community, but it's really being in touch with that community, understanding what their needs are, identifying the barriers that may have prevented them from actively engaging and then doing what you can to remove those barriers. And so, you know, it's expensive to go to conferences.

And, you know, even as a physician, sometimes the cost of conferences, certainly in the early part of my career, was a barrier for me. So I can't even imagine or, you know, someone who has a chronic illness for someone who may or may not be able to work regularly or just for whatever reason may be experiencing financial barriers to be able to participate and to travel and to stay in a beautiful hotel and to experience that conference is is just amazing. And I think it's also important to state that when we do these things, we benefit from the diversity of thought, the diversity of opinion, you know, the individuals that were at that conference were able to engage with presenters, engage with other attendees, engage with IDF staff, And I'm sure that all of us were were really enriched as a result of that experience. So kudos again. I I just can't say enough about how important that was.

So Megan, I wanna move to you because, you know, you and I had a lot of conversations with regard to the conference and the content and the agenda. And I was very appreciative of the thoughtfulness that you and other members of your team put into the agenda planning and and even, you know, what topics you wanted to include and who you wanted to present those topics. So how was IDF's desire to diversify this twenty twenty four PI conference reflected in the agenda, including how you selected topics and speakers.

Megan Messick: Right. So I am very value driven and simultaneously am also someone who leans heavily into understanding our data, our community feedback, and what we've done historically. And these have all been really critical elements and making decisions about what lies ahead for our programming. So myself and two team members involved in driving session content really started this process by looking out. So what are the opportunities to meet directly with community members and discuss what they need? Or, hey, let's compile survey results and see where they take us. But outside of looking, you know, out, again, I'm looking back. I'm looking at the last ten years of programs and I'm thinking to myself, what perspectives or topics have been excluded from our narrative? And this is the moment where we begin to see work at the twenty twenty four conference that looks and feels pretty different. This actually doctor Rochester inspired a personal project for me where I am in the final stages of reviewing about a decade's worth of our digital programming.

And what it's done has really, you know, created such reverence for me for the clinical champions who have shown up for us year after year who will continue to celebrate and integrate into our work but also this understanding that it's time to develop this next generation of voices at IDF. And I always say if I'm in the room, so is my team. So I'll take a moment to shout out Kat Steeber and Emma Mertens, who did great work in championing these new voices. You know, we had speakers like doctor Karen Tuano and doctor Richard Siegel. And, you know, Kat knew to work with doctor Siegel because he was recommended by a member of our youth advisory committee who also poured just so much love and perspective into this work.

So shout out to them that at the same time that I sing those praises, I also recognize that this work is never done. And that we need to continue upholding this commitment and to consider additional opportunities. Because as you know, there there is never the we did it in DEI. It's a we're doing it. Approach where there need to be these critical points of reflection and consideration to make sure that DEI is interwoven into the ongoing fabric of our work.

Dr. Rochester: Thank you, Megan. I just really appreciate show the approach that you and your team took. And I really appreciate what you said about new voices. And and really what you shared exemplifies this idea of who's not at the table, a a core principal as it relates to diversity and equity and inclusion and not resting on your laurels. I mean, IDF has given amazing conferences.

You had amazing speakers. And like you said, there are those who are you know, trailblazers and those who continue to do such a business and work. And we can't take away from that, and also recognizing that there are other unique voices who have been excluded, you know, intentionally or unintentionally, And so reaching out to those

individuals and leveraging your youth advisory committee is amazing, you know. We're not just when we talk about DEI, we're not just talking about race and ethnicity. We're talking about age.

We're talking about gender identity. We're talking about geography. And lots of other socio demographic characteristics. And we know that often in organizations, you and young adults are sometimes, you know, not always their voices are not always elevated. And so the fact that you all specifically included that population of the IDF community to help guide your speaker choices, I think, is amazing.

So, Alissa, I'm gonna go back to you. We've talked in our staff training sessions about how we can't stop at diversity. Our organizations. And we've talked about that on today's podcast and how inclusion is so important. We're engaging authentically with the more diverse people in groups that we have quote unquote invited to our party.

What was your approach in that of idea to ensuring that the conference attendees not only were invited, but that once they got to the conference that they felt comfortable and that they were able to experience the conference without barriers?

