# QUICK FACTS as of June 30, 2026

## MISSION: To Discover Treatments and the Cure for Progeria and its Aging-Related Disorders, Including Heart Disease

### PRF BY THE NUMBERS:

- Identified children/young adults living with Progeria and Progeroid Laminopathies: 223* in 55 countries
- PRF-funded Progeria Clinical Drug Trials: 5
- Grants funded: 85, totaling $9.3 million
- Cell lines in the PRF Cell & Tissue Bank: 211
- Participants in PRF's Medical & Research Database: 225
- International Scientific Meetings on Progeria: 15
- Number of languages into which PRF's program and medical care materials are translated: 41

*163 of these children/young adults have Hutchinson-Gilford Progeria Syndrome (HGPS or Progeria) and the other 60 have Progeroid Laminopathies.

### Total Revenue

*1999 through June 30, 2026*: **$103,518,722**

On average, over 80% of PRF's annual expenses are consistently dedicated to its programs and services – one factor in our achieving a coveted 4-star rating from Charity Navigator every year since 2014.

The support we have received made the Progeria gene discovery, the Progeria clinical trials, the first-ever treatment for Progeria, and all our other extraordinary progress possible. With the help of current and new supporters, we *will* win this race against time and find treatments and the cure for these special children. Moreover, Progeria treatment discoveries may also help millions with heart disease and the entire aging population.

**What is Progeria?**

Progeria, also known as Hutchinson-Gilford Progeria Syndrome (HGPS), is a rare, fatal genetic condition of accelerated aging in children. Without treatment, children with Progeria die of the same heart disease that affects millions of normally aging adults (arteriosclerosis), but at an average age of just 14.5 years. Remarkably, their intellect is unaffected, and despite significant physical changes in their young bodies, these extraordinary children are intelligent, courageous, and full of life.

**About PRF**

The Progeria Research Foundation (PRF) is the driving force behind the global effort to understand, treat and ultimately cure Hutchinson-Gilford Progeria Syndrome (Progeria), a rare and fatal genetic disease that causes rapid aging in children. Founded by the family of Sam Berns after his diagnosis in 1999, PRF has enabled or led every major scientific breakthrough in the field, from discovery of the gene that causes the disease to the first FDA-approved treatment, lonafarnib, to the advancement of gene-editing approaches now in development. Through rigorous science, global research infrastructure and close partnership with the worldwide patient community, PRF is advancing next-generation therapies, expanding diagnosis and care, and leading the Path to Cure Progeria program to determine whether a one-time gene-editing therapy can offer a durable, potentially curative treatment.

**PRF'S PROGRAMS & SERVICES**

- **First-Ever Progeria Clinical Drug Trials and Treatment:** PRF-Sponsored Clinical Drug Trials bring children from around the world for promising treatments that may help to improve disease and extend the lives of children with Progeria. ***In 2020, history was made with the United States Food and Drug Administration (FDA) approval of lonafarnib (trade name Zokinvy™), a farnesyltransferase inhibitor, as the first-ever treatment for Progeria and Progeroid Laminopathies***. Lonafarnib has been shown to improve many aspects of the disease including the vital vascular system and a 30% average increase in lifespan with long-term treatment. ***PRF is now developing a gene editing drug designed to correct the mutation that causes Progeria***, and advancing this gene therapy toward clinical trials. ***These are remarkable steps forward in the pursuit of a cure.***
- **International Progeria Registry** maintains centralized information on children and families living with Progeria. This assures rapid distribution of any new information that may benefit the children.

