



Global Genes is a rare disease patient advocacy organization, established in September 2008. Our mission is to connect, empower and inspire the rare disease community with a vision to create a globally connected community equipped to eliminate the challenges of rare disease.

# RARE COMPASSION PROJECT

Bridging Healthcare and Rare Disease



Medical professionals often do not encounter or recognize a patient with one of the nearly **7,000 identified rare diseases**; although, it is estimated that **35 million people in U.S.**, or **1 in 10**, are living with a rare condition. According to the National Institutes of Health, rare disease is defined as a disease that affects less than 200,000 people in the United States.

The **RARE Compassion Project** is a year-round opportunity for emerging medical and healthcare students to connect to the rare disease community with the goal of developing and understanding compassion for the challenges and lifestyles that patients diagnosed with a rare disease are faced with every day.

For more information please visit the RARE Compassion Project homepage: <http://globalgenes.org/cox-scholarship>

## RARE COMPASSION PROJECT

The RARE Compassion Project offers an opportunity year round to young medical and healthcare students to be matched with a rare patient or family in order to better understand and build compassion for the challenges and lifestyles these patients face every day. We hope that through participation in this program, medical and healthcare professionals will take action in their local community to help bridge the medical and rare disease community and to encourage rare disease learning early on in their career.

In addition, those students who match to a family or patient within the last year will have the opportunity to submit an essay about their experience for consideration to receive the David R. Cox Scholarship for Rare Compassion. To learn more about this opportunity, review the scholarship guidelines.



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## HISTORY

The RARE Compassion Project originally designed as a once a year opportunity for students developed from the David R. Cox Scholarship for Rare Compassion, was an initiative started by a group of motivated medical students who are now physicians across various specialties. Lead by Colton Margus, whose two brothers have a rare neurodegenerative disease, Ari Morgenthau and Brianne Doherty, this group of students approached Global Genes with a desire and dream to begin an initiative that motivated future clinicians to care about disease communities often neglected by the healthcare system. It is from their passion that this program exists today and is extended to the rare disease community.

## ABOUT DAVID R. COX

David R. Cox, MD, PhD was an extraordinary physician scientist, becoming Professor of Genetics and Pediatrics at UCSF and later Stanford, as well as shepherding development of genomic medicine at Pfizer. In addition to his participation in the Human Genome Project and service on numerous national advisory boards, Dr. Cox showed uncommon compassion in his involvement with advocates for rare diseases. He was especially helpful to the A-T Children's Project, an organization aiming to cure a rare and debilitating genetic disorder, ataxia telangiectasia (A-T).

Despite no personal ties to the A-T family community, over the course of 20 years, Dr. Cox gave his time and expertise, leading an advisory board and orchestrating focused, innovative research that accelerated the search for finding life-improving therapies for A-T children. Even after his passing in 2013, Dr. Cox continues to inspire future clinicians to engage the patient communities most in need.



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## MATCHING EXPECTATION

Students and patients will be matched based on geographic distance (in most cases within 40 miles from the medical student) and if applicable and requested, by sub specialty of student. Both parties will make a collaborative effort to build a relationship with one another to better understand the challenges and day-to-day experiences that these individuals have; this can be done through phone, email or in-person visits.

## STUDENT EXPECTATION

- Student will participate in pre-program survey and be provided match expectations prior to being matched.
- Once introduced to a patient, student will make efforts to introduce themselves to matched individual.
- Students are encouraged to engage with individual to learn more about day to day life.
- Student will determine with matched individual the length of time of their engagement.
- Student will treat the individual and family with respect and courtesy.
- Student will contact program administrator if match does not respond.

## PATIENT EXPECTATION

All rare disease patients are welcome to participate, please indicate in the request form whether the patient is you or your child.

*\*Patients are not guaranteed a medical student match.*

- Prior to match, patient will be provided an email with expectations.
- Once introduced to a student, patient or family will make efforts to introduce themselves to matched individual.
- Patient is encouraged to share their daily life, diagnostic journey and medical experience with the student.
- Patient is encouraged to learn about the challenges and obstacles in medical education and medical field.
- Patient will determine with matched student the length of time of their engagement.
- Patient will treat the student with respect and courtesy.
- Patient will contact program administrator if match does not respond.



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If you are interested in providing your information to be matched, review the next steps below. \*\*Participating patients contact information will be kept for 1-year to be considered for matching as medical students apply for participation.

## NEXT STEPS

### Step 1:

Read through this guidance, paying careful attention to the expectation and matching process.

### Step 2:

Patients may submit a participation form, found on our website, <http://globalgenes.org/cox-scholarship> to be paired with a medical student.

### Step 3:

Global Genes staff will provide program expectations. Once reviewed, Global Genes will match and provide introduction email to patient and student.

### Step 4:

Connect to family to set up desired meeting. Meetings may be through phone, email and/or in-person and may be as many times as both parties desire; duration of relationship is dependent upon both parties.

### Step 5:

Share your story and/or experience with us at [compassionproject@globalgenes.org](mailto:compassionproject@globalgenes.org).