

1. What is the RARE Compassion Program?

The RARE Compassion Program (RCP) is an opportunity for medical students to develop relationships with individuals and their families experiencing a rare disease diagnosis, with the goal of developing compassion and awareness for the challenges that individuals and families living with a rare disease are faced with everyday. Furthermore, this program provides a unique opportunity to better understand the importance of inclusion in providing care for individuals living with rare diseases, and how health inequities, including systemic biases in medical practice and availability of care and support resources affect this unique group of patients.



2. What is the time frame of the program?

RCP runs from April to November during which there will be two rotations of 4 months each. Students will be paired with two individual/family partners per rotation.

3. Why do you say 'individual / family' partners?

You will either be paired with an adult individual living with a rare disease or a pediatric person living with a rare disease. In either case, the person living with a rare disease may have a caregiver, parent, or guardian that will speak to you as the primary communicator.

4. How will I be paired with a patient?

Students will be paired with patients based on factors including location, background and interests.

5. How can I apply for the program?

Applications will go live mid January 2023. Please fill out the interest form found [here](#) to be notified when applications are available.

6. When will I find out if I have been paired with a patient?

Pairings will be announced in late March 2023. For the 2023 program, you will be paired with 2 individual / family partners during each four month rotation. You will receive an email from compassionprogram@globalgenes.org with the patients' name and contact information. **It is your responsibility to reach out to the patient within the first week of the program to set up an initial meeting.**

7. What is the time commitment for the program?

The program will require you to spend roughly 2 hours per month meeting with your paired individual / family partners (1 hr per month, per patient partner), as well as attending / viewing our program meetings that occur every two months for a duration of 1.5 hrs.

8. What are the requirements for completing the program?

Students are required to:

- » Meet with each of your individual/ family partners for 1 hour per month for a total of 2 hours per month
- » Submit a summary of your partner interactions at the end of each rotation - one survey should be completed per partner
- » Attend, or comment on the recordings of, each of the four program meetings hosted on Zoom every two months of the program's duration

9. How many patients will I be matched with?

Students will be matched with 4 patients throughout the course of the 8 month program.

10. How will I meet with my patient partner(s)?

Discuss how you want to meet with your patient partner directly. Make sure to also discuss if both of you are comfortable with video conferencing. You will be responsible for introducing yourself to the patient. Their email address will be provided. You are expected to meet via Zoom, Skype, Google Meet, FaceTime or other means of phone or web/video conferencing.

11. Will I have a chance to interact and network with others in the program?

- » Yes, we will have meetings throughout the program where you can meet other students participating in the RARE Compassion Program, discuss and reflect on your experience with your individual / family partner, as well as hear from a variety of advocates and health professionals in the rare disease community.
- » You are also encouraged to join our RARE Portal - an online community where you can make meaningful connections with others including patients, patient advocates and other healthcare students in the RARE Compassion program. We will use the portal to post resources and discussion topics for you to reflect on throughout the course of the program.

12. Am I allowed to stay in contact with my individual/family partners after the rotation and/or program has ended?

Yes! As long as you have discussed it with your partner and you are both comfortable and interested in maintaining a relationship after your assigned rotation, you are welcome to stay in touch.

13. Are there any other opportunities afforded to me as a student in the program?

- » Yes! After completion of the program you will be eligible to apply for the David R. Cox Scholarship.
- » The David R. Cox Scholarship is an opportunity offered to students who have completed the RARE Compassion Program. Students have the option to submit an essay and optional video about your experience with your individual / family partner for a chance to win upwards of \$7,500. More details will be provided about how to apply at the end of the program. You can read the winning essays from 2021 [here](#).

14. How can I contact you if I have any other questions?

If you have any other questions, please email us at compassionprogram@globalgenes.org.

About Global Genes®

Global Genes is a 501(c)(3) nonprofit organization dedicated to eliminating the burdens and challenges of rare diseases for patients and families globally. In pursuit of our mission, we connect, empower and inspire the rare disease community to stand up, stand out, and become more effective on their own behalf – helping to spur innovation, meet essential needs, build capacity and knowledge, and drive progress within and across rare diseases. We serve more than 400 million people around the globe and nearly 1 in 10 Americans affected by rare diseases. If you or someone you love has a rare disease or are searching for a diagnosis, contact Global Genes at 949-248-RARE or visit our [resource hub](#).