RARE Pride

People affected by a rare disease who belong to historically underserved communities often face increased and complex barriers to healthcare. This is true for the LGBTQIA+ rare disease population who may have limited opportunities for:

- access to safe spaces
- involvement in policy and legislative efforts
- opportunities to participate in advocacy events

As a result, there is limited data, awareness, and proposed policy solutions that could lead to improved access to care for this community. 40% of surveyed rare disease patient advocacy organizations are interested in offering support to the LGBTQIA+ rare disease community but lack the necessary resources.[1]

What Does RARE Pride Do?

- Provides a platform for resource sharing and community discussions on issues affecting the LGBTQIA+ rare disease community
- Offers advocacy training so community members feel confident sharing their story and unique experiences as someone in the LGBTQIA+ community living with or caring for someone with a rare disease
- Drives educational and legislative initiatives for the RARE Pride community
- Provides tools and resources for rare disease patient advocacy organizations to help them support their LGBTQIA+ community members

Join RARE Pride

- Connect with a community of people that understand you and your experiences
- Share your voice at advocacy events, RARE Pride meetings, and other program initiatives
- Participate in periodic opportunities from RARE Pride to help gather insights vital for advocacy efforts or toolkit development

[1]RARE Foundation. 2023 Annual Community Congress Member Survey.