



IMPACT REPORT

Letter from Leadership

Each year, Team Telomere releases our Impact Report on Rare Disease Day, a day to pause, reflect, and stand alongside millions of individuals and families whose lives are shaped by rare conditions. It is a day that reminds us why this work matters, and why showing up, year after year, is an act of commitment and care.

In 2025, together, we strengthened community, advanced research, expanded education, and deepened collaboration across the Telomere Biology Disorder field. These accomplishments matter not only because of what they represent on paper, but because of what they made possible – for individuals seeking answers, families navigating uncertainty, and researchers and clinicians working toward better care and treatments.

This year also demanded resolve. When progress felt vulnerable and systems were strained, our community did not retreat – we advanced. We were the resistance, creating change, keeping momentum forward, and holding fast to the belief that progress is built through persistence and shared purpose.

That resolve for our community carries us forward. As we look to 2026, I do so with excitement and determination. The year ahead will be our biggest yet, and we cannot wait to build it with you. As you read through this report, we hope you take a moment to reflect on the goodness captured here – and recognize that every milestone was made possible because we were all part of something bigger than ourselves.

In hope,



Katie Stevens

Executive Director of Team Telomere



Board of Directors 2025:

- Allison Kiene, President
- Nicole Bjerke, Vice President
- Kendall Davis, Secretary
- Dave Chan, Treasurer
- Susan Insley, Director
- Heidi Carson, Director
- Jeni Colter, Director

Our Mission and Vision

The mission of Team Telomere is to empower individuals worldwide impacted by Telomere Biology Disorders (TBDs) with information and support services, to advance improved diagnosis through education and advocacy, and to accelerate the medical and scientific community's research in finding causes, effective treatments, and a path towards a cure.

The vision of Team Telomere is **to see a world where every person impacted by Telomere Biology Disorders** – including the affected individuals, caregivers, researchers, and clinicians – **has accessible care, community, and resources**, with the goal of positively changing the course of this disease, **driving toward improved treatments and ultimately one day a cure**.

By the Numbers for 2025:

750+	Patient & Their Families Served Annually	\$1.3M	In Research Funding to date
300+	Clinician & Researchers in Scientific Network	18	Partner Centers of Excellence
30+	Countries Impacted by our Global Advocacy	35	Care Packages and Legacy Boxes Delivered
120+	Scientific Meeting Attendees	7	Conferences Attended
590+	Guidelines delivered to date	650+	Downloads of educational resources

From Our Community

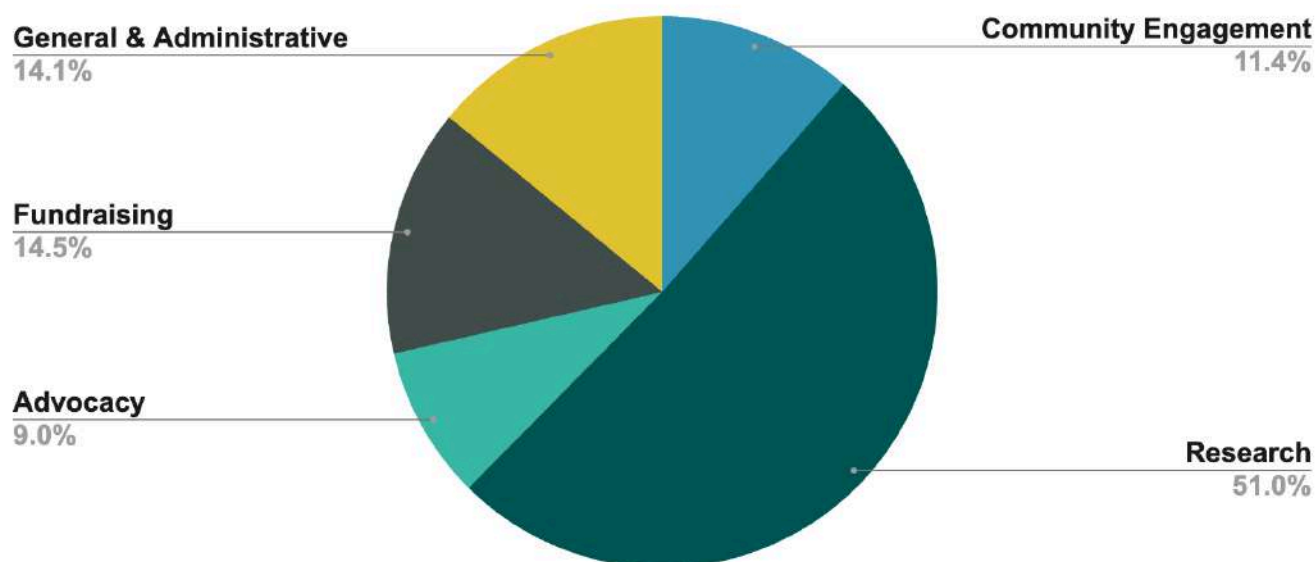
“Team Telomere is a great resource to have. It's amazing to see all the ways to support research and ways to keep up with new treatments and science.”

