

2011 ANNUAL REPORT

Together, we will find the cure!



This year's annual report reflects tremendous progress.

Due to the continuation and expansion of all of The Progeria Research Foundation's programs, our mission continues to progress at the phenomenal pace it has commanded for the past 12 years. In 2011, another potential drug treatment was identified, clinical trial activities continued for 42 children, 8 more children were identified, new evidence of Progeria-aging links were discovered, and the ever-growing interest in Progeria by researchers and the general public soared. As we have always done, PRF is seizing the opportunities these developments present, edging us ever-closer to our ultimate goal of a cure. From obscurity in 1999 to global prominence today, PRF is proud to detail another exciting year of advancements for Progeria and PRF. You make it all possible, and we are deeply grateful.

Together, we WILL find the cure!

Audrey S. Gordon, Esq. President, Executive Director

Leslie B. Gordon, MD, PhD Medical Director

Scott D. Berns, MD, MPH Chairman, Board of Directors



December 2011: PRF by the numbers

Known children living with Progeria: 86 in 29 countries

Increase in number of children identified since the October 2009 launch of PRF's proactive global campaign to find them:

Grants funded since PRF was established:

Cell lines in the PRF Cell & Tissue Bank:

Children part of PRF's Medical & Research Database: 110

PRF's International Scientific Workshops on Progeria:

PRF-sponsored Progeria Clinical Drug Trials: 3 and another planned for 2012

Number of languages into which PRF's program and medical care materials are translated:

Increase in scientific publications since the Progeria gene discovery:

1,500%

Progeria is a rare and fatal "rapid aging" disease that afflicts children, who die of heart disease at an average age of 13 years – the same heart disease that affects millions of normal aging adults.

The Progeria Research Foundation (PRF) was founded in 1999 to lead and help catalyze efforts to help children with Progeria. **Our mission:**To discover treatments and the cure for Progeria and its aging-related disorders.



Five children and their families gather for the PRF Ohio chapter's annual road race, "Kaylee's Course", in September 2011. front row: Kaylee (age 8), Carly (15 months) and Lindsay (age 7); back row: Zach (age 4) and Cam (age 5)

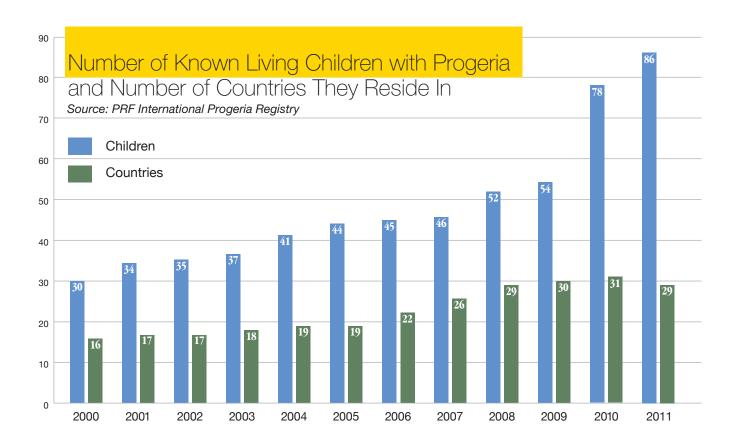
PRF's Programs and Services 2011

PRF's accomplishments in 2011 are highlighted in blue.

PRF has been the driving force behind the unprecedented pace of Progeria's bench-to-bedside success. All of this progress is due in large part to the creation of PRF's research-related programs and services enabling Progeria to travel from obscurity, to PRF's creation in 1999, to gene discovery in 2003, to the first-ever treatment trial in 2007, and ongoing treatment trials in 2011.

PRF operates an international patient registry, cell and tissue bank, diagnostics testing program, and medical and research database; organizes scientific workshops; funds and co-coordinates clinical trials; and manages the translation of important informational materials into 20 languages. All of these programs work cohesively together to provide the core structure essential not only to drive the field of Progeria forward, but also to discover what Progeria can tell us about heart disease and aging¹. All programs are thriving and expand annually with increasing numbers of children identified and researchers involved. Programs are affiliated with and approved by Brown University and Hasbro Children's Hospital Institutional Review Boards in Providence, Rhode Island.

