



rtw Foundation

2025 Annual Report



Our Mission

RTW Foundation powers health equity initiatives and rare disease foundations to improve the health of underserved populations. We are committed to supporting communities and empowering future innovators through sustained partnership.



Above: BioQuest mentors at the Year Three BioQuest Kick-Off Celebration in Hunts Point

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Letter from our Co-Chairs

Dear Friends,

2025 reminded us how powerful community, partnership, and shared purpose can be—especially during moments of uncertainty and change. As barriers to care continue to rise and financial strain is placed on communities and nonprofits alike, RTW Foundation stepped forward with a focus to show up intentionally, listen closely, and act with urgency where needs are greatest.

In response to the changing health landscape, RTW Foundation increased its community grants by over 80% to strengthen the local healthcare ecosystem and help ensure that access to safe, affordable care remains within reach.

As we move into 2026, we aim to power our community partners through added capacity-building opportunities, co-created Days of Action, and connections between partners.

This year also marked a defining moment for our Rare Disease Advisory Program. Through our partnership with Elly's Team, Elly Krueger became the first child to receive an investigational gene therapy for NEDAMSS—just 13 months after her diagnosis. This extraordinary milestone reflects what is possible when families, scientists, clinicians, and foundations work together with urgency and purpose. Since launching the program, our advisors have supported dozens of rare disease foundations and families, providing free, high-touch scientific guidance to help navigate complex drug development pathways and move research forward faster.

We continue to invest in the next generation of scientists and health leaders through our new STEM Education pillar.

BioQuest expanded this year with the launch of the BioQuest Ambassadors Program, offering paid internships, skill-building workshops, and hands-on experiences at institutions including Columbia University and Brown University.

By providing compensated, real-world opportunities, BioQuest is helping create more equitable pathways into science and medicine.

In parallel, we launched a landmark initiative at the Perelman School of Medicine at the University of Pennsylvania, giving \$8 million to reimagine medical education for the future, integrating technology, data, and personalized learning to better prepare physicians for an era defined by innovation.

None of this work happens in isolation. It is made possible by the dedication of community leaders, families, students, scientists, volunteers, and supporters who believe in a more equitable and compassionate healthcare system. Thank you for being part of a community that continues to show up when it matters most.

Sincerely,



Roderick Wong, MD

Co-Chair



Marti Speranza Wong

Co-Chair



Above: RTW Foundation Co-Chairs Roderick Wong, MD, and Marti Speranza Wong at the Year Three BioQuest Kick-Off Celebration in Hunts Point

Community Engagement



*RTW and RaisingHealth Partners
volunteers at Day of Action in
Sunset Park*

Community Impact to Date

In 2025, RTW Foundation's community engagement efforts translated into meaningful, measurable impact across New York City. Through deep partnerships with community-based organizations, we expanded access to care and reached thousands of New Yorkers with essential health services.

2020-2025 Impact



122,000+

New Yorkers reached through health equity initiatives



864

Healthcare providers & navigators hired or trained in NYC



\$3.9M

total community grants awarded



35

community partners across NYC

Right: Community health worker assisting community member at Day of Action with RaisingHealth Partners in Sunset Park

Closing the Gap in Health Access



In 2025, 60% of nonprofits surveyed by Brooklyn.org experienced cuts in government funding. This forced many organizations to scale back or suspend free health services at a time when barriers to care were rising in neighborhoods with unmet needs. In response, RTW Foundation increased community grant funding by over 80%, prioritizing communities disproportionately impacted by disruptions in safe, affordable access to care, in addition to long-standing health inequities, including maternal mortality and mental health access.

Day of Action

At RTW Foundation, we are focused on building true partnerships with community organizations. We go beyond funding to co-create programs and community events, such as community health fairs, to bring the community together, offer additional support, and further amplify the impact we can have together.



