A Happy, Healthy New Year to All!

Astounding Development: Studies Show Reversal of Progeria in Mice

In a stunning display of progress with the FTI drug, Dr. Francis Collins’ research team at the National Institutes of Health found that FTIs prevented and even reversed the most devastating effect of Progeria in mice: cardiovascular disease. What encouraging evidence for the current Progeria clinical drug trial! See page 4 for more details on this and other recent studies that are bringing us closer to treatments and a cure.

Countdown to the Completion of the Clinical Drug Trial

At this time next year, the Progeria clinical drug trial will be completed and the trial team will be hard at work compiling the data to determine if the FTI drug is an effective treatment. See page 6 for more details.

Growing by Leaps and Bounds

PRF celebrated the opening of two more chapters this year, and all chapters have had a phenomenal 2008 filled with record-breaking events supported by hundreds in their communities and beyond. Read all about them on pages 8-9
PRF’s Mission:
To discover the cure and effective treatments for Progeria and its aging-related disorders.

**Message from the President & Executive Director**

Happy Holidays everyone.

In 2009 PRF will celebrate ten years of existence, and what a decade it has been! By the time this newsletter reaches you, it will be only a few months before the first-ever Progeria clinical drug trial is completed, and we will know soon thereafter if we have found an effective treatment for the children. We started from ground zero and along with many supporters, quickly and efficiently did what was needed to bring Progeria into the spotlight and on the road to a cure.

We continue to run all of our programs with worldwide outreach. Researchers are getting our grants and cells and attending the scientific workshops; children are being tested for Progeria; families and their doctors continue to receive the medical information they need. These essential programs have made the tremendous progress toward a cure possible, and they are thriving thanks to your support.

The year 2008 ends with the exciting news that FTIs actually reversed the heart disease in Progeria mice, and the study also provides further confirmation of the link between Progeria and generalized heart disease. Imagine: Finding a cure for Progeria, one of the rarest diseases, could help millions with the most common illnesses—heart attacks and strokes. Amazing!

Our new partnership with GLOBALHealthPR (back page) will heighten global awareness to an unprecedented level, and with that exposure we will find more children who need our help, and more researchers who will help us.

2009 promises to be another exciting year of progress, and I look forward to working with each and every one of you to help the children.

May the New Year bring you all much happiness and good health, and bring us that much closer to a cure.

Audrey Gordon, Esq.
Executive Director

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PRF is a 501(c)(3) organization.

PRF’s Mission:
To discover the cure and effective treatments for Progeria and its aging-related disorders.

**In Loving Memory…**

of the beautiful young ladies who passed away this year…

They are gone from our sight, but never our memories

Gone from our touch, but never our hearts.
Great Science from PRF Grantees and Workshop Participants show a steady, swift movement toward treatments and cure.

One of us went to an international conference to share a presentation on his work. The audience was so captivated by the research that they asked for our website and other ways to stay informed about this groundbreaking work.

Two recent publications show that FTIs and gene therapy may reverse Progeria.

Two studies by a UCLA laboratory group help us understand the effects of FTI on Progeria.

The UCLA group of former PRF Grant Recipients Dr. Stephen Young and Loren Fong have created two mouse models to better understand how FTI may work in Progeria. The first mouse model makes progerin, but it is missing the side group that is attacked by FTI. These mice showed clinical improvement over mice with the longer version of progerin (produced in Progeria), but the disease was not completely erased. In the second mouse model, the researchers altered the progerin molecule again to mimic an alternative of the progerin that may make, and asked whether disease was changed. These mice also developed a milder form of Progeria than their counterparts with typical progerin.

Progerin leads disease phenotypes of progeria in mice whether or not it is farnesylated. “This study shows that a combination of two common drugs widely used in medicine, may be new and important treatments for patients with Progeria, and provide hope for a cure.”