¹ Research has shown that the toxic, Progeria-causing protein known as progerin is not only produced in children with Progeria, but it is also produced in smaller amounts in all of us, and progerin levels increase with aging.



The PRF International Progeria Registry

The Registry securely maintains centralized medical and contact information on children and families living with Progeria. This ensures rapid distribution to families and their physicians of any new information that may benefit the children. Because of the ever-increasing worldwide awareness resulting from successful PRF outreach, more children with Progeria are being found from more areas of the world, and undergoing genetic diagnostic testing at earlier ages.

In 2011, we experienced a 10% increase in the number of children registered, with a record 86 children living with Progeria now identified. The chart (below left) illustrates that the number of children has nearly tripled, and the number of countries nearly doubled, since PRF's inception.

Progeria Clinical Drug Trials: Forging Ahead Toward Treatments

Starting with the first-ever Progeria clinical trial in 2007, PRF has been bringing children with Progeria to Boston from all over the world since 2007. These trials have given the families hope – where none had existed before—that these drugs will give their children longer and healthier lives as the first-ever treatments for this devastating disease.

The trials also provide an opportunity to gather baseline data, information that is vital to understanding – and in some cases redefining – the natural history and pathobiology of disease in Progeria. A 2011 seminal paper² established brand new bone outcome measurements of disease improvement, which were discovered in the course of the Progeria clinical drug trials.

In 2007, with our then new partners at Harvard hospitals in Boston (Children's Hospital Boston, Dana-Farber Cancer Institute and Brigham and Women's Hospital), PRF made history when it launched the first Progeria clinical trial with farnesyltransferase inhibitors (FTIs), the first possible drug treatment for children with Progeria. Publication of the results is expected in 2012. If the study proves the effectiveness of the FTI drug, this will be one of the most singularly significant steps toward our mission to find treatments and a cure.



The doctor of Nihal, this 11-year-old boy from India, registered his patient with PRF in October 2011. We are now assisting the family with treatment guidelines and program participation so Nihal can qualify for future clinical trials.

Because of Progeria's connection to general heart disease and aging, what we learn from Progeria research has the potential to benefit all of us.

² Gordon CM, et. al., Hutchinson-Gilford Progeria is a skeletal dysplasia. J Bone Miner Res. Jul;26(7):1670-1679. (2011)



Clue to kids' early aging disease found

By Madison Park, CNN

uly 1, 2011 12:08 p.m. EDT



(CNN) -- Her name was Meg, 23, featherweight and feisty

ding 3 feet tall, Mog didn't look like her peers. Bald and skinny, her body was aging rapidly because she had a rare gen see called Hutchinson-Gifford progeria syndrome. People with properia wrinkle and develop the same circulation and cats as the elderly — except most of them die by age 13. Progeria affects 200,250 children worldwide, but research into see could offer clues on cellular function and how it affects human aging and other age-related diseases.

This week, a study about a possible treatment was published in Science Translational Medicine. Dr. Francis Collins, director of the National Institutes of Health, is one of the authors. About 30 years ago, Collins, then a young Yale University observe, met Meg. He realized there was link the could do for this patient, but the consider look may, "Is was compelling to any to understand why do something to understand the situation," Collins offered his concern and compassion, but there was no treatment for her disease.

Despite her grave prospects and appearance, Meg did not shy away from the public eye. Instead, she becume an outspoken advocate for disabled people in bdifford, Connecticut.

Lang before it became condensary to do so, "She got that fown to become friendly to the disabled," Collins said, "She made it happen." Just because she was diministric; it dight mean people could step all over her, memory.

The description of the property of the property

Collins' role as a geneticist is to decode the most complex puzzles of human life. He is best known as a leader of the Human Genome Project that mapped and sequenced the human DNA. The mystery of progeria remained one of his interests. Collins seven others are authors of a study that found an immune suppressing drug, called rapamycin, could possibly treat progeria.

