



(l-r): Chip Foose, Lynne Foose, Lindi Foose Oltmer, Terry Foose, Al Nodarse, Carol Caughlin . Not pictured are members Jodi Foose and Patrice Botto

Announcing PRF's First Chapter!

We are excited to announce the formation of our first chapter, located in sunny California. The group is led by Terry Foose, mother of Amy Foose, who had Progeria and for whom PRF's prestigious Amy Award is named.

The eager group met at Chip and Lynne Foose's house in southern California in October, with PRF's Executive Director Audrey Gordon making the trip to the west coast for the historic, initial meeting. The chapter's main goals are to raise awareness and funds, and recruit members to further PRF's mission to develop treatments and a cure. Lots of great ideas were discussed and we look forward to working with them.

**Chapters are vital to
PRF's growth!**

**Are you interested in
starting one?**

**Call or email
us today!**

Coming in 2006

*The PRF Wisconsin Chapter,
led by (ambassador family member)
Megan Nighbor's Aunt Sue!*

The Progeria Research Foundation

P.O. Box 3453
Peabody, MA 01961-3453

Non-Profit
US Postage
PAID
Permit #301
Peabody, MA

Together we WILL find the cure!



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

RETURN SERVICE REQUESTED



The Progeria Research Foundation

www.progeriaresearch.org

December 2005

What a Year!

PRF'S INTERNATIONAL WORKSHOP 2005 AN ASTOUNDING SUCCESS



In an unprecedented international exchange of ideas and data, 90 Scientists from 9 countries joined together for 3 days in Boston, Massachusetts for PRF's fourth scientific workshop. See pages 4-5 for more details on this historic meeting.

STUDIES SHOW POTENTIAL DRUG TREATMENT FOR PROGERIA

In August and September, researchers published PRF-funded studies that support a potential drug treatment for children with Progeria. Turn to page 6 to read about what these studies could mean and how PRF continues to help drive the research forward towards treatment and a cure.

Night of Wonder 2005- Celebrate the Science Brings in a record- breaking \$185,000



Sam Berns was all decked out for the *Night of Wonder*, pictured here with Brian Capell. Brian is first author of one of the recent studies on a potential drug treatment for children with Progeria.

What a night! An over-the-top auction, fantastic awards, moving speeches, lively dancing and much more – all contributed to a wonderful evening of celebration and fundraising for Progeria research. See pages 8-9.

Inside this Issue:

MESSAGE FROM THE PRESIDENT.....	2
IN LOVING MEMORY.....	3
WORKSHOP 2005.....	4-5
Q&A ON FTI's.....	6-7
NIGHT OF WONDER 2005.....	8-9
CIRCLE OF HOPE.....	9
MIRACLE MAKERS.....	10-11
MORE WAYS TO HELP.....	12
MORE EVENTS.....	13
OUR TIMELINE.....	14-15

Thank you to **CVS/pharmacy**® for sponsoring our 2005 Newsletters!



PRF's Mission:

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

PRF Volunteers

Corporate Officers:

Audrey Gordon, Esq., President
Carl Alvit, CPA, Treasurer
Barbara F. Gordon, Esq., Clerk

Board of Directors:

Carl Alvit, CPA	Monica Kleinman, MD	Robert K. Morrison
Scott D. Berns, MD, MPH	Rabbi Harold Kushner	John Seng
Sandra Bresnick, Esq.	Suzette Kushner, MS	Marcia Shapiro

Board of Advisors:

W. Ted Brown, MD, PhD	Mary Oh, MD	Mel Zuckerman
Robert N. Butler, MD	William Oh, MD	
George M. Martin, MD	Dr. William F. Schulz	

Medical Director:

Leslie B. Gordon, MD, PhD

Medical Research Committee:

Bryan P. Toole, PhD, Chair	Christine Harling-Berg, PhD
W. Ted Brown, MD, PhD	Monica Kleinman, MD
Judith Campisi, PhD	Paul Knopf, PhD
Thomas W. Glover, PhD	Frank Rothman, PhD
Leslie B. Gordon, MD, PhD	

Public Awareness Committee:

Scott D. Berns, MD, MPH, Chair	Suzette Kushner, MS
Leslie B. Gordon, MD, PhD	John Seng
Rabbi Harold Kushner	

Night of Wonder 2005 Committee

Co-Chairs: Kim & Joe Paratore Debbie & David Ponn
Melyssa & Douglas Beimler Marci & David Cohen Marni & Chip Correra
Phyllis & Ken Fine Marcia Glassman-Jaffe & Mark Jaffe
Debbie & Chris Glynn Marie & Nick Migliaccio Robyn & Tom Milbury
Julie & Bob Pritchard Victoria & Stuart Robbin Maura & Bob Smith

Publicist:

Spectrum Science Communications, Washington, DC

Legal:

Sandra Bresnick, Esq., Karen N. Ballack, Esq., Jeffery D. Osterman, Esq.,
Weil, Gotshal & Manges, LLP, NY, NY and Silicon Valley, CA
Lisa A. Samenfeld & Jeremy Grushcow, Kirkland & Ellis, LLP, NY, NY & Chicago, IL
Brian J. Del Buono, Ph.D., Esq., Sterne, Kessler, Goldstein & Fox PLLC,
Washington, DC 20005

Web Site Coordinator:

Karen Gordon-Betournay

Graphic Designers:

Julie Pritchard, JCR Design, Foxboro, MA
Marie Migliaccio

Accounting:

Carl Alvit, Matrix Financial, LLP, Wellesley, MA

PRF Staff

Audrey Gordon, Esq., Executive Director
Susan Rosenblatt, Executive Assistant
Lynne MacKenzie, Administrative Assistant

Message from the President & Executive Director

(Taken in part from Audrey's Night of Wonder speech)

I am overwhelmed by the events of November; the workshop and gala are the culmination of hundreds of hours of work by dozens of people. Heartfelt thanks to *Night of Wonder 2005* co-chairs Debbie and Kim, the gala committee members (listed to the left), workshop co-organizers Drs. Frank Rothman and Christine Harling-Berg, and Susan and Lynne from our staff. These events would most certainly not be possible without their tremendous passion and commitment.