Dr. Loren Fong, PhD

Clinical Studies Helped Prepare for Drug Trial


This New England Journal of Medicine article details new and important findings of the 2005-2006 longitudinal clinical studies on children with Progeria where in expert’s conducted extensive tests on fifteen children to assess the basic abnormalities associated with Progeria. Clinical studies done in collaboration with PRF helped us to understand more about which tests would be most helpful for the clinical trial to follow.


Another Potential Treatment!


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Studies by PRF’s Hardworking Grantees


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“Lamin A-dependent regulation of adult stem cell associated with accelerated aging” by Paul Scaffidi and Tom Misteli.

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“Peritonization of wildtype lamin A/mutation in a phenotypic model,” by Jose Candelario, Sivasubramaniam Sudhakar, Sonia Navarro, Sita Reddy and Lucio Comas.

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PRF Awards 24th Grant to Kris Dahl, PhD of Carnegie Mellon University in Pittsburgh, Pennsylvania.

Congratulations to Dr. Dahl, whose project entitled “Quantification of progerin recruitment to membranes” will investigate the fundamental mechanism of progerin-membrane interaction. Dr. Dahl recently published on the increased ability of Progera cells to withstand physical stress, similar to aging cells.

Forging Ahead at an Unprecedented Pace
Update on the First-ever Progeria Clinical Drug Trial

Our Best Hope Today to Treat Children with Progeria

It’s official!
In September we surpassed the halfway point in the clinical trial. PRF continues to work daily with the families, their physicians, Children’s Hospital Boston, Dana Farber Cancer Institute, Brigham and Women’s Hospital, Brown University Medical School, UCLA, and NIH to ensure the trial’s successful completion in December 2009.

The latest update:
An average of two families have been flying to Boston each week since the start of the trial in May 2007, returning every four months for testing and to receive new drug supply. To date, all the children have completed their one-year visit - marking their halfway point in the trial - and 15 have completed their 16-month visit so they only have 2 more visits left!

Getting Closer to the $2 Million Goal…
We are pleased to report that, thanks to your support, we have raised $1.7 million - 85% - to date to fund the clinical drug trial! Please help us with the final push to raise the remaining $300,000…

On behalf of the children and families that have been given hope - where none had existed before - through PRF’s work and this first-ever Progeria clinical drug trial, we thank you for supporting the critical mission of PRF: to develop treatments and a cure for Progeria and its aging-related diseases.

With your help, we WILL fund the clinical drug trial.

PRF’s Research-related Programs: The Engine for Progress

PRF owns and operates essential programs that provide the network of resources needed to advance the field of Progeria and discover more about what Progeria can tell us about aging and heart disease in all of us. Our programs have quickly led us from gene discovery to clinical trial and will keep us moving forward at great speed. We not only look to a future of treatments and cure, but we also help the children today.

The PRF International Registry maintains centralized information on Progeria children from around the world. Once a doctor or parent registers a child, we move quickly to provide information, medical recommendations, testing and opportunities to participate in our other PRF programs.

The PRF Diagnostics Testing Program provides genetic testing for the Progeria mutation. This means earlier diagnosis, fewer misdiagnoses and early medical intervention to ensure a better quality of life for the children. A positive diagnostic test is required for participation in any treatment trial for Progeria. Since its inception in 2003, we have tested 70 children from 25 countries.

The PRF Cell & Tissue Bank provides medical researchers throughout the world with biological material so that research on Progeria and other aging-related diseases can be performed. The Progeria gene finding was made possible by using Progeria cells. Treatments such as FTI, gene therapy, and stem cell therapy undergo their first tests on cells in the laboratory.

The PRF Medical & Research Database collects medical records of Progeria children and rigorously analyzes them to determine the best course of treatments and to understand more about Progeria. Our healthcare recommendations help the children in their daily lives so that their hearts and bodies are stronger and their joints more flexible. It helps them run and play with their friends! Records analysis through the PRF Database provided the essential clinical measures for the current Progeria clinical drug trial.

