QUICK FACTS as of July 1, 2017

MISSION: To Discover Treatments and the Cure for Hutchinson-Gilford Progeria Syndrome and its Aging-related Disorders, Including Heart Disease

PRF BY THE NUMBERS:

- Identified children living with Progeria: 145* in 46 countries
- PRF-sponsored Progeria Clinical Drug Trials: 5
- Grants funded: 68, totaling $7.3 million
- Cell lines in the PRF Cell & Tissue Bank: 205
- Children in PRF’s Medical & Research Database: 156
- International Scientific Meetings on Progeria: 11
- Number of languages into which PRF’s program and medical care materials are translated: 38

*Includes 33 children in the Progeroid Laminopathy category who have a mutation in the Lamin pathway, but do not produce progerin.

Total Dollars Raised

1999 through July 1, 2017: $25,286,239

More than 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 four years in a row.

The support we have received made the Progeria gene discovery, the Progeria clinical trials, the first-ever treatment for Progeria, and all of 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. 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 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) was established in 1999 by Drs. Leslie Gordon and Scott Berns, the parents of a child with Progeria, along with many dedicated friends and family who saw the need for a medical research resource for the doctors, patients, and families of those with Progeria. Since that time, PRF has been the driving force behind the Progeria gene discovery and the first-ever Progeria drug treatment. PRF has developed programs and services to aid those affected by Progeria and the scientists who conduct Progeria research. Today, PRF is the only non-profit organization solely dedicated to finding treatments and the cure for Progeria. PRF is hailed as a prime example of a successful translational research organization, moving from creation, to gene discovery, to first-ever drug treatment in just 13 years.

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 2012, history was made with the discovery that lonafarnib, a farnesyltransferase inhibitor or FTI, is the first-ever treatment for Progeria, improving many aspects of the disease including the vital vascular system. More recent studies conclude that lonafarnib extends estimated lifespan. In 2016, PRF initiated a two-drug trial, adding everolimus, with the hope that the two drugs together will be even more effective than lonafarnib alone. 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  (Updated April 19, 2017)
WHO’S WHO AT PRF?

Meryl Fink, Esq., President and Executive Director
Working closely with the Board of Directors, officers, staff, and volunteers, Ms. Fink 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-chair for the Progeria clinical drug trials. She is an Associate 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 is also President and CEO of the National Institute for Children’s Health Quality, an independent, nonprofit organization working to improve children’s health.

Audrey Gordon, Director of Donor Development, Co-Founder
Ms. Gordon is working closely with the Executive Director, Board of Directors, relevant Board committees, and PRF staff on setting and implementing PRF’s long-term fundraising plan to increase PRF’s visibility and generate a diversified, increased and sustainable income.

Meghan Waldron, PRF's Youth Ambassador
Meghan serves as a spokesperson for PRF, from the perspective of a youth with Progeria. Accomplished cellist and violinist, high school cross country and track team athlete, published poet – Meghan is a talented and busy 15-year-old living in Massachusetts.

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