Alissa Creamer: Yes, so we have taken all of our discussions with you Dr. Rochester to heart and we made some serious strides and efforts to ensure that this event was inclusive. Our conference committee really wanted this event to feel approachable I think we achieved that by doing a few core things. So while COVID was the only thing that was not invited to our party, it certainly informed a lot of our planning and the preparation and the experience. So masks were available and encouraged for all who felt comfortable being around others.

We used color coded lanyards for everyone's name badge to show their comparability with distancing. So green meant you were comfortable with a hug or being close by. Red meant distance and no contact and there was yellow for people who felt that in between component. We had hourly monitoring of the air quality in all the conference spaces. There was hand sanitizer stations throughout, and we also offered outdoor seating accommodations for those who didn't wanna in the larger conference group.

But beyond that, we also had the availability of interpretation. We provided the option for attendees to request the need for interpretation, which allowed us provide in person American sign language interpretation for two tracks in our program that were utilized by participants. All sessions were recorded for later distribution, and this was really important in order to accommodate those who couldn't attend. For various reasons who couldn't join us in Chicago, but also offers us the opportunity to include closed captioning and copies of the slides when possible. So that way, this content is able to reach others beyond just those who were on the ground with us in Chicago.

We also livestreamed the special screening of our documentary film, compromised life

without immunity. So again, even those who couldn't attend in person could take part in this really great event. Something more simple that we offered was microphones and screens. So all sessions were conducted in a conference room with a stage, microphones and a screen. Everyone could see the presentation and the presenter and hear the discussion.

And then microphones were also passed for q and a. And that sounds like such a simple thing, but making sure that people could see in here is a big deal. And then, again, when gathering a large group of people, you really you need to feed them. And many in our community have specific dietary needs or restrictions, so we ensured that meals were able to accommodate most needs, including those who are vegetarian, gluten free, and then children who are notoriously picky eaters. And then finally, we had really simplified signage and language and programming.

Our communications team did a phenomenal job at creating simple but informative signage and wayfinding for everyone who was there in attendance.

Dr. Rochester: Wow. I'm just struck because as as one of you mentioned in the beginning, IDF is a small organization. And as someone who consults with multiple size organizations. I'm not gonna call anyone out, but I'm just gonna say that there are some large organizations who sometimes feel that they can't do certain things that is out of their reach, it's out of their budget. And so just to hear all of the ways that this small but mighty organization really centered inclusion and equity in this conference.

It honestly blows my mind. So thank you for sharing that. Something I wanted to add as an attendee and a presenter, you know, as I was walking through the the hotel and the the conference venue and going in and out of the different rooms, I was struck by several individuals who were dragging IV poles. And as a physician, this is something that I see obviously all the time in a hospital, but I can tell you I've attended a lot of conferences in my years and I've never ever seen someone with an IV pole receiving a medication at a conference. And I just remember seeing that and just like feeling warm and fuzzy in my heart because even though we know that members of the community have to receive IVIG and other medications.

Again, these are things that might easily preclude attendance at a conference. And there were people regularly just moving, do you need help? Can I help you push your pole? You need a private room. I mean, it was just phenomenal to see.

And every time I saw someone who was, you know, actively receiving some type of medical therapy while still participating in the conference, it it really just it was an active demonstration of how IDF supports community. So I just wanna give you all kudos for that. So Megan, we're gonna stay on this theme of inclusivity. How did inclusiveness factor into the content for the twenty twenty four PI conference?

Megan Messick: Such a great question because as we've discussed, we're bringing in a lot of presenters from many different backgrounds who specialize in different PI. And who represent different identities and a range of knowledge, and they're all at our table, all at our party. So, you know, if we want community members to be able to see themselves within the work of our presenters, it was and it continues to be imperative that we trust presenters to do the work they wanna do. So to lead with different learning methods, to utilize the language and messages that they know resonate with them and the people they serve. Dr. Rochester, in our communication stream, I don't know if you recall, but we actually sent out information and objective sheets to all of our presenters where it called out general information, like, where the conference was located, length of session time slot, But in there, it was really important to me that we include the single line in all of our ask, which was we trust that you know the best way to lead your topic followed by, you know, please pick a sign of format that allows you to most effectively achieve the objectives and work with our guests.