Wonder – it's such a GREAT word! It evokes images of a child learning something for the first time, a scientist looking into a microscope and seeing a new discovery – who has not looked up into the star-filled night sky and asked, "What if...?" We dream for what seems at first impossible – that is what all of us together are doing for children with Progeria.

My *wonder* is YOU – every day, you show me your generosity. I have the best job anyone could ever offer me, because I get to experience these wonders on a daily basis, from thousands of people - people who contact me for one simple reason: they want to help these beautiful children live long and healthy lives.

In 6 years, we've pushed the envelope, with all the tools firmly in place to advance Progeria research, the international community working with us to achieve our goals of treatment and cure, and progress that makes heads turn in *Wonder*! You are contributing to our success, and you will all be ultimately responsible for the discovery of a cure for Progeria. But we must continue to increase the pace of accomplishments so we can win this race against time for children with Progeria. Please continue to support PRF.

I hope you enjoy this holiday season, and all the joys of knowing how very much you mean to all of us at The Progeria Research Foundation. It is only **together** that **we will find the cure**.

Sincerely,



Audrey Gordon, Esq.
President, Executive Director

As we reflect on 2005 during this holiday season, we dedicate this issue to our precious friends who passed away recently.

*They are Gone from our sight,
but never our memories;
Gone from our touch,
but never our hearts.*

Ronny

from
Venezuela,
3 days
before his
17th birthday



Stuart

from
Australia,
the day
after his
18th birthday



Sacha

from France,
9 years old

All three families spoke of the wonderful lives they lived, and that each one had recently enjoyed the company of friends and family.

International Progeria Workshop 2005 Another historic, effective conference

Ninety Scientists from nine countries working towards treatment and a cure

Over the 3-day workshop, 25 oral presentations and 20 poster presentations were given by experts from around the world, generating new ideas and collaborations that are sure to advance the mission toward treatments and a cure for Progeria, and explore the connection with heart disease and the aging process.

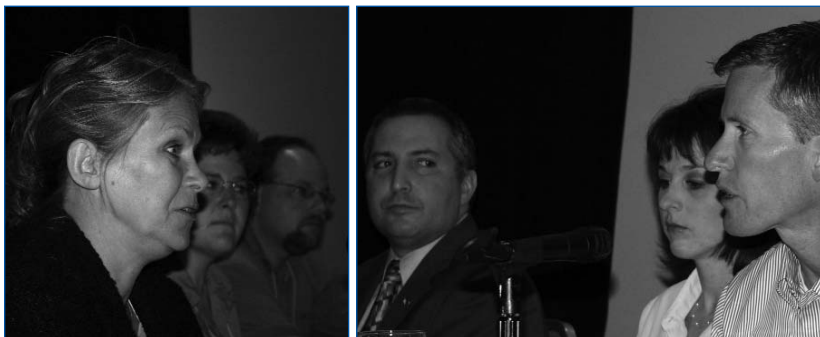
The soaring interest in Progeria was dramatically noted by workshop co-organizer and PRF Medical Director Leslie B. Gordon, MD, PhD:



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

“From 1950-2002, there were a total of 104 peer review publications on Progeria - about one per year on average. From 2002 to today, 54 publications have appeared. I wonder”, said Dr. Gordon in her opening presentation to the group, “is there any other disease field in the history of science that has

been able to generate this kind of interest and progress so quickly? We all have great hopes that this will translate into treatments and cure, the mission of PRF, in the near future... If history is a precedent, we shall leave here late Saturday, full of new ideas, and energized for continuing the task of conquering this devastating disease.”



The agenda included a very powerful session on Living With Progeria: A round table discussion with parents of four children with Progeria.



Dr. Nicolas Levy (center), University of Marseilles, France discusses the poster of Dr. Nursel Elcioglu (left) of Marmara University Hospital, Istanbul Turkey, with Dr. Manfred Wehnert, Institute of Human Genetics, Greifswald, Germany.



Dr. Giselle Bonne from the Institut de Myologie, Paris, France, talks about the genetic and clinical comparison between progeroid phenotypes



Dr. Raoul Hennekam, University of Amsterdam and Great Ormond Street Hospital, London chaired the session on Clinical Characterization of Progeria



Dr. Katherine Wilson of Johns Hopkins Univ. School of Medicine, Baltimore, MD and Dr. Richard T. Lee of Brigham and Women's Hospital, Cambridge, MA discuss the roles of Lamin A, Progerin, and how they apply to cell biology in Progeria



Dr. Carlos Lopez-Otin,
University of Oviedo,
Spain




Dr. Maria Eriksson,
Karolinska Institute,
Sweden




Dr. Francis Collins,
Nat'l Human Genome
Research Institute




Within the last two years, each of these speakers has created a novel progeroid mouse model and characterized its clinical and cellular features. At the workshop, they shared their respective data and compared models and scientific findings. Animal models are critical to the next step of testing potential treatments.



