

Rare Leader Roundtable: Virtual Platforms for Engagement
June 29, 2020
Zoom Audio Transcript

87

00:12:22.590 --> 00:12:27.780

Debbie Drell: Welcome to the National Organization for rare disorders special roundtable

88

00:12:30.360 --> 00:12:40.320

Debbie Drell: This roundtable is part of our rapid response leadership series. My name is Debbie Drell and I'm NORD's director of membership and your facilitator for this meeting. I want to thank all of you for joining us today.

89

00:12:41.040 --> 00:12:46.530

Debbie Drell: The lines are currently muted, but they will be unmuted. And you can unmute your line when we're in the roundtable

90

00:12:48.570 --> 00:12:55.530

Debbie Drell: We are creating a breakout room for all the different groups to be able to talk in a smaller setting.

91

00:12:56.340 --> 00:13:02.730

Debbie Drell: Please, update your zoom handle to show your first name and organization if possible. So I could put Debbie Nord.

92

00:13:03.480 --> 00:13:10.860

Debbie Drell: That's helpful for us if we want to know what organization you represent, but if it's not possible. If you could just rename it so that at least it has your name.

93

00:13:11.310 --> 00:13:18.450

Debbie Drell: If you're able to go on video when we move into the roundtable that would be helpful so people can see your face and we can make meaningful connections.

94

00:13:18.840 --> 00:13:24.990

Debbie Drell: To encourage a safe space for transparent and open conversation we will pause the recording when we move into the breakout rooms.

95

00:13:25.500 --> 00:13:34.800

Debbie Drell: For the roundtable however we will be taking notes, our staff moderators will be in the room, taking notes facilitating the dialogue and then we will reconvene and share those

96

00:13:35.610 --> 00:13:51.810

Debbie Drell: What we've learned. So this is NORD membership team. We're working for you. NORD's mission is your mission, if anything comes up that has not been resolved a question or an issue just email us at membership@rarediseases.org. The agenda is there.

97

00:13:53.280 --> 00:14:03.360

Debbie Drell: We will do this welcome. We'll talk about guidelines for participating and then we'll split off into the breakout rooms. We will come back in the last 10 minutes or so to do report backs.

98

00:14:03.900 --> 00:14:13.680

Debbie Drell: And you will get a message during the breakout for five minutes to wrap up, and then one minute to close. If you have a question, you can use the Q&A button located at the bottom of the window.

99

00:14:14.880 --> 00:14:23.640

Debbie Drell: And you can ask a question at any time during the meeting, but we will address them as best as we were able to, we really want to focus on having these breakout sessions.

100

00:14:24.720 --> 00:14:35.010

Debbie Drell: Our mission is your mission. This is Nord's mission, as you can see on the screen. We work with over 310 member organizations.

101

00:14:35.280 --> 00:14:45.450

Debbie Drell: And you're entitled to all the resources that NORD provides including state level advocacy policy communications public awareness education, patient assistance and more

102

00:14:46.470 --> 00:14:57.570

Debbie Drell: So our meeting has some specific objectives. One is, we've seen 1000 questions on virtual platforms. Everybody's got a different conference a different fundraiser a different need

103

00:14:59.130 --> 00:15:10.050

Debbie Drell: So your question may or may not be answered specifically. However, what we will do in the beginning is share what we've learned transitioning to

virtual platforms, or at least some of the resources.

104

00:15:10.560 --> 00:15:16.440

Debbie Drell: And then our second and third objectives in the roundtables is that you share your challenges.

105

00:15:17.070 --> 00:15:23.460

Debbie Drell: And you share your successful strategies. That's what the goal is to tackle in the breakout rooms. So let's begin.

106

00:15:24.450 --> 00:15:33.540

Debbie Drell: We've been hearing a lot from members about virtual platforms. Why did Nord go in this direction. What does Nord use for networking. What are you doing about Summit.

107

00:15:34.140 --> 00:15:43.860

Debbie Drell: How have you used virtual platform for fundraising? NORD is very specific. We are a type of organization that's an umbrella, the events that we're using

108

00:15:45.120 --> 00:15:54.120

Debbie Drell: These platforms for our multiple days they bring hundreds of people. It may not be your specific circumstance, but we want to share what we've learned so

109

00:15:54.630 --> 00:16:02.820

Debbie Drell: You can access our Facebook group to hear what other leaders are using. If you look up platforms or virtual you will find a lot

110

00:16:03.450 --> 00:16:09.240

Debbie Drell: We have a webinar on converting your in person event to virtual there's a discussion thread.

