



PRIDE IN RARE SURVEY SUMMARY

In June 2024, the EveryLife Foundation for Rare Diseases launched the LGBTQIA+ program, Pride in Rare! In partnership with the community, we are providing a distinct space for those living within the intersection of LGBTQIA+ identity and rare disease patient experiences. As part of our efforts, the EveryLife Foundation released the first Pride in Rare survey, which was open to people who live in the United States, are 18 years of age and older, have at least one rare disease, and identify as LGBTQIA+.

“ Providers are often wary of prescribing the treatments I need (including steroids) for my intersex variation due to a lack of knowledge and appropriate standards of care since it is such a rare condition without a well-established patient advocacy organization. ”

What is the Pride in Rare Survey?

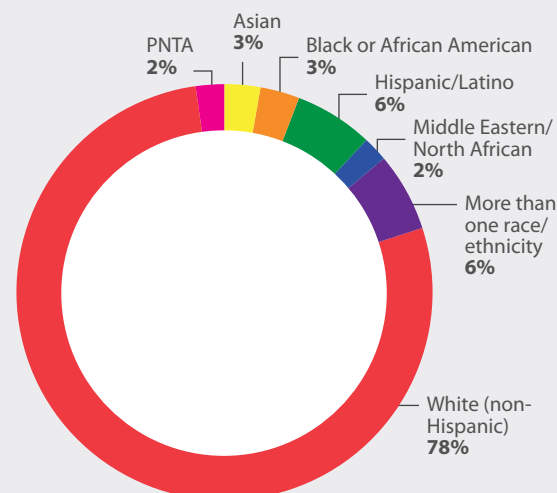
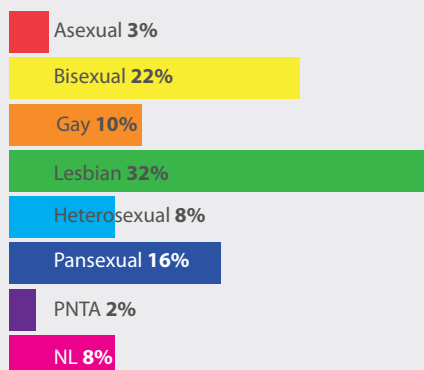
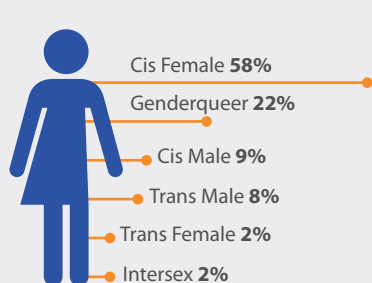
The Pride in Rare survey is a 34-question survey that gauged experiences, resource needs, and opportunities to better serve the LGBTQIA+ rare disease community.

- Received IRB approval from Pearl IRB.
- Digital survey to allow for flexibility.
- Remained open to participants for 30 days.
- Accessed through EveryLife's Pride in Rare webpage.

Who Participated in the Survey?

A total of 80 respondents from 25 states completed the survey, ranging from 18 to over 60 years of age.

PNTA = Prefer not to answer NL = Not listed



What are some policy issues impacting the LGBTQIA+ rare disease community?



41%

Stated their inability to access insurance coverage or high-quality insurance coverage.



21%

Stated their inability to travel across state lines to access care from an LGBTQIA+ friendly doctor knowledgeable about their rare disease.



47%

Stated having trouble interacting with health care providers due to their identity.

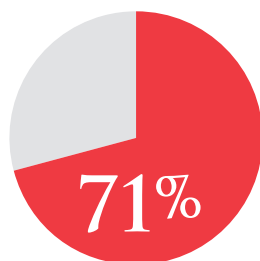


50%

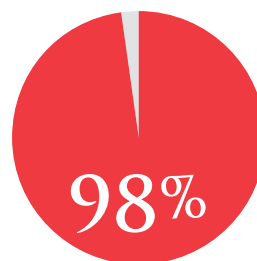
Stated that hospital intake forms are not inclusive of all sexual orientations or gender identities (SOGIs).

“ Being a disabled gay man/person, I’ve been looked over, dismissed, and pushed away. I’m very thrilled and thankful that The EveryLife Foundation is taking interest in this part of the community. ”

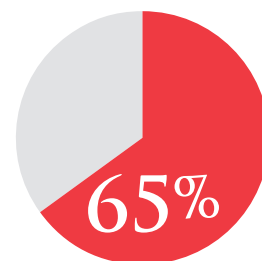
What did respondents have to say about existing community resources and engagement?



Are not currently a part of an LGBTQIA+ rare disease community.



Are not aware of any rare disease organizations that specifically serve the LGBTQIA+ community.



Feel that being a member of the LGBTQIA+ community has influenced their engagement with the rare disease community.



Scan QR code to learn more about the Pride in Rare program

For more information, contact the Diversity Inclusion Advocacy Manager at prodriguez@everylifefoundation.org

