



2021 RARE Compassion Program Overview

Patient/Patient Family

RARE COMPASSION PROGRAM OVERVIEW

Medical professionals often do not receive training to recognize a patient with one of the nearly 8,000 identified rare diseases; although, it is estimated that 30 million people in the United States, or 1 in 10, are living with a rare medical condition. Understanding the experience of a person with a rare disease can enable improved health, faster and accurate diagnosis, and experiences for rare disease families. The RARE Compassion Program is an opportunity for patients with a rare disease to develop relationships with medical students with the goal of fostering compassion and awareness for the challenges that patients diagnosed with a rare disease are faced with everyday.

The goal of this program is to foster meaningful relationships between medical students and patients from unique and underserved communities to enhance relationships, improve cultural congruence, and nurture future advocates in rare disease. This program provides a unique opportunity for patients to educate future medical professionals on their journey and advocate for themselves and the rare community. By sharing personal stories about the challenges of rare disease, patients can inform aspiring medical professionals about diagnosis, daily life, and what it means to be rare.

STUDENT-PATIENT PROGRAM OVERVIEW

Students will be paired with two patients over the course of eight months (four months with each patient/patient family). We will do our best to connect students and patients based on commonalities related to disease/disease interest. Both students and patients are expected to collaborate on a consistent basis in order to build a meaningful relationship with one another and better understand each other's story. In order to remain active in this program, students and patients will meet via phone or video conferencing once a month for a minimum of one hour for the entire 8 month program.

If you are interested in participating in the RARE Compassion Program, please visit www.globalgenes.org/compassion to learn more and complete an application. Applicants will be accepted through February 28, 2021.

Thank you for your interest and support of the rare disease community!

If you have any questions please email the Program Coordinator 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.