



The Progeria Research Foundation

www.progeriaresearch.org

December, 2008

# news

## A Happy, Healthy New Year to All!

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### 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 FTI's 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.

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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.**

**Finding the cure will help not only these special children, but perhaps also millions who suffer from heart attacks, strokes and other aging-related conditions.**

## 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.



# 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.



**Sarah,**  
14 years old,  
from Austria



**Megane,**  
15 years old,  
from France

# Forging Ahead at an Unprecedented Pace

Great Science from PRF Grantees and Workshop Participants show a steady, swift movement toward treatments and cure.

Check out our new website section: "What's News in Progeria Research" at <http://www.progeriaresearch.org/> Many thanks to Dr. Frank Rothman for helping to write science summaries for this newest website outreach page.

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

August and October 2008: Two separate studies show that Progeria is reversible in the cardiovascular system and the skin of mouse models. The experiments were significant in not treating the mice until they expressed Progeria symptoms, whereas most previous studies began treatment much earlier, before Progeria was apparent. Production of progerin (the damaging protein made from the Progeria gene) was inhibited either by treatment with a farnesyl transferase inhibitor (FTI) or by turning off the progeria gene. In both cases the mice reverted to normal or almost normal conditions – AMAZING!



**Dr. Francis Collins** "A farnesyltransferase inhibitor prevents both the onset and late progression of cardiovascular disease in a Progeria mouse model", by Brian C. Capell, Michelle Olive, Michael R. Erdos, Kan Cao, Dina A. Faddah, Urraca L. Tavaréz, Karen N. Conneely Xuan Qu, Hong San, Santhi K. Ganesh, Xiaoyan Chen, Hedwig Avallone, Frank D. Kolodgie, Renu Virmani, Elizabeth G. Nabel, and Francis S. Collins. "We were amazed that [the drug] worked so well," says Francis Collins, a geneticist and former director of the National Human Genome Research Institute, who was senior author for the research team that identified the Progeria gene mutation in 2003. "Not only did this drug prevent these mice from developing cardiovascular disease, it reversed damage in mice that already had it, which is critical given that Progeria is usually not diagnosed at birth, but only when children begin to show symptoms and part of the damage already has been done."

*Proc Natl Acad Sci* 2008, Oct 14;105(41)

"Reversible phenotype in a mouse model of Hutchinson-Gilford Progeria syndrome", by Hanna Sagelius, Ylva Rosengardten, Eva Schmidt, Caroline Sonnabend, Björn Rozell and Maria Eriksson.

Dr. Eriksson's research team at the Karolinska Institutet in Sweden created a mouse model of Progeria with skin abnormalities. The mice are genetically engineered so that the Progeria mutation can be shut off at any time. Once disease was apparent, the gene for Progeria was turned off by treatment with doxycycline, a type of antibiotic, and the skin returned to normal. This study illustrates that the expression of the Progeria mutation does not cause irreversible damage in the

skin, that some reversal of Progeria is possible, and that gene therapy is a promising treatment for Progeria. Dr. Eriksson's group first published the creation of this Progeria mouse model in the April 2008 *Cell Science* issue. They quickly followed up with this amazing finding.

*J Med Genet.* 2008 Aug 15. [Epub ahead of print].

## 2007 International Progeria Workshop Publication shows fast pace of advancements toward treatments and cure.

"Highlights of the 2007 Progeria Research Foundation Scientific Workshop: Progress in Translational Science", by PRF's Medical Director Leslie Gordon, and Medical Research Committee members Christine Harling-Berg and Frank G. Rothman. This article comprehensively describes how the PRF workshops on Progeria have provided a concentrated forum to facilitate the collective thinking of clinicians and scientists about Progeria, forge collaborations, and accelerate the discovery of new ways to push the field forward towards treatments and cure. The authors write, "The presentations, posters and discussion showed extraordinary progress at all levels: from basic science, to mouse and human studies that better define the biological effects of progerin on disease pathogenesis and on aging and cardiovascular disease in the general population, to the first clinical drug trial for Progeria. The discovery that progerin is found in normal humans in an age-dependent manner establishes a new link between Progeria and aging. This is the best example yet of how studies on Progeria may be valuable to understanding human aging."

