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## Workshop Success! Ten Years and Going Strong

*Hayley Okines answers a question about school during the family panel presentation, as mom Kerry looks on.*

In April 2010, The Progeria Research Foundation held its tenth anniversary scientific workshop, "From Bench to Bedside in a Decade." A record 140 participants from ten countries gathered in Boston to share their progress in Progeria research, making this our largest and most diverse workshop yet. Highlights included a Progeria family panel led by Pulitzer Prize-winning journalist Amy Dockser Marcus, an inspiring plenary address from PRF Medical Director Dr. Leslie Gordon, and tremendous excitement about the breadth and depth of knowledge we now have for Progeria and its window into aging. **Read more on pages 6-7.**



## PRF's Mission:

To discover the cure and effective treatments for Progeria and its aging-related disorders.

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**Progeria is a fatal, "premature 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.**

**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.**

## Message from the President & Executive Director

Hello everyone,

I wish each of you could have been there to experience the 2010 workshop. From the first night's family panel to the last day's wrap-up, the excitement was palpable. I found myself reflecting on past workshops, excited about the progress we've made. I have no doubt that this latest conference will help push Progeria research as far and as fast as we had imagined - but hardly dared to hope for — 11 short years ago.

### So much news to share with you!

- Thanks to our increased global awareness efforts, we're finding more children.
- Progeria is getting lots of exposure through television and other media.
- PRF spokespeople are sought after to speak at conferences around the U.S.
- Fundraisers abound.
- We are now reporting on multiple Progeria clinical drug trials

Lots of new people have joined in our efforts, too: Staff member Donna Bertko has taken the place of Kyra Johnson, who is pursuing her masters in teaching but vowed to stay involved; Stephanie Dutchen is our new newsletter editor and doing a terrific job; little Zach, sister Brittany, mom Tina, and dad Brandon are working diligently as our new Ambassador Family; Dozens of others — Miracle Makers, families of newly diagnosed children, researchers, donors, Twitterers, Facebook fans — are becoming part of the PRF team each year, doing their part to advance our mission. WELCOME!

With spring comes warm weather, warm greetings and heartfelt appreciation for your unwavering support from all of us at The Progeria Research Foundation.

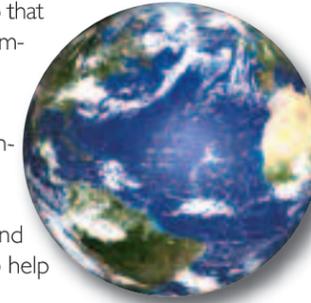
Audrey Gordon  
President & Executive Director

## PRF ON THE MOVE!

### Full Steam Ahead to "Find the Other 150"!

With a frequency of 1 in 4-8 million, there are an estimated **200 children** around the world who have Progeria. When our new "Find the Other 150" campaign began in October 2009, we only knew of 54 children. Since then, we've added an astonishing **9 more** to that total, largely due to our global awareness campaign efforts.

This global campaign seeks to find every child with Progeria worldwide, and help ensure they get the care and support they need. PRF has set up a special web site with Progeria fact sheets, photo galleries and a collection of podcasts in six languages to help put a face on Progeria.



We are thrilled that in just six months, we've seen an unprecedented jump from 54 to **63 children**. The most recent nine live in Brazil, India, Turkey, Pakistan, the Philippines, South Africa and the United States.

Working diligently with our friends at **Spectrum** and **GlobalHealthPR** to get the word out, we will find the other 150! Learn more about the campaign and how you can help at [www.findtheother150.org](http://www.findtheother150.org)

### Over 2,800 Join the Cause on Facebook

PRF's official Facebook page surpassed 2,800 members in April! Thanks to all of our followers for spreading the word and encouraging others to join.

Check us out at: [apps.facebook.com/causes/183613?m=92eea645&recruiter\\_id=39018947](https://apps.facebook.com/causes/183613?m=92eea645&recruiter_id=39018947)

### PRF Logo & Web Site Get a Facelift

April showers brought May flowers—and a new look for the PRF web site. Visit [www.progeriaresearch.org](http://www.progeriaresearch.org) to see the sleek redesign and explore new features, including a rotating photo spotlight, video page and drop down menus so visitors can easily find everything they want to know about Progeria and PRF.

Our logo enjoyed a touch-up, too, with a new layout and updated bird and hand of Sam Berns, a child with Progeria.



The Pickards participated in the 2010 workshop as one of their 1st Ambassador activities.

### Introducing PRF's New Ambassador Family

Tina, Brandon, Brittany and 3-year-old Zach Pickard were named PRF's Ambassador Family in January 2010. The Pickards live in Lexington, Kentucky, and are an integral part of PRF's efforts to raise public awareness, involve other families in our programs, and raise funds for research. We appreciate the time and effort they put into these important activities, along with all the other families that help in these vital ways.

Go to [www.progeriaresearch.org/spokespeople](http://www.progeriaresearch.org/spokespeople) to learn all about the Pickards!

And a huge THANKYOU to the Nighbors — Steve, Sandy, Josh, Michaela and Megan — for serving as our Ambassador family from 2005 through 2009.

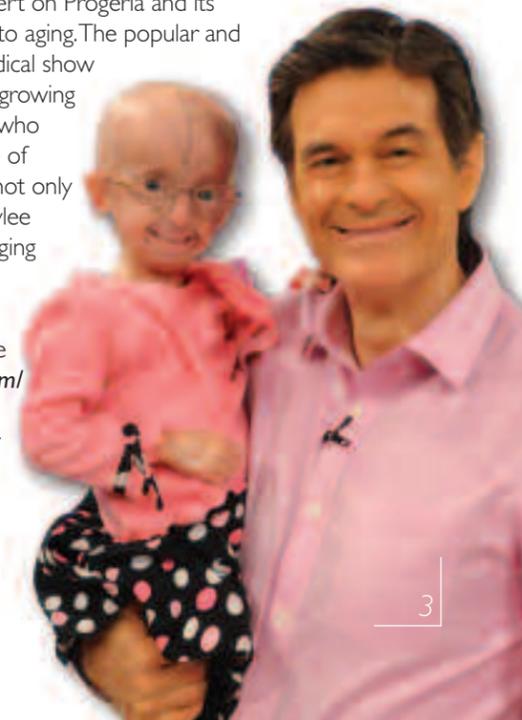


The Nighbors, with Dr. Leslie Gordon (bottom center), at NIH in 2006.

