

Team Telomere

IMPACT **REPORT**

Letter from Leadership

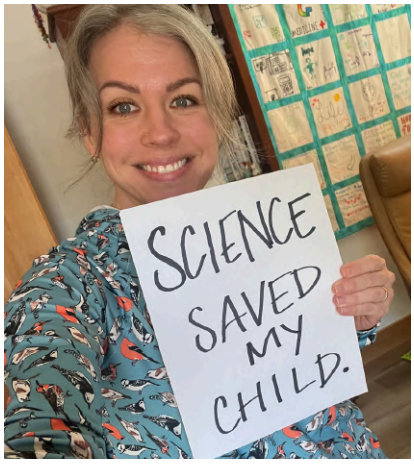
Fifteen years ago, our community came together with a promise: no one facing a Telomere Biology Disorder would ever walk alone. What began as a small but mighty network has grown into a global force - driving research, transforming care, and holding space for each other through every chapter of our journeys.

2024 was a landmark year. We hosted our largest-ever gathering in Coeur d'Alene, Idaho, which was a field-shaping week. We funded bold new research efforts. We launched our first cohort of Centers of Excellence. Through every Community Day and Community Chat, every care package sent, and every moment shared, we deepened the strength of our community.

Together, we've accomplished so much. And we know - we're just getting started. As we look ahead, we know there are mountains to climb. The evolving funding landscape is making it more challenging than ever to advance science and research, placing greater responsibility on patient advocacy groups like ours. Now more than ever, patients, care partners, researchers, and clinicians rely on us - and we will give everything but up.

With groundbreaking advancements unfolding and even more on the horizon, our advocacy is expanding to reach every corner of our community, our support services are growing and becoming more essential than ever, and our research efforts are driving new breakthroughs.

Together, we are not just hoping for progress - we are creating it.



Katie Stevens
Executive Director of Team Telomere

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 2024:

700+	Patient Families Served Annually
300+	Clinician & Researchers in Scientific Network
30+	Countries Impacted by our Global Advocacy
225	Summit Attendees
400+	Guidelines delivered to date
$173K	New Research Funding
18	Inaugural Centers of Excellence
40	Care Packages and Legacy Boxes Delivered
8	Conferences Attended
425+	Downloads of educational resources

From Our Community

"Telomere Biology Disorders are the pits... I wish we were not joined by such circumstances, but it's also nice to know the world isn't such a big place, and there's a global community out there supporting each other."

*"**I have hope** that through advocates, physicians and researchers, and awareness and accessible screening methods, one day more effective treatments and perhaps a cure will be found."*



Team Telomere Summit 2024

Held July 8th to 11th at the Coeur d'Alene Casino Resort on the sovereign land of the Coeur d'Alene Tribe, our inaugural Community and Scientific Summit brought together nearly 200 attendees for four days of education, connection, and celebration.

Scientific Summit

Tying the Laces Together

Team Telomere's Scientific Summit 2024: Tying the Laces Together was designed to reflect the evolving needs of the Telomere Biology Disorder field, covering topics from bench to bedside and beyond.

This dynamic convening brought together leading experts from across the globe to **climb together toward our shared goals of improved diagnosis, management, and treatments for TBDs**. Each session was intentionally crafted to highlight interdisciplinary collaboration and centered the experiences of our community.

Session topics included

→ Clinical Spectrum & Diagnostic Challenges
→ Clonal Hematopoiesis
→ Overcoming Barriers in the Field
→ Multi-Disciplinary Needs & Collaborative Care
→ Translational Research
→ Needs and Challenges in Adult Care

10 countries represented

9+ professional disciplines represented

40+ insightful talks

100% of participants found the content presented relevant to their work

100% reported they would apply the knowledge gained to their clinical practice or research

"The variety of subjects discussed and range of expertise was impressive... Overall, ***I left the summit feeling optimistic about the direction the field is headed and with plenty of new ideas to investigate****."*

> ***Without being hyperbolic, this was practically the perfect summit.***

Community Summit

Over the years, Team Telomere has hosted many events for the community. This year, **we were proud to host the Community Summit as a way to continue supporting, educating, and building lasting connections**. The Summit was open to all community members, including individuals living with TBDs, their families, care partners, and our bereaved community.