*J Gerontol A Biol Sci Med Sci.* 2008 Aug 63(8):777-87.

In an accompanying editorial, "Research on Hutchinson-Gilford progeria syndrome", Huber R. Warner addresses Progeria as a model for studying accelerated aging and therefore might provide unique opportunities to increase our understanding of the biology of aging and age-dependent disease.

*J Gerontol A Biol Sci Med Sci.* 2008 Aug 63(8):775-6.



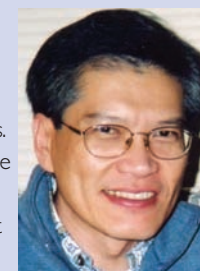
Drs. Christine Harling-Berg, Frank Rothman and Leslie Gordon



"The Progeria Research Foundation will continue to play a major role in fostering the translational research needed to find effective treatments and/or a cure for children afflicted with HGPS."

- Dr. Huber Warner

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



Dr. Loren Fong

The UCLA group of former PRF Grant Recipients Drs. Stephen Young and Loren Fong has 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 progerin that the body may make, and asked whether disease was changed. These mice also developed a milder form of Progeria than their counterparts with typical progerin. "Progerin elicits disease phenotypes of progeria in mice whether or not it is farnesylated." By Shao H. Yang, Douglas A. Andres, H. Peter Spielmann, Stephen G. Young and Loren G. Fong. *Journal of Clinical Investigation*, 2008 Oct; 118(10):3291-300 and "Increasing the length of progerin's isoprenyl anchor does not worsen bone disease or survival in mice with Hutchinson-Gilford progeria syndrome." By Brandon S. J. Davies, Shao H. Yang, Emily Farber, Roger Lee, Susanne B. Buck, Douglas A. Andres, H. Peter Spielmann, Brian J. Agnew, Fuyuhiko Tamanoi, Loren G. Fong, and Stephen G. Young.

*Journal of Lipid Research* 2008 Sep 8. [Epub ahead of print].

## Clinical Studies Helped Prepare for Drug Trial

"Phenotype and Course of Hutchinson-Gilford Progeria Syndrome", by Melissa A. Merideth, Leslie B. Gordon, Sarah Clauss, Vandana Sachdev, Ann C. M. Smith, Monique B. Perry, Carmen C. Brewer, Christopher Zalewski, H. Jeffrey Kim, Beth Solomon, Brian P. Brooks, Lynn H. Gerber, Maria L. Turner, Demetrio L. Domingo, Thomas C. Hart, Jennifer Graf, James C. Reynolds, Andrea Gropman, Jack A. Yanovski, Marie Gerhard-Herman, Francis S. Collins, Elizabeth G. Nabel, Richard O. Cannon III, William A. Gahl, and Wendy J. Inrone. This New England Journal of Medicine article details new and important findings from the 2005-2006 longitudinal clinical studies on children with Progeria, wherein experts conducted extensive tests on fifteen children to assess the basic abnormalities associated with Progeria. These 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.

*N. Engl. J. Med.* Feb. 2008;358:592-604.

## Another Potential Treatment!



Dr. Carlos Lopez-Otin

"Combined treatment with statins and aminobisphosphonates extends longevity in a mouse model of human premature aging", by Ignacio Varela, Sandrine Pereira, Alejandro P. Ugalde, Claire L. Navarro, Maria F. Suarez, Pierre Cau, Juan Cadinanos, Fernando G. Osorio, Nicolas Foray, Juan Cobo, Felix de Carlos, Nicolas Levy, Jose MP Freije and Carlos Lopez-Otin. Dr. Carlos Lopez-Otin flew from Spain to present initial findings for this exciting work at the PRF workshop last November, and recently published final results. This study shows that a combination of two common drugs widely used today, statins and bisphosphonates, markedly improves some aging-like symptoms in a Progeria mouse model, including an increased lifespan! These drugs may prevent progerin from effectively functioning, and may complement the FTI drug currently used in the Progeria clinical trial.

*Nature Medicine*, 2008. 14(7): p. 767-72.