**CONTACT US:** (978) 535-2594 * info@progeriaresearch.org * www.progeriaresearch.org (March 31, 2026)

- **Cell & Tissue Bank:** PRF's Bank provides researchers with genetic and biological material from Progeria patients and their families so research on Progeria and other aging-related diseases can be performed to bring us closer to the cure. PRF has collected an impressive 211 cell lines from affected children and their family members worldwide including 9 Induced Pluripotent Stem Cell(iPSC) lines.
- **Medical & Research Database:** The Database is a centralized collection of medical information from Progeria patients worldwide. The data is rigorously analyzed to help us understand more about Progeria and devise treatment recommendations. In 2010, this analysis contributed to PRF's comprehensive healthcare Handbook on Progeria aimed at optimizing quality of life. The 2019, 2nd Edition of the Handbook is available in Chinese, English, Italian, Japanese, Korean, Portuguese and Spanish.
- **Diagnostic Testing**: This program was developed in the wake of the 2003 gene discovery so that children, their families, and medical caretakers can get a definitive, scientific diagnosis. This can translate into earlier diagnosis, fewer misdiagnoses, and early medical intervention to ensure a better quality of life for the children.
- **Scientific Workshops on Progeria:** PRF has organized 15 conferences that have brought together scientists and clinicians from all over the world to share their expertise and cutting-edge scientific data. These workshops foster collaboration in the fight against this devastating disease.
- **Research Grants:** Through peer review by our volunteer Medical Research Committee, PRF has funded projects throughout the world that have led to important discoveries about Progeria, heart disease, and aging. This program was updated in December 2024 to reflect current research needs; There is now a proactive pathway, in which PRF identifies research needs and engages laboratories best suited to address them, and an investigator-driven pathway, in which PRF reviews investigator-initiated proposals.
- **Publications and Research:** Both clinical and basic scientists have utilized the PRF grants, cells and tissues, and database; their discoveries are published in top-notch scientific journals. The average annual number of scientific publications on Progeria since 2002 is more than 20 times that of the previous 50 years!
- **PRF Translation Program:** ***In touch with the world***. With a prominent global presence, PRF eliminates barriers to communication for patients and their families from around the world. This initiative has succeeded in translating PRF program and medical care materials into 38 languages.
- **Public Awareness: progeriaresearch.org** Our website provides access to the latest information on Progeria research and support for families. Through **Facebook**, **Instagram, YouTube, LinkedIn, TikTok** and other mediums, PRF's direct social media reach is over 1 million. PRF's story has appeared on CNN, ABC News, Primetime, Dateline, The Katie Couric Show, N P R, and The Today Show, in *Time and People* magazines, *The New York Times*, *The Wall Street Journal* and many other widely read, top-tier media outlets. In addition, the award-winning 2013 HBO film ***Life According to Sam*** has raised awareness in a unique and inspiring way. PRF also manages Find the Children, **a global awareness campaign** to find children with Progeria worldwide, so they can get the unique help they need.

**WHO'S WHO AT PRF?**

**Audrey Gordon, Esq., President and Executive Director**
Working closely with the Board of Directors, officers, staff, and volunteers, Ms. Gordon is responsible for day-to-day management and for ensuring The Progeria Research Foundation's financial growth and program development.

**Leslie B. Gordon, MD, PhD, Medical Director, Co-Founder**
Dr. Gordon co-founded PRF with friends and family after her son, Sam, was diagnosed with Progeria. Dr. Gordon oversees PRF's research-related programs and is a co-investigator for the Progeria clinical drug trials. She is a Professor of Pediatrics Research at the Warren Alpert Medical School of Brown University and Hasbro Children's Hospital in Providence, RI, and a Staff Scientist at Boston Children's Hospital and Harvard Medical School.

**Scott D. Berns, MD, MPH, FAAP, PRF Chairman of the Board, Co-Founder**
Dr. Berns, Sam's father, is a co-founder of The Progeria Research Foundation and serves as Chairman of the Board. He is a Board Certified Pediatrician and Clinical Professor of Pediatrics at the Alpert Medical School of Brown University. He recently retired as President and CEO of the National Institute for Children's Health Quality, an independent, nonprofit organization working to improve children's health.

**Carlos Luiz Silva, PRF's Youth Ambassador**
Carlos shares the unique perspective of his journey with Progeria through various media opportunities. Diagnosed with Progeria at age 4, Carlos is best known for being incredibly kind and smart and always putting a smile on people's faces with his warmth and humor. Today, he is in 9th grade at a charter school in Cambridge, Massachusetts, where his favorite subjects are Science and History. Carlos has always had a very bold and strong personality; He works hard at everything he sets his mind to!

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