



# The Progeria Research Foundation

www.progeriaresearch.org

December 2006

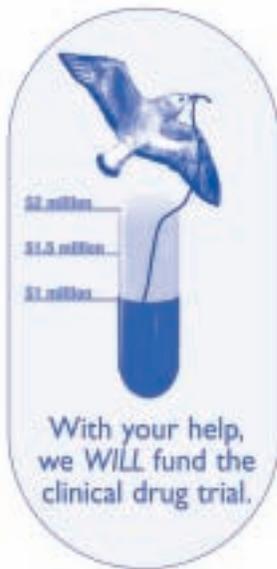
## Paving the Way Toward a First-Ever Clinical Trial!



### Look what's happened in just one year!

In September 2005 we announced that PRF-funded researchers had published studies supporting a potential drug treatment for children with Progeria – Progeria cells became normalized in a dish when given this drug, called FTIs. The next phase of testing was in animal models, and studies released in February and July of this year found that this drug prevents some signs of disease in Progeria mice. These and other recent studies have paved the way for PRF to begin raising money to look toward a drug trial for children with Progeria..

### Be Part of Progeria History...



### Support a First-Ever Progeria Clinical Drug Trial

PRF is raising approximately \$2 million toward funding a first-ever clinical drug trial for Progeria, and we are excited to announce that we are halfway there!

Turn to page 2 to learn more about the expansion of our *Circle of Hope* campaign, and to find out how you can help in our efforts to make Progeria **history!**

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

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## *You Can Be Part of History...* **Support a First-Ever Progeria Clinical Drug Trial**

**Please help us raise \$2 million towards funding a clinical trial!**

### **Our Circle of Hope has expanded...**

Eleven months ago, the Circle of Hope campaign was created to raise \$100,000 per year for five years to keep our Cell Bank, Diagnostics Testing, research grant funding, and other programs running full speed ahead. Meeting this fundraising goal would allow us to keep up with the ever-increasing interest in Progeria research, and to continue our record-breaking pace of progress.

Who could have imagined that less than a year later, we would be in the midst of a campaign to raise \$2 million to fund a first-ever drug trial for Progeria?!

**Our Circle of Hope campaign now includes this tremendously exciting undertaking.**

**Please help us keep the Circle intact, so the Hope of a cure becomes a reality.**



**Together we WILL find the cure!**

**Go to [www.progeriaresearch.org/ways\\_to\\_donate](http://www.progeriaresearch.org/ways_to_donate)**



## In Loving Memory of the Children

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



**Zach**  
3 years old,  
from the  
United States



**Kristian**  
3 years old,  
from the  
United States



**Michaela**  
11 years old,  
from England



**Juan Carlos**  
10 years old,  
from Columbia



**Mirko**  
21 years old,  
from Argentina



We are saddened by the loss of a great friend of The Progeria Research Foundation, Chris Williams, who passed away peacefully in his home on October 28, 2006. Chris was the drummer and a founding member of Pat McGee Band, which headlined our first benefit concert in 2000. He was a beloved friend to Sam and all children with Progeria and will be deeply missed. (Photo: Chris with Sam and Leslie)

## More PRF-Driven Studies Pave the Way for an FTI Clinical Drug Trial

– and Support the Link of Progeria to Heart Disease and Aging

*Investigators continue to drive Progeria research to new levels of progress in our quest for the cure*

### PRF-Funded Research

Last September, PRF-funded researchers published cell culture studies which gave support for moving ahead with an FTI drug treatment trial for children with Progeria – Progeria cells became normalized (in a laboratory dish) when given this drug.

The next phase of testing has been in animal models, which produced extremely encouraging results this year! Studies by UCLA researchers, including **Drs. Shao H. Yang, Loren G. Fong, and Stephen G. Young** have shown that an FTI prevents some aspects of disease in a Progeria mouse model, including improved bone density, reduced bone fractures, delayed onset of the disease, weight gain, and longer lives. **These studies provide vital support for clinical treatment trials in Progeria.**

- Prelamin A and lamin A appear to be dispensable in the nuclear lamina. *Journal of Clinical Investigation Vol 116, No. 3 March 2006*
- A Protein Farnesyltransferase Inhibitor Ameliorates Disease in a Mouse Model of Progeria. *Science*, Feb. 2006

Supporting Review Article:

- “Protein farnesyltransferase inhibitors and Progeria” by **Drs. Margarita Meta, Shao H. Yang, Martin O. Bergo, Loren G. Fong and Stephen G. Young** in *Trends in Molecular Medicine*, Volume 12, Issue 10, October 2006.

**Drs. Karima Djabali and Dayle McClintock** (Columbia U., NY) and PRF Medical Director **Leslie B. Gordon** (Brown U., Rhode Island) published a study concluding that the defective protein produced by the Progeria gene (called progerin) builds up in cells of the children's vessel walls. **This shows us, for the first time, that there is a direct connection between progerin and heart disease.**

- Hutchinson-Gilford progeria mutant lamin A primarily targets human vascular cells as detected by an anti-Lamin A G608G antibody. *PNAS* 2006.