## Studies by PRF's Hardworking Grantees

"Nuclear lamins: major factors in the structural organization and function of the nucleus and chromatin", by Thomas Dechat, Katrin Pflieger, Kaushik Sengupta, Takeshi Shimi, Dale K. Shumaker, Liliana Solimando, and Robert D. Goldman. This New England Journal of Medicine article details new and important findings from the 2005-2006 longitudinal clinical studies on children with Progeria, wherein experts conducted extensive tests on fifteen children to assess the basic abnormalities associated with Progeria. These 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.

*Genes & Development* 2008; 22:832-853.

"Lamin A-dependent misregulation of adult stem cells associated with accelerated ageing", by Paola Scaffidi and Tom Misteli. Drs. Scaffidi and Misteli provide evidence that progerin interferes with the function of human stem cells, which supports a model in which accelerated ageing in HGPS patients, and possibly also physiological ageing, is the result of adult stem-cell dysfunction and progressive deterioration of tissue functions.



Dr. Paola Scaffidi

*Nature Cell Biology* February 2008; 10(4): p. 452-9.

"Increased mechanosensitivity and nuclear stiffness in Hutchinson-Gilford progeria cells: Effects of farnesyltransferase inhibitors", by Valerie L.R.M. Verstraeten, Julie Y. Ji, Kiersten S. Cumming, Richard T. Lee, and Jan Lammerding. Dr. Lammerding's group has found that cells from Progeria skin are stiff and more susceptible to death when strain is placed upon them. Authors discuss the potential link between these findings and the cell death that may occur in blood vessels of children with Progeria when blood flow causes strain on the vessel wall.

*Aging Cell*. 2008 Jun;7(3):383-93.

"Perturbation of wild-type lamin A metabolism results in a progeroid phenotype", by Jose Candelario, Sivasubramaniam Sudhakar, Sonia Navarro, Sita Reddy and Lucio Comai. Dr. Comai's group is finding new overlap between Progeria and aging. The group created cells that make too much lamin A (the normal protein counterpart for progerin), and they stop growing and die in a way that mimics normal cellular aging. Treating the cells with FTI reversed the abnormalities; treated cells were able to reproduce and grow normally.

*Aging Cell* (2008) 7, pp355-367.

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

Congratulations to Dr. Kris 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 decreased ability of Progeria cells to withstand physical stress, similar to aging cells. **Nuclear mechanotransduction: Response of the lamina to extracellular stress with implications in aging.**

*Journal of Biomechanics* (2008) Oct. 20.



Dr. Kris Dahl

Dr. Dahl is an Assistant Professor in the Departments of Chemical Engineering and Biomedical Engineering at Carnegie Mellon University. She obtained her PhD in Chemical Engineering at the University of Pennsylvania and did a Postdoctoral Fellowship in the Department of Cell Biology at Johns Hopkins Medical School. Dr. Dahl's group focuses on the mechanical properties of cells.

# 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 half-way 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 half-way 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.



May 2008: Michiel, 8, from Belgium and Hayley, 9, from England proudly display their 1-year visit medals.



Megan, 7 years old, from Wisconsin was the first to participate in the trial

A local, Polish-speaking volunteer gets a hug from Julia, 8 years old from Poland, after picking Julia and her mom up at Logan airport and taking them to their room at the Devon Nicole House, one of two places that provide lodging to the families while in Boston for their trial visits. Families also stay at The Family Inn in Brookline.



# 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:



Programs are designed and run by PRF's Medical Director, Leslie B. Gordon, MD, PhD. For more information, contact Dr. Gordon at [Igordon@progeriaresearch.org](mailto:Igordon@progeriaresearch.org)



Some of our PRF research grantees gather at the 2007 workshop.

# 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/chapters1.html](http://www.progeriaresearch.org/chapters1.html) to learn more about their fantastic efforts – and join the hundreds of people who support them locally and from afar!

### Kentucky: Zach's Family Mobilizes Community



Founding volunteers and board members meet in August

Led by the Pickard family, PRF's newest chapter has found a real niche - pancake breakfasts at **Applebee's!** They held three this year, in Frankfort, Lexington and Louisville, raising a total of \$17,500 - now that's a LOT of syrup! Thanks to a wonderfully supportive, energetic and large group of family and friends in the Bluegrass state, they've held lots of other events this year – there's not enough room to list them all! Go to [www.zach-attack.org](http://www.zach-attack.org) for all the details.

