

Timeline Highlights 1999-2011: Our History, Our Future...



1999... March 1999: 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 1999: PRF awards its first research grant. To date, PRF has awarded 34 grants totaling over \$2.3 million. These projects have allowed innovative research in Progeria to thrive, and has helped Progeria scientific publications increase by over 1,000% since PRF was founded.

November 1999: PRF launches its web site, a comprehensive resource of information on Progeria for researchers, families of children with Progeria and their physicians, and the general public. The site is now visited by an average of 15,000 people per month, from around the globe! www.progeriaresearch.org

...2000... May 2000: PRF's Medical Director, Dr. Leslie Gordon's research on Progeria is featured in Scientific American's "The Quest to Beat Aging."



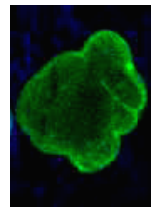
October 17, 2000: PRF is instrumental in securing language in the Children's Health Act 2000 that mandates activity by the National Institutes of Health (NIH) to report on its plan for supporting children with Progeria. As a direct result, PRF representatives meet with NIH officials, who commit to support Progeria research efforts spearheaded by PRF. Thereafter, NIH has co-funded every PRF scientific workshop, provided its first-ever funding for Progeria research, partnered on a first-ever natural history study of children with Progeria, and co-funded the Progeria Triple Drug Trial with PRF.

...2001... November 2001: PRF holds an historic, first-ever workshop in Bethesda, MD. PRF has organized six 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 2002: The PRF Genetics Consortium is formed. The goal of this group is to find the gene for Progeria, which was accomplished ten months later.

March 2002: PRF launches the Cell & Tissue Bank at Rhode Island Hospital and Rutgers University Cell & DNA Repository, so researchers have the biological tools needed to advance Progeria research. The Bank now holds over 160 lines, including cutting-edge Induced Pluripotent Stem Cells (iPSC's).

October 10, 2002: Using cells from the PRF Cell & Tissue Bank, PRF Genetics Consortium members Dr. Maria Eriksson and Dr. Francis Collins lead the Progeria gene discovery.



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

...2003... June 2003: In the wake of the gene discovery, the PRF Diagnostics program begins. With a definitive genetic test to diagnose children, earlier diagnosis, fewer misdiagnoses and early medical intervention ensure a better quality of life for the children.

...2004... August 2004: PRF awards its 10th research grant, funding the creation of a Progeria mouse.

...2005... November 2005: A record 96 scientists from 9 countries meet for PRF's fourth scientific workshop in Boston, MA.

...2006... June 2006: PRF launches a public service announcement (PSA) campaign featuring the recognizable voices of long-time PRF supporters Ted Danson and Mary Steenburgen. The PSA received endorsement by the Ad Council and aired on the Astrovision in NYC's Times Square in November 2006.

February/July 2006: PRF-funded studies find that FTIs – a potential new drug treatment for Progeria – 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.



...2007... **April 2007:** Children's Hospital Boston approves the first-ever Progeria Clinical Drug Trial, funded and co-coordinated by PRF. For the first time, we have a possible treatment for children with Progeria.



May-October 2007: 28 children with Progeria from 16 countries come to Boston to enroll in the Progeria FTI Clinical Trial. Over the next 2 years, these children come to Boston every 4 months for treatment and drug supply.

...2008... **August 2008:** PRF's 7th chapter opens in Kentucky. Chapters are helping raise awareness and funds through local events so that PRF's goal of developing treatments and the cure for Progeria will be achieved more rapidly, to win this race against time for all children with Progeria worldwide.

October 2008: 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 led by Dr. Francis Collins found that FTI's prevent the most devastating effect of Progeria in mice: cardiovascular disease.

...2009... **April 2009:** In a spectacular show of support for children with Progeria, supporters made PRF's first annual campaign, called the ONEpossible Campaign, a success, reaching our \$100,000. They are each ONE who will make a cure POSSIBLE!



August 2009: Clinical Trial #2 begins! On the heels of the first treatment trial, PRF and Children's Hospital Boston begin a 3-drug combination trial after researchers identify two additional drugs that, when used in combination with the current FTI drug being tested, may provide an even more effective treatment for children with Progeria than FTI's alone. This much larger "Triple Drug Trial" includes 45 children from 24 countries.

October 2009: 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. www.findtheother150.org.



... 2010... Media coverage reaches new heights with The Dr. Oz Show, Barbara Walters' 20/20, CNN, The Wall Street Journal and more.

January 2010: The Triple Trial is fully enrolled. It took less than 6 months to get all 45 children from 24 countries started, thanks to the remarkable teamwork of the families, their doctors, PRF and its trial partners.



April 2010: PRF's 10th anniversary workshop, *From Bench to Bedside in a Decade*, is held. With speakers including leading scientists in the fields of heart disease, aging, genetics, and lamins, it was clear that the depth and breadth of research into Progeria grows stronger with every meeting.

PRF publishes the first ever *Progeria Handbook: A Guide for Families & Health Care Providers of Children with Progeria*, offering extensive treatment guidelines to improve the children's quality of life.

September 2010: a landmark study led by PRF's medical director demonstrates the Progeria-causing protein *progerin* exists and increases in everyone as we age, suggesting a new risk factor for heart disease and confirming that by examining one of the rarest diseases, we gain crucial insight into the heart disease that affects millions, and the aging that affects us all.

April – December 2010: PRF unveils its new logo, web site and brochure, producing a fresh look and updates to its brand and informational material.



... 2011... **June 2011:** PRF-funded study identifies the drug rapamycin as a possible treatment for Progeria. Rapamycin has been shown to extend the lives of non-Progeria mouse models, providing another link between Progeria and the aging process that affects us all.

July 2011 – date: PRF plans for a new, 4-drug clinical trial with the three drugs currently being tested, plus everolimus, a form of rapamycin. This trial will include approximately 70 children from 30 countries.

October 2011: After 23 months of proactive outreach through the Find the Other 150 campaign, which has raised awareness of Progeria in new areas of the world, PRF sees an astonishing 53% increase in the number of known children living with Progeria.

**We have come so far in such a short time, well on our way to treatments and the cure.
With your continued support, Together, we WILL find the cure!**