111

00:16:10.230 --> 00:16:19.560

Debbie Drell: Ongoing virtual media companies. These are specific threads within the Facebook group that has 400 leaders, they're really robust conversations

112

00:16:20.040 --> 00:16:30.240

Debbie Drell: And our rapid response leadership series has an on demand video that features Carrie Lucas, who's our Associate Director of Development and events and she's the mastermind behind

113

00:16:30.720 --> 00:16:42.090

Debbie Drell: A lot of our work in creating and finding these platforms, she recorded this before she went on maternity leave, but she was getting a lot of questions. Why did or what is NORD using. So we just put it together

114

00:16:43.290 --> 00:16:54.300

Debbie Drell: and made this webinar 30 minutes with what NORD did and what the thought process was behind in creating a request for proposals.

115

00:16:54.870 --> 00:17:05.850

Debbie Drell: If you're not aware BoardSource has made available free of charge their best practices on virtual meetings. It's called Virtual Meetings Untangled and you can Google it and it's on BoardSource.

116

00:17:07.170 --> 00:17:08.340

Debbie Drell: So, next slide please.

117

00:17:10.650 --> 00:17:12.360

Debbie Drell: If you're not familiar with Nord.

118

00:17:13.710 --> 00:17:16.710

Debbie Drell: You are familiar with NORD, or if you're not familiar with zoom. Sorry.

119

00:17:18.930 --> 00:17:23.490

Debbie Drell: Zoom has all sorts of fun functionalities and when you're in the breakout room

120

00:17:24.540 --> 00:17:30.900

Debbie Drell: you will be grouped by size of your organization. And there's a NORD staff note taker.

121

00:17:31.290 --> 00:17:43.410

Debbie Drell: And what we're going to do for how to call on you because we don't want the most aggressive person to be heard. Every time we want everybody to take their turn. We're going to use the raise hand function. So you click on participants

122

00:17:44.550 --> 00:17:49.950

Debbie Drell: And on participants, there is the functionality to raise hand.

123

00:17:51.840 --> 00:17:53.490

Debbie Drell: And I had to click on more

124

00:17:57.210 --> 00:18:07.590

Debbie Drell: Well, I can't raise my hand as the host, but you can use a function to use the raise hand if you want to practice it right now. We can see you raising your hand.

125

00:18:09.840 --> 00:18:21.690

Debbie Drell: But when when our facilitator says raise hand and you do this [motions raising hand], that, unfortunately, we won't call on you because it doesn't put you in the right order. And that's harder for us to do. So you have to use the raise hand function.

126

00:18:22.890 --> 00:18:23.760

Debbie Drell: If you're able to

127

00:18:24.930 --> 00:18:34.290

Debbie Drell: So that is just a little bit about that functionality that the raise hand function will actually order you by the order in which you use the raise hand.

128

00:18:35.520 --> 00:18:48.630

Debbie Drell: So now we will break out for the next 40 minutes and the recording will be paused. During the breakouts, you should be broken out by the size of your organization. So I'm going to pause

129

00:18:51.180 --> 00:18:53.040

Debbie Drell: We're going to start the recording back up again.

140

00:19:56.370 --> 00:20:07.650

Debbie Drell: Yep. Okay. So if you're interested in the closed caption function. It's available there. Now we're going to report back and it's 4:52 so we might go a little bit over the hour. If you miss any of the report back, it will be recorded and

141

00:20:08.940 --> 00:20:12.270

Debbie Drell: So thank you for your patience as we navigated some challenges.

142

00:20:13.500 --> 00:20:18.330

Debbie Drell: So let's report back, we'll start with Amanda's room, Amanda.

143

00:20:19.650 --> 00:20:20.310

Debbie Drell: What did you learn

144

00:20:20.730 --> 00:20:35.340

Amanda Thomas: So I think everybody in my group, their biggest concern and challenge with moving to virtual is the engagement aspect, the networking. That happens kind of

145

00:20:37.530 --> 00:20:51.210

Amanda Thomas: organically at a live event. So that is definitely something that they are hoping to be able to offer in a virtual setting, as well as, you know, same

146

00:20:52.620 --> 00:21:02.640

Amanda Thomas: attendee to attendee as well as attendee to exhibitor and just kind of the challenge of "missing the fun" someone

147

00:21:04.350 --> 00:21:20.670

Amanda Thomas: Used as a quote because the in person event is fun. Then, you know, the idea of a gala or a fun run or just being on site. So how do we replicate that in a virtual setting were the challenges that my group faced

148

00:21:23.910 --> 00:21:26.340

Debbie Drell: And then your successful strategies?