Above: Healthcare professional helping a community member at RaisingHealth Partners Community Health Fair

Above: RTW volunteer handing food to a community member at a Community Health Fair



This year, we collaborated with RaisingHealth Partners on their 10th Annual Health Empowerment Celebration in Sunset Park, providing over 1,500 community members with a variety of health screenings, fresh produce, health resources, and family fun activities. Thirty RTW Foundation and RTW Investments volunteers powered the event alongside the RaisingHealth team and over a dozen other community-based partners including Mixteca, Weill Cornell, and NYU Langone.

RaisingHealth Partners continues to expand access to essential healthcare services for immigrant communities across New York City. Through bi-monthly health clinics, RaisingHealth provided free screenings—including blood pressure, cardiovascular disease, diabetes, cancer, BMI, and vision—along with flu vaccinations and enrollment in ongoing case management and care navigation services. In 2025, the program reached 13,527 community members with health education and 476 with free screenings. Their outreach team focused on Medicaid and NYC Care enrollment, mental health programming, nutrition education, and food access.

Strengthening the Local Health Ecosystem

RTW Foundation was proud to host its first Community Health Kick-Off Celebration with community leaders, researchers, and healthcare providers from our eleven 2025 community grant organizations. This event created meaningful opportunities to build connections, share ongoing work, and explore collaborative approaches to advancing health equity. We were honored to hear from local health leaders at Karen's Club, Saving Mothers, and RaisingHealth Partners, who offered powerful perspectives on patient-centered advocacy and expanding access to care. We are deeply grateful to our partners for their unwavering commitment to the communities they serve, and look forward to the collective impact we will build together in the year ahead.

Our community partners often serve as the entry point to health services for families facing systemic barriers, delivering free to low-cost healthcare coverage, including primary, specialized, and mental health care, in addition to healthcare navigation, and supports like transportation and economic incentives to ensure people can access care.



Above: RTW Foundation and community partner leaders at Community Kick-Off Celebration



Above: RTW Foundation and RaisingHealth leaders at Community Day of Action



I'm so proud of the work we've done in NYC to educate a subset of patients diagnosed with advanced disease, who are trying to navigate within the clinical research system and not really sure what comes next. Their trust in our ability to support their goal of making an informed decision is a huge testament of our value to the community.

- Karen Peterson,
Founder & Chief Patient Advocate at Karen's Club



Community Impact in Action



Our returning grant partners, Mixteca and East Harlem Health Outreach Partnership, continue to lead impactful, community-driven work across New York City. From expanding access to high-quality care for uninsured patients to connecting immigrant communities with critical health services and coverage, these organizations are addressing urgent needs while advancing long-term health equity.

Mixteca

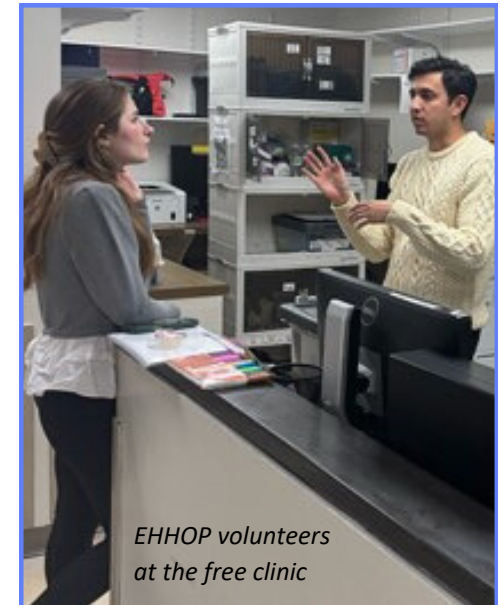
Mixteca Organization Inc. is a community-based organization and third-time grant partner that addresses critical needs in health, education, social, and legal issues facing the burgeoning Mexican and Latin American immigrant community in Brooklyn. This past year, Mixteca reached 2,000 community members through two health fairs and eight days of action. They also provided 70 flu vaccines, enrolled 840 people into NYC Care, and provided 260 people with free screenings including HIV testing, glucose testing, mammograms, and prenatal exams. We're grateful for Mixteca's continued partnership and commitment to expanding access to care for immigrant communities.