Dr. Betsy Nabel,
Nat'l Heart, Lung and
Blood Institute



Dr. Steven Young,
University of California,
Los Angeles



Dr. Colin Stewart,
National Cancer
Institute

The workshop received the highest ratings from those that attended!

Here is just a sampling of the outstanding comments received:

- "I think this was one of the best, if not the best, conference I have ever attended. It was very motivating and exciting and really a privilege to attend. You all did a wonderful job and I hope I can contribute to the cure."*
- "The meeting with the families was essential. They lent an irreducible immediacy and urgency to the otherwise abstract questions addressed by the basic science alone, and provided a personal motivation to be involved in finding a cure."*
- "The workshop has reinforced the idea that study of HGPS offers the opportunity to blend basic and clinical research to potentially cure a terrible disease."*
- "It was very valuable that competitors and collaborators were all present and could exchange ideas and information. This will break down obstructive barriers in the field and hasten progress."*
- "There was excellent interaction between clinical and basic scientists, which is often rare."*
- "Emotionally moving and scientifically excellent. The meeting represented the top notch knowledge in the field."*
- "After this meeting I feel more motivated than ever to search for treatment options for HGPS"*
- "The speakers and the quality of their data made several of the sessions outstanding. I was able to evaluate the enormous progress in the field over the past 2 years and better understand the direction(s) now possible to pursue."*
- "This was one of the best workshops that I have attended. It provided an excellent introduction to the field with a detailed insight into the condition and state of the science from the clinical to the molecular level. I believe that the relatively small size of the Progeria research community, the availability of a specific target of intervention and therapeutic potential, and the potentially broader relevance of the question towards understanding the aging process are important factors in establishing the cooperative and highly interactive atmosphere at the meeting."*

For more details on the PRF International Workshop on Progeria go to www.progeriaresearch.org

Many thanks to the workshop sponsors:



THE MAX AND VICTORIA DREYFUS FOUNDATION

Farnesyl Transferase Inhibitors as Potential Drug Treatments for Children with Progeria

Recent Research Findings and Frequently Asked Questions

By Leslie B. Gordon, MD, PhD, Medical Director

Researchers have recently published several studies that support a potential drug treatment for children with Progeria (see references at end of article). We're proud that PRF has funded or participated in many of these studies, and are excited about the implications they may have for children with Progeria. Below we have addressed the frequently asked questions that will help you to understand where we are with discerning how FTI's might be used in Progeria, and how the research community is taking steps to test its safety and potential effects for the children.

Many thanks to the following researchers for their input on this document:

Francis Collins, MD, PhD, National Human Genome Research Institute, NIH, Bethesda, MD

Thomas Glover, PhD, Department of Human Genetics, University of Michigan, Ann Arbor, MI

Susan Michaelis, PhD, Department of Cell Biology, Johns Hopkins' Institute for Basic Biomedical Sciences, Baltimore, MD

Stephen G. Young, MD, Gladstone Institute of Cardiovascular Disease, UCLA, Los Angeles, CA



Dr. Mark Kieran of Dana-Farber Cancer Institute, Boston, MA gives a presentation on the use of FTIs in the clinical setting at the recent PRF International Workshop on Progeria.

What are FTI's?

Farnesyl transferase inhibitors, or FTI's, are a class of drugs that can reverse an abnormality in laboratory-grown cells from Progeria patients, and cells engineered to contain the Progeria gene in their DNA. Progeria cells have nuclei that aren't round like normal nuclei but instead have multiple "lobes" and can even look like a cluster of grapes or bubbles. In the laboratory, however, treating these cells with an FTI restored their nuclei to a normal appearance, as recently reported in several journal articles (1-5) and reviewed in (6). The drug blocks the first step in processing the faulty protein that causes Progeria. Because FTI's have been in clinical trials for some time now for treatment of certain cancers and in patients with neurofibromatosis, with few negative effects, we are hopeful of the possibility of treating HGPS patients with FTI's.

How long have you been aware that FTI's may help children with Progeria?

Some of the research into FTI's specifically for Progeria has been taking place since October, 2002. Finding the gene for Progeria was the key element to this entire avenue of exploration. The gene responsible for Progeria is LMNA, and many years' worth of research on that gene and its protein product gave us the ability to understand that FTI's may be a viable treatment for Progeria. Recent publications are the products of up to two and a half years of scientific research on FTI's in Progeria.

Can you explain the basic principle behind possible FTI treatment in Progeria?

The gene that when mutated causes Progeria normally produces a protein called Lamin A. Lamin A has a molecule attached to the end of it called a farnesyl group. It needs this farnesyl molecule, in order to anchor onto the inner nuclear membrane (the nucleus is a structure in the center of cells that contains DNA). In normal cells, this farnesyl group is removed, but this step does not take place in Progeria, and the resulting mutant progerin protein remains attached to the membrane, where we believe the progerin does its damage. Enzymes called FTI's don't allow this farnesyl molecule to attach onto the mutant protein. Drug companies have been developing medicines that are manufactured FTI's and can be administered to cells, mice and people. In essence, we hope that FTI's will paralyze the damaging protein because they will not allow the newly formed damaging protein to attach to the nuclear membrane. The progerin will be "stuck" in the middle of the nucleus in the nucleoplasm instead of being anchored into the nuclear wall where it does its damage.