### Kaylee Halko Shines on The Dr. Oz Show

In March, *The Dr. Oz Show* aired a very special segment on Progeria with PRF's Medical Director Dr. Leslie Gordon, Kaylee and her parents, and geneticist Dr. Jeffrey Innis. Six-year-old Kaylee charmed the audience, and Dr. Gordon spoke to 3.5 million viewers as the expert on Progeria and its fascinating relation to aging. The popular and well-respected medical show host joins the ever-growing number of people who recognize the value of Progeria research, not only for children like Kaylee but for the entire aging population.

Read more about Kaylee's appearance at [www.doctoroz.com/videos/progeria-and-mysteries-aging](http://www.doctoroz.com/videos/progeria-and-mysteries-aging)



# Progeria Clinical Drug Trials Update

## Pressing Forward in the Search for Treatments

### First-Ever Progeria Clinical Drug Trial: All patient visits completed!

Three years ago this month, PRF and Children's Hospital Boston began the first clinical trial for Progeria in history. We are thrilled to report that as of December 2009, all patients have completed their Boston visits! Stay tuned for details, as the trial team analyzes the data and prepares to announce the results.

Thanks to the support of thousands, we were able to raise all the funds necessary to cover the trial costs, including testing, staff, travel, food and lodging expenses for the 28 families from 16 countries who came to Boston every four months for two years. Our heartfelt gratitude goes out to everyone who contributed their "time, talents and treasure" to make this incredible achievement possible, and of course to all the courageous families who participated.

Imagine: In a single decade, we have gone from founding PRF to coordinating the first clinical trials for Progeria. Most satisfying of all is the knowledge that this trial may make a difference in the lives of children around the world. And not only that, but because of Progeria's connection to general heart disease and aging, what we learn from this and other trials has the potential to benefit all of us.

### Progeria Triple Drug Trial: Fully enrolled and well underway!

While the first Progeria clinical trial was wrapping up, the team transitioned into an even bigger trial without missing a beat. The new trial began in August 2009 and is now fully enrolled. With a grand total of 45 children from 24 countries speaking 17 languages, this is our largest and most diverse group yet!



*In March, Adalia, Nicholas and Julia were together in Boston for their triple trial visits. With 2-3 families coming in weekly, children with Progeria and their parents have a unique opportunity to meet in person.*

For Triple Trial details, go to [www.progeriaresearch.org/tripledrugtrial](http://www.progeriaresearch.org/tripledrugtrial). The new trial is testing a combination of three drugs: the FTIs studied in the first trial, pravastatin, and zoledronate. All three drugs act in different ways to affect progerin, the protein that causes Progeria.

Of course, a clinical trial of this magnitude is expensive to manage, and there are precious few sources of support for rare disease research.

But in October 2009, the NIH's National Heart, Lung, and Blood Institute awarded the triple trial team a prestigious "Grand Opportunities" grant that will cover many of the costs. We are thrilled to have earned this extraordinary support from NIH.

However, the grant doesn't cover all of the triple trial expenses. PRF will raise about \$200,000 for some costs not covered by the NIH grant.

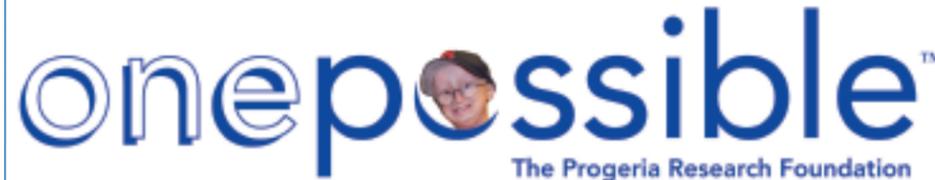
Visit [www.progeriaresearch.org/ways\\_to\\_donate.html](http://www.progeriaresearch.org/ways_to_donate.html) to find out how you can help.

*All of the children received trophies at their final, 2-year visit for the first-ever Progeria clinical drug trial. Here, Mateo, Milagros and Jesper are thrilled to get their awards.*



# It's time for PRF's Annual Campaign 2010:

## May 1st to June 15th. The cure starts with one -YOU.



The Progeria Research Foundation

PRF is now embarking on historic clinical trials with drugs that show great promise to effectively treat the children. **For the first time, there are possible treatments – and just ten years ago there was nothing being done!** Please help us keep this extraordinary momentum going.

Last year over 800 people participated in the ONEpossible campaign, raising \$100,000 of much-needed funds. **Please help us reach this year's goal of \$150,000** and give children with Progeria a chance at the long and healthy lives they deserve.

**Whatever you can give will make a difference** - \$25, \$50 or more – every ONE of you and your donations counts.

To donate, go to [www.onepossible.org](http://www.onepossible.org). Choose a team, write a note, and enjoy team leaders' photos and stories of why they are involved in PRF's work:

**TEAM AARON'S PRIDE**, led by Ariel Kushner Haber, in loving memory of her brother Aaron

**TEAM BALLACK**, led by PRF Board member Karen Ballack from California

**TEAM FACEBOOK**, for all those who have Facebook pages and want to show how powerful the social media world can be in making the dream of a cure POSSIBLE, ONE by ONE

**TEAM FOOSE**, led by Terry Foose from California, in loving memory of her daughter Amy

**TEAM PARATORE**, led by PRF Board member and campaign chair Kim Paratore from Massachusetts

**TEAM PRF**, led by PRF Chairman of the Board Scott Berns, for those who are not affiliated with any of the other teams but who want to contribute

**TEAM SCHOONOVER**, led by Cam's grandparents from Pennsylvania

**TEAM ZACH ATTACK**, led by Zach's parents from Kentucky

**TEAM ZOELY**, led by John Marozzi of New Jersey, the grandfather of 6-month-old Zoely who was recently diagnosed with Progeria

**You can also send a check in the enclosed envelope and note "ONEpossible."**



*Zoely's smile lights up the room...*

### What Your Money Goes To

- Drug trials
- PRF's 6th scientific conference
- Testing undiagnosed children
- Creating standards of care for families and their doctors
- Family-to-family communication
- Funding at least 6 research projects
- Collecting cells and sending them to researchers around the world
- Spreading the word about Progeria and PRF's work
- Advancing the quest for a cure

## THANK YOU for being ONE who makes a cure POSSIBLE!

# 2010 Progeria Research Foundation Workshop: From Bench to Bedside In a Decade

From April 11-13, PRF held its 6th Scientific Meeting at the Seaport Hotel and World Trade Center in Boston, MA. A record 140 attendees congregated from 10 different countries to hear expert oral presentations and view a record-breaking 36 poster presentations. Doctors and scientists - who often work in separate worlds, either in the clinic or in the lab - inspired one another as they came together to share cutting-edge findings and directions for future research. The depth and breadth of research into Progeria grows stronger with every meeting. Speakers included leading scientists in the fields of heart disease, aging, genetics, and lamins.