Above: Mixteca staff at a community event

East Harlem Health Outreach Partnership

East Harlem Health Outreach Partnership (EHHOP), another third-time grant partner, delivered meaningful impact this year by expanding access to care for uninsured patients while deepening its commitment to training the next generation of health professionals through a health equity lens. In response to community-identified needs, EHHOP strengthened its primary and specialty care offerings—providing free primary and specialty services to more than 300 uninsured patients—and implemented patient-centered strategies that improved appointment attendance and continuity of care, contributing to a 25.5% reduction in no-show rates over two years.



EHHOP volunteers at the free clinic

By addressing practical barriers such as transportation, cost, and access to supportive services, EHHOP helped patients stay engaged in their care. They provided 750 appointment incentives, distributed 900 MetroCards to reduce transportation challenges, provided durable medical equipment, and connected 50 patients to dental referrals and free services—ensuring more comprehensive, coordinated care.

Beyond direct care, EHHOP continues to serve as a critical training ground for medical and graduate students, offering hands-on experience grounded in health equity and community-based care. Over 400 students across clinical and pre-clinical stages took on roles spanning care coordination, language interpretation, preventive health, nutrition support, research, and community engagement.

Community Impact Across Our Grant Partners



Community Health Action of Staten Island

Community Health Action of Staten Island is a returning grant partner whose project will educate 1,000 NYCHA residents on hypertension, deliver health screenings to 250 patients, and support 250 patients with care navigation and follow-up appointments.



Violence Intervention Program

Violence Intervention Program (VIP) is a returning grant partner that will hire a new bilingual Healthcare Specialist to provide direct referrals and navigation for about 500 low-income Latina women and their children.



The Floating Hospital

The Floating Hospital provides affordable care to underserved patients in New York through their Good Health Shuttle, providing free transportation to over 15,000 patients from shelters and safe houses across the five boroughs this year, building access to care.



Saving Mothers

Saving Mothers is another second-time grant partner that is dedicated to eradicating preventable maternal deaths and birth-related complications in New York City, where Black women are nine times more likely to die from pregnancy or childbirth than white women. With this grant, Saving Mothers will provide 300 mothers with mPOWHER Mom's Kits.



Hamilton-Madison House

Hamilton-Madison House is another third-time grant partner that expands access to behavioral health services for the Asian American community. The grant will support a psychology fellow's hands-on behavioral health service training focused on the linguistic and cultural needs of New York City's pan-Asian-American community.



RaisingHealth

RaisingHealth Partners is a third-time grant partner whose project will provide free, bilingual individual and group mental health counseling to community members in Brooklyn. The team will also reach 2,000 New Yorkers in Brooklyn through psychoeducational outreach and monthly workshops.



Grameen America

Grameen Promotoras, a Grameen America community health program, is a new grant partner that supports thousands of underserved women across New York City with health education, screenings, and personalized referrals and care navigation. With our support, Grameen America will hire and train an additional community health worker who will deliver health curriculum, create health action plans, provide navigation support, and screenings.



The NYU Langone Health Undiagnosed Diseases Program

The NYU Langone Health Undiagnosed Diseases Program, provides long-awaited diagnoses for medically complex patients who have gone years without answers after standard clinical evaluations. With this grant, the team will enroll 25 families in the program this year, providing state-of-the-art genetic and genomic testing for rare disease patients regardless of socioeconomic status.



Karen's Club

Karen's Club is a new grant partner dedicated to providing personalized and culturally-responsive consulting to cancer patients of color. Before each patient's initial consultation, Karen's Club equips a research team with a concise summary of the patient's concerns and barriers, which helps clinicians offer tailored education and guidance during 1:1 navigation sessions.