There have been no approved drugs or treatment to slow the course of the disease. Children with this rare genetic condition less ship begins to wrinkle and sag. Most of them die of ago-related causes, like heart disease, heart attack or stroke, before they start attack or stroke, before they start

In 2009, concurrent with the first trial, PRF took action in response to the identification of two additional drugs that, when used in combination with FTI's, may provide an even more effective treatment than the single FTI drug. PRF initiated a phase 1 trial to test safety of the drug combination, followed by a phase 2 Triple Drug Trial, with participants and their families traveling to Boston every six months for medications and study testing. In 2011, 41 trips were successfully completed.

PRF is already planning future trials as research uncovers more drug candidates. In 2011, researchers identified a new drug called rapamycin that not only extends the lifespan of normal aging mice, but also shows pre-clinical improvement for Progeria³. This drug has been

shown to target the toxic, Progeria-causing progerin in a completely different way than the three other drugs currently being tested. Building upon the success of the first clinical treatment trials for children with Progeria, PRF will fund investigators at Children's Hospital Boston to conduct a fourth clinical treatment trial that will add a rapamycin-like drug to the current three-drug regimen. We hope to include more and more children in future clinical trials as we find them throughout the world.

We are thrilled to offer multiple potential treatment options where just five years earlier none existed. We hope these promising trials help to improve disease, and possibly even extend the lives of children with Progeria. Moreover, new discoveries like those that will come from these trials will help us to understand Progeria's relationship to aging.

³ Cao et. al., Rapamycin Reverses Cellular Phenotypes and Enhances Mutant Protein Clearance in Hutchinson-Gilford Progeria Cells, Science Translational Medicine 29June2011 Vol3 Issue89

CNN article about the rapamycin studyone of dozens of media outlets around the world that reported on this new potential treatment for Progeria.

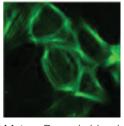
The PRF Diagnostics Testing Program

Immediately following the gene discovery in 2003, the first genetic test for Progeria was created. Used in conjunction with clinical information, the test provides a definitive, scientific diagnosis. Earlier diagnosis, fewer misdiagnoses and earlier medical interventions make it possible to provide a better quality of care for these children and access to PRF resources. Since the gene discovery, 99 children have been tested.

In 2011, children from Brazil, Colombia, the Dominican Republic, India, Mexico and the United States were diagnosed with Progeria through this program.

The PRF Cell & Tissue Bank

This essential resource provides precious biological materials to scientists throughout the world who are exploring the biology behind Progeria, conducting the science that will bring us to treatments and cure, and discovering the biological links between Progeria and aging. In collaboration with Hasbro Children's Hospital and Brown University in Rhode Island, and Rutgers University Cell & DNA Repository in New Jersey, PRF established The PRF Cell & Tissue Bank in 2002.



Mature Progeria blood vessel cells, created from an iPSC line.
By using the Bank's iPSCs, scientists have a new tool for making novel discoveries in Progeria and aging.

PRF now has an impressive 161 cell lines and various tissue samples from individuals with Progeria and their family members. The cell lines include 95 lines from affected children worldwide (with ages ranging from 8 months to 17 years), 62 lines from their immediate relatives, and in December 2011 the bank was expanded to include four induced pluripotent stem cell (iPSC) lines⁴.

⁴ Using a cutting-edge new research technology, Induced Pluripotent Stem Cells were created from mature Progeria patient cells, such as skin cells or blood cells, which we already had in the PRF cell bank. The mature skin or blood cells were reversed in the laboratory to become Progeria stem cells. From this point, scientists can choose to explore stem cells in Progeria, or they can use these iPSC to create cells that are important for understanding heart disease in Progeria such as cells of the blood vessel wall, which are difficult to obtain by any other means.



Carly was diagnosed with Progeria in April 2011 at 10 months old, the age at which she is pictured here. Identification at such a young age was virtually unheard of 10 years ago, but thanks to our successful awareness efforts, children are now frequently diagnosed before they reach 1 or 2 years of age.

"Thanks for all your help and caring. We know our little Carly-Q is in good hands with PRF."

