PROGERIA RESEARCH FOUNDATION™

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We are advancing gene therapy and a path to the cure!

One misspelled DNA "letter" in the genetic code causes Progeria, and SamPro-2 is the gene therapy designed by PRF's phenomenal Gene Team to permanently correct that genetic code at the source. Read the latest updates, as PRF leads the way towards a first-ever gene therapy clinical trial for children and young adults with Progeria – SO exciting!

See Page 4 for details.

A MILESTONE DECADES IN THE MAKING:

Four Adults Making Progeria History!



In October 2025, four remarkable young adults with Progeria referred to as "The Fab Four" — **Merlin** (24), **Kaylee** (22), **Amber** (19), **and Michiel** (27) **— made history** by taking the stage together at **PRF's 12th International Scientific Workshop,** forming the very first adult patient panel of its kind. They were joined by Riccardo, who gave a moving tribute to his late best friend **Sammy Basso**. Their candid stories on living with Progeria and hopes for the future impacted everyone in the room, and stood as living proof of how far the field has come: before PRF, the average lifespan for children with Progeria was just 14.5 years. Today, thanks to the FDA-approved treatment lonafarnib, PRF's ongoing research, and the support of thousands globally like you, more young adults with Progeria are living longer, fuller lives than ever before. The workshop's scientific discovery presentations were just as historic, culminating in a landmark meeting summary published in Nature Aging that defines six strategic pillars to guide the next era of Progeria research. ***See Page 5 for details.***

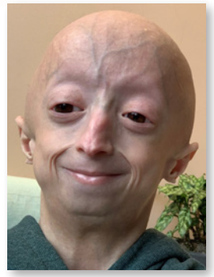
Progeria is an ultrarare, fatal, "rapid-aging" condition

PRF's Vision:

A world in which every child and young adult with Progeria is cured.

PRF's Mission:

To discover treatments and the cure for Progeria and its aging-related disorders, including heart disease.



STAFF:

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Tracy Lessor, PhD *Director of Communications*
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There are SO many people involved with PRF, we couldn't possibly name them all! To every volunteer who gives their time, energy, and heart - thank you. We couldn't do this without you!

A Message from the President

Hello everyone,

Notice something a little different in this newsletter and online?

That's because we've launched a new look, including an updated logo and a brand-new website! Thanks to feedback from supporters like you, our website is easier to navigate, provides streamlined access to scientific information, and better showcases PRF's resources, activities, and the beautiful children and young adults we serve. We've also introduced a refined version of our logo that complements the new website while preserving the elements that are so meaningful to us all.

Most importantly, although our look and feel have changed, our mission and vision have not. We remain focused on the same unwavering goal: finding the cure for Progeria.

This issue is full of reasons for hope:

- Young adults with Progeria publicly share their hopes, fears, and dreams with a roomful of riveted scientists.
- Researchers gather to share their work and collaborate, knowing that this close-knit scientific community offers the best path toward treating and curing Progeria as quickly as possible.
- Siblings, bikers, and athletes raise awareness and funds in a wonderful variety of ways. They join thousands of past event organizers and participants in doing what they can, however they can, so PRF can continue its quest for the cure.
- The first stage of a clinical trial for another potential treatment is complete, thanks to the courageous families who participated.
- We're making extraordinary advances in the development of SamPro-2, our Progeria gene therapy, moving steadily closer to human clinical trials.

And none of this happens without you. You are the driving force behind this phenomenal progress, and I cannot thank you enough for continuing to fuel our mission and move it forward.

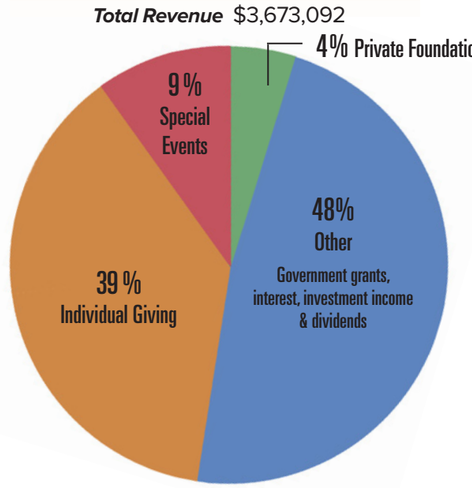
Please visit our new website, explore these stories in full, and celebrate the progress we have made, as we continue our journey together.