“I am fortunate to be part of this amazing community. I sincerely want to express my gratitude for everyone working at Team Telomere, and hope to continue working with them to help improve the lives of patients afflicted with telomere disorders.”

Financial Summary

We raised \$657,723.75 in 2025!

How are donor dollars used?



Total income: \$657,723.75
Program service expenses: \$ 419,773.90
Administrative expenses: \$ 82,803.91
Fundraising expenses: \$ 85,289.00
Net assets at year end: \$86,268

Our Approach

We believe in maximizing impact.

At Team Telomere, **nearly 80 cents of every dollar go directly to programming and research** – immediately impacting the families, researchers, and clinicians who need it most.

We work hard to keep overhead low and accountability high, so your gift makes the greatest possible impact in driving connection, care, and scientific discovery forward.

Thank you for trusting us to steward your generosity.

50+

Cents of every dollar
donated goes directly to
impactful research



Community

Community is the lifeline that carries our work forward. Over the last year, Team Telomere supported individuals and families impacted by Telomere Biology Disorders, creating spaces for honest conversation, accessible expertise, and meaningful connection.

Whether gathering to learn, sharing experiences, or sending support, our community programs reflected the heart of our mission: ensuring that no one walks the TBD journey alone.

Community Chats

Coming Together

Community Chats are a cornerstone of Team Telomere's commitment to connection, education, and empowerment. In 2025, **these sessions created meaningful opportunities for individuals and families impacted by Telomere Biology Disorders to access expert knowledge**, ask questions in real time, and engage with others navigating similar journeys. By bringing medical experts and community voices together around shared themes, Community Chats **equip community members with information and support.**

Chat topics in 2025 included

- Genetic Predisposition to Blood Cancers, in partnership with Blood Cancer United
- Liver Complications
- Young Adult Open Forum
- Legacy Chat
- Bone Marrow Failure

- Bone Marrow Transplantation & Emerging Therapies
- Adult Open Forum
- Pulmonary Complications
- Genetics & TBD Subtypes
- Open Discussion on TBDs
- Skeletal System

The most valuable thing for me was...

"Being able to ask questions directly to medical experts and get a range of perspectives."

"Not only learning about a new treatment but just listening to others give their personal stories."

"Being able to ask questions directly to medical experts and get a range of perspectives."

11

Community Chats and Open Forums hosted

147

Registrants across chats

100%

of surveyed community members said their questions were answered

Care Package Program

Community to the Doorstep

In 2025, Team Telomere's Community Care Packages delivered comfort and connection directly to individuals and families navigating Telomere Biology Disorders. **During moments of uncertainty or isolation, these packages served as a tangible reminder that no one in the TBD community walks this journey alone.** Pairing warmth from comforting items and care with trusted educational resources, the program helped families feel seen, supported, and connected to resources and information.

23 Care Packages
mailed in 2025

362 Care Packages
sent over the years



From Our Community:

"When we received our care package last year it brought a smile to our faces – for so long I felt so alone because we didn't have a name for anything, and her genetics are just so so rare. [A]lthough we don't like that she has telomere disorder one bit, we at least felt apart of a community for the first time since she was born and on this journey."