### Southwest Michigan: Small Town, Big Results

To kick off their chapter, a dozen people met in April at the Stevensville home of Stephanie and Jason Howard, parents of 2-year-old Cameron, to talk about PRF's history, goals, accomplishments and how the chapter can help. In September they held the 1st Annual Kilometers for Cam 5k and, with over 500 people participating, they raised \$47,000! "We cannot thank our friends, family and community enough for their tremendous support!", said Cam's parents, "So many put their heart and soul into this event, and it really showed!"



Stephanie, Cam and Jason enjoy race day.

### England: Hayley's Friends and Family are Busy in Britain

Our PRF partners across the Atlantic have been active running, baking and selling their goods for Progeria research. Hayley's friend Antonia got all the teachers to take part in a Fun Run that they all had to dress up for; she and friend Lydia held a bake sale at school, and the whole Okines family worked with Hayley's grandmum to sell toys, refreshments and various household items at a local summer festival. Whew!



Teachers, many in their costumes, with Hayley after the race.

### Pennsylvania: Purses for Progeria the Latest Fashion

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.purses4progeria.etsy.com](http://www.purses4progeria.etsy.com)



Carolyn and grandson Cam

### Ohio: Kaylee's Race is Wet 'n Wild

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 four US families together in Montclova, Ohio. On the left is PRF national board member Chuck Bresnahan, who traveled from Cincinnati to meet the families.

### Michigan: Miles for Miracles True to its Name

The morning started off wet and gray, and just minutes before the race started, the skies opened, the sun came out, and a rainbow in the shape of a smile shined brightly in the sky. "It was the most amazing thing I ever saw", said Lindsay's mom Kristy. "The rest of the day just took off from that point on." With hundreds of walkers, runners, sponsors, and auction bidders, the race raised nearly \$30,000!



The "smile rainbow" that appeared just before the start of Lindsay's Miles for Miracles Race 2008

### California: Foos Fans Continue to (Car) Show Their Support

Car enthusiasts across the US and Canada are joining PRF's west coast chapter in a stunning show of support for children with Progeria. For the 3rd year, YearOne teamed up with famous automotive design guru Chip Foos at its Braselton Bash in Georgia, raising an astounding \$133,000. The show featured a fabulous silent auction, raffles, autograph session with Chip and other celebrities, Foos Select Car Show and a Burnout to top off the day's success!

Fans of Chip and family continue to support PRF with proceeds from their shows. Here are just some; visit our web site for more details!



YearOne President Kevin King, Chip and Sam are all smiles at the autograph tent.

- Canada's Atlantic Nationals Automotive Extravaganza
- Camaro Country F-Body Group Show and Shine
- Canyon Lake Car Show
- Foos Wheels & Waves
- Good Guys Show
- Grand National Roadster Show
- NY Rod Benders Annual Charity Show
- PinStriper Reunion
- RIDEMAKERZ and the Woodward Dream Cruise
- Trinity Restoration Grand Opening

## EVENTS CELEBRATE EVENTS CELEBRATE

**FUN**raising 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

Deb Michienzie and her team of volunteers had another successful event at her home, raising \$8,000. The fun-filled night included delicious food, great shopping, fabulous entertainment and terrific company. "This is an opportunity to teach my neighbors about Progeria, while raising funds to support research. It's also a way to show my love for Sam and all children with Progeria, and my appreciation for all that PRF does." AND WE APPRECIATE YOU, DEB!



Sam, Matt and Chris greet guests at the Michienzie home

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

It was a terrific day on the links, as golfers teed off at Eagle Valley Golf Course to raise \$13,000 in support of local sweetheart Sarah Kennedy. Event organizer Chris Kempf (Sarah's grandfather) does a terrific job. "It's my way of giving back for all that The Progeria Research Foundation does for Sarah and our family," he says. HOW WONDERFUL!



Sarah enjoys the putting area.