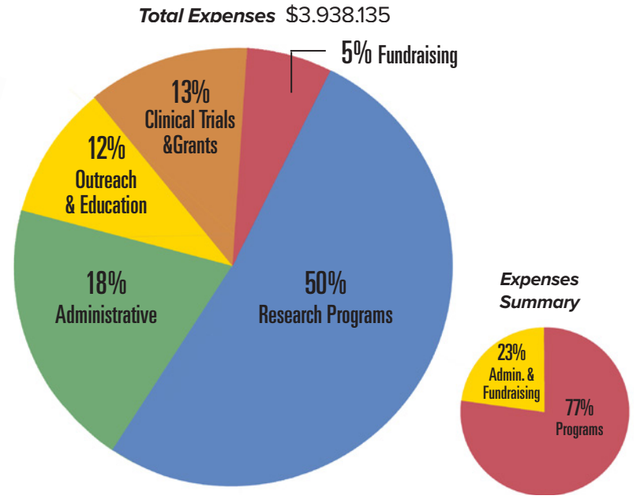
Because it is only Together, that we *WILL* find the cure!



Audrey Gordon, Esq.
President and Executive Director

PRF 2025 Annual Report





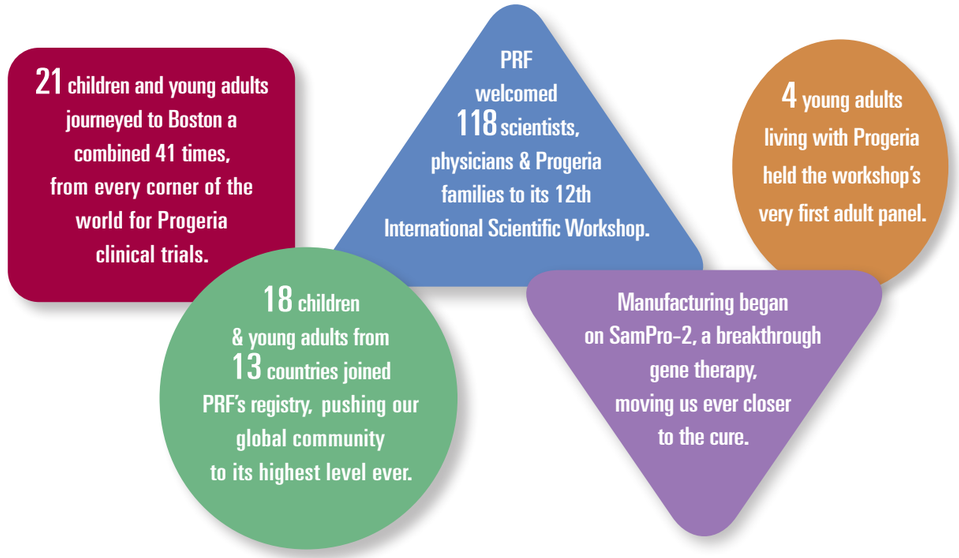
Net Assets : $49,452,201

Mainly attributable to proceeds from the 2021 sale of the Priority Review Voucher (PRV) issued after the historic FDA approval of lonafarnib as a treatment for Progeria. PRF's 10-year average net assets prior to this historic payment = 4.63 million.

Source: PRF 2025 Audited Financial Statements

Your generosity is working. In 2025, we took some of the most important steps yet toward the CURE!

Here are some 2025 highlights...



PRF's other programs include **Research Grant Funding**, **Medical & Research Database**, **International Scientific Workshops**, and **Public Awareness**. For more information on these programs, go to *progeriaresearch.org/prf-by-the-numbers/*.

Research Updates

Progerinin Phase 2A Clinical Trial Visits Complete!

