



PATHWAYS™ TO TRUST

Impact Report

2023

A Message From Our Founders

January 2024 marks the fourth anniversary of Pathways™ To Trust. Over these past four years, we have strived to bring the rare disease patient's voice to the center of provider, institutional and industry healthcare goals.

We have carried out our mission by

- Delivering educational programs for healthcare providers and students in the healthcare field focused on various rare diseases
- Reaching out to rare disease patients to empower them to take control of their health by partnering with their medical team
- Developing and executing social media campaigns to promote rare disease awareness and foster health equity by combatting bias in the healthcare system
- Building a network of partners in philanthropic, healthcare and corporate circles who are helping us serve the rare disease community

This past year has brought us opportunities to reach a broader audience than ever before, and we look forward to expanding our reach even further in 2024. We thank you for supporting our work, and we ask that we can continue to count on you as we grow our programs on a global scale to deliver world class care that rare disease patients deserve.

Cheryl and Maybelle

What Drives Us

Our Mission

To bring the rare disease patient's needs to the center of provider, institutional and industry healthcare treatment goals.

Our Vision

- Healthcare professionals will effectively, appropriately and compassionately treat rare disease patients, especially those who experience bias
- Rare disease patients will be empowered 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

Impact: 2023 Programs

New Program Milestones in 2023



- Global Genes invited Pathways™ To Trust back to lead the RARE Compassion Program Orientation for rare disease patients/families and medical students from around the globe
- Time to Listen™ to Sickle Cell Disease (SCD) for School Nurses debuted in March 2023, educating these NJ professionals about how to help student with SCD stay healthy and successful in the school setting
- The Healthcare Foundation of New Jersey awarded Pathways™ To Trust a grant to support Time to Listen™ to Sickle Cell Disease for Medical Students, a program providing clinical education and insights into the experience of SCD patients for future providers that will be presented beginning January 2024
- Walk In My Shoes, an SCD awareness program developed in partnership with the University of Illinois Chicago, received approval from the Institutional Review Board, a committee that ensures the ethical treatment of patient participants. This development clears the way for us to film an educational video about the experience of SCD patients attempting to access care, and best practices for treating this community optimally
- Time to Listen™ to Sickle Cell Disease for the Emergency Department programming was developed

Impact: Driving Change Through Collaboration

Ongoing Alliances



University of Illinois
Chicago



HOWARD
UNIVERSITY



New Relationships in 2023



Impact: Development Efforts



**THE HEALTHCARE
FOUNDATION OF NJ**
founded by the Jewish community

In 2023, Pathways™ To Trust established a relationship with the Healthcare Foundation of New Jersey and received a grant in support of Time to Listen to Medical Students which will debut in January 2024



New members for the Board of Directors were elected in December who will be instrumental in fundraising and program development

Impact 2023



Expanding Reach and Increasing Name Recognition

- 38% average increase in social media followers across Facebook, Instagram and LinkedIn
- Tripled the number of medical schools in which we deliver a Time to Listen program
- Expanded Time to Listen to Sickle Cell Disease programs to school nurses

Changing Perceptions of Rare Disease Patients in the Healthcare Industry

- Program participants report increased awareness of the impact of rare disease on patients' family life, relationships, education, finances and professional life
- Post-program surveys demonstrate greater emphasis on importance of pain management

Building a Strong Infrastructure

- 66% increase in program and fundraising revenue
- Four new members elected to the Board of Directors with backgrounds in non-profit management, philanthropy, program development, healthcare delivery and clinical research

Impact 2023

What are they saying about us?

- I really appreciated hearing a personal testimonial about living with Sickle Cell disease. More than any classroom learning I have had so far in my medical school career this provided me with context and insight for patients with Sickle Cell disease.
-Cooper Medical School student
- “Pathways™ To Trust partnered with Global Genes to develop two interactive and dynamic workshops to kick off our RARE Compassion Program... 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.”
-Rachel Barron, Senior Manager Health Equity, Global Genes
- “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
- “I think the program is great. It really opened my eyes and I am very appreciative.”
-St. George University Medical School student

Goals for 2024

- CME/CEU programs on clinical, emotional, social and behavioral aspects of SCD (especially in Emergency Medicine) beginning with the New York metro area and the Washington DC metro area.
- Develop patient-facing empowerment programs, focusing on red blood cell health
- 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 Functional Fluidics, Novartis and Gates Foundation in Africa
- Work with existing rare disease partners (Community-Based Organizations and philanthropic organizations) to develop and execute actionable plans to improve the health and experiences of rare disease patients
- Launch rare disease podcast
- Develop a social media strategy, increase engagement, and expand to a presence on TikTok and YouTube
- Focus on operational fundraising in addition to program grants/sponsorships
- Add new grants, matching funds and ambassadors through partnerships