Thanks to the generosity of our donors and partners, Team Telomere covered the full cost of registration, lodging, meals, and activity programming

> *"Meeting other families who understand was life-changing.*

Attendees experienced:

→ Sessions on Navigating the TBD Research Landscape, Addressing Care Needs, Storytelling and Six-Word Memoir, and Self Care for the Care Partner & the Individuals
→ Paint and Sip Session led by a Coeur d'Alene Tribe artist
→ Field Trip with the Coeur d' Alene Tribe: Historical Canoes

35% of the programming featured crossover between Community and Scientific participants:

→ Scientist and Community Meet & Greet featuring a special community-facing poster session
→ 1:1 meetings with TBD experts
→ 'You're Never Alone' Dinner Cruise on Lake Coeur d'Alene
→ Centers of Excellence Awards and Closing Ceremony

22 U.S. states represented

4 countries represented

100% of attendees were "very likely" to recommend the Summit to other community members

"What I loved most was meeting Team Telomere and discovering that we are not alone."

*"My daughter made real friends who also live with a TBD. **That's something we'll carry forever.**"*

Boots and Genes

Celebrating Community

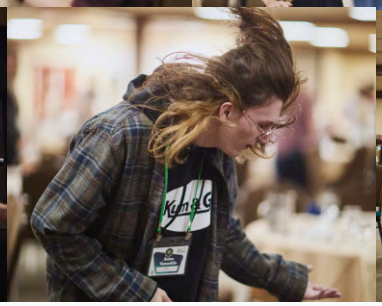
Our fourth annual gala - Boots & Genes - brought together supporters from across the country to celebrate the strength of our community - and to fuel our mission forward.

Together, **we raised an incredible $75,000 in support of Telomere Biology Disorder research, community programs, education, and advocacy**.








Watch the Scientific & Community Summit Recap

Watch the Boots & Genes Gala Recap



Community

Community is at the heart of everything we do. Whether it is sending a care package across the country, gathering, hosting chats, and beyond, every connection we make is rooted in the belief that no one should ever walk this journey alone.

In 2024, we grew stronger and more connected than ever, fueled by support and by the people who make up the global TBD community.

Community Chats

Coming Together

Team Telomere created Community Chats to be safe spaces for individuals impacted by Telomere Biology Disorders to connect, ask questions, and learn together. Each chat centers around an overarching theme and features experts in the field.

Chat topics in 2024 included
→ Bone Marrow Transplant
→ Open Discussion on TBDs
→ Liver and TBDs
→ Open Forum Disucssions
→ Genetic Counseling
→ Education
→ Pulmonary
→ Diagnosing TBDs and the Subtypes
→ Hematology

The most valuable thing for me was...

"Learning new things about TBD's and starting to feel more a part of the Team Telomere community."

"Ability to ask a question to an expert and learning from other people's Q&A"

12 Community Chats and Open Forums hosted

141 registrants from **21** U.S. states and **9** countries

"Thank you for hosting these community chats, I always feel more informed afterwards and I enjoy connecting with other individuals with similar problems and concerns that I have."

"Many thanks for these chats. They provide a lot of information. Absolutely essential for us."

Team Telomere Days

Coming Together

One of Team Telomere's goals is to meet people where they are - whether that's through virtual programming or in-person visits across the country.

Over the last couple of years, when members of our team travel, we extend an invitation to connect with local families impacted by Telomere Biology Disorders.

In 2024, we had the privilege of sitting down with families in Kansas City. What began as virtual connection through Community Chats and emails culminated to an in-person dinner.