STEM Education

A young woman with brown hair, wearing a blue lab coat with a BioQuest name tag, is looking through a black and white microscope. She is smiling slightly. In the foreground, the back of a person's head is visible, looking towards the microscope. The background is a bright, slightly blurred laboratory setting.

*BioQuest students conducting an experiment
at the Natural History Museum*

BioQuest STEM Mentoring Program

BioQuest is RTW Foundation's STEM mentoring program designed to give middle and high school students opportunities to explore diverse careers in science, biotechnology, and medicine. In its first three years, BioQuest programming has reached over 300 students from the South Bronx, Harlem, and Washington Heights. We are proud to collaborate with passionate leaders from Areté Education, Hunts Point Alliance for Children, Futures Ignite, Mott Hall II, BioBus, and more.

BioQuest Impact to Date



300+

students reached



6:1

student to mentor ratio



25

STEM programs provided for middle and high students



10+

STEM education partners across NYC

BioQuest student exploring microscopes with a family member at Back to School event



BioQuest School Partners



Areté Education

Areté Education provides academic, social, and emotional support to students while working hand in hand with the schools students attend.



Hunts Point Alliance for Children

Hunts Point Alliance for Children aims to expand the hopes and potential of Hunts Point children—nurturing young scholars along their path to college or career.



Mott Hall II

Mott Hall II is dedicated to the academic and personal development of scholars who will become tomorrow's leaders.



Futures Ignite

Futures Ignite works in New York City's public school system to advance programming, counseling, and advocacy to equip BIPOC students to direct their college and career futures.

NYC School Districts Served

BioQuest currently serves students across 8 of the 32 New York City Department of Education districts, reaching 25% of all NYC DOE districts.



BioQuest Student Ambassador Program

In 2025, the BioQuest Ambassador Program came to life as students completed paid summer internships and research at leading institutions, including Brown University and Columbia University. Ambassadors engaged in hands-on learning with mentors focused on career and college readiness, while also meeting mentors virtually to strengthen leadership, communication, and professional skills. Beyond the classroom and lab, students built meaningful relationships, expanded their networks, and formed friendships that made the experience both impactful and fun. Through mentorship, real-world research, and a strong sense of community, the Ambassador Program supported students as they took confident next steps toward STEM careers and leadership pathways.



Above: BioQuest students, alumni, and mentors at City College for Career Readiness Day

In the Fall of 2025, BioQuest hosted its first College and Career Readiness Day for ambassadors at the Advanced Science Research Center and City College, giving students hands-on exposure to STEM pathways and opportunities. Students also participated in mentor-curated workshops at the New York Genome Center and Cientifico Latino, designed to build professional skills and better prepare them for future careers in science, technology, engineering, and mathematics.

Meet Our BioQuest Associate



Steve Raymundo joined BioQuest in April 2025 as our BioQuest Programs Associate. Since then, Steve has launched the Ambassadors Program, strengthened engagement with alumni, and expanded opportunities for students while updating programming to better support their interests and future goals in science and medicine. We're grateful for his leadership in empowering the next generation of innovators.

Above: Steve Raymundo helping students at BioQuest Kick-Off celebration

Year Three BioQuest Programming

BioQuest provides monthly in-person STEM experiences, where students engage in labs, workshops, and career exploration alongside scientists and industry professionals. Each monthly program is supported by dedicated mentors who guide students through activities, share their career journeys, and help build confidence in STEM spaces. Select high school students join our BioQuest Ambassador Program, an internal leadership cohort made up of returning students. Ambassadors take on added responsibility by supporting monthly sessions, helping welcome new students, and serving as peer leaders within the community, while continuing to receive mentorship and leadership development opportunities.



Life Sciences Day

High school students and mentors explored labs and career opportunities across NYC through the support of Life Sciences Cares, while middle school students and mentors explored the American Museum of Natural History.