149

00:21:27.030 --> 00:21:44.370

Amanda Thomas: Um, well, we're still working on it. Most of our events are scheduled for either later this year or in 2021 so we were still in a bit of the early phase, but we did discuss ways of incorporating things like gamification.

150

00:21:45.510 --> 00:21:57.600

Amanda Thomas: Earning points to attend certain sessions or engaged and exhibiting. And we talked a little bit about fundraising instead of doing, you know, kind of a large group fundraiser.

151

00:21:58.800 --> 00:22:02.910

Amanda Thomas: engaging people in smaller group events so

152

00:22:04.110 --> 00:22:13.230

Amanda Thomas: Smaller group dinners at somebody's home versus one large gala. Or instead of regular 5k

153

00:22:14.970 --> 00:22:31.530

Amanda Thomas: Kind of take take kicking that up a notch and taking elite runners and pairing them with patients and having teams behind that. So I'm just ways to engage smaller groups on a smaller level, but so with a big impact.

154

00:22:32.220 --> 00:22:32.490

Great.

155

00:22:34.260 --> 00:22:34.770

Debbie Drell: Julie.

156

00:22:36.600 --> 00:22:39.060

Debbie Drell: How was your group challenges and strategies.

157

00:22:40.080 --> 00:22:47.820

Julie Manus, NORD: Okay, I can unmute myself to that was the first challenge and strategy we talked about how do you present research.

158

00:22:48.630 --> 00:22:55.470

Julie Manus, NORD: How are the poster sessions where we talked about networking as well. And we really talked about how do you address content.

159

00:22:55.830 --> 00:23:05.970

Julie Manus, NORD: When you have multiple audiences are lots of things that you want to present on we touched briefly and I think it would be great to share notes so that the groups can all benefit about

160

00:23:06.600 --> 00:23:12.240

Julie Manus, NORD: How do you think about registration and fundraising, especially in difficult times, but

161

00:23:12.840 --> 00:23:23.820

Julie Manus, NORD: didn't quite get to that in our addressing that too. So perhaps that's another conversation that we can follow up on to when we've done parts of that that through events. Perhaps that's another conversation to have.

162

00:23:24.660 --> 00:23:37.470

Julie Manus, NORD: And we talked as far as tips and strategies to think about content, perhaps not being just in the two day block or however long the conference by be but to break it up and present things at different times.

163

00:23:38.190 --> 00:23:49.470

Julie Manus, NORD: Thinking about how much you're able to present in those days, but what can you can you do before and after. One strategy was to do weekly webinars to address content that you weren't able to have all on site at one time.

164

00:23:50.010 --> 00:23:58.380

Julie Manus, NORD: We talked about thinking of keeping accessibility in mind and having different strategies, depending on your community. We love there was lots of

165

00:23:59.280 --> 00:24:12.780

Julie Manus, NORD: Lots of good ideas as far as lots of conversation about having a closed caption or. So how do you do that or present things in written form to what are the ways that you can solve those challenges as well and then

166

00:24:13.440 --> 00:24:20.850

Julie Manus, NORD: We were talking also about the types of platforms. I think that the group would really like a list of platforms or

167

00:24:21.270 --> 00:24:28.350

Julie Manus, NORD: What are some platforms that we know organization to view perhaps organizations have already had their conferences could share what platforms they use

168

00:24:28.770 --> 00:24:41.520

Julie Manus, NORD: And they'd like to see and a platform RFP that was used by NORD or another organization or even just a mock up of what kinds of questions to ask to get the information you need to get quotes from companies.

171

00:24:47.730 --> 00:24:50.310

Debbie Drell: Alright, that's great. So we'll pass it to Allie.

173

00:25:05.670 --> 00:25:21.000

Allie Crafton: So some of our challenges that we discussed was what does a budget

look like when you go from an in person to a virtual event. Is there more flexibility with your budget when going to virtual event since You don't have a lot of in person costs.

174

00:25:22.140 --> 00:25:28.290

Allie Crafton: And also, I think, similar to what Julie said, you know, which platforms are legitimate which ones have our members used.

175

00:25:29.190 --> 00:25:34.800

Allie Crafton: Seems like our members are experiencing a delay to their RFP or request for a demo.