- Heather and Ryan, Carly's parents From its inception through the end of 2011, the Cell Bank has distributed 281 cell lines and DNA samples, plus many pathology specimens, to 43 teams of researchers at 38 institutions in 16 states and eight other countries: Germany, Sweden, Israel, Italy, Canada, Austria, China and England.

In December 2011, PRF expanded its supply of available cell lines to include 11 atypical Progeria lines, and 14 control lines from their parents. The complete list is available on PRF's website, along with a list of citations and links to all publications that include the use of PRF cell lines and tissues in the invaluable research that pushes this field toward treatments and cure. This can be found at: *Home » Medical Research » Cell & Tissue Bank » Available Cell Lines*

The PRF Medical & Research Database

This program entails collection and analysis of clinical data, medical records and radiology scans such as X-rays and MRIs, from individuals with Progeria worldwide. The data are rigorously analyzed (and translated, if necessary) to understand clinical disease in Progeria, and inform general treatment guidelines to help optimize children's quality of life. Importantly, the program also includes a "weighing-in" component where children are weighed routinely at home and report weights to program staff. These weights are used to prepare data for clinical trials. This essential resource was developed in 2002, in collaboration with the Brown University Center for Gerontology and Healthcare Research.

Our published and ongoing studies on the natural history of Progeria have allowed us to define and understand the disease, and will also help us to determine new measures of treatment success for future clinical trials. By understanding how Progeria progresses, we can measure whether or not drugs are working.

In 2011, PRF's web site was updated with a complete list of publications stemming from the Medical & Research Database at *Home* » *Medical Research* » *Medical Database*. These scientific studies and textbook chapters are helping to advance our understanding of Progeria, and how to best treat the children.

Progeria Health Care Handbook Expansion

In April 2010, PRF published The Progeria Handbook, a portable book that provides families, researchers, and caregivers such as physicians and teachers easy access to information ranging from basic health facts and daily care recommendations to detailed medical treatment guidelines. Information



"Very happy for the Spanish manual that you sent me. Thank you, I was feeling alone in the world but now I feel better and I know there are people that care about us, hugs."

(Translated from Spanish)

- Sent to PRF in July 2011 from the mother of a ten-yearold child with Progeria who lives in the Dominican Republic gathered from the Medical & Research Database was vital to this handbook, as was the clinical expertise of Progeria experts from Children's Hospital Boston and other institutions.

Through 2011, this Handbook has been distributed to nearly 280 families, physicians, teachers and other caretakers. In July 2011, we completed the translation of the handbook into Spanish, and distributed 30 books to families and others in Argentina, Brazil, Chile, Columbia, Dominican Republic, Mexico, Peru, Spain, the United States and Venezuela. In addition, we began translating the handbook into Portuguese, and going forward we will translate into other languages as the global presence of PRF expands.

Research Grants

Basic laboratory science using cells grown in a dish and animal models of disease give us critical information about how the body works. PRF supports scientists in their quest to understand Progeria by funding research and supplying essential research materials to aid in new discoveries about Progeria. Thanks to these research studies, we now know more about Progeria and its biological link to heart disease and aging than ever before.

To date, PRF has invested nearly \$3.1 million to fund 39 basic science grants for Progeria-related research performed in 14 states and 7 other countries.

Five new research grants were awarded in 2011, with a record-breaking 13 active projects taking place throughout the year. We welcome our new research collaborators at Cornell University, University of Colorado, Medical University of Vienna, Institute of Medical Biology – Singapore and Karolinska Institute – Sweden.

One way that PRF measures its success towards supporting basic "preclinical" progress is by looking at the productivity of our funded scientists. More than 60% of new articles are published by scientists who have been funded by PRF. Our grantees are changing the landscape of Progeria research and giving the world ever-increasing hope for treatments and cure.

