

RARE ADVOCACY SUMMIT 2023 RECAP

#RAREAdvocacySummit

615
in-person
attendees

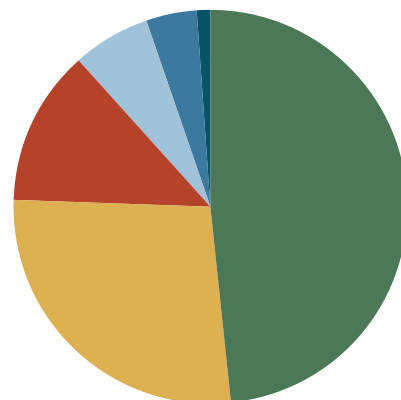
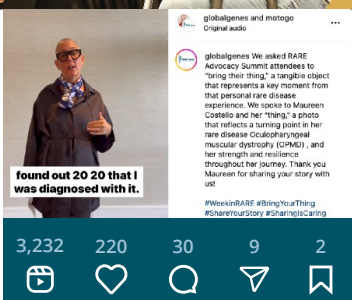
1,153
participants

538
live stream
attendees

64k
total social
reach

#RAREAdvocacySummit

Reach is defined as the number of users who came across the hashtag on their social media feed. 70% of the reach before RAS was on Twitter. 81% was on Twitter during RAS.



- Patient Advocate (46%)
- Corporate/Industry (26%)
- Caregiver (12%)
- Patient (6%)
- Scientist/Researcher (non-industry) (4%)
- Government (1%)



“ We’re dealing with rare diseases, but they all have common issues and common needs. We can try to fight barriers together and figure out how to move forward.
– Joni L Rutter, PhD ”

User Experience

84%

of attendees felt more knowledgeable about patient advocacy and opportunities for patient advocates/organizations to engage.



88%

of attendees made important connections with others in the rare disease community during this event.



“ Your flock is in this room. You find your flock at these meetings by engaging and talking with other groups and realizing that there are common opportunities to work together. This isn't isolated to foundation groups. At the academic level, I collaborate with lots of institutions and other providers. In rare disease, everything you accomplish that's meaningful happens because of collaboration.
– Scott Demarest, MD ”