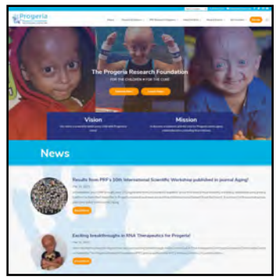
TIMELINE HIGHLIGHTS 1999-2021: OUR HISTORY, OUR FUTURE...

1999

March: The Progeria Research Foundation (PRF) is incorporated as a Massachusetts non-profit organization. On June 9, 1999, the Board of Directors holds its first meeting.

August: PRF awards its 1st research grant. To date, PRF has awarded 77 grants totaling over $8.4 million. The projects have allowed innovative research in Progeria to thrive.

November: PRF launches its website, a comprehensive resource of information on Progeria for researchers, families of children with Progeria and their physicians, and the general public. Together with social media sites (nearly 1 million Facebook followers!), millions around the world follow PRF's progress regularly.



1999

2000

January: PRF launches its International Patient Registry, maintaining centralized information on children and families living with Progeria. This program assures rapid distribution of new information that may benefit the children.

October 17, 2000: PRF is instrumental in securing Progeria-specific guidelines for the National Institutes of Health (NIH) in the 2000 Children's Health Act. As a result, NIH has regularly supported Progeria research efforts, including all PRF scientific workshops, a first-ever natural history study of children with Progeria, the Progeria Triple Drug Trial, and preclinical research.

2001

November: PRF holds its premier workshop in Bethesda, Maryland. PRF has organized 13 successful scientific conferences that have brought together scientists and clinicians from all over the world to share their expertise and cutting-edge scientific data, and foster collaboration in the fight against Progeria.

2002

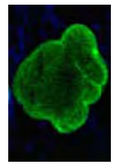
January: The PRF Genetics Consortium is formed with the goal of finding the gene for Progeria, which was accomplished ten months later!

March: PRF launches the Cell & Tissue Bank at Rhode Island Hospital, providing researchers the biological tools needed to advance Progeria research. The Bank contains thousands of samples and cell lines, distributed to hundreds of laboratories in over two dozen countries.

The PRF Medical & Research Database is created, to help learn more about the disease and provide treatment recommendations.

2003

May: PROGERIA GENE DISCOVERED!
Using cells from the PRF Cell & Tissue Bank, PRF Genetics Consortium members Drs. Maria Eriksson and Francis Collins lead the Progeria gene discovery, published in the journal Nature.



June: In the wake of the gene discovery, PRF launches its Progeria Diagnostics Program, enabling earlier diagnosis, fewer misdiagnoses and early medical intervention.

2004

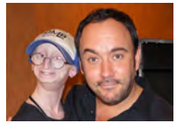
August: PRF awards its 10th research grant, funding the creation of a Progeria mouse. Animal models provide essential preclinical testing for new drugs.

2005

November: PRF's 1st chapter opens in California. Chapters, as well as thousands of other volunteers worldwide, help raise awareness and conduct local fundraising events in support of PRF's mission.

2006

June: PRF launches a public service announcement (PSA) campaign featuring voices of long-time PRF supporters Ted Danson and Mary Steenburgen. PRF has since created many PSAs with other celebrities, including Boston Bruins players and Dave Matthews.



February/July:
PRF-funded studies find that farnesyltransferase inhibitors (FTIs) are a potential treatment for Progeria, as they prevent some signs of disease in Progeria mice. These and other studies, along with data analyzed from PRF's Medical & Research Database, pave the way for a clinical drug trial using the FTI lonafarnib.

2007

April: Boston Children's Hospital (BCH) launches the first-ever Progeria Clinical Drug Trial, funded and co-coordinated by PRF, bringing hope of a possible treatment for children with Progeria.

2008

October: In a stunning display of progress with the FTI drug, and providing further confirmation of how Progeria research may help millions with heart disease, an NIH study finds that FTI's prevent the most devastating effect of Progeria in mice: cardiovascular disease.

2009

April: PRF's first annual 'ONEpossible' campaign successfully reaches our $100,000 goal. To date, ONEpossible supporters have raised $2 million towards making a cure POSSIBLE!

October: PRF partners with Spectrum and GLOBALHealthPR to launch "Find the Other 150", a global campaign to find all children with Progeria so they can get the support they need.

To date, along with other public awareness efforts, PRF has found hundreds of children with Progeria from more than 65 countries.

2010

April: PRF publishes the first Progeria Handbook: A Guide for Families & Health Care Providers of Children with Progeria.