Legacy Program

Community to the Doorstep

The Legacy Program honors lives lost to Telomere Biology Disorders while providing ongoing support to families navigating grief. Legacy Boxes offer comfort and connection during some of our community's most difficult moments. These packages hold a prism to let the light lend color when someone feels most grey, a candle to warm when they may feel alone and to give light in the darkness, as well as a grief journal to help document, explore and process grief.



10 Legacy Boxes
mailed in 2025

98 Legacy Boxes
sent over the years

From Our Community:

"Thank you for everything you do... You have helped my family more than once. Thank you for sending the package after my [daughter] passed... Keep doing what you are doing. You are making a difference in so many families' lives."

Nancy Cornelius Scholarship Fund

The Nancy Cornelius Scholarship Fund continues to transform possibility into opportunity for those impacted by Telomere Biology Disorders.

Shortly before her passing, Nancy established this scholarship to support young adults affected by Telomere Biology Disorders in pursuing higher education. Rooted in Nancy Cornelius's belief that no one should ever be alone, the scholarship has helped those across the TBD community take meaningful steps toward their goals.

In 2025, **Team Telomere** was proud to award our eleventh **Nancy Cornelius Scholarship**, continuing Nancy's legacy of courage, connection, and unwavering belief in what our community can achieve.



Congratulations to our
2025 NCSF recipient,
Andrew Aguilar!

From our recipient:

"Despite the condition I live with, I am convinced that it is not an obstacle to achieving my goal."

Read his essay on
[our webpage](#):



Community Days

Hosted at Camp Sunshine

Camp Sunshine provided a space for individuals and families impacted by Telomere Biology Disorders to connect and learn together. Team Telomere convened community members across ages, diagnoses, and stages of their TBD journey for an **experience that combined expert-led education, reprieve activities, and meaningful connection**. Camp Sunshine beautifully strengthens community and reinforces that no one faces a TBD journey alone.

Expert Talks Included

- Telomere Biology Disorders 101
- Community-Powered Research
- Bone Marrow Failure: Screening and Management
- Lung Disease and TBDs
- What are clinical trials?
- Developing therapeutics for telomere diseases
- Updates on Gene Therapy for Telomere Elongation in TBD
- Care for adult patients with TBDs
- Finding Your Allies in Life and Medicine

Recorded sessions are available for on-demand viewing on our YouTube channel.



70+ Community attendees

9 Expert talks on TBD topics

20+ Facilitated one-on-one sessions

"I thank everyone for all the hard work... It was another special experience and it felt good to see so many new families because being involved has helped and continues to help me navigate this..."



Education & Advocacy

Education and advocacy are integral to our mission. From helping community members understand a new diagnosis, equipping clinicians with the latest guidelines, or speaking up in research and policy spaces, our goal is to make sure no one walks this path without the tools and support they need.

This past year, we continued building and sharing resources developed alongside and for the Telomere Biology Disorder community - resources to inform and empower across every stage of a TBD journey.

Clinical Guidelines & One-Pagers

Education in Community's Hands

Access to clear, accurate information can change the course of care. Team Telomere's *Telomere Biology Disorders: Diagnosis and Management Guidelines*, Second Edition **serve as a cornerstone resource**, helping patients, families, clinicians, and researchers across every stage of TBDs.

These resources do more than inform – they empower individuals to ask questions, advocate, and ensure care decisions are grounded in the best available evidence.

To expand access, **One-Pagers were translated into Spanish**. More language translations to come – stay tuned!

Team Telomere's **video educational series has gained 260+** views to date, **offering another pathway for learning and engagement**.

“Thank you Team Telomere for your hard work in putting this together for the TBD community.”

“This book has been a huge blessing to our family. I have learned so much and feel like I can better advocate for my boys because of the knowledge I have...”

“Invaluable resource for TBD information. Well written and easy to understand and navigate through.”

