

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 patient?

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

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

Pairings will be announced March 21, 2022. 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.

How many patients will I be matched with?

Students will match with four patients. Every two months, you will be paired with a new patient partner for a total of four rotations. During the course of the program you will meet with at least one pediatric and one adult patient.

How often are participants expected to meet with each patient?

You are expected to meet at least three times (45 - 60 minutes per meeting) over the course of each two month rotation. In order to receive a certificate of completion, you must meet with four patient partners three times each, and 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 students participating in the RARE Compassion Program, discuss and reflect on your experience with your patient partner and hear from experts in the medical field who work in rare diseases as well as 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 patient?

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 and phone number will be provided. You are expected to meet via Zoom, Skype, Google Meet, FaceTime or other means of phone or web/video conferencing.

What if I can't get in touch with my patient?

You should have initial contact with your patient partner within a week of being paired. If you don't hear from them by the end of the first week of each rotation, reach out to the program team as soon as possible at compassionprogram@globalgenes.org.

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 report after meeting with my patient partner and how often?

Students are expected to submit a summary of patient interactions at the end of each rotation. You will need to submit a total of four reports. Instructions for how to do so will be provided on the RARE Portal.

Where do I submit my final report?

Final reports should be sent via the link provided on the RARE Portal. If you are experiencing any issues you may send it to compassionprogram@globalgenes.org.

Will I be able to apply for the David R. Cox Scholarship if I complete the program?

Yes, to be eligible for the Cox Scholarship you must:

- Have met with four different patient partners; three meetings with each partner (45 - 60 minutes each)
- Completed four end of rotation reports and have attended all four end of rotation meetings
- Join at least two activities in the community portal

When will I receive my certificate of completion?

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

Who do I contact if I have any other questions?

You can contact the program team 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 at www.globalgenes.org.