What will improve with FTI treatment in the children?

As with any experimental protocol, we won't know how it affects disease until we implement treatment. Ongoing baseline clinical studies of Progeria children at NIH will give us sophisticated baseline measures of disease status. We will use these studies to develop methods of measuring the impact of any progeria treatment on the children. With our current clinical studies, we are making sure that we recognize and can objectively measure all of the disease characteristics that may change with treatment.



FTIs are currently being used to treat some types of cancer. Is there a connection between Progeria and Cancer?

No, Progeria is not cancer; it is an entirely distinct disease. However, there are hundreds of molecules, both in normal daily cellular functioning and in some forms of cancer, that use this farnesyl group to do their jobs. Scientists developed the concept that we might be able to fight cancer by blocking farnesylation of certain “cancer-causing” proteins (not progerin, but other proteins linked to some cancers) with FTI’s. This is why drug companies have been developing and testing FTI’s for the past 10 years. It means that drug companies have spent the last 10 years and millions of dollars developing FTI’s that they hope will be effective for cancer, bringing them through toxicity testing all the way to clinical trials in adults with various types of cancer and in children with brain tumors.

If the Progeria cells can be repaired, how is there risk the child will develop cancer?

Cancer would not be caused by this treatment. If cancer were to occur, it would do so because the child could live long enough for cancer to come to clinical significance because Progeria children may have a higher risk of cancer due to cellular damage. This is extremely speculative.

How close are we to treating Progeria children with FTI?

Many researchers are working as quickly as possible to assess FTI treatment in Progeria, but there are no guaranteed time lines for the trials. There are two essential elements we need to move into clinical trials:

- 1) **Safety Testing:** This drug is presently undergoing testing in the laboratory to ensure that it will be safe for use in Progeria, and we hope to see the potential benefit it may have for these children in the near future. We are continuing to test the drugs in the laboratory in a dish, and are starting to give the drug to “Progeria” mice. This will help us to be sure, to the best of our abilities, that the treatment will be safe for Progeria children.
- 2) **Clinical Markers of Disease:** We must define which disease characteristics are most likely to objectively and systematically tell us whether the treatment is effective for Progeria. This is why we have been bringing children with Progeria into the National Institutes of Health for baseline clinical studies. These ongoing studies will provide the key elements to assessing treatment effects in the children.

Are conclusions made by treating Progeria mice with FTIs valid for the children?

Whenever possible, new medications are given to mice before they are considered for humans. These mice are observed for side effects and toxicity effects, as well as for changes that may indicate they would improve disease in people. There is never a perfect model of disease in mice, since mice are not human beings, but it’s the best we have to work with. The mouse will tell us as best it can whether there is safety in using FTI’s in the children. Non-progeria mice have been used to test FTI’s with success by the drug companies. Nothing will give us 100% assurance of safety or efficacy, but the prior work done with these drugs in normal mouse models and in people makes this a great candidate treatment. There are also several types of Progeria mouse models that are currently being given FTI’s. Within the next year or two, studies in mice should provide the information that we need to make a decision about testing FTI’s in humans.

How are FTI’s given? They are given to people in pill form.

How do FTI’s repair the defect in Progeria cells without involving other cellular processes?

FTI’s do affect the function of other proteins in the body. However, clinical testing in cancer studies has shown us that these drugs can be used in adults and children with tolerable side effects. There are always risks associated with new treatments. This is why the decision to move into treatment is so difficult for everyone, especially Progeria children and their families, who ultimately make highly personal treatment decisions for themselves. Our responsibility is to do everything we can to fully test the drugs, and fully inform parents before implementing an experimental treatment on any child with Progeria.

References

1. Mallampalli MP, et al. Inhibiting farnesylation reverses the nuclear morphology defect in a HeLa cell model for Hutchinson-Gilford progeria syndrome. *Proc Natl Acad Sci USA* 2005. **PRF funded this study.**
2. Toth JJ, et al. Blocking protein farnesyltransferase improves nuclear shape in fibroblasts from humans with progeroid syndromes. *Proc Natl Acad Sci U S A* 2005;102(36):12873-8.
3. Capell BC, et al. Inhibiting farnesylation of progerin prevents the characteristic nuclear blebbing of Hutchinson-Gilford progeria syndrome. *Proc Natl Acad Sci USA* 2005;102(36):12879-84. **PRF’s Medical Director Leslie B. Gordon, MD, PhD is a co-author on this study.**
4. Glynn MW, Glover TW. Incomplete processing of mutant lamin A in Hutchinson-Gilford progeria leads to nuclear abnormalities, which are reversed by farnesyltransferase inhibition. *Hum Mol Genet* 2005. **PRF funded this study.**
5. Yang SH, et al. Blocking protein farnesyltransferase improves nuclear blebbing in mouse fibroblasts with a targeted Hutchinson-Gilford progeria syndrome mutation. *Proc Natl Acad Sci USA* 2005;102(29):10291-6.
6. Young S, Fong L, Michaelis S. Prelamin A, Zmpste24, misshapen cell nuclei, and progeria - New evidence suggesting that protein farnesylation could be important for disease pathogenesis. *J Lipid Res.* 2005; 46(12):2531-58. **PRF funded this study.**

Raising over \$185,000, it was a true Celebration of Science!