Expanding PRF's Grant Program

To further propel research progress in Progeria, PRF's Medical Research Committee (MRC) created an entirely new grant system during a full-day MRC Summit Meeting. In September 2011 PRF increased and expanded grant funding, with a goal of doubling the investment in grants by 2014. PRF's Grant Program has seen tremendous success. This science has yielded major advances that have propelled Progeria from a disease about which virtually nothing was known at the cellular and molecular levels, to one that was understood well enough to begin clinical drug trials. Our new grant structure fosters both new and established investigators who will lead the charge for Progeria's future scientific discovery.

Beginning with applications for the December 2011 review, proposals are being accepted in three categories of differing type, funding levels and length of time:

Innovator Awards: 2-year awards of up to \$75,000 per year. The aim of the Innovator Award is to allow an investigator to embark on new lines of investigation, and to produce enough preliminary data to be competitive for longer-term funding by NIH and/or other agencies.

Established Investigator Awards: up to 3 years and up to \$100,000 per year. For senior investigators established either in Progeria or a field that can be directly applied to it.

Specialty Awards: Funding amounts and lengths are flexible. For smaller, more technology-driven projects such as sequencing, screening potential drugs, and preparation of antibodies.

Scientific Progress through Publications

Progeria studies that both advance the field and demonstrate Progeria's connection to aging are at an all-time high. This graph shows that such findings have spurred broad international interest in Progeria research. From 2010 to 2011 alone, the number of peer-reviewed scientific publications increased from 36 to 63. They include a National Institutes of Health study that discovered a previously unknown link between the toxic, Progeria-causing progerin and telomeres, which protect the ends of DNA within cells until they shorten over time and the cells die⁵. The study concludes that in normal aging, short or dysfunctional telomeres stimulate cells to produce progerin, thus these two processes, both of which influence cellular aging, are actually linked.

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PRF's critical impact on Progeria-related research is evident.

In 52 years, from 1950-2002, there were just 104 peer review publications on Progeria, averaging two per year. In the 7 years from 2003-2010, 272 articles were published – an average of 30 per year – with a record high of 63 in 2011. This represents an extraordinary average annual increase of over 1,500% since 2003, the year PRF co-discovered the Progeria gene.

⁵ Cao et. al., Progerin and telomere dysfunction collaborate to trigger cellular senescence in normal human fibroblasts, J Clin Invest 2011 Jul 1; 121(7): 2833-44

"Connecting this rare disease and normal aging is bearing fruit in an important way... valuable biological insights are gained by studying rare disorders such as Progeria. Our sense from the start was that Progeria had a lot to teach us about the normal aging process."

- Dr. Francis Collins
Director of the National Institutes of
Health, on a groundbreaking telomere
study linking Progeria to normal aging.



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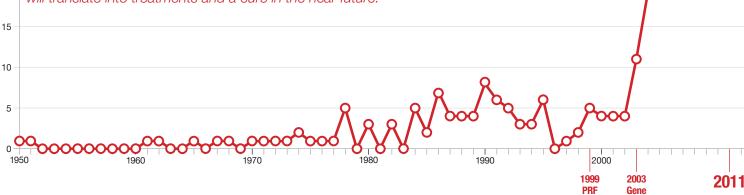
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There is likely no other disease field in the history of science that has been able to generate this kind of interest and progress so rapidly, and we are optimistic that these stunning statistics will translate into treatments and a cure in the near future.



Many of these studies were conducted using PRF grant funding, Cell & Tissue Bank materials and Medical & Research Database data, and are published in well-known, respected scientific journals and medical textbooks read by researchers and doctors worldwide.

Workshops on Progeria

Since 2001, PRF has conducted 6 successful scientific conferences, all with support from the National Institutes of Health and The Ellison Medical Foundation.

The depth and breadth of research into Progeria grows stronger with every meeting, as the number of participants and countries from which they originate increases each time. PRF is committed to this process of global medical collaboration, as further evidenced by the 2011 planning of a "New Frontiers in Progeria Research" workshop for January 2012. This is a small, targeted, invitation-only meeting that will convene high-level researchers who have not previously been involved in PRF-funded research, but whose expertise may be able to fill essential "holes" in the field and stimulate new ideas. We are excited to take PRF's scientific meetings to a new level, expanding and invigorating

to take PRF's scientific meetings to a new level, expanding and invigorating the field of Progeria research by enlisting top researchers in fields of study such as cardiology and genetic therapy that can be applied in new, crucial ways to Progeria.