## Workshop Organizers:

**Leslie B. Gordon, MD, PhD**, Medical Director, The Progeria Research Foundation

**Frank G. Rothman, PhD**, long-standing member of the PRF Medical Research Committee, and Professor and Provost Emeritus at Brown University.

**Robert D. Goldman, PhD**, Stephen Walter Professor and Chair of the Department of Cell and Molecular Biology at the Feinberg School of Medicine at Northwestern University, and former President of the American Society of Cell Biology.

**George Martin, MD**, Professor Emeritus of Pathology and Director Emeritus of the Alzheimer's Disease Research Center at the University of Washington School of Medicine, Scientific Director of the American Federation for Aging Research and former President of the Gerontological Society of America.

**Tom Misteli, PhD**, Director of the Cell Biology of Genomes Group at the National Cancer Institute, NIH.

The stage was set during the first evening with a **Progeria Family Panel**, moderated by Wall Street Journalist **Amy Dockser Marcus**.



Sam and Devin, both 13 years old, chat during the welcoming dinner.

Researchers had a unique chance to meet some of the people their work could help: **Hayley Okines** and her parents, **Mark** and **Kerry**, from England; **Devin Scullion**, along with his mom **Jamie** and step-dad **Shawn**, from Canada; and **Zach Pickard**, with his

parents **Tina** and **Brandon**, from Kentucky. Hayley, Devin, and the adults talked about what it's like to live with Progeria, and

answered questions from the attendees who wanted to better understand how they can continue to help the children.

The family panel was followed by a plenary talk with Leslie Gordon, who brought us through a journey from obscurity, through gene discovery, on to treatment trials, and presented a vision of where the field is headed in the push towards new treatments and a cure.

## Scientific Session Topics:

**Clinical Trials in Progeria:** The American and European teams conducting the world's first Progeria clinical drug trials opened the scientific presentations. U.S. trial Principal Investigator **Mark Kieran** (Dana-Farber Cancer Institute, Boston) and trial co-coordinator **Leslie Gordon** presented an overview of trial design, baseline analyses, and toxicity, pharmacokinetics, and other aspects of the FTI clinical trial, designed to create a comprehensive baseline and detailed clinical description of Progeria. **Marie Gerhard-Herman** (Brigham and Women's Hospital, Boston) described the dramatic vessel wall abnormalities in Progeria, and **Catherine Gordon**



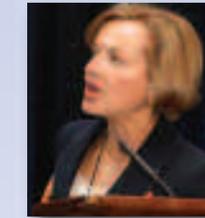
**Nicolas Lévy, MD, PhD**, Professor of Human and Molecular Genetics, head of the Medical Genetics Department and of the Inserm Research Center, and Director of the French National Institute for Rare Diseases.

(Children's Hospital Boston (CHB)) presented growth and bone health as a distinct skeletal dysplasia which shows some unique abnormalities through testing during the clinical trial. **Nicolas Ullrich** (CHB) discussed her novel findings on the natural history of neurovascular disease and stroke in Progeria. Finally, **Nicolas Lévy** (University of Marseille, France) presented exciting preliminary results from their Phase II treatment trial for Progeria and laminopathies with pravastatin and zoledronic acid, the two non-FTI drugs involved in the triple drug trial (see page 4).

*Thanks to all of this year's workshop attendees for becoming part of the Progeria research community – you are an incredibly dedicated group of scientists. Your discoveries are our past, and will be our future.*

- PRF Medical Director  
Dr. Leslie Gordon

**Aging, Cardiovascular Disease, and Progeria:** **George Martin** (University of Washington) addressed unanswered questions regarding the pathogenesis of the vascular pathology associated with normative aging and Progeria. **Elizabeth Nabel**



**Elizabeth Nabel, MD**, President of Brigham and Women's Hospital, Professor of Medicine, Harvard Medical School, and former Director of the National Heart, Lung, and Blood Institute at NIH.

(Brigham & Women's Hospital, Boston) described the commonalities between cardiovascular disease in Progeria and the aging population as demonstrated in both progeria mouse models and in human pathology specimens. **Michael Gimbrone**, (PRF grantee, Brigham & Women's Hospital) described the importance of endothelial cell influence on heart disease in Progeria and on normal aging. PRF grantee **Thomas Wight** (Benaroya Research Institute at the Univ. of Washington) presented his key findings on the Progeria extracellular matrix integrity. Finally, **Yosef Gruenbaum**, (Hebrew University, Israel) talked about drug and genetic manipulations in a new lamin worm model.

## Lamin Biochemistry and Pathophysiology:

Lamin is the normal protein counterpart to progerin, which causes disease in Progeria. The more we understand lamins, the better we can understand Progeria. In this session, former PRF grantee **Robert Goldman** (Northwestern U., Chicago) addressed lamins as essential building blocks of nuclear architecture. **Ueli Aebi**, (Univ. of Basel, Switzerland) presented the structure and assembly of wild-type and disease variants of human lamins A/C. PRF grantee **Kris Dahl**, (Carnegie Mellon University, PA) presented her data on the multi-scale mechanical changes in progerin-expressing cells. **Maria Eriksson**, (Karolinska Institute, Sweden) demonstrated the effects of stem cell depletion in a mouse model of Progeria. Finally, PRF grantee **Bryce Paschal**, (U. of Virginia) presented his discoveries on defects in the Ran GTPase system in HGPS.



**Ueli Aebi, MA, PhD**, Director of the M.E. Müller Institute for Structural Biology at the Biozentrum, University of Basel, Switzerland.