Co-chairs Kim Paratore and Debbie Ponn are all smiles during the evening's phenomenal success.

What an incredible night of wonder as 400 people were dazzled by colorful beakers filled with molecular "science stuff", gourmet food, glowing drinks like the "Lamin-A elixir", hundreds of auction items, dancing, moving speeches and beautiful images of children with Progeria. PRF's 2005 Night of Wonder fundraiser was an overwhelming success, using the theme of **"Celebrate the Science!"** to toast PRF's tremendous scientific accomplishments and the exciting future of developing treatments and the cure, made possible in large part by the money raised from Night of Wonder events.



Guests were greeted by the "mad scientist"; all volunteers wore lab coats donated by various companies.

Honorary chair CNN's Dr. Sanjay Gupta, and former chairs Mary Steenburgen & Ted Danson joined us via videotaped messages to pledge their continued support of PRF's efforts.

Many of the scientists that participated in the workshop also came to the gala. They were greeted with a standing ovation from the crowd, to thank them for the work they are doing. "We raise this money so you can continue your work to find a cure for children with Progeria", said PRF Executive Director Audrey Gordon.



Congressman John Tierney, his wife Patrice and Friend Lumber sponsor Mark Jaffee at the VIP reception



The MacWilliams and Dinkels with Audrey Gordon and husband Rich.



Zach (above) and Megan (below) joined the party to greet many of the guests.



After a moving speech by Ambassador Family parents Steve and Sandy Nighbor, dozens pledged support of the Circle of Hope campaign (see page 9 for more details)



All photos courtesy of John Hurley

EVENTS | CELEBRATE | EVENTS | CELEBRATE



Chip hugs mom Terry as he gives her his Amy Award in loving memory of his sister.



Congratulations to our very first Amy Award recipients Chip Foose and Kim Paratore! This prestigious award is named after Chip's sister Amy (1969-1985), whose sunny personality and love of life inspired all who knew her. After Chip's moving acceptance speech and dedication of his award to mom Terry, a surprise second Amy Award was presented to Kim, who has chaired all three galas and has been a tireless supporter of PRF since its inception.



Kim is happily surprised!

Thank you to our **WONDER**-fully generous sponsors



Linda & Bob Mendelson
WEIL, GOTSHAL & MANGES, LLP
The Karen A. Martin Memorial Fund
Leslie Gordon and Scott Berns
Elliott & Marjorie Hillback Foundation
Therese & Kurt Melden
Lew and Alice Berns
Jim & Lee Neighbors
The Flynn Family
Burt & Barbara Gordon
The Elovitz Family



Introducing the **Circle of Hope**

Our progress is truly amazing, isn't it?! But despite our accomplishments and record fundraising, we still need more revenue to (financially) keep up with the pace of our scientific growth – now more than ever – as we explore treatment trials, review dozens of research proposals, test more children than ever before, and experience an exponential increase in activity.

To accomplish this, PRF introduces the first-ever major gift campaign, launched at the *Night of Wonder: The Circle of Hope*. The **Circle** consists of all of our programs: diagnostic testing, cell bank, etc. All are essential, but one or more programs will have to be cut down or even eliminated if we don't raise this money – will it be the clinical studies? The workshops? The answer is, none can be cut, not if we want to save the lives of children with Progeria. So **our goal is to raise \$100,000 from this campaign to keep the circle unbroken**. We've already raised \$9,000 from our generous Night of Wonder attendees, so we're well on our way!

Joining the **Circle of Hope** requires a donation of at least \$250, and you will receive a beautiful circular pin to signify your support of this campaign. So please check off the box on your enclosed envelope that puts you in the Circle.

If we keep the **circle** in tact, the **hope** of a cure becomes a **reality**. **Thank you all so very much for your support.**

Miracle Makers

Our list of heroes continues to grow, as more and more volunteers are raising awareness and money for PRF in innovative ways. **THANK YOU!**

Visit http://www.progeriaresearch.org/miracle_makers.shtml for more Miracle Maker stories and be inspired to be a part of making the miracle of a cure HAPPEN!

NORTH HIGH SCHOOL STUDENTS HELP "CHANGE THE WORLD" WITH TALENT SHOW

Students at North High in Evansville, Illinois were assigned this: "change the world, or, at least a small part of it". Crista, Ryland, and Nicole took action, hosting a talent show to benefit PRF. Their show was a huge success! Over 350 attended, raising \$2,800. Thank you, girls, you certainly have helped change the world of children with Progeria!



EBAY AUCTIONS RAISE OVER \$600 FOR PRF

Hand-made with love, unique items went on the auction block to help find the cure for Progeria. Penny Davis of England made Humphrey, accompanied by his special friend Lila, donated by Cee Newbould, and both were "adopted" by the highest eBay bidder!



Maria Grimes created a glass bead bracelet in memory of Amy Foose, with green flowers for Amy's September birthstone, and yellow beads for her upbeat, sunny personality. Thank you, Maria, Cee and Penny!

INSPIRED MOM HOLDS NBA RAFFLE

Karen Sussman-Bard of Texas Orthopedic Hospital held a raffle for a basket full of NBA goodies in the hospital's lobby. Inspired to action after seeing a TV special on children with Progeria, Karen said: "Your organization touches so many and it also provided me with an opportunity to share your newsletter to educate others". Thank you Karen, for raising \$375 and for spreading the word!



