



PATHWAYS™ TO TRUST

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

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 informed and effective care of rare disease patients

Pathways To Trust



Rare Disease Educational Programs

At Pathways To Trust, our mission is to bring the rare disease patient's needs to the center of provider, institutional and industry healthcare treatment goals.

In healthcare, the patient's needs and goals can get lost. From medical school to continuing medical education programs, clinicians are taught a clinical approach to treating patients, but there is less of a focus on the full, 360-degree patient experience: physical, emotional, social/behavioral, professional and financial impacts of being a rare disease patient.

Rare disease patients also face the high hurdles of implicit bias in healthcare settings. Sometimes they face racial bias, sometimes gender bias. And because their symptoms and conditions are so complex and difficult to diagnose, there is often a bias that paints rare disease patients as attention-seekers, drug-seekers, or emotionally unstable in general.

Our experience has proven that the key to eliminating biases is education that leads providers to an understanding of the patient's perspective. We founded Pathways To Trust in 2020 to address this challenge by creating disease-specific educational programs built on the expertise of patients, patient advocates, and rare disease thought leaders.

Negative experiences with the healthcare industry have eroded patients' trust in the system and their own confidence in advocating for themselves. To rebuild their self-confidence and encourage patients to participate as full partners in their care, we have developed patient empowerment programs that guide learners to advocate for themselves and to navigate social/behavioral barriers to care.

By bringing together all these perspectives with the patient's voice at the center, we foster trust among all stakeholders to build a better healthcare system that is responsive, empathetic, and focused on patient-identified outcomes.

Current Programs

Community Events

- Reimagining Pain Through Art: An exhibit of various genres of art created by patients with rare diseases experiencing chronic pain
- Using Art Therapy to Help Manage Sickle Cell Pain
- Paint and Sip for Newark Beth Israel Sickle Cell Disease Center
- Meet the Author featuring works on the healing nature of art and health equity
- Spoken Word poetry and prose readings by patients with rare disease
- Symphony of Voices showcasing the experience and art of patient literature

Rare Disease Education Programs

- Panel Discussions: Navigating the Financial Challenges of Sickle Cell Disease (6 sessions)
- Beyond Academic: Tools for Supporting Health and Academic Success for Students with Sickle Cell Disease
- Time to Listen to Sickle Cell Disease for Medical and Nursing Students
- Walk In My Shoes videos illustrating challenges faced by Patients with Sickle Cell Disease and promoting best practices in interdisciplinary care

Impact in the Healthcare Industry

Changing Perceptions of Rare Disease Patients

- Rare disease program participants report increased awareness of the impact of rare disease on patients' family life, relationships, education, finances and professional life
- Post-program surveys from Time to Listen to Sickle Cell Disease for Healthcare Students indicate that participants found the program extremely helpful in understanding the challenges faced by patients. On a scale of 1 (not at all helpful) to 5 (extremely helpful), learners gave the program an overall rating of 4.7 based on how much they learned about the clinical, emotional/psychological and social/behavioral aspects of SCD.

Expanding Reach and Increasing Name Recognition in 2024

- 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 nursing students
- 38% average increase in social media followers across Facebook, Instagram and LinkedIn
- Expanded into community programs to elevate patient's voices and raise awareness

Making Connections Among Stakeholders

- “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 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
- “The event gave me an opportunity to share with a broader audience the pain and transformative powers of my journey...Making stuff brought me into states of ecstasy and gratefulness that I never felt before...This show feels like I am welcomed into the larger group and it pulls me out of the ghetto of self-pity... to a celebratory new dance, a new beat that reminds me with each step to celebrate being alive. Thank you for the chance to share. “
-Fausto Sevilla, Artist , Poet, Individual with Guillian Barre Syndrome
- The event on Sept 12th at Maplewood Arts Center was a beautiful time of meeting new friends, sharing time together, learning from many who presented and connecting with old friends. Seeing the expression that shines through the artwork of the many resilient warriors was both inspiring and heartwarming. This was a gem!!
Jennifer Hoffman, Northeast Patient Affairs Liaison, Pfizer
- “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

Current Programs

Patients and Caretakers



- Confidently advocate for their personal treatment goals and form a therapeutic alliance with their care team
- Develop strategies to address the behavioral and social determinants of health that impact the trajectory of their disease
- Navigate relationship/educational /career challenges encountered in the rare disease community

Healthcare Students



- Identify trends in the historical healthcare experience of rare disease patients
- Formulate a strategy to develop an interdisciplinary approach to rare disease patient care
- Evaluate the impact of emotional, social, behavioral and financial factors on rare disease patients

Healthcare Providers



- Recognize unconscious bias in the system and perceptions of rare disease patients
- Identify complications and comorbidities of a specific rare disease
- Interact respectfully with rare disease patients and caregivers
- Formulate an ongoing treatment plan for rare disease patients

Driving Change Through Collaboration



Newark Beth Israel
Medical Center

RWJ Barnabas
HEALTH

Ongoing Alliances



University of Illinois
Chicago



Hackensack Meridian
JFK University Medical Center
Muhlenberg
Harold B. and Dorothy A. Snyder
Schools of Nursing and Medical Imaging



THE HEALTHCARE
FOUNDATION OF NJ
founded by the Jewish community



Cooper Medical School
of Rowan University



HOWARD
UNIVERSITY

RUTGERS

New Jersey Medical School



UCNJ
Union College of
Union County, NJ



Rare New England

Coordinating Resources for Patients and Families
With Rare and Complex Disorders



rsdsa
SUPPORTING THE
CRPS COMMUNITY



Join Us

Help us improve the lives of rare disease patients facing high hurdles to care.

Contact us now to start the conversation.

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www.timetolistentoraredisease.com

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