Grant Awards of up to $100,000 each drives the research that has led us to this point, and will carry us all the way to a cure! PRF has awarded over $1.5 million to date, and it’s paying off tremendously. We know more about Progeria and its connection to heart disease and aging than ever before, and we’re on our way to a future of better health and longer lives for the children.

Scientific Workshops facilitate sharing of new ideas for moving ahead and discovering more about Progeria. Our five international meetings have hosted hundreds of scientists and spawned new collaborations each and every time.

Many thanks to our partners in these important programs:

On behalf of the children and families that have been given hope - where none had existed before - through PRF’s work and this first-ever Progeria clinical drug trial, we thank you for supporting the critical mission of PRF: to develop treatments and a cure for Progeria and its aging-related diseases.

With your help, we WILL fund the clinical drug trial.
Chapter News

Seven PRF Chapters and Counting...

With new groups in Kentucky and Michigan, our chapters are growing steadily as their dedicated leaders raise much-needed funds and awareness for Progeria research. Check out our new chapter section at www.progeriaresearch.org/chapters.2.html to learn more about their fantastic efforts—and join the hundreds of people who support them locally and afar!

Kentucky: Zach’s Family Mobilizes Community

Pennsylvania: Purses for Progeria the Latest Fashion

Ohio: Kaylee’s Race is Wet ‘n Wild

Michigan: Miles for Miracles True to its Name

England: Hayley’s Friends and Family are Busy in Britain

California: Foam Fans Continue to (Car) Show Their Support

With Carolyn Schoonover’s leadership, these beautiful, handmade creations are being sold nationwide, raising nearly $10,000 in the first year. “When Cam was diagnosed with Progeria, my family and friends encouraged me to turn my long-term hobby of making felted purses into a means of fundraising—and Purses for Progeria was born!”, says Carolyn. In addition to local craft fairs and the chapter’s now-annual open house party you can buy yours at www.pursesforprogeria.etsy.com

Hundreds ran and walked in the rain for the 3rd Annual Kaylee’s Course, raising nearly $40,000. It was an extra special day for 5-year-old Kaylee, as she was joined by Lindsay, Cam and Zach, whose families are now getting together at each other’s chapter events.

The fun US families together in Monticello, Ohio. On the left a PRF national board member Chuck Brennan, who traveled from Cincinnati to meet the families.

The ‘tiny rainbow’ that appeared just before the start of Lindsay’s Miles for Miracles Race 2008

Field of view is limited. The whole family was outside in a downpour. Zach was particularly excited.

4-year-old Kaylee was diagnosed with Progeria on her 4th birthday...now her 5th year. It was a special day for the Roberts family. They are in the lead group for the 3rd Annual Kaylee’s Course.

EVIDENCE CELEBRATE EVENTS CELEBRATE

FUNraising events – it’s what keeps PRF’s work going, and participants have a great time – a WIN-WIN for all! Many events are now annual, thanks to volunteers’ steadfast commitment to finding a cure. Here are some highlights – come join one or more next year or start your own - and THANK YOU ALL for your support!

March in Foxboro, Massachusetts: 2nd Annual “ShopAround” a fun night for all

April in Evansville, Indiana: 4th Annual Kennedy Golf Scramble has another great year

May in Brownstown, Indiana: 1st Annual Zach Pickard Pelican Run a true team effort

September in Middleboro, Massachusetts: Rain doesn’t stop 3rd Annual Walk Kristian’s

Walk for Progeria Research

The 2-mile walk in honor of this wonderful boy’s memory raised over $8,000. In a true testament to Kristian’s spirit, the rain stopped as the walk began. “It keeps Kristian’s memory alive,” says parents Tom and Kathy, “and everyone can celebrate his life with an upbeat event that will help other kids with Progeria.” WE ARE HONORED…