And and for me, what's always gonna be a hundred percent clear is at the end of the day, great work will always flourish in a culture of trust. And to that point, you know, when we talked to our presenter The presenter experience is critical for me. We actually did a survey specifically for that subset this year and in creating that culture where we also focused on excellent communication and establishing relationships with every speaker Every single speaker who participated in that survey ended up giving five out of five stars that they enjoyed their experience and they would be open to participating in future events, which is phenomenal. And I know in my heart that that's not worker feedback that happens by a happy surprise, but what it happens from is the work of intentional engagement, not only from the planning team, but from the larger group of IDF staff who worked on-site and who were on, you know, as you said, offering our attendees help, can I get you a personalized room? But also mirroring that same experience for our presenters as well.

Dr. Rochester: And as a presenter, Megan, I can say that I really appreciate it. You know, that, again, these the the entire experience for me was just very different, in a good way, very different. I've spoken at a lot of conferences that the communication that I have with you and your team and, again, the intentionality behind the Zoom calls, the emails, It was it was very different, and it was very unique, and and just the in the inclusiveness was palpable. And so I personally appreciated it as a presenter. And I do wanna just take this time to also personally thank you because you took me outside of my comfort zone for those who may not know.

I know that some of the videos are on IDF YouTube channel, so I definitely encourage you all to head over there and look at the presentations that have been uploaded. And I think there will be more to come but I was asked to present from the physician side about really

the challenges that we face in caring for patients and in navigating the healthcare system and admittedly it was a difficult ask because I am so invested in advocating for patients and advocating for their care partners. And I felt a little weird about taking the stage and kind of sharing in a way that, you know, for me, it was important that it didn't come across as, like, whining or what was meant?

Megan Messick: Right. Yeah.

Dr. Rochester: And and wanting to do it in a way that still centered the needs of patients and families, but also humanized doctors and other healthcare professionals. And so you helped me to that, you know, with that request. And I think I may have pushed back just a teeny bit, but I trusted you and you trusted me, and it was a beautiful experience. And one that I will honestly never forget. So again, like, this this conference really meant so much to me in so many ways.

And I was just thankful to have been a part. So as we start to wrap up, I want to hear from each of you about the feedback. I mean, I've given some feedback here. You mentioned Megan, this feedback you got from your presenters. I mean, unanimously five out of five. Again, this is unheard of. But what feedback have you all received about the conference? Anything that maybe you haven't already shared? What's your what was your favorite part personally about the conference? And so I'll start with you, Megan.

Megan Messick: Yes. So, you know, building on that presenter experience, we also heard a lot of great feedback from guest. My favorite thing to read are the stories that we get, not even just from the surveys, but in the emails, in the handwritten thank you notes about community members who have found such great connection. You know, I'm very focused on the educational experience, but what I know happens when we bring our community together are these lifelong bonds, these life on connections that we're able to facilitate. So that's that's a little piece of the joy for me is hearing that.

And I know Alissa touched on scholarships, but I I just wanna hit home and and especially in reading the feedback from attendees that I have never worked at an organization as committed as IDF when it comes to the provision of need based scholarships and it was felt by our attendees. And we'll certainly, you know, continue the legacy of accessibility in our work. But looking ahead, you know, my my wheels are always turning. You know, what what are we doing next? How do we build on this? How do we continue to make an event feel like this one felt?

But continue to to deepen the way that that we include those new voices. And I'm really interested in thinking through more of our peer to peer learning opportunities. You know, and peer to peer learning is something that we facilitate very well virtually in opportunities like our get connected groups. But how can we make that concept thrive? In a conference

setting.

How can I bring that to life in a in person venue? Because as I said, you know, we worked with a lot of great clinical champions as well as members of the community who who served as presenters. But for me, it is how do I continue to support a pipeline where the community voice can be heard as equally loud as our clinician heroes.

Dr. Rochester: Thank you. Thank you, Megan. And what about you, Alissa? Any highlights from the conference, and and what do you all plan to do differently? How will you improve on this?

I don't know how you could improve, honestly. But how how will you improve in the next conference?

Alissa Creamer: Of course. So speaking from the community perspective, we heard from so many people. So many people. How they were so appreciative of us for not only hosting this event, but making the possibility for them to be there and participate a reality. You mentioned seeing IV poles and people who were undergoing some of their treatments while they were there on-site with us in Chicago.

And we heard from many in our community who were nervous and terrified to attend a conference. Many of them have been diagnosed since COVID or haven't traveled since COVID. They have not left their homes or they only stay in their local communities and they were nervous to attend, but many of them saw this as an opportunity of I'm gonna be amongst like minded people. I'm gonna be amongst people who get it. If I wear a mask, I'm not gonna be looked at funny for doing so.