Trial visits at Boston Children's Hospital for a clinical trial with a drug called Progerinin that assessed side effects and optimal drug dosing, are complete! Ten children and young adults with Progeria, from seven countries, were enrolled: eight received Progerinin with lonafarnib, while two took lonafarnib alone as a comparison.

Results are now being evaluated by Korean company and trial sponsor PRG Science & Technology. If Progerinin proves well-tolerated with early signs of benefit, a larger trial to test effectiveness will be considered. This builds on encouraging mouse-model data showing Progerinin extended lifespan in the mice by about 30%.



Bastian in Boston for his Progerinin trial visit.

Great Progress Being Made to Bring Groundbreaking Gene Therapy, SamPro-2, to Clinical Trials!



PRF Ambassador Carlos!

We're incredibly excited to share the tremendous progress we are making in our search for the cure: In every cell it reaches, SamPro-2, our gene therapy "base editor" is capable of permanently correcting the single DNA misspelling that causes Progeria is closer than ever to being administered in human clinical trials. PRF has partnered with gene therapy manufacturing leader Forge Biologics to produce a clinical-grade supply of SamPro-2 that meets rigorous US FDA standards. PRF and The Gene Team also met successfully with the FDA — with our own ambassador Carlos at the table! — to align on the experiments needed to create a path to clinical trials of SamPro-2 for children and young adults with Progeria. Finally, PRF continues to meet with our most important partners — patients and families — to inform them, answer questions and obtain patient perspectives. The Progeria community is extremely well-informed, and the feedback has been overwhelmingly in favor of PRFs plans to conduct clinical trials with SamPro-2!

The moment that decades of research has been building toward is approaching. Stay tuned for more details as they unfold – as a supporter who has helped make this extraordinary progress toward the cure possible, you'll be in the know!

Path to CURE PROGERIA

PRF and the Progeria Gene Team have been pouring their enthusiasm, energy and resources into activities needed for human trials to begin, including manufacturing of SamPro-2, FDA clearance, and clinical trial readiness.

REACHING FOR THE CURE:

Progeria Research Comes of Age at its International 2025 Scientific Conference

Two and a half days. Groundbreaking science. Powerful human connection. A community more determined than ever to find the cure. That's what unfolded at our **PRF 12th International Scientific Workshop**. The full meeting summary, written by PRF's Medical Director and the entire workshop scientific organizing committee, is now published in the peer-reviewed journal *Nature Aging*, free for everyone to read and share:



Eriksson, M., Andrés, V., Kieran, M.W. Gordon, L.B. Reaching for the cure as progeria research comes of age at the 12th international scientific workshop. *Nat Aging* 6, 1354–1357 (2026).



The workshop opened with a moment none of us will forget: an unprecedented patient panel made up entirely of young adults living with Progeria. **Merlin**, **Kaylee**, **Amber,** and **Michiel** spoke candidly about navigating life with Progeria from childhood into adulthood. The community also honored **Sammy Basso**, beloved researcher, advocate and patient, through a moving tribute film presented by his best friend **Riccardo**. The evening closed with a musical performance by **Dr. Francis Collins**, former NIH Director and 20+-year champion of Progeria research.

The workshop closed in a circle, literally, with a conversation about where the field goes next. From that conversation, **six strategic pillars** emerged to guide the development of novel therapies for Progeria:

1. **Advance promising therapies to the clinic – PRF is the collaborator, partner, and now the developer of new promising therapies on our path to the cure!**
2. **Decode disease mechanisms – understanding what drives disease and how to measure changes in those drivers will give us better ways to measure treatment effects.**
3. **Validate predictive models – build more cell, blood vessel and animal models that can predict what therapies might work in children with Progeria.**
4. **Optimize clinical trial design – create smarter trials that will tell us if a drug is working, more rapidly and safely.**
5. **Bridge to physiological aging – Progeria and generalized aging can each inform the other and lead to better treatments and the cure!**
6. **Sustain global collaboration – we must keep our global Progeria community working as one.**

Thank you to our workshop sponsors:

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SENTYNL THERAPEUTICS, INC.