Winter Celebration

Students gathered at the New York Genome Center for an exciting end of year winter celebration and hands-on STEM activities. Ambassadors participated in mentor-led sessions on career skills.



Science Discovery Day at Advanced Science Research Center

Students will build models, solve optical illusions, meet STEM experts, and get exclusive access to high-tech MRI and X-ray labs.



BioQuest Kick-off Breakfast & Back to School Fair

Students and families connected with mentors, built their own biomes, and explored hands-on science aboard the BioBus at Hunts Point in the Bronx.



Lab Day at GenSpace

Students stepped into GenSpace, a community biology lab in Brooklyn, for a special hands-on science experience! Guided by mentors and scientists, students explored how biotechnology uses microbes to solve real-world problems.



Genetics Day at DNA Learning Center

Students explored the science behind lactose intolerance from scientists at the DNA Learning Center, and built mini bioreactors to create lactose-free milk, and learned how gene therapy works.



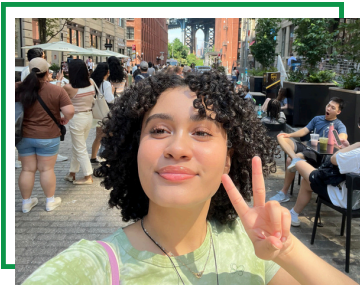
Graduation Ceremony and Museum Day

Students, mentors, and family members will explore the Liberty Science Museum, then gather for lunch and celebration!

BioQuest Alumni in STEM



2025 was our first year with graduates of the BioQuest program! BioQuest continues to invest in its alumni by providing sustained guidance and skill-building that supports long-term success in STEM pathways. Through strategic advising, including dedicated office hours, individualized academic and career advising, and support with research planning and time management, alumni receive the tools needed to navigate increasingly complex academic and professional environments. Together, these efforts ensure BioQuest alumni are supported not only at critical milestones but throughout their journeys in science and beyond.



Lianny

College: City College of New York
Major: Psychology & Nursing



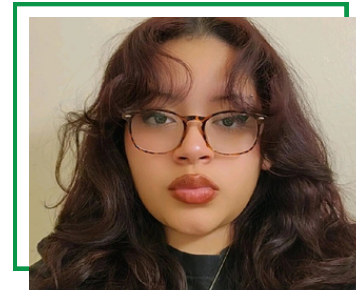
Angel

College: Fordham University
Major: Biochemistry



Anthony

College: City College of New York
Major: Biology & Biochemistry



Shailyn

College: Muhlenberg College
Major: Neuroscience & Finance



Above: BioQuest alumnus, Anthony, receiving BioQuest graduation diploma from Sarah Garwood, BioQuest mentor and Director of Community Engagement



The Cientifico Latino workshop helped me connect with PhD students and peers, get feedback on my writing, and learn about research opportunities. It gave me new ideas and more confidence and showed me how valuable these connections are for my future.

- Anthony, BioQuest Alumnus



RTW Foundation's Partnership with the Penn Perelman School of Medicine

The University of Pennsylvania Perelman School of Medicine and RTW Foundation are proud to announce a landmark \$8 million gift from our Co-Chairs Roderick Wong, M'03, and Marti Speranza Wong, C'98, to reimagine medical education.

This once-in-a-generation investment will support a transition to a competency-based, flexible curriculum that allows medical students to self-pace their learning while engaging with cutting-edge technology, AI, and emerging trends in global health equity. We are excited for this opportunity to allow more space for complementary exploration in entrepreneurship and innovation.



Above: RTW Foundation Co-Chairs Roderick Wong, MD, and Marti Speranza Wong, with Penn Medicine Dean Jonathan Epstein, MD; President J. Larry Jameson, MD, PhD; and curriculum leaders Lisa M. Bellini, MD, and Jennifer R. Kogan, MD



“I believe medical innovation is the key to life being better in the future than it is today. And as science accelerates, to train physicians for the future, so should education. Penn has the courage and the team to pursue this, which is why I am so excited to have the opportunity to support this effort.”

