

1. What is the RARE Compassion Program?

Each year, the RARE Compassion Program connects medical students and individuals / families with rare diseases to help foster meaningful doctor-patient relationships, inspire careers in rare disease care and research, and ultimately, through patient-centric listening and interactions, build the next generation of future medical professionals as key advocates for their patients. These connections give our individual / family participants the chance to influence the future of medicine, share their stories, and learn more about the medical system from their student partners.



2. How will I be paired with a student?

Individuals and families will be paired with a student based on a few factors including location, background and interests.

3. 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.

4. What is the time frame of the program?

The program runs for 8 months, from April to November. There are two 4 month rotations, during which students and patients are paired. You are not guaranteed to be paired for both rotations.

5. When will I find out if I have been paired with a student?

Pairings will be announced late March, 2023. If you have been paired with a student, you will receive an email from compassionprogram@globalgenes.org indicating as such.

6. What is the time commitment for the program?

The program will require you to meet with your medical student partner for roughly 1 hour per month. You will also be required to participate in a 1.5 hr program meeting every 2 months.

7. What are the requirements for completing the program?

Participants are expected to:

- » Meet with their partners roughly 1 hour per month
- » Submit a summary of your partner interactions at the end of each rotation
- » Attend, or comment on the recordings of, each of the four program meetings hosted on Zoom every two months of the program's duration

8. How will I meet with my student partner?

Your email address will be provided to your student partner and they will reach out to introduce themselves. You will discuss how you want to meet with the student directly. You can meet virtually via phone or video conferencing (Zoom, Skype, Google Meet, FaceTime or other means of phone or web/video conferencing) or in person if you are paired with someone in your area.

9. 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 patients and families participating in the RARE Compassion Program, discuss and reflect on your experience with your student 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.

10. Why should I participate in the RARE Compassion Program?

The program is a chance for you to share your story with future healthcare providers ultimately affecting the future of healthcare by increasing the knowledge and awareness of rare diseases as well as gaining a better understanding of the healthcare system and some of the challenges and barriers that providers face when providing care.

11. 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](#).