

What is the RARE Compassion Program?

The RARE Compassion Program 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.

How will I be paired with a student?

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

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

Pairings will be announced March 21, 2022. If you have been paired with a student, you will receive an email from compassionprogram@globalgenes.org indicating as such.

How many students will I be matched with?

Individuals and families will match with up to four students (not guaranteed).

How often are participants expected to meet with students?

You must meet with your student three times (for a minimum of 45 minutes per meeting) in the course of a two month period. In order to receive a certificate of completion, you must attend all four required end of rotation meetings.

What are the end of rotation meetings?

The end of rotation meetings are a chance for you to 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 past participants of the RARE Compassion Program.

What if I can't attend one of the end of rotation meetings?

Please notify the program administrator at compassionprogram@globalgenes.org as soon as possible.

How should I plan to meet with the student?

Discuss how you want to meet with the student directly. Make sure to also discuss if both of you are comfortable with video conferencing. The student will be in touch with you to introduce themselves. Your email address and phone number will be provided to your student partner. You are expected to meet via Zoom, Skype, Google Meet, FaceTime or other means of phone or web/video conferencing.

What is the RARE Portal?

The RARE Portal is intended as a community for individuals, caregivers, members of non-profit patient advocacy organizations, and academia members of the rare disease community. You can use the portal to make meaningful connections with others including patients, patient advocates and other medical 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.

Where do I go for help with the RARE Portal?

Please contact us at careaboutrare@globalgenes.org.

Do I need to submit a monthly report and how often?

Individuals and families are expected to post a summary of your interactions with your student after each pairing. Instructions will be provided on the RARE Portal.

Where do I submit my final report?

Final report instructions will be provided on the RARE Portal. If you are experiencing any issues you may send it to compassionprogram@globalgenes.org.

When will I receive my certificate of completion?

At the end of the program, you will receive it by email.

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 at www.globalgenes.org.