## Cutting Edge Strategies for Research and Discovery

PRF grantee **Tom Misteli**, (National Cancer Institute, NIH) brought us a glimpse of the future, with a thrilling presentation on the status of drug development in Progeria. **Fyodor Urnov**, (Sangamo Biosciences, CA) then took us to the realm of genetic therapies for Progeria by proposing we apply human gene editing with engineered zinc finger nucleases to treat Progeria in the future. PRF grantee **William Stanford**, (Univ. of Toronto, Canada) then brought us to the cutting edge by developing induced pluripotent stem cells (iPS cells) in Progeria and Laminopathies, which will be invaluable for studying Progeria in the near future. Finally, PRF Medical

Research Committee member **Judy Campisi**, (Buck Institute for Age Research and Lawrence Berkeley National Laboratory, CA) brought her expertise to bear with new insights and new targets for Progeria, aging and the inflammation that affects them both.



**Judy Campisi, PhD**, Professor and Senior Scientist at The Buck Institute for Age Research in Novato, CA.

• Young investigators took the stage, with two poster abstracts were elevated to oral presentations. **Giovanna Lattanzi**, (Institute for Molecular Genetics, Italy) presented data on prelamin A in diverse tissues, What happens in health and disease? **Ylva Rosengardten**, (Karolinska Institute, Sweden) presented her work on Embryonic expression of the HGPS mutation in epidermis.

• The Poster session, boasting 36 cutting edge projects, displayed the many new directions Progeria research is headed in. Congratulations to **John Graziotto** (Mass. General Hospital, Charlestown), who won best basic science poster on "Lamin A and Progeria Degradation: Influence of Farnesyltransferase Inhibitors," and to **Kelly Littlefield** (CHB) who won best clinical poster on "Progeria Clinical Trials: Patient Life at Children's Hospital Boston."



**Michael Gimbrone, MD**, Ramzi S. Cotran Professor of Pathology at Harvard Medical School, Chairman of the Department of Pathology at Brigham and Women's Hospital.

"This workshop clearly set a new benchmark," said **Michael Gimbrone**. "It was one of the most interactive and informative meetings of its kind I have ever attended. The spirit of the meeting was remarkably collaborative, upbeat and inspiring."



It is PRF's privilege to thank the workshop organizers for their insightful and invaluable contributions to this event (left to right): Bob Goldman, Frank Rothman, Leslie Gordon, Tom Misteli and George Martin

## Thank you to our co-funders



American Federation for Aging Research

THE MAX AND VICTORIA DREYFUS FOUNDATION, INC.

# What's News in Progeria Research?

Here is just a sampling of the many recent publications on Progeria that now appear on a regular basis. The average annual number of articles since 2002 is 25, whereas in the previous 50 years it was just 2 — now that's progress!

## Prior PRF Grantees Provide More Evidence that FTIs Act on Farnesylated Progerin

Researchers believe FTIs help alleviate Progeria symptoms because the drug prevents the protein progerin from becoming farnesylated. But what if FTIs actually work because they're preventing the farnesylation of other proteins? Researchers from UCLA and the University of Kentucky set out to find the answer. The team created mice that made only unfarnesylated progerin. As expected, the mice developed Progeria-like symptoms. When treated with FTIs, they didn't improve. If FTIs work by acting on proteins other than farnesylated progerin, the authors reasoned, then the mice would have improved. So the key to FTIs' benefit must be in the mice's missing biochemical step.

Yang SH, Chang SY, Andres DA, Spielmann HP, Young SG, Fong LG. "Assessing the efficacy of protein farnesyltransferase inhibitors in mouse models of progeria." *J Lipid Res.* 2010 Feb;51(2):400-5. Epub 2009 Oct 26.

## Art Meets Science in 'Benjamin Button' Story

If you've ever wondered about the connection between Progeria and the movie *The Curious Case of Benjamin Button*, this paper may interest you. In the movie and the F. Scott Fitzgerald story that inspired it, Button is born looking elderly and then ages backwards. Dr. Maloney argues that Fitzgerald based this fictional malady on Progeria. After outlining Progeria's dental, jaw, head and neck symptoms, the author wonders whether Progeria offers "a rare and precious opportunity" to study natural aging on fast-forward.

Maloney, WJ. "Hutchinson-Gilford Progeria Syndrome: Its Presentation in F. Scott Fitzgerald's Short Story 'The Curious Case of Benjamin Button' and Its Oral Manifestations." *J. Dent. Res.* 2009 Oct 88(10):873-6.

## Progeria's Link to Normal Aging: An Impressive Detailing of the Evidence

Progeria is caused by a genetic mutation in the gene called LMNA, pronounced "lamin-a". Studies of the worm *C. elegans* and the fruit fly *D. melanogaster* have provided more evidence that lamin is involved in aging. Because these organisms have short lifespans and can be studied in large quantities, researchers can more easily study how changes in the nuclear lamina - of which lamins are major components - affect lifespan. The authors' detailed review of the evidence that lamins are involved in aging also includes their own original results. Eriksson is the co-discoverer of the Progeria gene, along with PRF, and her laboratory at the Karolinska

Institute in Stockholm remains a major research lab working on Progeria.

Rodríguez S, Eriksson M. "Evidence for the Involvement of Lamins in Aging." *Curr Aging Sci.* 2010 Jan 2. [Epub ahead of print]

## Progeria Research a Hot Topic at Conferences Nationwide

Many organizations now seek PRF's participation in their conferences, where PRF spokespeople share their success stories so others may learn from them, and describe exciting new ventures to prospective partners. Here are the latest presentations given:

**Arlington, VA:** PRF Medical Director Dr. Leslie Gordon and PRF Board Chairman Dr. Scott Berns were featured speakers at the Pharmaceutical Research and Manufacturers of America (PhRMA) annual meeting in March. In addition to Progeria being mentioned by other featured speakers



Scott Berns, Merck CEO Richard Clark, Leslie Gordon and Sigma-Tau Pharmaceuticals CEO Gregg LaPointe.

including NIH Director Francis Collins and PhRMA President and CEO Billy Tauzin, the co-founders of PRF urged attendees to partner with PRF to develop new drug treatments.

**New York, NY:** Dr. Gordon and PRF Executive Director Audrey Gordon presented an overview of PRF and strategies for drug development at the **FasterCures Partnering for Cures** conference in December; a first-of-its-kind meeting that brought together philanthropy, medical research foundations, and the biopharmaceutical industry in an effort to forge collaborations, featuring nonprofit leaders who are producing dramatic results for patients.