176

00:25:35.490 --> 00:25:50.040

Allie Crafton: So, like, how would we overcoming those delays. And then finally, another challenge was just the kind of managing the technical backend of virtual platform, how do you get that hands on support and tech support to ensure the meeting goes smoothly.

177

00:25:51.510 --> 00:25:55.110

Allie Crafton: So, in terms of tips and best practices and lessons learned

178

00:25:56.640 --> 00:26:07.110

Allie Crafton: I think you know we discuss it as we've looked into some new platforms. They don't always have all the capabilities that we're looking for, especially this kind of so breakout session, where we can raise our hands.

179

00:26:07.500 --> 00:26:24.450

Allie Crafton: But the more expensive platforms do seem to have more technical support and we discussed having a test with your speakers we have moderators before host a hug reverts back to get your community more familiar with using that virtual platform.

180

00:26:26.130 --> 00:26:40.470

Allie Crafton: And yeah, we also has a lot of discussion about actual platforms themselves, but I think we'd like to learn more about what platform can use for virtual auction what platform for virtual 5k with what are some platforms that are members of us that have worked

181

00:26:41.610 --> 00:26:42.180

Allie Crafton: Alright I will stop there.

182

00:26:49.710 --> 00:26:53.550

Debbie Drell: Thanks, Allie, and I'll pass it to Jamie. Jamie, you literally have two minutes.

183

00:26:53.910 --> 00:27:04.710

Jaime Pacheco: Don't worry, we had such a great group. I only need two minutes. They really moved into what really worked best for them. Once it became a going from in person to virtual events.

184

00:27:05.340 --> 00:27:20.400

Jaime Pacheco: Challenges that have arised are Making it engaging timing of, like, how long should the events be building momentum and also thinking about the minutia of the events of leaving breaks in between, bio breaks or just to get something to drink.

185

00:27:21.690 --> 00:27:25.740

Jaime Pacheco: And in person, networking, which seems to be a theme for everybody.

186

00:27:27.210 --> 00:27:34.830

Jaime Pacheco: The positives are calling it something other than a support group. It's a virtual meetup, making it more engaging.

187

00:27:36.180 --> 00:27:47.250

Jaime Pacheco: And making it a social outlet and then gearing it towards making something the first Tuesday of every month, a webinar monthly webinars and about stress management or a speaker.

188

00:27:48.690 --> 00:27:51.720

Jaime Pacheco: And you know just continuously keeping people engaged.

189

00:27:55.500 --> 00:27:55.980

Debbie Drell: Thank you.

190

00:27:58.110 --> 00:28:11.940

Debbie Drell: So that said, we're at the hour, but want to thank you all for joining us. This was a an experiment of the roundtables that technologically didn't work exactly the way we liked, but we hope that you learn from each other, that you have the opportunity to share

191

00:28:12.150 --> 00:28:13.410

Debbie Drell: If you have feedback you can

192

00:28:13.440 --> 00:28:20.580

Debbie Drell: Email. If it's positive feedback. You can email Debbie Drell and if it's negative, you can email Allie Crafton thank you so much for joining and

193

00:28:21.330 --> 00:28:31.860

Debbie Drell: Giving a clap to you all our rapid response coven 19 webinar series is going to end on July 8 and Joan Gary is the Dear Abby, or the savage love or the nonprofit whisper.

194

00:28:33.060 --> 00:28:40.560

Debbie Drell: Of the nonprofit world. She is really spectacular she's going to talk about what to do when you're board isn't doing anything.

195

00:28:40.890 --> 00:28:47.430

Debbie Drell: Or when there are particular members of your board who are just maybe burned out from coronavirus pandemic and all the challenges.

196

00:28:48.210 --> 00:28:58.410

Debbie Drell: This will light a fire, and you should invite your board members to participate. It's our grand keynote, she speaks to thousands of people and in person meetings and has spoke to the Boys and Girls Club.

197

00:29:00.540 --> 00:29:04.710

Debbie Drell: Maybe it's not the Boys and Girls Club, but it's another like maybe it's the Girl Scouts.

198

00:29:05.670 --> 00:29:13.860

Debbie Drell: But to like 10,000 people last month, so she's speaking to our rare disease community and that's on July 8 so that's our next big webinar.

199

00:29:14.520 --> 00:29:24.750

Debbie Drell: Thank you all. Hope you have a wonderful Fourth of July weekend. Stay safe cover yourself if you can with something very fashionable and have a great rest of your day. Bye everybody.