

Rutgers Graduate Students for Rare- NORD Chapter

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What is a Rare Disease?

- According to the National Organization of Rare Diseases, any disease, disorder, illness, or condition affecting fewer than 200,000 people in the US is considered rare.
- Rare diseases alone are uncommon but cumulatively constitute a major health concern
- If rare disease patients globally made up a country, it would be the third most populace in the world

Challenges with Rare Diseases:

- One barrier rare disease patients encounter to treatment is low community and provider awareness of rare disease
- Many rare diseases can lead to life altering symptoms for patients and significant financial strain on families due to complexity of symptoms and insurance barriers
- Government funding for research is low,
- More than 90% of rare diseases are without an FDA approved therapy
- Difficult to find others with your experience
- Many experience a diagnostic odyssey

Importance to Developmental Disabilities

- Rare disease represents a significant cause of developmental disability
- The disability community should not be exclusive in its advocacy

Connect With US!

Email: rutgersnordchapter@gmail.com

Instagram: [@rutgersstudentsfornord](https://www.instagram.com/@rutgersstudentsfornord)

Facebook: [@RuRareNORD](https://www.facebook.com/@RuRareNORD)

Rutgers Students for Rare

In order to increase rare disease advocacy, we started RuRare to be a Rutgers chapter of Students for Rare, the student branch of NORD advocacy

Mission Statement: To promote awareness, education, and advocacy of rare diseases not only to the future health care professionals here on campus but also to the community at large.

We are:

- A Rutgers graduate student organization
- Affiliated with the National Organization for Rare Disorders (NORD)

Past Events

Talk focused on accessibility for individuals with rare diseases

Talk with non-profit rare disease support organization

Trivia Night for Rare Disease Day (spread awareness)

Rare Disease Day Fundraiser

Blood Disorders Panel

Tabling to recruit more multidisciplinary members

Lived Experience Patient stories



Possible Future Directions:

- Increase the number of members and diversify the graduate programs involved
- Continue advocacy and educational outreach
- Lecture Series from a Pharmaceutical Company
- Educational Outreach to Local High Schools