**Bethesda, MD:** On Jan. 10th, 2010, Dr. Leslie Gordon spoke at the **Genetic Alliance (GA)** meeting entitled, *Genetic Alliance Bootcamp on Disease Registries*. Addressing the topic of the need for registries and cell bank repositories to accelerate research in rare diseases, Dr. Gordon presented PRF's International Registry and Cell & Tissue Bank programs as successful models to emulate.

**Bethesda, MD:** At the **NIH Office of Rare Diseases Research** workshop, *Advancing Rare Disease Research: The Intersection of Patient Registries, Biospecimen Repositories and Clinical Data* held Jan. 11 - 12th, 2010, Dr. Gordon was part of a panel that included

# PRF Awards Three More Research Grants!

As of May 2010, PRF has funded 29 grants - over \$2 million for Progeria-related research projects performed in 4 countries and 13 U.S. states! We continue to solicit proposals worldwide, in our ongoing effort to support the research that will bring us to a cure. All projects are carefully evaluated by our Medical Research Committee and Board of Directors.

## Kris Noel Dahl, PhD, Carnegie Mellon University, Pittsburgh, PA "Quantification of progerin recruitment to membranes: The role of farnesylation and local electrostatic interactions in HGPS"



Kris Dahl

The devastating structural and functional cellular changes associated with Progeria, appear to be caused by the protein named progerin. Progerin maintains its lipid properties and therefore remains embedded in the nuclear membrane, where it can be extremely damaging. Dr. Dahl's work will quantify and characterize the membrane interactions of progerin, compared to its normal counterpart protein, lamin A. With a better understanding of the role of these protein-membrane interactions, we hope to develop strategies for treatment through lipid mediators, such as cholesterol.

**Dr. Dahl** is an Assistant Professor in the Departments of Chemical Engineering and Biomedical Engineering at Carnegie Mellon University. In Dr. Dahl's lab, they study the biophysical and mechanical properties of the nucleus at the molecular, cell and tissue levels.

Project Collaborator: **Mathias Lueche**, Professor of Physics and Biomedical Engineering, Carnegie Mellon; Project Postdoctoral fellow: **Peter Yaron**.

## Jason Lieb, PhD, University of North Carolina, Chapel Hill NC "Interactions between genes and lamin A/progerin: a window to understanding Progeria pathology and treatment"

Dr. Lieb hypothesizes that abnormal binding or dissociation of genes with lamin A or progerin in HGPS cells causes misregulation of genes, ultimately leading to HGPS. Using ChIP-seq method, his laboratory will assess which genes interact with normal lamin A and progerin across the entire human genome.

representatives from the National Organization for Rare Disorders and GA. She presented PRF as a role model for conducting successful translational research in rare diseases, an achievement PRF is now widely known for.

## Educating the Medical Community about Progeria in Medical Textbook

Dr. Leslie Gordon is a contributing author for the 7th edition of the *Brocklehurst's Textbook of Geriatrics and Clinical Gerontology*. Popular with generations of practitioners, this textbook is an authoritative reference in the field of geriatric care.



Jason Lieb

He aims to identify genes that abnormally bind to or detach from lamin A or progerin in HGPS cells, both with and without farnesyltransferase inhibitor (FTI) treatment. The data will allow his team to predict signaling pathways that may be responsible for HGPS, provide a better understanding of how FTIs treat progeria, and provide clues towards new treatments which may target pathways that FTIs do not affect.

**Dr. Lieb** is an Associate Professor in the Department of Biology and Carolina Center for Genome Sciences. The projects in his laboratory are united by the scientific goal of understanding relationships between DNA packaging, transcription factor targeting, and gene expression.

Project postdoctoral fellow: **Dr. Kohta Ikegami**.

## Tom Misteli, PhD, National Cancer Institute, NIH, Bethesda, MD "Identification of small molecule modulators of LMNA splicing"

**Dr. Misteli** and his team are bringing drug development to the field of Progeria. In collaboration with the NIH Chemical Genomics Center, Dr. Misteli has created a high throughput assay to discover chemicals that interfere with progerin production. This assay has the power to reveal drugs and chemicals that actually rid the cell of progerin altogether. It is the first step in drug discovery that could lead us to novel treatments and a cure.

**Dr. Misteli** is a Senior Investigator at the National Cancer Institute where he heads the Cell Biology of Genomes Group and the NCI Cellular Screening Initiative. He is a member of the NCI Center for Excellence in Chromosome Biology, and has pioneered technology to analyze the function of genes in living cells. This is the second grant awarded to Dr. Misteli for drug development in Progeria.

Project Participants: **Douglas Auld, PhD; Paola Scaffidi, PhD; Sara Snyder, PhD; and Pilar Saladores, BSc.**



Tom Misteli



**Mission:** To discover the cause, treatment, and cure for Hutchinson-Gilford Progeria syndrome and its aging-related disorders.

**PRF BY THE NUMBERS:**

- Children living with Progeria: **63 children in 30 countries**
- Children tested through the PRF Diagnostic Program: **85**
- Grants funded since PRF was established: **29**
- Cell lines in the PRF Cell & Tissue Bank: **133**
- Children participating in the PRF Medical & Research Database: **92**

**Total Dollars Raised from 1999 to March 2010: \$8,323,581**

85-90% of PRF's annual expenses are consistently dedicated to its programs and services. The support we have received made the Progeria gene discovery, the Progeria clinical trials and all of our other extraordinary progress possible. With the continued help of our supporters, we will win this race against time and find treatments and the cure for these special children – and perhaps also help millions who suffer from heart disease and other, aging-related conditions.

**What is Progeria?**

Progeria, also known as Hutchinson-Gilford Progeria Syndrome (HGPS), is a rare, fatal genetic condition characterized by an appearance of accelerated aging in children. **All children with Progeria die of the same heart disease that affects millions of normal aging adults (arteriosclerosis), but instead of occurring at 60 or 70 years of age, these children may suffer strokes and heart attacks even before age 10.** Remarkably, the intellect of children with Progeria is unaffected, and despite startling physical changes in their young bodies, these extraordinary children are intelligent, courageous, and full of life.

**What is PRF?**

The Progeria Research Foundation (PRF) was established in 1999 by the parents of a child with Progeria, Drs. Leslie Gordon and Scott Berns, and many dedicated friends and family who saw the need for a medical resource for the doctors, patients, and families of those with Progeria, and for funding of Progeria research. Since that time, PRF was the driving force behind the discovery of the Progeria gene, and has developed programs and services to aid both those affected by HGPS and the scientists that 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 model for disease-research organizations and a prime example of successful translational research, moving from creation, to gene discovery, to treatment trials in just 10 years.