Karen, (left) and lucky winner Candy, one of the chefs at the hospital

INDIANA HOME SALE BENEFITS PRF

Richard Greer, Real Estate Broker in Evansville, Indiana, donated 5% of his commission from a home sale to PRF as part of his charity program in which buyers donate the money to a charity of their choice. And to Keith and Deb Thompson, who chose PRF, thanks for the "housewarming" gift!

STUDENTS RALLY AT BASKETBALL GAME FOR PROGERIA

7th grade students Hilary, JaQuae, Matt, Shane and Christina at Monessen Middle School in Pennsylvania selected Progeria for their Community Awareness Project. They handed out flyers and collected money at a basketball game. Thank you - You certainly scored winning points for PRF!

SENIOR PROJECT RAISES AWARENESS, FUNDS FOR PRF

Caitlyn of Shepaug Valley High School in Washington, Connecticut sold homemade Progeria pins, held a raffle, placed collection cans around the community, and ran a concession stand at a high school play, raising nearly \$1,300. She also informed students, parents, and teachers about Progeria. Thank you for all your time and energy, Caitlyn, we think you deserve an A+!



MATCHMAKERS PAIR UP CLASSMATES FOR PRF

Samantha saw a documentary on Progeria one day, and knew she wanted to help out. So she and her friends held a Matchmaker event for Valentines Day at her high school in Sulphur, Louisiana. Students were matched based on a survey, and results were sold. Everyone had a great time and \$350 was raised for PRF. Thank you, Samantha, with love!

PRF CHOSEN FOR CHESHAM HIGH'S CHARITY WEEK

Every year the students in Buckinghamshire, England, hold a charity week, during which they run a variety of events to raise money PRF was the lucky pick this year, receiving £200. Our thanks to the students and staff of Chesham High School!

BRITISH SOCCER TEAM KICKS IN FOR PROGERIA

Many thanks to the pro Chelsea Football Club of London, England for their fantastic fundraising efforts. The team raised £3,281.58 (over \$6,100!) for PRF through a charity raffle in honor of Hayley O'Kines. They are the 2004-05 Champions, and certainly champions for PRF!



DONATION | HIGHLIGHTS | DONATION | HIGHLIGHTS

Miracle Makers

People like you...doing what they can, for the sake of helping children with Progeria.

THEATER DIRECTOR PRODUCES PLAY ON PROGERIA

Meredith Ashley Rettner, actress, director and producer of theater in Rye Brook, NY raised \$240 for PRF at a candy sale during a play about Progeria, written by David Lindsay Abaire. Thank you, Meredith, David and all who contributed, for using your talent to raise awareness and funds for Progeria research!

CANADA'S "BUD BOYS" HAVE FUN WITH FUNDRAISERS THROUGHOUT SUMMER 2005



The "Bud Boys", led by Mike "Fiveoh" Ellis, raised money all summer in Hamilton, Ontario, Canada for PRF, in honor of Canadian boy Devin. At this season's CFL Hamilton Tiger Cat football games, they held BBQs, a car wash, sold 400 wristbands (with

Devin's help!) and collected donations, raising over \$7,000! And Joannie, the owner of A-Cross the Roads bar, organized a motorcycle poker run. "We are having a blast doing this", said Mike, "There were lots of tears in the house when we presented the check to Devin and Jamie." We thank Mike and the boys all for their efforts, you guys are amazing!

"ROWDY RABBLES" HOLD BAKE SALES FOR PRF

Carol Beane, great great aunt to Kaylee Halko of Ohio, gathered her "Rowdy Rabbits" chapter of the Red Hat Society and held two huge bake sales for PRF. They sold yummy baked goods, PRF's cool wristbands, and handed out newsletters and flyers to help get the word out on PRF's mission. Hats off to all of you, ladies, for raising almost \$900!



2/2/06 Dear Progeria research fund,
my name is Esther
I am 8 years old and I live
in ny. I would like
to help the progeria research fund
as part of my tzedakah. It
is a donation. This is also
part of my Hebrew school lessons
so I hope you can find a
cure for this disease.

Best wishes
Esther

P.s I am donating ten dollars
from my allowance and a
picture of myself so you know who
I am.

"PROJECT PROGERIA" GROUP RAISES MONEY WITH CAR WASHES, GARAGE SALES AND MORE!

Raising \$1,637, this group of college students based at the University of Texas in Arlington braved scorching weather for car washes, stayed up late to prepare fresh food to sell, and gathered their belongings for a garage sale. We appreciate their tremendous efforts!

MARBLEHEAD, MA COHEN HILLEL ACADEMY 6TH GRADERS CHOOSE PRF FOR END-OF-YEAR CHARITABLE GIVING CAMPAIGN



Brett Ponn asked fellow classmates to choose PRF as the recipient of their \$350 collection of money for charity, and they said yes! PRF's Executive Director was very impressed by the level of interest they expressed. "We encourage the students to ask questions and become involved", said teacher Rose-Jane Sulman. Thank you, Hillel students, for setting a great example for kids your age!

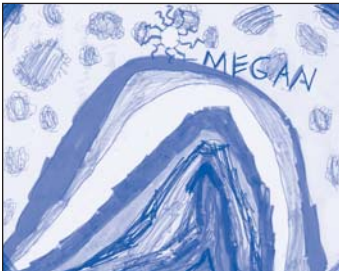
BEST FRIENDS ASK FOR DONATION IN LIEU OF BIRTHDAY GIFTS

Sam Berns' best friends, 9-year-old Dylan and 7-year-old Orion Cross, asked all their friends to make a donation to PRF instead of buying them presents this year, raising \$360. Thank you, boys, you certainly know the true meaning of friendship!