The PRF Translation Program: In touch with the world

With a prominent global outreach, PRF eliminates barriers to communication for patients and their families around the world. The potential isolation and anxiety a non-English-speaking family could feel after their child is diagnosed is greatly softened by our ability to effectively communicate with them. This initiative has succeeded in translating PRF program and medical care materials into 20

different languages.

In 2011, there were 40 active volunteer translators working with PRF to help families coming to Boston for the clinical trials, as well as translating over 300 emails and 13 important informational materials such as facts about Progeria, program consent forms and the 100-page Treatment Guidelines Handbook.



ⁱⁿ Progeria Research

Public Awareness

Before PRF was formed, virtually no one knew what Progeria was.

Information about this ultra rare disease and our far-reaching

message – that finding a cure may also help those with heart disease
and other aging-related conditions – has now reached millions
through PRF's website, newsletters, educational materials, and social
and traditional media. In 2011, print, internet and broadcast media
coverage of Progeria and PRF reached over 206 million people
through nearly 400 pieces that aired worldwide, including every
major US TV and cable news network and major outlets in 9 other
countries. PRF's website enjoyed over 235,000 visits alone – a 26%
increase from 2010.

The public's fascination with Progeria and its possibilities of unlocking clues to aging is vital to every aspect of PRF's work, spurring more children coming to PRF for diagnosis and care; more researchers applying for grants and cells to support their work; more scientists participating in PRF's workshops; more resources developing to support this growth; and more individuals and organizations offering their support.

We are Finding More Children Than Ever Before

An impressive number of children are being identified, diagnosed and connected to PRF's resources, thanks to the success of outreach efforts like PRF's *FindTheOther150* campaign, whose goal is to search globally for the 150 undiagnosed children with Progeria so they can receive the unique care they need and help advance clinical science for Progeria. Partnering with GlobalHealthPR, the largest worldwide health communications group, PRF launched this international awareness campaign in October 2009.

Throughout 2011, *FindTheOther150* continued to drive the search for previously unidentified children with Progeria worldwide, resulting in a jump from 78 to 86 children – a 10% increase and 3 times the average annual number of children that came to us before the campaign began. Overall, the 2 ½-year old campaign has helped PRF significantly increase the number of known children, from 54 at the end of 2009 to 86 as of 12/31/11, a 60% increase. The children span five continents, and range in age from 5 months to 21 years. Stretching across language and geographic barriers, the campaign's results to date are a true testament to the power of global collaboration.



CBS Evening News was among the many media outlets to report on the telomere study in June 2011.



In an exciting expansion of FindTheOther150, players from the Boston Bruins hockey team recorded public service announcements (PSAs) in 2011 in both English and the players' native languages. The PSAs are being aired in Canada, the Czech Republic, Finland, Serbia, Slovakia, and U.S. outlets with ties to those countries. Partnering with the players gives PRF the unique opportunity to raise awareness about Progeria in new areas, and find more children. Pictured here are Bruins player Milan Lucic and Sam recording PSAs now airing in Slovakia and Canada.

Support for PRF through social media outlets such as Facebook and Twitter exploded in 2011. As part of our communications plan, we engaged our volunteers and supporters through a directed social media campaign. The results were remarkable – a 400% increase in Facebook "Likes" and a 450% increase in Twitter followers. Such advances will help in our continuing efforts to communicate globally with the widest audience possible.

Volunteers

PRF has an enthusiastic and growing volunteer community. PRF's Board of Directors, committee members, corporate officers, lawyers, accountants, graphic designers and public relations representatives all devote their time, energy and talents to PRF at no cost, to ensure less is spent on administrative costs and more on raising awareness, research, and finding a cure for Progeria. Our volunteers, young and old, host events, collect change in our Coins to Cure Progeria® cans, and help spread awareness in their communities.

In 2011, PRF's seven dedicated chapters and other volunteers saw significant increases in fundraising revenue, with a total of over \$1.2 million raised by special events – a 45% increase from 2010!