"Now every time we talk, we can say, **'I know exactly what you mean.' That connection changed everything."**

Care Package Program

Community to the Doorstep

Our team has a favorite saying: "it takes a village." For us, that means **coming alongside every person in our community**. Team Telomere's Community Care Packages are sent to individuals impacted by Telomere Biology Disorders. Each package includes items designed to bring a smile - like blankets, hats, and soft toys - alongside a copy of our *Diagnosis and Management Guidelines* and educational brochures.

32 care packages mailed in 2024

339 care packages sent over the years



From Our Community:

"I received my Community Care Package yesterday. It brought me to tears. When I opened it, I could feel the love and compassion that went into its creation."

"Thank you for sending the care package. My son was so happy - he loves the hat and blanket."

"Receiving a care package helped our whole family feel close to others like us."

Legacy Program

Community to the Doorstep

Developed in 2018, this program supports individuals who have lost a loved one to a Telomere Biology Disorder. **Legacy offers space to grieve, connect, and continue contributing to our shared mission.** Every box, is filled with thoughtful items and resources with the reminder of our promise to our community that *you are never alone*.



8 legacy boxes mailed in 2024

88 legacy boxes sent over the years

From Our Community:

"Legacy has been a continued source of healing to my soul."

"This is the first book I've picked up on grief in a long time. Even a few pages in, I feel hope again - which is a big deal."

"Thank you for sending the package after my daughter passed. That meant a lot to our family."

Nancy Cornelius Scholarship Fund

Team Telomere's Core Founder, Nancy Cornelius, believed that "no one should ever be alone." Throughout her life with a Telomere Biology Disorder, she led with courage and hope, igniting a community that continues to grow, connect, and support one another.

Shortly before her passing, Nancy established a college scholarship to support young adults affected by TBDs. **We were honored support our tenth offering of the Nancy Cornelius Scholarship Fund in 2024**, helping those in our community pursue their dreams through education.

Congratulations to our 2024 NCSF recipient,
Jonathon Hornback!

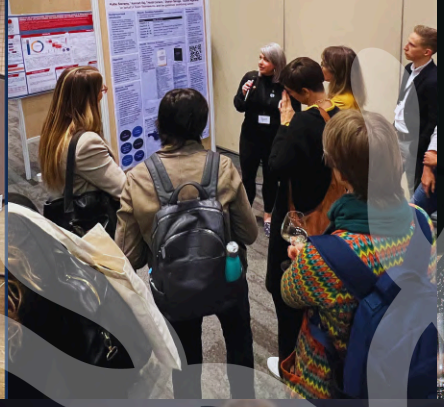


From our recipient:

"Thank you so much for awarding me the Nancy Cornelius Scholarship Fund! I am incredibly honored and excited to be this year's recipient. ***Words cannot express my gratitude for this generous support****. Over these last [months], the amount of support I have received from Team Telomere is truly remarkable!"*

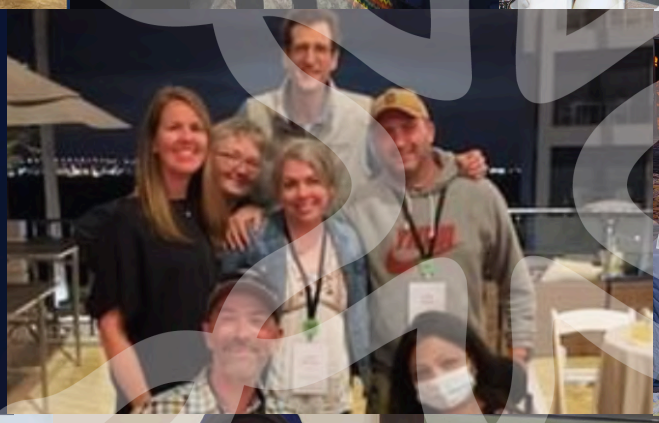
Read his essay on
our webpage:







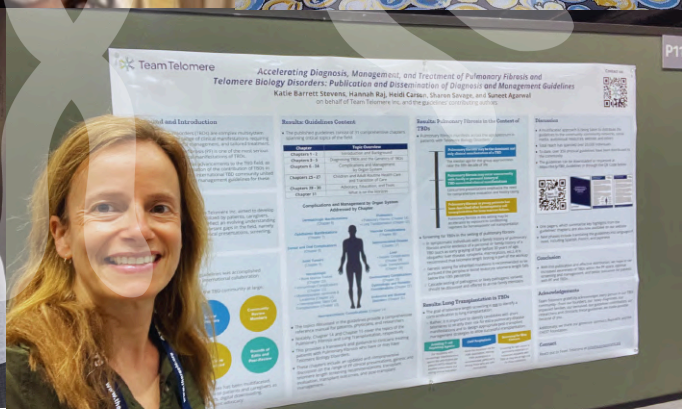












Education & Advocacy

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.

In 2024, we continued building and sharing resources created with and for the Telomere Biology Disorder community.

Clinical Guidelines & One-Pagers

Education in Community's Hands

Our cornerstone educational resource, the *Telomere Biology Disorders: Diagnosis and Management Guidelines*, Second Edition, **equips community members, clinicians, and researchers** with trusted information on TBDs.

> *"This book helped me better understand the care I needed. These guidelines are thorough, prescriptive, and lifesaving."*

To help make information even more accessible, **in 2024 we created our One-Pager Resources**, designed to highlight key insights from the Guidelines.

From information on diagnostics, clinical manifestations, and management, these tools were built to empower our community and help individuals advocate for themselves and others.



"I have learned so much and feel like I can better advocate."

"Invaluable. Easy to understand and navigate for patients, caregivers, researchers, and clinicians."

125+ Guideline copies distributed in 2024

400+ Guideline copies distributed to date

425+ Downloads of One-Pagers

Conferences

Connecting to Advance Together

Connecting with researchers, clinicians, and other organizations is vital to driving our mission forward. Conferences allow Team Telomere to share our work, learn from others, and collaborate in new ways to support those impacted by Telomere Biology Disorders.

Education and advocacy remain critical to raising awareness, accelerating research, and expanding care. In 2024, we continued showing up at critical convenings, bringing the community voice front and center.

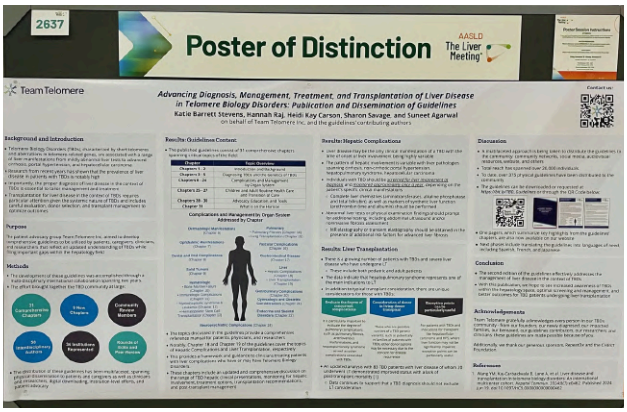
Places our advocacy took us:

→ American Thoracic Society (ATS) International Conference 2024
→ The Liver Meeting by American Association for the Study of Liver Diseases (AASLD)
→ Chan Zuckerberg Initiative Rare As One annual convening
→ EMBO Workshop: Telomere function and evolution in health and disease
→ Global Genes' RARE Advocacy Summit
→ Clinical Cancer Genomics Community of Practice meeting
→ ESH-EBMT-EHA-IPIG 3rd Translational Research Conference: Bone Marrow Failure and Leukaemia Predisposition Syndromes
→ American Society of Hematology Annual Meeting



150+ resources distributed on average per conference

200 connections on average per conference



Centers of Excellence

Elevating Care Through Partnership

In 2024, Team Telomere was proud to launched our Centers of Excellence (CoE) program. These 18 centers were carefully selected based on their commitment to advancing coordinated care, advocacy, support, education, collaboration, and research for the TBD community.

Our Centers of Excellence serve as trusted guides for patients and clinical teams seeking high-quality, specialized care. We are honored to partner with these outstanding institutions and look forward to their growing impact in the years to come.