December in Italy: Group Holds Theater Event

The Italian Association for Progeria – Sammy Basso (A.I.Pro.Sa.B.) continues its astounding support of PRF by holding their annual drama production; this year it’s “Beauty and the Beast”. Along with other donations, they raised $50,000! “Please don’t thank us”, says parents Amerigo and Laura, “We thank you for all you’re doing for Sammy and the other children.” REMARKABLE!

continued on page 10
**PRF’s Annual Events – they get better every year!**

7th Annual International Race for Research a day to remember

On a day that supposedly had 100% chance of rain, the skies cleared and a record 250 people came out to run and walk for Progeria research – miraculous! This year’s race was the largest yet, raising over $25,000 – an all-time high. Everyone enjoyed the after-party at Peabody City Hall, and what a sight: the smiling faces of Sam, Hayley, and Michel on stage, holding their trophies.

**Marathon Runners Cross the Finish Line for PRF**

Congratulations to Paula Kelly, Wendy Nelson and Meg & Kevin Gannon for completing the 26.2 mile, 11th Boston Marathon in April – whew! Many PRF supporters cheered them on as they ran the final stretch, and the group raised over $20,000. “It was an honor to cross the finish line for Sam and all the children and families living with Progeria”, they said. “These are the people who run marathon’s every day”.

**Continues!**

**Team “G-Unit” Competes for PRF**

Employees of Viva International Group of Somerville, NJ participated in a week-long community service project called “The Challenge of Champions”, where 9 teams compete in a series of challenges from a tug-o-war contest to a companywide scavenger hunt. Due to the tremendous response and enthusiasm for this event, each team was able to give their charities $1,000 – and G-Unit chose PRF. What great teamwork!

**Fitness Expert Helps Raise Awareness**

Amanda Lynn Mayhew, creator of Fytanik Magazine, has included PRF information and photos of children with Progeria in her paper and online magazine since its launch in November 2006. “Our mission is to inspire every person to become active in any way they can, and to encourage others to do so.” Thank you, Amanda, for inspiring your readers to support PRF.

**Karl Traeger of Pennsylvania honored the memory of his cousin Jace, who had Progeria.**

**Everyone’s a winner at the 3rd Annual Poker for Progeria tournament**

It was truly an international event with “sise champions” Sam from the US, Michel from Belgium and Hayley Louisa from England, pictured here with winners of the 2nd and 1st place run/walk.

**Wild and Crazy Michigan Kids!**

13-year-old Kim Bizenov spent weeks collecting toys, activity books, and games for children in the Progeria Clinical Drug Trial, and also designed and created special bracelets for them, incorporating PRF’s colors and bird symbol. The kids are really enjoying these thoughtful gifts. Thanks Kim, you’re terrific!

**How fantastic to have so many people raise awareness and money for Progeria research!** Enjoy these heartwarming stories of how students, business owners and employees, and others are helping to Make the Miracle of a cure come true. We hope you inspire you to take action in your community!

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**Cousin Honored with Guitar Hero Contest**

Karl Traeger of Pennsylvania honored the memory of his cousin Jace, who had Progeria. Karl got his fraternity, Delta Chi, and sorority Alpha Sigma Tau to hold a Guitar Hero contest fundraiser, and also put a Coins to Cure© can in a local store. They raised $350 – twice as much as last year! Thank you, students, for putting yourselves on the auction block for Progeria.

**Everyone’s a winner at the 3rd Annual Poker for Progeria tournament**

It was a fun night out in Boston’s North Shore with Texas Hold ‘em Poker, silent auction items, complementary food and raffles which raised nearly $9,000. NOW THAT’S GAMBLING FOR GOOD!

**Counting Coins in California**

15-year-old Devin took one of our Coins to Cure© Progera! cans to school, and so far has raised $100. A true example of how people of all ages can use the collection cans to help make a difference – call us today and we’ll send you one!

