Global Genes®
RARE Compassion Program

2021 RARE Compassion Program Overview
Medical Students

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 a unique opportunity for medical students to develop relationships with patients and their families experiencing a rare diagnosis, with the goal of developing compassion and awareness for the challenges that patients diagnosed with a rare disease are faced with everyday. Furthermore, this program is committed to address inequities within the medical profession by pairing medical students and patients from underserved communities with the goals of fostering meaningful patient-doctor relationships, improving cultural congruence, and nurturing future advocates in rare disease.

By providing an opportunity for medical students to better understand the importance of diversity and inclusion in providing care for patients with rare diseases, and how health inequities, including systemic biases in medical practice and lack of quality care and specialized support resources, greatly affect this unique group of patients, we hope to continue to improve patient care within the rare disease community.

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.

RARE COMPASSION ALUMNI COMMUNITY

Medical students will also have the opportunity to join the RARE Compassion Alumni community to connect with other clinicians and researchers in the rare disease community who are accelerating breakthroughs in the diagnosis, treatment, and care of rare disease patients. Students who participate and complete the program will be provided a certificate of completion and be invited to join the alumni program.

COX SCHOLARSHIP FOR RARE COMPASSION

Medical students who successfully complete this program will have the opportunity to apply for the David R. Cox Scholarship for RARE Compassion. To learn more about this opportunity, please contact us at compassionprogram@globalgenes.org.

For more information please visit the RARE Compassion Program resource page: globalgenes.org/compassion.
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.