ASOCIACIÓN PROGERIA Alexandra Peraldi

NIH National Institute on Aging

Read the full report in *Nature Aging*, and stay tuned for updates on these six pillars - our roadmap to the cure!



FUNdraising Events - Fun Times, Fabulous People!

The Okie Boys Jet Ski 1,300 Miles for Progeria Research



Derek age 8, sister Courtney age 9, and Zach age 3.

The Okie Boys, a group of friends from Oklahoma, rode jet skis 1,300 miles from Miami to Puerto Rico to help raise money and awareness for Progeria research. For organizer Derek Hallaway, this adventure carried deep personal meaning: his younger brother, Zachary, died of Progeria in 2006 at just three and a half years old.



The grueling journey was documented in videos that have racked up an estimated 25 million views, introducing Progeria to millions around the world.

We're so grateful to Derek and the Okie Boys for turning personal loss into public generosity and helping our community feel seen. Follow along on Instagram, Facebook, TikTok, and YouTube as Okie Boys Productions, or at ***okieboys.com***.

15th Annual Zach Attack Ride for Progeria Research & 1st Annual Memorial Ride Honoring Zach

On July 18, riders gathered at Man O' War Harley-Davidson in Lexington, Kentucky for the **15th Annual Zach Attack Ride for Progeria Research**, which also served as the **first memorial ride** honoring Zach, whom we sadly lost in 2024.



Zach Attack Ride 2023.

Zach was the heart and driving force behind this event. His strength, his infectious smile, and the mark he left on his community will never be forgotten. This year, they rode not only to raise awareness of Progeria, but also in tribute to a legacy that continues to move them forward.

To everyone who participated in the Ride, in past years and this July: Thank you all – for your enduring commitment to our mission and for your love for Zach and his family.

TEAM PRF Completes Boston Marathon AND Their Fundraising Goals!

On April 20, 2026, 10 runners laced up as **TEAM PRF** and took on one of the toughest challenges in sports: the iconic 26.2 miles of the **Boston Marathon**.

Months of relentless training led to this moment — and every runner crossed the finish line carrying more than just their own determination. They carried the names and stories of children and young adults living with Progeria, running not for medals, but for a cure. That purpose fueled every mile, and every dollar raised – for a total of over $150,000!

Now, the money they raised is carrying the mission forward — powering research that brings us closer, step by step, to a future without Progeria. Thank you, Team PRF, for running for those who can't.



Nazar Gulyk, Greg Waetzig, Francis Walsh, John Henry Slonieski, Joel Derechinsky, Bo Di Chen, Ivy Sparks, Ali Delarosa Not shown: Matt Hopkins, Bethany Hudson.

We Celebrated 25 Years: PRF's International Race for Research

Saturday, September 19, 2026

This fall marked a major milestone for The Progeria Research Foundation as we celebrated 25 years of this signature community event!

Twenty-five years ago, this was a small, local 5K run and 2-mile walk in Peabody. Today, it's an international event with hundreds of participants! We were joined in person at **Leather City Common in Peabody, MA,** and virtually from around the world!

Every step, every dollar, brought us closer to the cure. Thank you for celebrating 25 years of progress, community, and hope!

Gone from our sight, but never our memories ~
Gone from our touch, but never our hearts.

In Loving Memory...



Aluisio
17 years old
From Brazil



Megan
26 years old
From the USA



Michiel
27 years old
From Belgium



Maryana
3 years old
From Russia



Haram
8 years old
From Pakistan

Forever part of our community and our purpose,
their light will continue to shine
in our hearts and minds forever.

PROGERIA RESEARCH FOUNDATION

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Together, we *WILL* find the cure!®

Night of Wonder

November 14, 2026

Westin Boston Seaport District



The era of Progeria gene therapy has arrived, bringing us ever closer to a cure – so let's celebrate!

Come eat, drink, bid, dance, and enjoy this inspiring, lively, full-of-purpose PARTY!

Sponsor, ticket, and room information available at ***www.PRFnow.org***





Get Ready to Party on the PATH to CURE PROGERIA!

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youtube.com/user/progeria123