- Roderick Wong, MD

Rare Disease Advising



Finding Hope for FRRS1L family photo

Rare Disease Advisory Program



Our Rare Disease Advisory Program has had a strong year, supporting over 47 ultra-rare disease foundations as they navigate the complex landscape of gene therapy and rare disease research. We work closely with each organization providing free, expert guidance and operational support at every stage of development to guide research strategy, while also helping them communicate their message and impact. By providing tailored support across both research and outreach, we empower foundations to advance progress for conditions that are often overlooked and bring renewed hope to affected families.

1. Intake Process



We begin by learning about your foundation, disease, and current stage. A structured intake helps assess readiness and align the right advisors and resources from the start.

2. Understanding Disease Landscape



We synthesize scientific literature and ongoing research to clarify the disease landscape and identify promising development opportunities.

3. Identifying Research & Partners



We deliver a live, recorded disease review that translates complex science into a clear, shareable narrative for outreach and collaboration.

4. Supporting Early Execution



We advise on structure, early agreements, and proposals to support smooth research launch and sound governance.

5. Advancing Active Research



Once research is underway, we provide strategic advisory support, including partner assessment, milestone review, and risk identification.

6. Building Toward Independent Operations



Over time, engagement shifts to lower-frequency advisory check-ins as foundations develop the capability to independently guide their research.



Above: Rare disease team meeting with Birdie's Flight for a KDM5C Cure CEO

We are grateful to continue accelerating progress toward new treatments for diseases that might otherwise be overlooked. Our experienced team partners with organizations that are interested in pursuing research to ensure that even the most underfunded and underrepresented diseases receive the strategic support needed to advance research and bring hope to affected families.

2025 Grant Cycle

Our 2025 rare disease grant cycle provides targeted funding to rare disease foundations—often led by families—to advance drug development and gene therapy research. Grants support a range of critical activities, including testing new therapies in the lab and in rodents, checking safety, and preparing for FDA approval. Grants also help with making new gene therapy products and running experiments to see if the treatment works in disease models. In clinical studies, funding helps figure out safe doses, track how well the therapy works, and monitor safety over time. By giving this support, the program helps families and foundations move research faster and bring life-changing gene therapies closer to the patients who need them most.

Rare Disease Advising Impact to Date



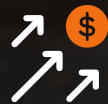
95

applications received and reviewed 2021-2025



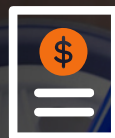
47

rare disease organizations engaged in RDAP



\$4.8M

total rare disease grants awarded



33

rare disease grants funded

Right: Annabel, from RARE Hope, taking a stroll with her family behind her

A Breakthrough for Elly's Team and the NEDAMSS Community

Beginning in early 2024, RTW Foundation advisors worked closely with Elly's Team, a family-led organization founded by Elly's parents shortly after her NEDAMSS diagnosis, an ultra-rare neurodegenerative disease caused by mutations in the IRF2BPL gene. We helped assemble a multidisciplinary team, evaluate therapeutic options, and navigate the regulatory pathway in real time. Through our partnership with Elly's Team, RTW Foundation helped achieve a major milestone in the fight against NEDAMSS. Just 13 months after diagnosis, the FDA approved an Investigational New Drug (IND) application allowing an experimental gene replacement therapy to be used on Elly Krueger—an unusually rapid timeline in gene therapy development. Elly received the therapy on April 3, 2025, at Weill Cornell Medicine, marking the first time a gene replacement approach has been used for this condition. Early follow-up indicates the treatment has been well tolerated, with continued monitoring underway. To learn more about Elly's journey and the path to gene therapy, listen to the [full story on the RTW podcast](#) hosted by our President, Stephanie Sirota.