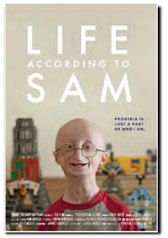
September: A landmark study led by PRF's medical director, in partnership with NIH, shows that the Progeria-causing protein progerin exists and increases in everyone as we age. The study confirms that by examining one of the rarest diseases, we gain crucial insight into the heart disease that affects millions, and the aging affecting us all.

2012

September:
FIRST-EVER TREATMENT FOR PROGERIA DISCOVERED!
PRF makes history, publishing trial results showing that every child experienced improvement in one or more areas, including the vital cardiovascular system. With a definitive finding that a drug (lonafarnib) altered the Progeria disease process, the quest for a cure is stronger than ever.

2013

January: HBO Film's *Life According to Sam (LATS)* debuts at the Sundance Film Festival. Featuring Sam Berns and his parents (PRF co-founders) Drs. Leslie Gordon and Scott Berns, this riveting documentary about love, life and hope for children with Progeria received an Emmy, Peabody and Christopher Awards, and ten festival awards.



December: Sam presented his wildly popular TEDx talk, "My Philosophy for a Happy Life." Both this and LATS have vastly raised awareness of Progeria and the importance of PRF's mission, resulting in an unprecedented surge in supporters, social media presence and general interest in these remarkable children. Today, Sam's talk is the second most viewed TEDx talk, with over 85 million views!

2014

July: While PRF continues to search for more effective drug candidates, the PRF-funded extension and expansion of the clinical trial gives every child with Progeria access to lonafarnib, the drug that could give them longer and healthier lives.

The drug trial expansion allowed Prachi, age 4, from India to receive lonafarnib.

2015

PRF continues its remarkable pace of progress, working on a multitude of research-related projects and achieving a record-high $1 million investment in research grants this year.

July: PRF and Merck make lonafarnib available to the research community through the PRF Cell & Tissue Bank, fostering more basic science studies to further investigate the effects of lonafarnib on Progeria.

2016

April: Children begin to enroll in a new, 2-drug trial with lonafarnib plus everolimus, with the hope that the two drugs together will be even more effective than lonafarnib alone.

NEW DRUG, AND NEW HOPE FOR CHILDREN WITH PROGERIA.

Zoey (left) and Carley enroll in the PRF-funded 2-drug trial at Boston Children's Hospital.

2017

Phase 1 of the 2-drug trial is completed, and Phase 2 begins. Phase I determined the best dose of everolimus to give the children. Phase 2 determines whether the combination therapy is effective. Children from 27 countries, speaking 20 languages, come to Boston to participate.

Mio, 13 years old traveled from Japan to Boston to participate in the 2-drug trial.

2018

April: In a spectacular development, a new study published in The Journal of the American Medical Association (JAMA) shows that lonafarnib extends lifespan in children with Progeria. This is the first evidence that lonafarnib improves the children's survival – a remarkable feat that demonstrates our work is resulting in longer, stronger lives for them.

May: On the heels of the JAMA study, PRF partners with Eiger BioPharmaceuticals to pursue U.S. Food and Drug Administration (FDA) approval of lonafarnib, marking the first Progeria therapy to be submitted to the FDA.

2019

December: PRF's biopharmaceutical partner, Eiger, submits a New Drug Application (NDA) to the FDA for lonafarnib, a major step toward approval as the first-ever treatment for Progeria.

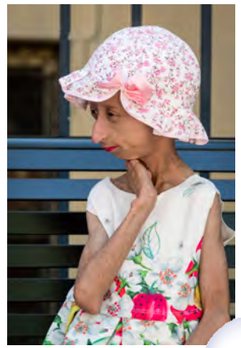
2020

November: PRF holds its 10th international scientific workshop, with over 370 registrants from 30 countries coming together on Zoom to share the latest findings in Progeria research and hear from some of the families being helped by their work.

FDA APPROVAL FOR LONAFARNIB
(now branded as 'Zokinvy') is granted! Progeria now joins fewer than 5% of rare diseases with an FDA-approved treatment.

2021

January and March: Breakthrough studies on Progeria mouse models, co-funded by PRF and co-authored by PRF's Medical Director Dr. Leslie Gordon, are published in the journal *Nature and Nature Medicine.* One study shows that genetic editing in mice can correct the mutation that causes Progeria, improves several key disease symptoms, and dramatically increases lifespan in the mice. The other studies used RNA therapies to reduce the toxic protein, progerin, and improved survival in the mice. Additional preclinical studies are needed to investigate these results, which we hope will one day lead to a clinical trial.



2021

We've come so far
In such a short time.
With your continued support,
Together, we *WILL* cure Progeria!

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

Progeria Research Foundation
FOR THE CHILDREN ♥ FOR THE CURE