

RARE COMPASSION PROGRAM OVERVIEW

It is estimated that around 400 million people globally and 1 in 10 in the United States are living with a rare medical condition. Understanding the experience of a person living with a rare disease can enable improved health, faster and more accurate diagnosis, and better health for individuals and families living with rare diseases. Healthcare professionals often do not receive training to recognize a patient with one of the nearly 10,000 identified rare diseases.

The goal of the RARE Compassion Program is to foster meaningful relationships between medical students and individuals living with a rare disease to enhance understanding, improve cultural congruence, and nurture future advocates in rare disease. This program provides a unique opportunity for individuals and families living with rare diseases 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, individuals living with rare diseases can inform aspiring medical professionals about diagnosis, daily life, and what it means to be rare.



STUDENT-PATIENT PROGRAM OVERVIEW

Individuals and families will be paired with a medical student(s) over the course of eight months. We will do our best to connect students and patients based on commonalities related to disease/disease interest, geographic location, and preferred spoken language. 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.

If you are interested in participating in the RARE Compassion Program, please visit globalgenes.org/participate/rare-compassion-program to learn more. Please fill out our interest form [here](#) to be notified when applications go live in January 2023.

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

If you have any 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](#).