**PRF's Programs & Services**

**First-Ever Progeria Clinical Drug Trials for Progeria:**

PRF funded and co-coordinated a \$2 million, first-ever clinical drug trial for Progeria that took place in Boston with partners Children's Hospital Boston (CHB), Dana-Farber Cancer Institute and Brigham & Women's Hospital. The trial drug is called a farnesyltransferase inhibitor, or FTI, a drug that has shown great promise in the laboratory and in animal models. The trial enrolled 28 children from 16 countries, ages 3 to 15 years. Trial results are expected to be published in 2010. If the drug proves effective, it will be a remarkable step forward in the pursuit of a cure.

Since the start of the first trial, researchers identified 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 the single drug. PRF moved quickly to explore these additional treatment options. PRF and CHB began a second clinical trial for Progeria in August 2009. The "Triple Drug Trial" is much larger than the first, involving 45 children from 24 countries, speaking 17 different languages.

**Cell & Tissue Bank:**

The PRF Cell & Tissue Bank provides medical researchers with genetic and biological material from Progeria patients and their families, so that research on Progeria and other aging-related diseases can be performed to bring us closer to finding the cure. PRF has collected an impressive 83 cell lines from affected children worldwide (with ages ranging from 2 months to 17 years), and 50 lines from their immediate relatives.

**Medical & Research Database:**

The Database is a centralized collection of medical information from Progeria patients worldwide. The data is rigorously analyzed to help us understand more about Progeria and devise treatment recommendations. Database analysis was critical in determining the primary clinical outcome parameter for the first-ever Progeria clinical drug trial, and in 2010, this analysis contributed to PRF's comprehensive healthcare recommendations handbook on Progeria aimed at optimizing quality of life.

**Diagnostic Testing:**

PRF developed a diagnostic testing program for Progeria in the wake of the 2003 gene discovery so that children, their families and medical caretakers can get a definitive, scientific diagnosis. This can translate into earlier diagnosis, fewer misdiagnoses and early medical intervention to ensure a better quality of life for the children.

**Scientific Workshops on Progeria:**

PRF has organized six 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 this devastating disease.

**Research Grants:**

PRF has awarded 28 research grants totaling over \$2 million through peer review by our volunteer Medical Research Committee. Awards of up to \$100,000, for up to two years, have allowed innovative new research in Progeria to thrive.

**Publications & Research:**

A major goal of PRF is to promote awareness about Progeria and the progress being made in the field of Progeria research. Both clinical and basic scientists have accessed the PRF grants, cells and tissues, and database; their discoveries are published in top-notch scientific journals. The average annual number of scientific publications on Progeria since 2002 is more than 12 times that of the previous 50 years.

**Website/Public Awareness:**

ProgeriaResearch.org provides visitors with access to the latest information on Progeria research, support, and education for families and caregivers, and enjoys an average of 15,000 visitors per month. PRF's newsletters reach nearly 10,000 people in 52 countries. PRF's story has appeared on CNN, *The Dr. Oz Show*, *Primetime Live*, *Dateline*, and *The Today Show*, and in *Time* and *People* magazines, *The New York Times*, *The Wall Street Journal* (front page!) and dozens of other widely-read media outlets.

PRF and its partner GlobalHealthPR recently launched a global awareness campaign called **Find the Other 150**, to drive the search for unidentified children with Progeria worldwide by raising awareness of the disease among both the general public and medical communities. The campaign has already helped PRF to discover new families and children with Progeria who need our help.

**Progeria Family Outreach-The PRF Family Chat Room:**

To further provide valuable resources for families of children with Progeria, PRF has created a private Web site to help the families get to know each other and develop a support network where they can share concerns and ideas on how best to care for their children.

**Who's Who at PRF?**

**Audrey Gordon, Esq., President and Executive Director, Co-Founder**

Audrey Gordon, Esq. oversees all administrative aspects of The Progeria Research Foundation, including the Board of Directors' activities, fund-raising events, grant writing, medical research projects administration, and volunteer programs.

**Leslie B. Gordon, MD, PhD, Medical Director, Co-Founder**

Dr. Gordon co-founded The Progeria Research Foundation with friends and family after her son, Sam, was diagnosed with Progeria. As PRF's medical director, Dr. Gordon oversees the Diagnostics Testing Program, Cell & Tissue Bank, and Medical & Research Database, and is a co-chair for the Progeria clinical drug trials. She is Associate Professor of Pediatrics Research at the Alpert Medical School of Brown University and Hasbro Children's Hospital in Providence, RI, and a staff scientist at Children's Hospital Boston and Harvard University 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 the 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 Senior Vice President of Chapter Programs at the March of Dimes.

**Tina, Brandon, Brittany, and Zach Pickard, PRF's Ambassador Family**

In January 2010, the family of 3 year-old Zach Pickard was named PRF's Ambassador Family. The Pickards live in Lexington, Kentucky, and are an integral part of PRF's efforts to raise public awareness, involve other families in our programs, and raise funds for research. We appreciate the time and effort they put into these important activities.

The Quick Facts are updated every few months and are available at [www.progeriaresearch.org/quick\\_facts](http://www.progeriaresearch.org/quick_facts)

# Hundreds RIDE THE WAVE at PRF's signature "Night of Wonder" gala!

In Cambridge, Massachusetts, nearly 400 people celebrated THE WAVE of progress and the tremendous advancements PRF is making toward our ultimate goal of a cure for Progeria.

## Many Thanks to our Generous Sponsors...

Alice & Lew Berns  
 Leslie Gordon & Scott Berns  
 Sandra Bresnick & Peter Armenio  
 Fran & David Elovitz  
 The Flynn Family  
 Barbara & Burt Gordon  
 Elliott and Marjorie  
 Hillback Foundation  
 Lori & John Ledoux  
 Therese & Kurt Melden  
 Robyn & Tom Milbury  
 Gretchen & Bob Morrison  
 Kim & Joe Paratore  
 Debbie & David Ponn  
 Elaine & Skip Wohlner



A huge crowd from Foxboro, MA attended.



Gala co-chairs Vickie Robbin and Debbie Michienzie were all smiles at the evening's success.



Rabbi and Suzette Kushner and friends.



Jim Goh flew in from Colorado and brought his daughter Lauren, who attends Harvard.