“

At the beginning, we talked to anyone and everyone in the space about all of the different treatment or care options, including all specific aspects of pursuing a gene therapy. And through many of those calls, Joe joined us. He took notes. He digested it. He spoke to the scientists in ways that we never could have. He also helped us determine when we hit a dead end. This consistent and scientifically-based advice allowed us to make decisions and move quickly.

- Michelle Krueger, Co-Founder of Elly's Team

”



Above: Elly's Team board members including the founders, researchers, and RTW Foundation's Director of Research

This milestone reflects the purpose of RTW Foundation's Rare Disease Advisory Program, launched in 2024 to provide free, high-touch scientific and strategic guidance to families and foundations pursuing treatments for diseases that often have no existing options. With over 10,000 rare diseases worldwide, and the vast majority lacking approved therapies, this collaboration demonstrates what is possible when families, scientists, and foundations work together with urgency, expertise, and shared purpose.

Finding Hope for FRRS1L

Finding Hope for FRRS1L is a family-led organization working to advance gene therapy for children with FRRS1L. Chrissy Green, the founder, joined our Rare Disease Advisory Program in May 2025, preparing an FDA application for an AAV9-based treatment, and working to advance a potential gene therapy. Our team reviewed their progress and helped them identify a clearer, stronger path forward by evaluating their options, connecting them with the right partners, and shaping a strategy that gives their program the best chance of success. With this support, the foundation is now moving ahead with a more promising approach that brings them closer to their mission—and closer to delivering hope to families.

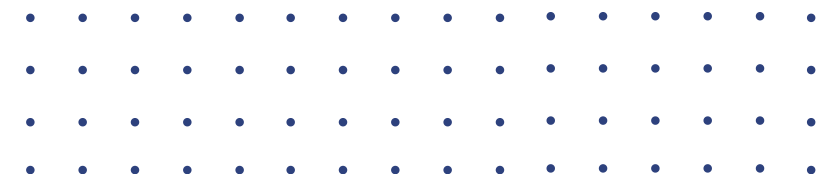


Above: FRRS1L patient from Finding Hope for FRRS1L



Finding Hope for FRRS1L
Founder, Chrissy Green,
helping her daughter

2025 Rare Disease Partners



Lachie's Wish 4 Christianson Syndrome

Lachie's 4 Christianson Syndrome (CS) is a family-led organization dedicated to advancing research and building awareness for CS. Through our partnership, RTW Foundation has supported Lachie's 4 CS as they work to strengthen their research strategy, connect with experts, and move closer to meaningful treatment options. This collaboration reflects our shared commitment to empowering families and accelerating progress for rare diseases with limited resources and urgent unmet needs.

RTW Foundation partners with family-led rare disease organizations that are driving progress for conditions often overlooked by traditional research pathways. Together, we support these partners with strategic guidance, scientific insight, and connections across the research and clinical landscape—helping turn urgency into action and move promising ideas closer to treatment for patients and families.



TBRS Community (Tatton Brown Rahman Syndrome)

The TBRS Foundation is an organization focused on finding treatments for Tatton-Brown-Rahman Syndrome (TBRS). Kit Donahue, TBRS Foundation's Community and Research Engagement Manager, joined the Rare Disease Advisory Program in March 202. Since then, we've helped them understand the challenges of developing a treatment for DNMT3A—a gene that is difficult to target—and supported them in exploring different research paths. This includes reviewing potential treatment strategies and helping them work with scientists to test what might be possible.



Chelsea's Hope

Chelsea's Hope is a family-led organization working to advance treatments for Lafora disease and joined our Rare Disease Advisory Program in May 2025. Chelsea's Hope works to complete a 10-patient Safety Study in partnership with Ionis Pharmaceuticals—an important step toward moving a potential therapy forward. Chelsea's Hope has also built a strong global patient community across the U.S., Europe, and South America to support clinical readiness. Through RDAP, we help guide their development strategy and close key funding gaps to keep progress toward the clinic on track.