PRF volunteers helped make our 3rd Annual ONEpossible™
Campaign a tremendous success. In just 6 weeks our teams,
consisting of 32 people from 11 states, raised over \$178,000, with
the highest increase in donations (up from 2010) in the \$100-\$249
and \$500-\$999 ranges. The 2011 campaign also had the highest
number of donors to date (907), and more than half of these
contributors were new. Our growing community of volunteers and
supporters demonstrate once again that they are each ONE who will
make a cure POSSIBLE.



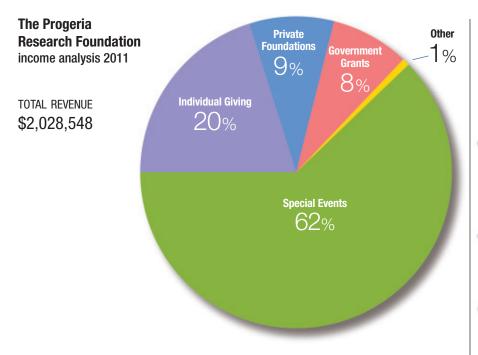
"I am still overwhelmed by the incredible amount of generosity and support we received, not only yesterday, but over the past three months. I am truly in awe of the selfless donation of time and money children with Progeria have inspired in others. Saturday was a great reminder that we have so much to be grateful for in this life."

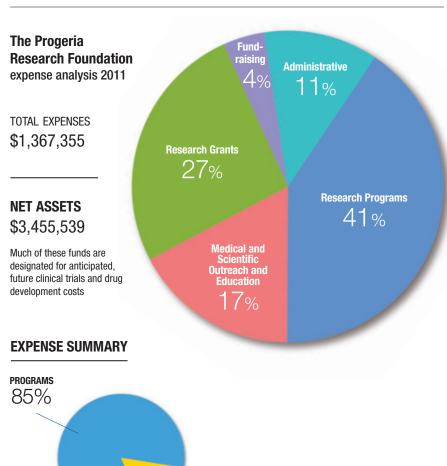
- 2011 first-time volunteer, the day after a New Jersey road race she organized, which raised over \$37,000



A team of nearly 40 volunteers worked tirelessly on the Night of Wonder gala, PRF's major fundraiser held every two years, raising nearly \$250.000 in November 2011.

Above, Sam and NIH Director Francis Collins celebrate the night's success and Dr. Collins' Science & Medicine (SAM) Award for his contributions towards finding the cause, treatment and cure for children with Progeria.

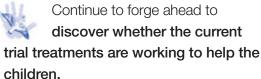




ADMINISTRATIVE AND FUNDRAISING 15%

PRF in 2012 and Beyond

In the years to come, we intend to live up to our reputation of rapid and impactful accomplishments, including the following:



Work towards **new treatments**and treatment trials for children
with Progeria.

Continue our efforts to promote drug discovery and partner with drug companies, to develop potential treatments and the cure for Progeria.

Continue to expand the *Find the Other 150* Campaign globally, to increase awareness of Progeria so more children will be found and helped by PRF.

Increase the number of participants in the International Registry, Cell & Tissue Bank and Medical & Research Database projects, so that scientists can continue to use them as research tools to understand Progeria, heart disease and aging.

Fund additional research proposals that focus on studying the Progeria gene and how this defect can be corrected.

Continue to **engage** and **motivate** our enthusiastic **volunteer community** to further increase revenue and expand our programs

"I have long wanted to communicate with the foundation, and thank God that he has given me the opportunity to say thanks to you. I have hope for my son, born with Progeria syndrome and am interested in knowing more about the treatment and foundation to see if I can help give my son a better quality of life. Thank you very much for your attention...

God bless."

- Sent to PRF in early 2011 from the mother of a 9-year-old boy from Columbia whose hand is pictured here.



2011

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With the support of dedicated staff and volunteers, a talented board of directors, courageous families, and thousands of generous people around the world, we are pushing the field of Progeria forward towards

discovery, treatments and cure.



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