Debbie Ponn is surprised and thrilled to be this year's Amy Award recipient, in recognition of her all-around support of PRF.



Kim and Kevin King enjoy the opening reception with the Gordon-Berns family: Sam, Leslie and Scott.



**Over \$260,000 was raised – how WONDERful!**

More details and photos at [www.progeriaresearch.org/ridethewave2009](http://www.progeriaresearch.org/ridethewave2009)

# Annual & Chapter Special Events Abound!

So many people now look forward to annual PRF events in their communities, thanks to our dedicated families, chapters and other steadfast supporters. Visit our web site to see if there are any upcoming events in your area.

## Another Amazing Year at YearOne in Georgia!

For the 4th year in a row, the YearOne Hot Rodders Children's Charity teamed up with automotive design guru Chip Foose at the Braselton Bash car show. YearOne has raised hundreds of thousands of much-needed dollars to help find a cure for Progeria.

We hope to see you at this year's event on September 18th!



Chip, Sam and Kenney Wayne Shepard get together at the poker tournament.

## Kaylee's 5K Course in Ohio Breaks all Records!

Raising an astonishing \$58,000, last year's race was the biggest yet. On a sunny day in October, hundreds of people – including three other families – came out to



support the Halko family and children with Progeria around the world.

Kaylee gives the "peace" sign as she and her friends Zach, Cam and Lindsay hang out after the race. The families of all 4 children hold races in their communities – amazing!

## 4th Annual Walk in Honor of Kris McGuinness Filled with Massachusetts Sunshine

How wonderful that Kris is honored every September by family and an ever-growing number of friends who join in a 2-mile walk around Kris' hometown of Middleboro, Massachusetts. Hundreds enjoyed the sunny morning, refreshments, raffles, music and the company of others, all to support Progeria research.



The 1st Annual Ride for Progeria in Canada took place on July 4th, 2009 with motorcycles riding from Listowel to Kincardine, Ontario to promote awareness for Progeria. A big THANK YOU to Amanda Lynn Mayhew, event organizer and creator of *Fyttness Fanatik* Magazine, which includes promotions for PRF in every monthly issue. **This year's ride is June 26th** and includes a concert, photo shoots and more. Benefits include friends, fun and bugs in your teeth! Details at [www.fyttnessfanatik.com/ride](http://www.fyttnessfanatik.com/ride)

## Rain Doesn't Dampen PRF's 8th Annual International Race for Research in Peabody, MA

It's official: PRF supporters are so committed, they'll show up no matter what the weather is! What a day - hundreds braved the rain to make this race a memorable one. The after-party inside City Hall kept everyone dry and cheerful; we had more participants, sponsors and donors than ever; and PRF's executive director met her goal of a first-time 5K run. **This year's race is September 11th** – see you at the finish line!



Sam and Jesper had a blast!



## 2nd Annual Kilometers for Cam 5k Raises \$30,000 in Michigan!

The Southwest Michigan chapter is now an expert at race organizing! The group held its 5k Run / Walk and

3k Fun Walk last September along scenic Lake Michigan with live music, silent auction, games and face painting. **Join them this year on September 25th** for a guaranteed day of fun. Details at [www.iamcam.org/kmForCam](http://www.iamcam.org/kmForCam)

# More Special Events

## PRF Leaders and Special Guest Sam Berns Appear on SpikeTV



PRF Executive Director Audrey Gordon, Chairman of the Board Dr. Scott Berns, and Scott's son Sam appeared in a segment about Progeria and PRF during SpikeTV's show *MuscleCar* in February. The piece

was filmed in September at the CA chapter's YearOne event. *MuscleCar* is an automotive how-to program that airs every weekend and reaches more than 4 million viewers. Thanks to steadfast supporters YearOne, Chip Foose and RTM Productions for helping to drive awareness!

## Everyone's a Winner at PRF's 5th Annual Poker for Progeria Game



(left to right) Brittany Carnegie (who helped sell loads of raffle tickets!), Boston Bruins player Milan Lucic, and former NHL player and current Director of Development for the Boston Bruins Foundation Bob Sweeney all came to support Sam, who is appropriately dressed for the occasion! Also pictured (center) is PRF Executive Director Audrey Gordon.

In March, nearly 120 people had a blast playing Texas Hold 'em Poker and Black Jack, bidding on fabulous auction items, eating, drinking, and socializing in Peabody, MA at this increasingly popular event. Many thanks to long-time event chair Maura Smith, the many sponsors, volunteers and food donors, and everyone who came—you helped raise nearly \$9,000!



The excitement grew when the final table of ten gathered to compete for the top cash prizes.

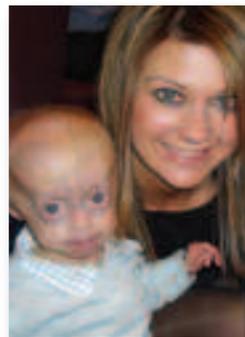
# Our Latest Miracle Makers -

Helping to Make the Miracle of a Cure Happen

**A Miracle Maker is a volunteer who raises awareness and money for PRF by running a fundraiser or other activity to help PRF carry out its mission. Enjoy these wonderful stories of creative and generous people who are making a difference in the lives of children with Progeria.**

## Aunt Emily's Endless Devotion

Motivated by her nephew Cam, Emily Howard is one of the family's hardest-working fundraisers. She has set up collection cans, hosted bake sales and poker games, collected race sponsorships and much more. How wonderful to have such close family ties!



## AAA: Another Amazing Aunt!

Congratulations to Cameron's great-aunt Jody, who ran her first half-marathon in November and raised nearly \$7,000! "I was awe-inspired by everyone's generosity. Yes, we knew we could count on our friends and family, but the outpouring from complete strangers was so touching," said Jody. And so is her dedication to her grand-nephew...

## Blogging About Progeria

Amanda, a junior broadcast journalism major at Quinnipiac University in Hamden, CT, produced a blog called "Ensure a Cure" as a school project. It includes photos, podcasts and a



Amanda and her Professor Brett Orzechowski review her blog.

video interview with PRF's Director. Check it out at [ensurecure.wordpress.com](http://ensurecure.wordpress.com). Great job, Amanda, and remember to feature us when you're a famous news anchor!