Four new ways to donate to PRF!

Options on how you can help us find a cure continue to grow. Here are some more creative ways you can contribute. For other ideas, visit <http://www.progeriaresearch.org/help.shtml>



"Over the Rainbow"
Artist:
Megan,
from
Wisconsin,
age 5

BUY OUR BEAUTIFUL CARDS DEPICTING ARTWORK FROM THE CHILDREN

Send special notes to your friends and family using these precious cards, and raise awareness and funds for PRF at the same time. Each card has a different picture on the front drawn by our young artists, and an artist profile with PRF information on the back. It's only \$10 for a package of six – place your order today!

MAKE A DONATION IN HONOR OF ONE OF OUR MIRACLE MAKERS THROUGH JUST GIVING

Just Giving is a website dedicated to getting the word out about people who do good deeds for charity, and PRF is proud to be a part of it! Make a donation in honor of these terrific Miracle Makers who have "gone the extra mile" to raise money and awareness about Progeria and PRF:

England's Steve Keens completed a 1000-mile cycle ride in the classic "End to End" trail – WOW!

Steve rode from Lands End in the South West of England to John O'Groats in the far North East of Scotland. He was inspired to ride for Hayley Okines after reading an article about her and seeing her on TV programs about Progeria. Go to Steve's "Just Giving" page at: <http://www.justgiving.com/pfp/stevekeens>



12 year old Amanda from Switzerland has reached new heights!

On October 7, 2005 she climbed Mt. Kilimanjaro to raise money for PRF. Even before this amazing feat, Amanda had raised over \$5,000 in sponsorships from her friends, family and school! If you'd like to make a donation in support of Amanda's efforts, go to <http://www.justgiving.com/pfp/amandachidekel>



SELL ON eBAY!

Through MISSION FISH, people can sell items on eBay and donate all or a part of the proceeds from each sale to a non-profit of their choice. If you are an eBay seller or know someone who is, please check into donating through Mission Fish for PRF. <http://www.missionfish.org/>

DONATE YOUR CAR TO BENEFIT PRF THROUGH CARS HELPING AMERICA

It's the end of the year, and many people are thinking about donating their car, truck, or boat to charity. These donations are tax deductible - it's a Win-Win for you and PRF! We have teamed up with a vehicle donation agent that handles the entire process; they provide tax documentation, schedule free pick up and sell your vehicle, and PRF gets 50%. Please call 1-866-949-3668 or fill out an on-line donation form at www.carshelpingamerica.org.



WRISTBAND SALES TOP 3,000!

Join the thousands of people who are wearing PRF wristbands! Place your order on line today by going to www.progeriaresearch.org



And they're off! The walkers head out shortly after the runners, all determined to cross the finish line in record time!



Andrew's Walkers received a special award for their support of all 4 races. The group walks in loving memory of Andrew Cummings. Pictured are Andrew's friends and relatives, with PRF Board member Scott Berns, Executive Director Audrey Gordon, and Sam.

International Race for Research breaks all records, raising \$24,000!!

With a picture perfect day in PRF's hometown of Peabody, Massachusetts, loads of runners and walkers enjoyed a morning of exercise, costumed characters, food, drinks, t-shirts and awards. Thanks to the tremendous support of local businesses, the generosity of our participants and sponsors, and Rosie's satellite race, we raised over \$24,000!



Lindsay is all smiles as she walks in Michigan's first PRF Race for Research



Lindsay's Grandma Rosie held her own Race for Research in Michigan

Thanks to Rosie for raising over \$7,000 and gaining new awareness and support for Progeria research.

If you'd like to run a Race for Research in your area in 2006, please contact us at info@progeriaresearch.org

More family events: Ambassador Family and Friends raise \$8,000 at "Brat Fry" and "Packers Party"/Walk in Wisconsin

Hats off to Michaela and Josh Nighbor for their help at the Nighbor family's recent fall fundraisers. Proud mom Sandy says, "Michaela was 'awesome' - she would ask certain ones if they would buy a PRF wristband and of course most couldn't say 'NO' - if they did she'd shrug it off and ask someone else. Josh stayed all day cooking bratwurst and serving the customers." And in October, this energetic group, led by Amazing Aunt Sue Giese, held a 2 mile walk & Packers party. The 2 events brought in \$8,000 for Progeria research – **WOW! Thank you, everyone!**

Photo courtesy of Joy Waterbury



STEPPING OUT IN THE RAIN about 25 walkers took part in a Walk-a-thon for Progeria in Marquette.

Thank you to all of our Race for Research major sponsors:

NORTH SHORE BANK

Alice & Lew Berns

B & B Gordon Associates

Eastman Gelatine

Gravoc Associates, Inc.

Jack Keilty, Esq.

North Shore Tile & Marble

Peter Albert of Northwestern Mutual Financial Network

Total Entertainment

The Progeria Research Foundation Timeline. . .

March 1999: The Progeria Research Foundation is incorporated as a non-profit, and holds its first board meeting June 1999.

