PATHWAYS™
TO TRUST

Impact Report

2022

Add Footnote or disclaimer

A Message From Our Founders

We founded Pathways To Trust in 2020 because we believe that the patient's voice needs to be at the center of healthcare. We chose to serve rare disease patients, and specifically focus on Sickle Cell Disease and Ehlers-Danlos Syndrome, because these patients experience significant biases which make accessing care particularly challenging. Consequently, their trust in the healthcare system has been eroded.

Bias is eliminated through understanding. Pathways to Trust develops programs that leads professionals in the healthcare industry to understand the full, multi-dimensional experience of rare disease patients. We educate learners in the clinical aspects of these conditions, and to empathize with the emotional, psychological, social and professional challenges that are part of rare disease.

In addition, we empower patients to become full partners in their care with our patient programs, developed by professional advocates that guide individuals in the rare disease community to confidently express their own treatment goals.

As we begin 2023, Pathways To Trust looks forward to touching more lives affected by rare disease so these patients become seen and heard! We hope you will join us in the important goal.

Cheryl and Maybelle

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What Drives Us

Our Mission

To elevate the rare patient's voice to increase access to care and eliminate bias by bringing stakeholders together

Our Vision

- Healthcare professionals will effectively, appropriately and compassionately treat rare disease patients, especially those who experience bias
- Rare disease patients will beempowered to become full partners with their healthcare team in their medical care
- Medical students will be inspired to commit themselves to the respectful and effective care of rare disease patients

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Impact: 2022 Programs

New Program Milestones in 2022

- Global Genes RARE Compassion Medical Student Orientation debuted in March 2022 with participants from around the globe
- Global Genes RARE Compassion Rare Disease Family Orientation debuted in March 2022 serving international rare disease families
- First Patient Empowerment Program launched: Pediatric Pain Through the Lens of Ehlers-Danlos Syndrome
- Instituted a Health Equity for All initiative in programming and social media
- Developed a Sickle Cell Disease Consortium Mental Health and Wellness Initiative video

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Impact: New Partnerships

Program Partners

Global Genes®

Dreamsickle Kids Foundation

SCRHED
THE SICKLE CELL REPRODUCTIVE HEALTH EDUCATION DIRECTIVE

HealthspanAction.org

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Community Health Engagement Partners

SOUTH ORANGE | MAPLEWOOD COMMUNITY COALITION ON RACE

FIRST BAPTIST CHURCH OF SOUTH ORANGE

TOWNSHIP OF MAPLEWOOD · ESSEX COUNTY · NEW JERSEY ·

ROTARY INTERNATIONAL

Maplewood, NJ

Impact: Development Efforts

In 2022, Pathways To Trust launched our first fundraiser by participating in Giving Tuesday with an online auction

Giving Tuesday
November 29, 2022

Online Auction and Fundraiser

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Impact 2022

Growth Toward a Strong Financial Position

- 130% increase in fundraising event revenue
- 260% increase in donations
- 163% increase in programming revenue

Expanding our Reach on a Global Scale

- **220 Medical Students** from around the world
- **350 Rare Disease Families**
- **30 full Healthcare Professionals** online and in-person

A Powerful Social Media Presence Promoting Lively, Engaged Discussion

- 893% increase in LinkedIn followers
- 470% increase in Facebook followers
- Featured posts average 21% engagement rate

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Impact 2022

What are they saying about us?

- "I think the program is great. It really opened my eyes and I am very appreciative."

-St. George University Medical School student

- "Keep up the excellent work and thank you for spreading awareness regarding EDS!!!!"

-EDS patient

- "The team's approach to educating clinicians is innovative and provides a safe space for health professionals to be aware of their implicit bias and how to provide quality care."

-Dr. Judy Washington, Associate Chief Medical Officer, Atlantic Health Group

- "Pathways To Trust partnered with Global Genes to develop two interactive and dynamic workshops to kick off our RARE Compassion Program and help inform and educate both medical students and individuals/families living with a rare disease better understand how to navigate communication challenges in the patient-provider relationship. The resulting workshops really engaged the students, the patients, and families, and helped both sides of the rare disease community understand the perspective of the other and develop the skills to build better therapeutic partnerships. We are looking forward to working together again in the future."

-Rachel Barron, Senior Manager Health Equity, Global Genes

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Goals for 2023

- CME/CEU programs on clinical, emotional, social and behavioral aspects of SCD throughout the RWJ/Barnabas and Meridien Health systems in NJ and 20 hospitals in the greater New York metro area, reaching approximately 500 healthcare providers
- Develop community engagement program to foster awareness of the needs of SCD patients and encourage active support in meeting these needs in Essex, Morris and Union counties in NJ
- Launch Global SCD initiative through partnerships with the Sickle Cell Foundation of Nigeria and Project Mzigo, a film and educational initiative launched in Nigeria, Kenya, Tanzania, Ghana, Canada, the United Kingdom and the United States
- Increase partnerships with rare disease non-profits and Community-Based Organizations
- Launch rare disease podcast by Second Half 2023
- Increase social media engagement and expand to a presence on TikTok and YouTube
- Focus on operational fundraising in addition to program grants
- Add new volunteers through corporate partnerships

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