## Teen Devises "Crafty" Way to Support PRF

Thirteen-year-old Allie from Melville, NY, learned of Progeria when she saw "Hayley's Story" last spring. That summer at camp, while making bracelets, Allie decided to turn the craft into a fundraiser. She raised \$200 from selling her colorful bracelets, and sent PRF several to give to the children to "put a smile on a child's face." We're lucky to have such a talented, generous and thoughtful young lady!

## Couples Celebrate their Weddings with PRF

Brett & Michelle Dressler of Cornelius, NC are long-time supporters who decided to honor PRF on their wedding day. In lieu of gifts, they asked their guests to make a donation to PRF. And across the Atlantic, Andrea & Letizia Millionini of London made a generous donation in honor of their marriage.

To the new Mr. and Mrs. Dressler and Mrs. & Mrs. Millionini: Congratulations on your unions and thank you for including PRF in such a special celebration!

## Third Graders Show the Spirit of Giving

Students at Temple Beth Shalom in Peabody, MA collected *tzedaka* ("charity") money, and chose to donate the funds to PRF. "The kids were moved by the fact that someone their age could have this disease," said teacher Barri. And we are moved by their kindness and generosity.



## October 2009: Student Holds Bake Sale and Volunteers with California Chapter

Aidan, from Santa Barbara High School in California, is a friend of the Foose family. She has volunteered to help with several CA



Chapter events and has raised money on her own as well with a bake sale at the show grounds where she rides her horse - running back and forth between the show arena and the bake sale table! Thank you, Aidan, for being such a great volunteer!

Aidan on her show horse.

## Students Organize Coins for Cure Competition

After seeing a show on TLC about Progeria, Kellye and Cheyenne held a Coins for Cure Challenge at their school in Idaho, offering the winning class a pizza party. The class that won collected over \$100 in less than a week! The girls also held a bake sale, using PRF balloons and brochures to spread the word. "It was such an accomplishment for us, we are so proud of what we did for Progeria!" And so are WE!

## Pedaling for Progeria!

Kim Russell, a spinning instructor at Boston Sports Clubs, charged members to participate in special "Pedal for Progeria" spin classes. The group raised \$580 and got a great workout as well - Pedal on, Kim!



## Sisters Raise Awareness and Donations at "Founder's Day"

Caitlin and Lauren of Foxboro, MA hosted a booth at their city's Founder's Day event after learning about Progeria and PRF. The girls

passed out brochures and held a raffle for beautiful baskets they put together. Thanks, girls - you're a real find for PRF!

## Dorm Students Paint Murals in Honor of PRF!

The University of Nebraska's Residential Enhancement Committee, in charge of improving dorm life for students, held a fundraiser in their tornado shelter.

Blocks of walls were "sold" to students, who then painted a mural on that space. This is definitely one of the more creative ways to raise money! "It was cool to spread the word while we were painting", said event chair Colleen Settle. "I chose PRF because it's a very serious disease, but every Progeria child I've seen has a tremendous spirit," Many thanks to the students for their artistic support.



One of the many walls painted in honor of PRF.

## Interact Club chooses PRF for Donation

The Berwick, Pennsylvania Senior High School Interact Club (a sister club to Rotary) is a service club that holds various fundraisers each year, then provides donations to many organizations worldwide. Having watched documentaries about Progeria, the group chose PRF to receive a donation of \$500! Our thanks to Debbie Kern, the Interact Club Advisor, and all the students who chose to support PRF

## Canadian Girls Turn Project into Fundraiser

Inspired by a documentary on Hayley of England, Lindsay and Sara of Woodland Christian High School in Ontario chose to do their Biology project on Hutchinson-Gilford Progeria Syndrome. While reading PRF's web site, they learned of the fundraising efforts for the clinical trial, and decided to help out.



The girls organized a bake sale and created handmade bracelets to sell, raising \$185! Thanks, Lindsay and Sara, for going beyond the schoolwork to support the children.

Please join our ever-growing group of heroes.  
Working together in a variety of ways, we WILL find the cure!



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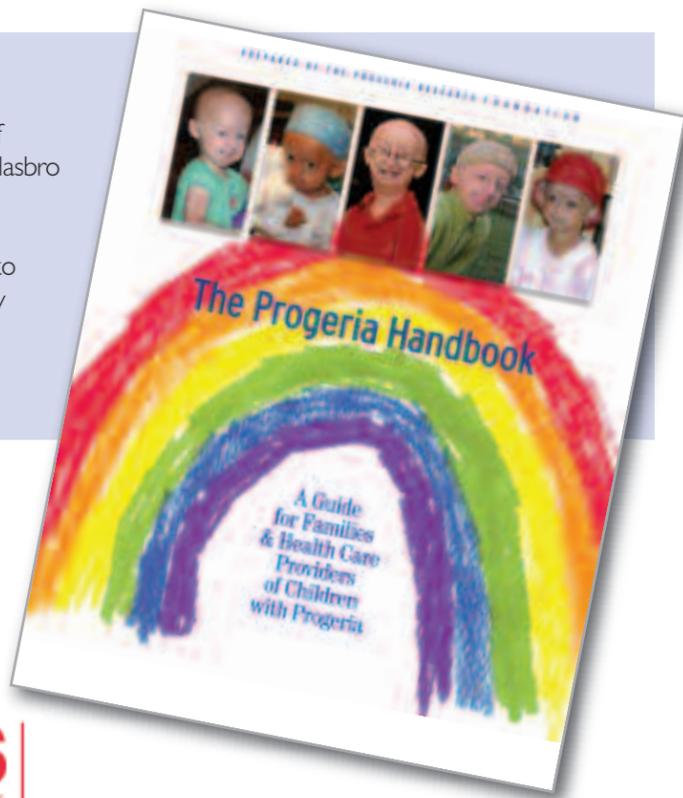
Happy Mother's Day

### Hot off the Presses! Progeria Handbook Now Available

PRF is proud to present the first handbook dedicated to the care of children with Progeria. With contributors from Brown University, Hasbro Children's Hospital, and Harvard University Hospitals, the 100-page handbook contains a wealth of information for families and medical caretakers. From basic health facts to daily care recommendations to extensive treatment guidelines, the handbook will help answer many questions for children with Progeria throughout the world.

The handbook is also available to download at  
[www.progeriaresearch.org/patient\\_care](http://www.progeriaresearch.org/patient_care)

Thanks to the American Legion Child Welfare Foundation and CVS Caremark for providing grants that helped make this project possible!



American Legion  
Child Welfare Foundation