So even though I'm nervous to leave the comfort of my home or my bubble, there's no better place to kind of test this than to be amongst friends at an immune deficiency foundation PI conference. And I think that was the biggest component of feedback. That I saw and heard from individuals is just we allowed people to be themselves and created a community, which is what IDF is all about. We really were able to foster a community in Chicago this past summer. As for what we plan to do in twenty twenty six, we have a lot of great ideas.

Again, this twenty twenty four conference, we had to bet on ourselves as to whether our community would respond and be excited and encouraged about something like this. So we're going to take the lessons learned. We're glad that they did respond with a resounding excitement. So we're going to take that knowledge as we plan twenty twenty six. We have a little bit more time and a little bit more space in our conference venue.

So we're gonna see how we can set up our schedule to allow for more breaks, maybe allow for more opportunities for people to truly just sit and connect with one another, opportunities for youth or young adults to hang out and just give people space to breathe and just to be in the presence of one another while also offering them really robust

opportunities to learn and be educated it. So that's what's to come in twenty twenty six, and I think we're really excited.

Dr. Rochester: I'm really excited as well. This is awesome. Well, as we close, you know, I mentioned that there are other organizations who are likely gonna hear this and be like, wow, how can I do the same thing? And so I'd love for each of you to share maybe one or two pieces of advice for other patient advocacy organizations who themselves are preparing to host conferences and hopefully after hearing this, if not before they also have a desire to improve with regard to diversity and equity and inclusion and belonging. And so what can they do to plan a conference that really embodies these principles? So I'll start with you, Megan.

Megan Messick: I think for me, the the advice is pretty simple. I think really challenging them to think about their capacity to listen and also their capacity to trust. You know, when we bring community members in to provide feedback, we have an obligation as an organization to to trust that feedback, to respond to that feedback, to take it as a call to action. But outside of just the content, also trust your team members who are executing the work. Trust them to to know the way to work with our presenters. Trust them to to guide the work in the direction of the mission. I I think trust as we speak about it externally with our presenters is critical, but to also allow your team internally to to do that good work that we all know that they're capable of.

Dr. Rochester: Thank you, Megan. What about you, Alissa? What advice do you have?

Alissa Creamer: I think my biggest piece of advice is to be intentional about your vision for your event and then the efforts that you have to take to get there. As I shared earlier, we had to really bet on ourselves for this event given so much uncertainty surrounding the pandemic and in person events. And throughout the eighteen month planning process, we certainly encountered financial, physical, and emotional ups and downs. We really had some logistical puzzles, some really hard conversations, and there were a lot of things we had to say no to. However, our team decided early on that we wanted this conference to feel approachable and accessible for everyone.

And we said yes to so many components and made really intentional efforts for that to come to fruition. As we've talked about in this discussion, IDF is a small organization, but we're really invested and committed to doing the work to ensure that we are building a community that is connected, engaged, and empowered by advocacy see, education and research. And I think many in our community saw our efforts to offer scholarships to reduce financial barriers, efforts to create an educational program that was interesting, broad, and unique, Our inclusion of diverse presenters, who are experts in their field, and

these individuals answered the call and said, hey, I think I'd like to go to that and see what this IDF, this immune deficiency foundation, is all about.

Dr. Rochester: Well, thank you both. This has been an awesome conversation. For me, it was somewhat of a debrief. I got to learn even more about what was going on behind the scenes. And, you know, if I could just summarize really the crux of this conversation, it's what you each talked about.

It really starts with your mission and your vision and your core values and living that out. And so I'm just so honored and thrilled to be a part of the immune deficiency foundation and organization that truly walks the talk as evidenced by the twenty twenty four PI conference. So thank you to each of you, thank you to your teams, thank you for the leadership of IDF and, you know, I'm looking forward to the twenty twenty six conference. And again, for those of you that are listening, I invite you to go on over to IDF's YouTube channel so that you can watch some of the presentations from the conference and stay tuned for updates related to the twenty twenty six conference. Thank you both.

Alissa Creamer: Thank you, Dr. Rochester.

Megan Messick: Thank you. It was such an honor to talk about the conference. And again, to to work with you on our session and to to get to know you through the mission of this work. So thank you. And for your vulnerability in in doing all of those things so well.

Dr. Rochester: It was my pleasure. And thank you all for listening and I look forward to having you join us here again for the next episode of Bold Conversations.