163+

Guideline copies distributed in 2025

594+

Guideline copies distributed to date

667+

Downloads of One-Pagers

Conferences

Connecting to Advance Together

Progress in Telomere Biology Disorders depends on collaboration across disciplines, institutions, and sectors. By engaging directly with researchers, clinicians, policymakers, and partner organizations, Team Telomere brings the priorities of the TBD community into broader scientific and advocacy spaces.

Conferences serve as critical points of connection – where we share our work, learn from parallel fields, and build relationships that accelerate research and care. Across meetings, Team Telomere advances progress through scientific presentations, panels, educational booths, and collaborative abstracts.

Places our advocacy took us:

- FDA-NIH Rare Disease Day 2025
- Transplantation & Cellular Therapy Meetings of ASTCT and CIBMTR
- Cold Spring Harbor, Meeting on Telomeres & Telomerase
- Chan Zuckerberg Initiative Rare As One Network Annual Meeting

- Pulmonary Fibrosis Foundation Summit
- American Society of Hematology Annual Meeting
- Internal institutional meetings, grand rounds, educational session, and more!

View conference summaries on our Research Corner.



150+

Resources distributed
on average per
conference

200

Connections on
average per
conference



Centers of Excellence

Elevating Care Through Partnership

Team Telomere's Centers of Excellence represent a working partnership built to move care forward for the Telomere Biology Disorder community. Over the last year, **Team Telomere strengthened collaboration across participating centers by sharing clinical and educational resources, convening regular cross-center conversations**, and providing advocacy guidance rooted in community need. These efforts support centers navigating complex care, improved pathways for patients seeking specialized expertise, and helped align institutions around shared standards and priorities.

Our Center of Excellence Network

Tier 1

- Boston Children's Hospital
- Children's Hospital of Philadelphia
- Cincinnati Children's
- Dana-Farber Cancer Institute
- Mayo Clinic
- Schneider Children's Medical Center of Israel
- Texas Children's Hospital
- UW Health and University of Wisconsin School of Medicine and Public Health
- University of Minnesota and M Health Fairview
- University of Utah / Huntsman Cancer Institute
- University of Pennsylvania

Tier 2

- Children's Hospital Colorado
- Cohen Children's Medical Center
- IRCCS Istituto Giannina Gaslini
- St. Jude Children's Research Hospital
- University Hospital Aachen

Tier 3

- Rady Children's Hospital
- Tel Aviv Sourasky Medical Center (TASMC)

Learn more and visit
our interactive map

teamtelomere.org/centers-of-excellence/





Research

At Team Telomere, we believe that advancing science must go hand-in-hand with the needs and voices of our community.

This year was the most significant year of research support in Team Telomere's history. Together with our community, we surpassed a defining milestone - **over \$1 million invested in Telomere Biology Disorder research** - fueling work that spans the full research continuum, from foundational discovery to translational and therapeutic development.

This record year is proof of what is possible when community and science move forward together for the even greater progress ahead.

Registry Advancement

Driving Forward Science

In 2025, Team Telomere established a **community-powered digital natural history** study through our partnership with Citizen Health – **marking a major step forward in how Telomere Biology Disorder research is driven.**

70

Patient Registry
participants

This initiative enables individuals and families to securely centralize their medical records and contribute real-world data to research. This registry strengthens the foundation for discovery, helping researchers better understand TBDs and accelerating progress towards future cures.

Research Roundtables

Fostering Collaboration

Team Telomere's Research Roundtables bring together clinicians and researchers from across the globe to tackle shared challenges in Telomere Biology Disorders and move the field forward together.

These focused discussions create cross-disciplinary learning and collective problem-solving, turning expertise into actionable next steps.

25+

Attendees from
across the globe
per Roundtable

100%

of post-event survey
respondents said they
were "very satisfied"
with the roundtable

Micro Meeting

Accelerating Collaborative Discovery

Team Telomere held the 2025 Micro Meeting at Mayo Clinic on October 17 & 18th.

More than 120 attendees from 11 countries joined us both virtually and in person for two days of collaboration and discovery. The Micro Meeting, originally intended to be a smaller, more focused gathering, quickly became the largest meeting of scientists and clinicians for Telomere Biology Disorders to date, coining the phrase "Micro becomes Macro!"