August 1999: PRF awards its first research grant

November 1999: PRF launches its web site, a comprehensive resource on Progeria, now visited by 15,000 people per month worldwide.
www.progeriaresearch.org

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

June 2000: PRF hosts an ice cream social on Capitol Hill for families of children with Progeria. The event was attended by Congressmen and Senators who pledged their support for PRF's efforts.

October 17, 2000: The Children's Health Act 2000 is passed; PRF helps secure language that mandates activity by the National Institutes of Health (NIH) in support of children with Progeria. As a result, PRF representatives met with NIH officials in November and all parties committed to hold a joint workshop, the first of four held to date.

March 24, 2001: The Friends of PRF hold "A Night of Wonder", raising an astounding \$160,000 for research. This is now PRF's signature special event fundraiser.

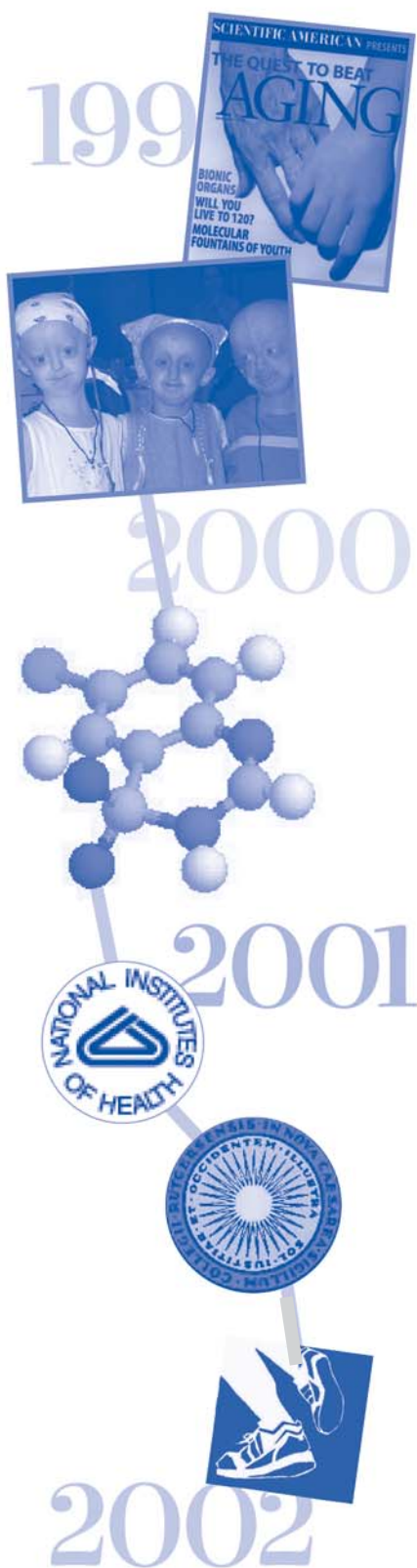
November 2001: PRF and NIH hold an historic, first-ever workshop in Bethesda, MD, bringing together leading researchers interested in Progeria.

January 2002: The PRF Genetics Consortium is formed. The goal of this group is to find the gene for Progeria, which was accomplished less than ten months later.

March 2002: PRF launches its Cell & Tissue Bank so that researchers have the biological tools necessary to further Progeria research. The Bank now holds an impressive 43 cell lines.

April 2002: Thanks to the joint workshop and PRF's efforts, NIH announces first-ever funding for Progeria research.

September 2002: PRF's 1st annual International Race for Research is held in Peabody, MA.





...Celebrating Our History, Planning for Our Future

October 10, 2002: Working with PRF Genetics Consortium members, and with cells from the PRF cell bank, Maria Eriksson and Dr. Francis Collins discover the Progeria gene. Dr. Leslie Gordon, PRF's Medical Director, is a co-author.

November 2002: The PRF Medical & Research Database is launched, to help us understand more about the basis of Progeria and enable us to provide treatment recommendations. PRF received a 2-year, \$200,000 NIH grant in June 2003 for the Database project.

April 16, 2003: The gene discovery is announced to the general public in Nature magazine.

June 2003: In the wake of the gene discovery, The PRF Diagnostics program begins. With a definitive way to diagnose children, earlier diagnosis, fewer misdiagnoses and early medical intervention ensure a better quality of life for the children. 44 children from 21 countries have been tested thus far.

July 2003: PRF and NIH once again bring scientists and clinicians together to share their expertise in a second Progeria workshop, with the gene discovery the main topic.

April 2004: PRF and NIH co-host a workshop to explore the potential for stem cell transplantation as a direction for research in Progeria.

2005: PRF awards another 4 research grants, bringing the total to 15, with a record 8 active research projects currently being conducted. To date, these projects have resulted in 10 peer-reviewed scientific publications in well-known scientific journals that are read by thousands of researchers worldwide.

February 2005: In collaboration with NIH, clinical baseline studies of children with Progeria begin, accelerating our movement toward treatments.

August-September 2005: Groundbreaking studies are published on a potential new drug treatment for Progeria. PRF was involved in either funding or co-authoring all of these works, and is hopeful that clinical studies will begin in the near future.

November 2005: PRF's first-ever international scientific conference is held in Boston, MA. Researchers joined forces to explore potential treatments, with a record 90 scientists from around the world attending.

Wow! We have come so far, and could not have done so without you. With your continued support, we will add to our impressive timeline - all the way through treatments and to the end - a cure!

2002



nature

2003



2004



2005
New to 2006...

