Global Genes is a leading rare disease advocacy organization with the mission to eliminate the challenges of rare disease.

DAVID R. COX SCHOLARSHIP

Established in September 2008, Global Genes is a rare disease patient advocacy organization. Our mission is to eliminate the challenges of rare disease by building awareness, educational tools and resources and providing connections and resources to help patient advocates become well-equipped activists for their disease. To learn more about Global Genes, please visit: www.globalgenes.org.

OBJECTIVE

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 **David R. Cox Scholarship for Rare Compassion** is an opportunity for emerging medical 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 everyday.

For more information please visit the David R. Cox Scholarship for Rare Compassion homepage: https://globalgenes.org/coxprize/

HISTORY

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.

DAVID R. COX SCHOLARSHIP FOR RARE COMPASSION PROGRAM

The David R. Cox Scholarship for Rare Compassion Program is offered to young medical students who are matched with a rare patient or family to better understand and build compassion for the challenges and lifestyles these patients face every day. Each matched medical student will have the opportunity to submit an essay or audio submission about their experience for consideration to receive a scholarship.

KEY DATES

David R. Cox Scholarship for Rare Compassion Opens	Monday, January 1, 2018
David R. Cox Scholarship for Rare Compassion Closes	Thursday February 15, 2018
Families and medical students are matched	Thursday February 15, 2018 – Thursday, March 1, 2018
Scholarship submissions due	Tuesday, May 15, 2018 by 11:59 p.m. PT
Submissions reviewed by program committee	Tuesday, May 15, 2018 – Friday, June 15, 2018
Recipients are notified	Wednesday, June 20, 2018
Recipients announced	Wednesday, June 27, 2018
2018 Patient Advocacy Summit *(optional to attend)*	October 2–5, 2018

ELIGIBILITY

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.*

MEDICAL STUDENTS

1. All medical students are welcome to apply to be matched with a rare disease patient; however, those matching to residency as of July 2018 are unable to submit for a scholarship.
2. Must be attending medical school in the United States, Canada or United Kingdom.

MATCHING EXPECTATION

Medical students will be matched with patients based on geographic distance (in most cases within 40 miles from the medical student) and if applicable and requested, by sub specialty. The medical student will build a relationship with the patient/family to better understand the challenges and day-to-day experiences that these individuals have; this can be done through phone, email or visits.

If a medical student already has a relationship with a rare disease patient and would like to be matched with them or would like to utilize local resources through their medical schools to find rare families, please inform Ashley Yee at ashleyy@globalgenes.org.

**Patient/Student relationship must have begun no longer than 12 months prior to the opening of scholarship submission period.

NEXT STEPS

Step 1:

Read through this guidance, paying careful attention to the eligibility, key dates, matching process and scholarship guidance.

Step 2:

Families: Submit your match request form.

Medical Students: Submit your match request form or email Ashley Yee at ashleyy@globalgenes.org if you already have a family or will be using other resources.

Step 3:

Global Genes staff will match and provide introduction email to families 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.

Step 5:

If interested and eligible, prepare scholarship submission and submit through this **LINK** by the Tuesday, May 15, 2018 deadline.

Step 6:

Share your story and/or experience with us by emailing Ashley Yee at ashleyy@globalgenes.org.

SCHOLARSHIP GUIDELINES

- Patient relationship must have been begun within the past 12 months (from date of scholarship submission)
- English-language submissions only
- Must follow **HIPAA** requirements
- Submissions may only be essay or audio format. **Submissions that do not meet these requirements will not be accepted.**
    - Essay
        - No more than 3-pages (two-sided)
        - 1' inch margins around
        - Roman numeral, 12-pt font
        - Double spaced
        - PDF submissions only
    - Audio
        - No more than 5-mins
        - WMV or MP3 files only
        - Only audio recordings, videos will not be accepted

SUBMISSION GUIDELINES

Submitted essay or audio content must not have any identifying information on author

- Submit file with the following file name: AuthorFirstName_LastName_2018
- Must be submitted by Tuesday, May 15, 2018 at 11:59pm PST

Essay and Audio submissions should address the following prompt:

1. Background
    a. Prior knowledge and/or experience, if any, to the rare disease space.
2. Experience
    a. Summary of experience and/or interaction
        i. Can include but not limited to: what disease and scope and significance of the disease's effect on the patient, family, or society
    b. What, if anything, was unexpected or surprising about your encounter?
    c. What is your understanding of a day-to-day life for this community?
3. Response/Insight
    a. How does this experience impact you professionally?
    b. What is your biggest takeaway?
    c. What can you do as an emerging medical leader to improve the understanding and compassion for the rare disease space?
        i. Can include but not limited to: increase awareness and interest among medical students, strategies to improve patient-physician relationship, and/or help patients and families cope with all aspects of living with a rare disease.

SCHOLARSHIP EVALUATION

Submissions will be blind and evaluated by a panel of professionals. Submissions will be evaluated on the following criteria:

- Ability to address the prompt in a clear and concise manner
- Extent of contact/interaction/experience
- Expression of understanding the disease and its effect on individual, family and society
- Insight gained and analysis of professional impact
- Strategies for improvement

SCHOLARSHIP

Recipients will be notified Wednesday, June 20, 2018. The following amounts will be awarded:

- **1st Place:** $5,000.00 and complimentary registration to the Global Genes 2018 RARE Patient Advocacy Summit plus a travel support scholarship of $600
- **2nd Place:** $2,500.00
- **3rd Place:** $2,500.00