**Students Raise $5 and Awareness for PRF**

Jordan, a senior at Gann Academy in Walhamb, MA was drawn to Progeria after Rabbi Harold Kushner, whose son had Progeria, spoke at their school. She then gave a presentation on Progeria to her biology class and wanted to do more, asked her class to hold a ‘Yard Sale’ at school. They raised $300, and were so excited with its success that they’re making this an annual tradition. GO GANN!

**Students Raise Some Dough for PRF!**

Children at Zach Pickard’s school raised $650 for PRF by holding a Bake Sale. Many thanks to Ms. Laura and Ms. Lora who organized the students, and the kids and their parents who baked and bought the yummy treats!

**What a Grand Idea!**

North Carolina’s Grand Design Matt owner Phil Madren learned about PRF after meeting Chip Foose at a Mustang Show, and wanted to do something to help. So he donated a percentage of a month’s website sales, and wants to continue to support PRF; for which we are SO grateful!

There are dozens of others whose extraordinary and generous acts have made them Miracle Makers – too many to list here! Please go to www.progeriarsearch.org/miracle_makers.html to enjoy reading all about them.

**Talented Girls Sell Jewelry**

Lindsay, Gabrielle, Alexa, and Carley spent months crafting beautiful jewelry to sell as part of their mitzvah (Hebrew for “good deed”) project. The girls took their unique and colorful earrings, necklaces and bracelets to the Danvers, MA Wal-Mart store and sold them to delighted shoppers. These industrious young ladies also held a raffle and educated their customers on Progeria. They raised lots of awareness and $700 – now THAT’S a mitzvah!

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**West Coast Brothers Save for Progeria**

Brothers Tyler (8) and Julian (7) from Fallbrook, California didn’t save up their allowance for toys, they gave half of one year’s earnings to PRF – $125. Thank you, boys, for such a wonderful act of generosity.

**Kentucky Kids Jump Up and Down for Progeria!**

Kindergarten and 1st graders from Ms. Angie and Ms. Joby’s class at Zach Pickard’s school held a Jump-a-Thon for PRF – they had family and friends sponsor them, spent an afternoon jumping rope at school and raised over $200. Now THAT’S a fun way to fundraise!

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**Many thanks to Norseland INC for sponsoring this Newsletter!**

www.norseland.com
The Progeria Research Foundation
P.O. Box 3453
Peabody, MA 01961-3453

We know the economy is uncertain and appreciate all you do to support children with Progeria. Please know that whatever you give will make a difference.

To learn more about how you can help, contact us:
info@progeriaresearch.org
www.progeriaresearch.org
978-535-2594

RETURN SERVICE REQUESTED

PRF On the Move:
PRF Goes Global!

Children with Progeria live all over the world and we need to reach every one of them. Thanks to our new partnership with GLOBALHealthPR, we will meet this challenge!

GLOBALHealthPR is an international partnership of some of the world’s most successful public relations firms, all dedicated exclusively to the health and medical fields. This impressive group has generously offered their services to help raise awareness of Progeria and PRF’s work around the world – HOW EXTRAORDINARY!

This initiative was led by PRF board member John Seng of Spectrum Science Communications in Washington, DC, the headquarters for GHPR. The other partners are located in Argentina, France, Germany, Italy, Japan, Mexico, Spain and the United Kingdom.

GLOBALHealthPR
A BETTER WAY

“Just when you think you’ve heard everything…”

“We’ve had people climb Mt. Kilimanjaro, parachute from planes and sumo wrestle for Progeria – all wild and crazy events that made us laugh and shake our heads with wonder at the lengths people will go to support Progeria research. Here’s this issue’s winner – we invite you to think of a unique way to raise money and get in this new section!”

Savage and Associates employee Benji Steinberg told his co-workers if they raised $500 for PRF he would shave his (very) full head of hair. They ended up raising almost $900, and Benji was true to his word – the “event” took place in the company parking lot with a huge crowd, an emcee and good-natured Benji in a hula skirt!

Ohio chapter leader Tim Halko gives fellow worker Benji a close shave.