



NORD[®]
National Organization
for Rare Disorders

VIRTUAL EVENT ENGAGEMENT

A Few Best Practices from NORD Member Organizations



THANK YOU TO OUR MEMBERS

This presentation includes best practices for virtual engagement kindly shared by the following NORD member organizations:

- Alpha-1 Foundation
- Friedreich's Ataxia Research Alliance
- Familial Dysautonomia Foundation
- FD/MAS Alliance
- GBS | CIDP Foundation
- National PKU Alliance
- Our Odyssey
- Tatton Brown Rahman Syndrome Community
- The Life Raft Group
- United MSD Foundation



CONFERENCES & LARGE EVENTS

Duration & Structure

- Shorten sessions to create digestible content. Adjust a typical full-day in-person program to be a half-day virtually with shorter sessions.
- Alternate the session topics to help engagement. For example, if your conference contains a mix of clinical and basic research presentations, alternate between the two.

Format & Platform

- If a multi-hour virtual event is not the right fit for your community, try a different format such as dividing the main event content into several webinars over the course of a few weeks.
- Create and share a navigation video of your event platform to ensure attendees become familiar with it and know how to engage during your event.



CONFERENCES & LARGE EVENTS

Engagement

- Schedule an informal virtual gathering such as a coffee chat before the start of the main event to promote connection and socializing as well as encourage registrants to log in.
- If your audience looks forward to engaging with your speakers, consider inviting the speakers to a pre-event virtual gathering to build excitement and start the dialogue. You could also host breakout meetings post-event to offer additional time for interactive Q&A.

Event Reminders

- Create video teasers for upcoming programs and share them on social. The teasers could feature the program speakers in a fun and more informal setting.
- Send an event reminder the morning of the meeting (and as often as needed leading up to the event date) to remind registrants to log in and participate.



INFORMAL GATHERINGS

Coffee Chats

- Coffee chats hosted on Zoom (or any meeting platform) can serve as informal group gatherings to promote socializing.
- Some members have had success hosting one-off coffee chats during lunch hours.

Best Practices

- To create more intimate group meetings, cap the meeting at a set number of people. This will help ensure that everyone has a chance to speak up and participate in the discussion.
- To promote a variety of attendees at each chat meeting, wait to advertise sign-up until the week prior to the meeting date.



MEET YOUR COMMUNITY'S NEEDS

Meeting Format

- Experiment with structured meetings versus informal chats.
- A reserved group of attendees might appreciate having a moderator available to engage the group (such as through games, time for sharing stories, discussions of current events, etc.).
- A more outgoing group may enjoy an informal setting to socialize.

Your Community's Preferences

- Does your community want more informal meetings or formal webinars with experts? Do they prefer to log in during the day or in the evening? Not sure? Ask them in a survey!
- Adjust your programs as needed to meet the interactivity or engagement needs of your patients and families.



Unique Community Activities

- Does your community face a unique challenge? How can you meet that need and make it fun? For example, if your community has specific nutritional needs, host a virtual cooking class featuring diet-appropriate recipes for a fun activity and a shared bonding experience.

FUNDRAISING EVENTS

Swag

- Send a swag box or welcome packet to those registered for an event. Branded items can help foster a sense of community, especially for local events turned virtual.

Make It a Game

- Gamify your virtual event to keep attendees engaged and excited.
- One of our members turned their 5k in-person fundraiser virtual by using a free online app to bike or run “around the world.” They invited participants to log their minutes of physical activity into an app which advanced the community on their path around the world. Participants were even able to virtually visit specific places around the globe along the way!

Thank you.