121 Attendees in total
11 Countries represented

"[T]he collegiate atmosphere among the scientists/clinicians - a sense that we are only going to beat this disease by all working together."

Session Topics Included:

- Advances in Telomere Length Testing and Diagnostics
- Genetics
- Bone Marrow Transplant & Bone Health
- Clonal Hematopoiesis & Blood Surveillance
- Pulmonary Manifestations
- Liver manifestations
- Novel Therapies for TBD
- Breakout Sessions

8 Session topics

40 Scientific community speakers

7 Patient community speakers

"This was a great balanced integration... It inspires us to work harder."

“ *Starting every session with a patient perspective was so powerful - like a North star, it served as a reminder of why we do the science that we do and how important our work is."*



were satisfied with the overall experience at Micro Meeting 2025



were likely to recommend the Micro Meeting to another individual in the field

Cocktails & Chromosomes

Celebrating Community & Advancing Research

Cocktails & Chromosomes brings together the heart of the Team Telomere community – patients, families, clinicians, researchers, advocates, and supporters – to celebrate progress and fuel the future of Telomere Biology Disorder research. In 2025, these events captured what makes this community extraordinary: shared purpose, collective hope, and a commitment to turning connection into impact.

New York City

More than 170 guests gathered for Team Telomere's first-ever Cocktails & Chromosomes: NYC, creating an unforgettable evening of connection, storytelling, and momentum. Clinicians from leading institutions, alongside families, friends, and new members of the Team Telomere community, came together in support of advancing TBD research and care.

Together, the community raised \$75,000, helping Team Telomere reach a major milestone – \$1 million toward a \$1.5 million goal to fund our **first-ever mission driven grant**.

\$75K+

Raised to fund our first mission-driven grant, Trail Fund

Minnesota

Following the 2025 Micro Meeting, Team Telomere hosted its fifth annual Cocktails & Chromosomes gala at the Mayo Civic Center in Rochester, Minnesota.

\$55K

Awarded in research funding for bold, innovative projects

A defining highlight of the night was Team Telomere's first-ever live Shark Tank-style scientific grant competition, which awarded \$55,000 in research funding to bold, innovative projects with the potential to advance TBD diagnosis and treatment. Four investigators were funded through the inaugural competition, supporting research spanning telomere dysfunction, variant analysis, RNA-based therapeutics, and cryptic mutation detection.

Research Grants

Catalyzing Discovery

Read about the impactful, patient-centered work funded in 2025:

Uplifting Athletes' Young Investigator Draft Pick

Dr. Helen Reed, Dana-Farber Cancer Institute / Boston Children's Hospital

Project: Deoxynucleoside Therapy in Telomere Biology Disorders: A Phase I Clinical Trial

Award: \$20,000

Lay Summary: Telomere biology disorders can lead to complications, including bone marrow failure and increased risk of blood cancers. Dr. Reed's project is titled "Deoxynucleoside Therapy in Telomere Biology Disorders: A Phase I Clinical Trial" and aims to explore using nucleoside therapy, which has data showing promise in supporting telomere maintenance.

The project will involve a clinical trial at Boston Children's Hospital to evaluate the safety and potential benefits of this therapy in individuals with TBDs. Dr. Reed is a dedicated clinical researcher with a strong focus on TBDs. She has experience in clinical study design and a passion for improving therapeutic options, and she will be helping lead the trial.



Shark Tank Grant

Team Telomere's first-ever live Shark Tank-style grant competition debuted at Cocktails & Chromosomes! The goal of this grant was to fund bold and innovative ideas with the potential to move the field of Telomere Biology Disorders forward. From shark costumes to shark tattoos mixed with groundbreaking science, it was an unforgettable experience celebrating scientific creativity!