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. Through strategic grantmaking, research roundtables, registry data collection, and direct collaborations, we are working to accelerate discoveries that lead to better diagnostics, treatments, and ultimately, a cure.

In 2024, we supported innovative studies through the Carson Family Research Award, our Micro Grant, and the Million Dollar Bike Ride Grant, and we launched quarterly Research Roundtables.

Registry Advancement

Driving Forward Science

Team Telomere's patient registry, hosted on the RARE-X platform, continues to grow as a foundational resource for researchers seeking to better understand Telomere Biology Disorders.

80+
patient registry participants

In 2024, our registry surpassed 80 participants, each contributing valuable insights to drive research. By collecting and sharing real-world data, we are helping ensure that the lived experience of the TBD community informs the science shaping their care.

Research Roundtables

Fostering Collaboration

In November 2024, Team Telomere hosted our inaugural Telomere Research Accelerating Collaborative Translational Science (TRACTS) Roundtable.

These gatherings are designed to bring together researchers, clinicians, and collaborators in the TBD field to explore timely and critical topics in TBD research.

25+ attendees from across the globe



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

Research Grants

Catalyzing Discovery

Read about the impactful, patient-centered work funded in 2024:

Million Dollar Bike Ride Grant

PI: Dr. Suneet Agarwal, Boston Children's Hospital
Project: Nucleoside therapy for TBDs
Award: $63,000



Lay Summary: We recently discovered that molecules called nucleosides can increase telomere length in human cells, including those from patients with TBDs. In this proposal, we will now rigorously test whether these same nucleosides can effectively increase telomere length in human stem cells, both in the dish and in animal models. If successful, these experiments will provide critical results that will help take nucleosides into clinical trials for patients with TBDs.



Carson Family Telomere Biology Disorder Research Award

PI: Dr. Alison Bertuch, Baylor College of Medicine
Project: Small molecule compounds to elongate telomeres
Award: $100,000

Lay Summary: Our goal is to identify small molecule compounds that increase telomere length and serve as the basis for the development of effective treatments and cures for individuals with dyskeratosis congenita (DC) and related telomere biology disorders (TBDs). Here, we will optimize our screening approach to identify small molecules that will specifically block TIN2-TRF1 interaction. Our research represents the first application of DEC-Tec screening to the discovery of drugs to treat DC/TBDs.

2024 Micro Grant Research Award

PI: Dr. Kelvin Cesar de Andrade, NIH/NCI
Project: Founder mutation in Ashkenazi Jewish populations
Award: $10,000