Above: Lachie's Wish 4 Christianson Syndrome family

Expanding Our Impact at Rare Disease Conferences

RTW Foundation intentionally engages in rare disease conferences throughout the year as part of our commitment to accelerating paths to treatment. We attend these convenings to listen, learn, and contribute—connecting with families, researchers, clinicians, and industry partners to better understand where challenges exist and how progress can be unlocked. These conversations help align scientific efforts, share hard-won knowledge across disease areas, and build the relationships needed to move research forward. By showing up in these spaces, RTW Foundation strengthens collaboration across the rare disease ecosystem and ensures our work remains grounded in the needs of patients and families.



Above: Director of Research Joe Katakowski, PhD, on a panel with rare disease research leaders at the Alliance for Regenerative Medicine's 2025 Cell & Gene Meeting on the Mesa

FEB: Rocket Rare Disease Day

Our Director of Research, Joe Katakowski, PhD, attended Rocket Rare Disease Day, a patient-centered event, where he outlined how the Foundation partners with patient-led groups to provide scientific diligence, translational guidance, and strategic support across early research and development.

APR: INTERPHEX Global

Our rare disease team had the pleasure of attending the World Orphan Drug Congress in Boston, where leaders across biotech, government, patient advocacy, and research came together to advance rare disease treatment and access.

JUN: World Orphan Drug Congress

Our Director of Research, Joe Katakowski, PhD, took the stage at INTERPHEX Global, where he shared our mission with Deanna Porto from the Orphan Therapeutics Accelerator, after she highlighted the urgent need for a sustainable path forward in ultra-rare disease drug development.

SEP: Global Genes

Our rare disease team attended the Global Genes Rare Disease Summit in Boston this year, where patients, advocates, researchers, industry leaders, and policymakers gathered to strengthen collaboration across the rare disease ecosystem.

OCT: Meeting on the MESA

Our Director of Research, Joe Katakowski, PhD served as a panelist alongside rare disease research leaders at the 2025 Cell & Gene Meeting on the Mesa, participating in a discussion on how patient groups are driving innovation and accelerating progress in the cell and gene therapy.

NOV: FAST Global Science Summit

Our Rare Disease Program Manager, Nicole Litt, attended the FAST Global Science Summit & Gala in Orlando, focused on advancing therapeutic development for Angelman syndrome while offering insights broadly applicable across rare diseases.

NOV: Evolution of the CGT Sector Conference

The rare disease team joined fellow leaders Dr. Panteli Theocharous, Charlene Son Rigby, Brad Watts, and John Aguilar at the Evolution of the CGT Sector conference to discuss how the field can scale innovation and reach more patients worldwide.

Team



David Pan
Chief Financial Officer



Joe Katakowski, PhD
Director, Research



Sarah Garwood
Director, Community Engagement



Nicole Litt
Program Manager,
Rare Disease Advising



Steve Raymundo
BioQuest Program Associate



Samantha Darris
Communications Manager



Christina Mastrangelo
Executive Assistant

Board of Directors



Roderick Wong, MD
Co-Chair



Marti Speranza Wong
Co-Chair

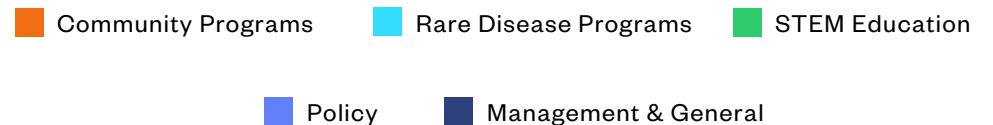


Stephanie A. Sirota
President

Financial Report

2025 Functional Expenses As of December 31, 2025

Community Programs	\$1,139,589
Rare Disease Programs	\$1,220,404
STEM Education Programs	\$317,103
Policy Programs	\$581,001
Management & General	\$616,762
Total	\$3,874,859



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