Dr. Daria V. Babushok

Project: Telomere Dysfunction- Associated DNA Damage Response as a Risk Factor for Complications in TBD

Award: \$25,000

Dr. William Mannherz

Project: Saturating variant analysis of the human Telomerase RNA Component (TERC)

Award: \$15,000

Dr. Neha Nagpal

Project: Novel RNA-based therapeutics to rescue human telomerase *in vivo*

Award: \$10,000

Dr. Jeannette Wong-Siegel

Project: Expression Analysis of Telomere Related Genes for Detection of Cryptic Mutations

Award: \$5,000



Research Grants

Catalyzing Discovery

Funding research takes multiple trails. Getting to the top of the scientific summit may require many routes: early discovery, translational models, and multiple clinical trials before therapies reach patients. The Team Telomere Trail Fund is designed to move us up that mountain by fueling innovative research with flexibility and sustainability.

The first of its kind, the Telomere Trail Fund was designed to provide direct, mission-aligned support to priority projects identified by Team Telomere's leadership, with input from members of the Telomere Biology Disorder community.

Trail Fund

Project Lead: Suneet Agarwal, MD, PHD, Boston Children's Hospital

2025/2026 Award: Nucleoside therapy for telomere biology disorders

Award: \$206,250 in total costs

Lay Summary: Telomere biology disorders (TBDs) are rare genetic conditions that cause serious health problems like bone marrow failure, cancer, and lung or liver disease. These disorders happen when protective caps on the ends of chromosomes, called telomeres, become too short due to inherited mutations. Currently, the only cure is a bone marrow transplant, which comes with significant risks and isn't available to everyone. We recently discovered that a natural substance called thymidine may help lengthen telomeres in cells from TBD patients. Thymidine has already been safely used in small studies for other diseases. This new clinical trial will test whether thymidine is safe and potentially helpful for people with TBDs. If successful, it could lead to a much-needed new treatment option for patients living with these rare and life-threatening disorders.



Thank You to Our Trail Funders

The 2025/2026 Trail Fund Grant was made possible through the generous support of our community. We are deeply grateful for all those that made this milestone possible: the Desmond Kiene Family (\$100,000), the Tully Family (\$100,000), the Carson Family (\$25,000), and the ongoing commitment of our community.

2025 Partners

We are deeply grateful to every partner, donor, and sponsor who made advancing our mission possible in 2025. Your support has helped create lasting impact across the Telomere Biology Disorder community - we could not do this work without you.

BOLANDER RepeatDx



**REJUVENATION
TECHNOLOGIES**

ultragenyx



THE
DESMOND KIENE
FAMILY



Goldman
Sachs



THE
TILIAKOS
FAMILY

THE
TULLY
FAMILY

Siegfried



Carson
Family



ANDY
BORST

SAMUEL LISS

THOMAS A
BRADLEY

Donate to our
annual fund!



Support in 2026

We have exciting opportunities ahead in 2026, and we invite you to be a part of it. Whether through a one-time gift or a tailored sponsorship, your support will directly power Team Telomere's work across the areas of community, education, advocacy, and research. Explore ways to get involved:

Annual Partnership

Our most comprehensive sponsorship, offering visibility across all initiatives and events.

[Learn more](#)



Program Sponsor

Have a program that catches your eye? Support specific efforts across Team Telomere.

[Learn more](#)



Team Telomere Summit 2026

The Team Telomere Summit 2026 is a field-shaping convening that brings together researchers, clinicians, and the Telomere Biology Disorder community to move science forward, together. Taking place July 7 to 10, 2026, in Missoula, Montana, this concurrent Scientific and Community Summit is designed to accelerate discovery, strengthen collaboration, and ensure research remains grounded in lived experience.

United by the theme *A River Runs Through Advocacy and Research*, the Summit connects science, care, and community, creating momentum that drives progress long after the week ends.

[Learn more](#)



Your support of Team Telomere's Annual Fund powers the gamut of our work - community, education, advocacy, and research - throughout the year.

[Donate to our annual fund!](#)



Keep the Momentum Going in 2026 and Beyond!

2025 was defined by connection, collaboration, and impact. With your continued support, we are excited to carry that momentum forward – growing hope in 2026 and beyond.



**Donate to our
annual fund!**



Questions?

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