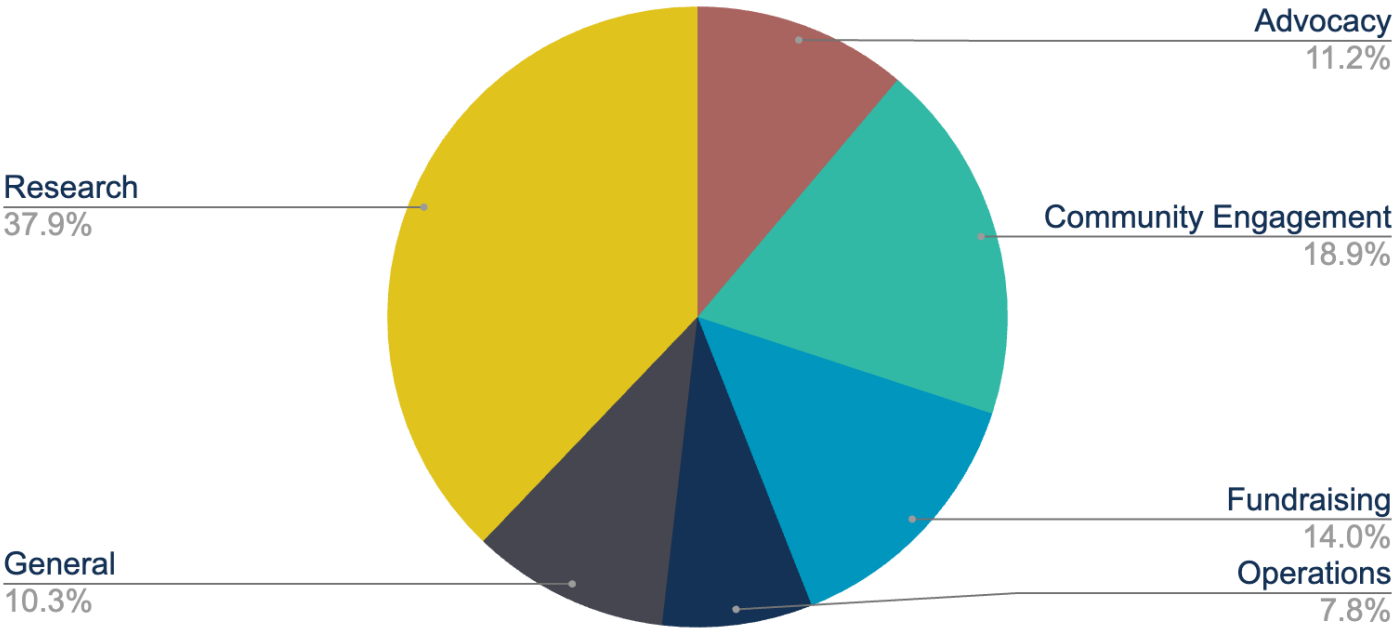
Lay Summary: Dr. de Andrade's study will evaluate if individuals of Ashkenazi Jewish ancestry carry a common genetic alteration associated with increased risk of developing telomere biology disorders. These results will form the foundation for future tailored clinical management strategies and specific genetic counseling recommendations for the Ashkenazi Jewish community.

Financial Summary

We raised $614,503.53 in 2024!

*Includes $200,000 from the CZI Rare As One Project

How are donor dollars used?



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.

80

cents of every dollar donated go directly to programming and research

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.

2024 Partners

We are deeply grateful to every partner, donor, and sponsor who made advancing our mission possible in 2024. Your support has helped create lasting impact across the Telomere Biology Disorder community - we could not do this work without you.

Rare As One

elixirgen THERAPEUTICS

RepeatDx

REJUVENATION TECHNOLOGIES

THE INSLEY FAMILY

THE DESMOND KIENE FAMILY

THE TULLY FAMILY

Cincinnati Children's™ changing the outcome together

ultragenyx

ARGO GROUP

NORTHWEST SPECIALTY HOSPITAL
QUALITY CARE SINCE 2003 | PROUDLY OWNED AND OPERATED BY PHYSICIANS

CCCTAA

StateFarm®

Greene Idaho Foundation

Cornelius Family
Never Alone Dinner Cruise

Carson Family
Telomere Biology Disorder Research Award

Donate to our annual fund!

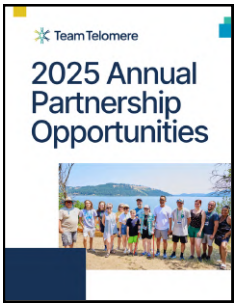
Support in 2025

We have exciting opportunities ahead in 2025, 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 Partership

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

Learn more



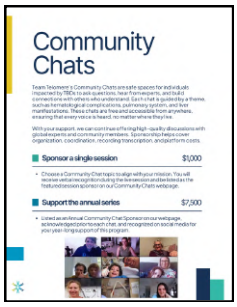


Program Sponsor

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

Learn more





Micro Meeting 2025

Bring researchers and clinicians together for a focused convening to move science forward.

Learn more

Cocktails and Chromosomes

Sponsor our 2025 gala, a special celebration of strength, community, and progress.

Learn more

Donate to our annual fund!

Keep the Momentum Going in 2025 and Beyond!

2024 was a year of connection, collaboration, and impact - and we are just getting started. With your continued support, we can keep hope growing in 2025 and beyond.









Donate to our annual fund!

Questions?

Email info@teamtelomere.org to connect

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