

PRF is dedicated to finding the cure. The Progeria Research Foundation (PRF) was established in 1999 by the parents of Sam, a child with Progeria. PRF is the only non-profit organization solely dedicated to finding treatments and the cure for Progeria.

**So much progress.** In 2003, PRF's collaborative research team discovered the gene that causes Progeria. Since then, the support of researchers, doctors, families of children with Progeria and people like YOU have brought us to first-ever clinical drug trials and a treatment that gives children with Progeria stronger hearts and longer lives. PRF is hailed as a model for disease-research organizations and a prime example of successful translational research, moving from the lab to treatments at a pace virtually unheard of in the scientific community.

The cure for Progeria could help all of us. Studies confirm the link between Progeria, heart disease and the general aging process that affects us all. New treatments, further research and the cure may also answer questions about cardiovascular disease and the aging process.

Zach, USA

"The drug trials give us renewed hope that Zach's heart will be stronger, his smile will be brighter and his life will be longer. Thank you to everyone involved with PRF.. the doctors, the researchers and the staff. You are our heroes!"

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- Zach's parents, Tina and Brandon



Meghan, USA

Brennen, USA Lindsay, USA

Since PRF was formed in 1999, Progeria has rocketed from obscurity to clinical treatment trials and discovery of the first treatment. PRF is forging ahead at a phenomenal pace

towards new treatments and the cure for Progeria. We need your help NOW to reach

these goals and win the race against time for these extraordinary children.

### Together, we WILL find the cure!



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## What is Progeria?

Also known as Hutchinson-Gilford Progeria Syndrome (HGPS), Progeria is a rare, fatal, "rapid aging" disease. Children with Progeria die of heart attacks or strokes, usually in their early teens.

### PRF's Mission

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

# Progeria is taking the lives of children around the world

PRF has identified children in more than 50 countries living with Progeria. These children are born looking healthy, but within months they display early signs of the disease, including failure to grow, loss of body fat, hair loss and aged-looking skin. Within just a few years they also develop stiff joints, hip dislocations and heart disease. Eventually a heart attack or stroke will claim their lives. Children with Progeria live an average of 14 years.

PRF has identified half of the children with Progeria worldwide, and we are determined to find them all through our global awareness programs.

Centralizing the Needs... Pushing Forward...
PRF's Programs and Services

PRF-Sponsored Clinical Drug Trials bring children with Progeria from around the world for promising treatments that may help to improve disease, and extend their lives. In 2012, history was made with the discovery that lonafarnib is the first ever drug treatment for Progeria, strengthening the children's hearts and extending their lives. Today, PRF continues with new drug trials at Boston Children's Hospital in the US. Trial expenses for travel, lodging, testing and translation services are all paid for by PRF, so that the children and their families can participate free from financial concerns.

**PRF's International Progeria Registry** maintains centralized information on children and families living with Progeria in 55 countries. This assures rapid distribution of any new information that may benefit the children.

**PRF's Diagnostics Testing Program** offers genetic testing to confirm the diagnosis of Progeria; then PRF can offer intervention and recommendations.

**PRF's Medical & Research Database** analyzes medical records data to learn more about the natural history of Progeria, provide treatment recommendations and discover new research directions for Progeria, heart disease and aging.

**PRF's Cell & Tissue Bank** provides medical researchers with biological material such as cells and DNA, so that research on Progeria and other aging-related diseases will continue to advance.

**PRF Medical Research Grants** support scientists worldwide, creating valuable partnerships, allowing innovative research in Progeria to thrive, and opening new avenues for discovery in Progeria, heart disease and aging.

**PRF-Sponsored International Scientific Workshops** bring together scientists and clinicians to share expertise and cutting edge scientific data.

**PRF Translation Program:** PRF eliminates barriers to communication for patients, their families and doctors. PRF program and medical care materials are translated into 35 different languages.

**Public Awareness Efforts** tackle the challenge of educating the public about Progeria and its connection to aging through media, social networks and PRF's web site.



Carly, USA Jesper, Denmark Luke, Germany



With your help, PRF can continue its crucial programs to find the cure for Progeria, while helping discover more about the aging and heart disease that affects us all. To make a contribution and learn how you can help, e-mail us at *info@progeriaresearch.org* or call **978.535.2594** or visit www.progeriaresearch.org.

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