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

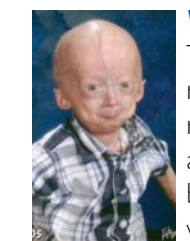
The extraordinary efforts of employees at Brownstown Electric Supply Company (BESCo) helped raise \$22,000! "We want to thank PRF", said race organizer and BESCo operational manager Brett Turner, "for giving us this opportunity to come together for something so meaningful. It was the best teambuilding experience this company has ever had." GO TEAM BESCo!!



Zach enjoys a special moment with BESCo owner Carl Shake

### 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," say 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!



Sammy, in Boston in November for the clinical trial.

continued on page 10

## EVENTS CELEBRATE

continued from page 9

### 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 gathering 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 Michiel on stage, holding their trophies!



It was truly an international event, with "race champions" Sam from the US, Michiel from Belgium and Hayley and Louis from England, pictured here with winners of the 2-mile fun run/walk.

Many thanks to major sponsors **NORTH SHORE BANK** and **Walmart** and all the other generous supporters of this event. THE RACE FOR A CURE CONTINUES!

#### Everyone's a winner at the 3rd Annual Poker for Progeria tournament



These players are all smiles as they socialize and compete for the top prizes.

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!

## Miracle Makers in 2008

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 they inspire you to take action in your community!

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



The athletes and Sam are all smiles at a post-race celebration.

Congratulations to Paula Kelly, Wendy Nelson and Meg & Kevin Gannon for completing the 26.2 mile, 112th 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 marathons' every day."

#### Michigan High Helpers go to Highest Bidder

After meeting Lindsay at the Miles for Miracles walk (see page 8), Kate got her senior student council to choose PRF to benefit from their annual fundraiser. Underclassmen bid on seniors to carry their books and bring them lunch, raising \$300 – twice as much as last year! Thank you, students, for putting yourselves on the auction block for Progeria.



Students at Grosse Ile High School advertise the Senior Helper Auction.

#### 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 – make some noise for this great group!



Employees of Farmers Bank with Zach during "Jeans Day"

#### KY Farmers Bank Employees Raise Money in Style

Kristin Pickard, Marketing Assistant and aunt of Zach, persuaded the five Frankfort branches to hold a Jeans Day to benefit PRF. Dozens of employees paid \$5 to wear jeans one day, raising \$600. Thank so much to all who "got casual" for Progeria research!

#### Student Inspired by Father's Find

After her father brought home a pamphlet on Progeria, Elizabeth of Bucksport, Maine knew she had to do something to help raise money and awareness for PRF, so she got her fellow Human Anatomy classmates to raise over \$1,000 from individual donors, a bake sale, and a raffle with donations from local businesses. The initiative was such a huge success that the school plans to continue their efforts annually until a cure is found – now THAT'S inspiring!

#### 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!



The G-Unit team proudly holds their team flag.

#### Fitness Expert Helps Raise Awareness

Amanda Lynn Mayhew, creator of Fytness Fanatik Magazine, has included PRF information and photos of children with Progeria in her paper and on-line 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.



#### 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!

#### Teen Brightens Trial Kids' Day

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!



#### Wild and Crazy Michigan Kids!

Middle school students Ashley, Mara, Jasmine, and Brianna, led by their counselor Heather Setlock, held a very creative event - a "Crazy Hair Day". Students paid \$1 to style and color their hair any way they wanted for one day. The event was a huge success raising \$140 – we love your "crazy" idea, girls!



#### Counting Coins in California

Fifth-grader Devin took one of our Coins to Cure Progeria® 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 \$\$ and Awareness for PRF

Jordana, a senior at Gann Academy in Waltham, 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 wanting to do more, asked her class to hold a Yard Sale at school. They raised \$200, and were so excited with its success that they're making this an annual tradition. GO GANN!!



#### 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. Jody'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!



#### Students Raise Some Dough for PRF!

Children at Zach Pickard's school raised \$600 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 Mat 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.progeriaresearch.org/miracle\\_makers.html](http://www.progeriaresearch.org/miracle_makers.html) to enjoy reading all about them.

Many thanks to

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## PRF On the Move: **PRF Goes Global!**



**GLOBALHealthPR**  
A BETTER WAY

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.



*John Seng (right), PRF Board member and President of Spectrum Science Communications with Audrey Gordon and Alliance for Aging Research Director Dan Perry*

## “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.*