In an international collaboration, **Drs. Joan Lemire** (Tufts U., Boston MA), **Carrie Patis and Anthony Wiess** (U. Sydney, Australia), **Leslie Gordon** (Brown U.), **John D. Sandy** (Shriners Hospital, FL), and **Bryan Toole** (Med. U. South Carolina), have examined the expression of genes in HGPS fibroblasts. They found elevated expression of aggrecan, a component of cartilage. Basic studies of this type contribute to our understanding of the many tissues of the body that are affected in Progeria.

- Aggrecan expression is substantially and abnormally upregulated in Hutchinson-Gilford Progeria Syndrome dermal fibroblasts. *Mech Ageing Dev.* 2006 Apr 28.

### Selected Studies by PRF Workshop Attendees

For a complete list of ongoing scientific studies, go to [www.progeriaresearch.com/scientific\\_publications](http://www.progeriaresearch.com/scientific_publications)

In another stunning display of advancements in Progeria research, a study conducted by **Drs. Tom Misteli and Paola Scaffidi** from NIH's National Cancer Institute (Dr. Misteli is a newly-funded PRF research grantee!) found that cells taken from normal healthy adults over the age of 75 showed many similar defects as cells taken from children with Progeria. These findings present the closest link between Progeria and normal aging to date.

- Lamin A-Dependent Nuclear Defects in Human Aging. *Science*, April 27, 2006

The laboratory of **Dr. Francis Collins**, Director of the NIH's National Human Genome Research Institute, has forged ahead and produced a Progeria mouse that carries a genetic mutation identical to that of children with Progeria. This mouse model will be pivotal to our understanding of how children with Progeria develop heart disease, and can be used to explore cardiovascular disease in general. It will also serve as an excellent model for testing new treatments and genetic therapies for treating and curing Progeria. This two-year project was a tremendous cooperative endeavor, involving researchers from the National Human Genome Research Institute (MD), Karolinska Institute (Sweden), National Heart, Lung and Blood Institute (MD), U. Washington (WA), and Brown U. (RI). Kudos to authors **Drs. Renee Varga, Maria Eriksson, Michael R. Erdos, Michelle Olive, Ingrid Harten, Frank Kolodgie, Brian C. Capell, Jun Cheng, Dina Faddah, Stacie Perkins, Hedwig Avallone, Hong San, Xuan Qu, Santhi Ganesh, Leslie B. Gordon, Renu Virmani, Thomas Wight, Elizabeth Nabel, and Francis Collins.**

- Progressive vascular smooth muscle cell defects in a mouse model of Hutchinson-Gilford progeria syndrome. *PNAS* 2006 Feb 28;103(9):3250-5.

Clinical Geneticist **Dr. Raoul C.M. Hennekam** (U. of Amsterdam) has published a detailed clinical characterization of Progeria that not only analyzes medical charts from 10 children with Progeria, but provides a full review of the published clinical field.

- Hutchinson-Gilford progeria syndrome: Review of the phenotype. *Am J Med Genet A.* 2006, Jul 12

## PRF Awards Four More Research Grants

PRF continues to invest your generous contributions in the work of dedicated researchers who are working intensely every day to find treatments and a cure for Progeria. In 2006, four more grants were approved, bringing our total to 19 research grants PRF has funded.



**Zhongjun Zhou, PhD**  
**University of Hong Kong**  
**China**

### *Stem Cell Therapy of Laminopathy-Based Premature Aging*

Stem cells are the cells that can self-renew and differentiate into a variety of different cell types. They are important because

they replace the worn-out cells in the body and maintain the functional integrity of our body. The various tissues in our bodies are rapidly renewed by stem cells and it is common that stem cells decline in aged people. Dr. Zhou hypothesizes that stem cells in HGPS patients are compromised and cannot provide enough new cells for the renewal of various tissues, therefore leading to an accelerated aging process. In this project, Dr. Zhou will use a mouse model for HGPS to test whether the number and functions of stem cells in HGPS mice decline and whether stem cells (bone marrow) derived from healthy mice will rescue the aging phenotypes in HGPS mice. This work directly tests the feasibility of a potential therapeutic strategy for a number of premature aging diseases.

Dr. Zhou is an Associate Professor in the Department of Biochemistry and Faculty of Medicine at the University of Hong Kong and obtained his PhD in Medical Biochemistry from Karolinska Institute in Sweden, where he also performed his postdoctoral training in the Institute's Department of Medical Biochemistry and Biophysics. His group's main focus of research is on molecular mechanisms of laminopathy-based premature aging. In addition, his group, in collaboration with groups in Spain and Sweden, genetically engineered a Zmpste24 deficient mouse to serve as a mouse model for HGPS.



**Michael Sinensky, PhD**  
**East Tennessee State University**  
**Johnson City, TN**

### *Effect of FTIs on the Structure and Activity of Progerin*

Hutchinson-Gilford Progeria Syndrome (HGPS) arises from a novel mutation in the gene encoding the protein prelamin A.

Normally, prelamin A undergoes a series of biochemical alterations which allow it to form a part of a structure in the nucleus called the nuclear lamina. The mutant prelamin A formed in HGPS (called progerin) is defective in the last of these biochemical alterations leading to accumulation of an intermediate molecule bearing a lipid group referred to as farnesyl. Compounds, called FTIs, which block the formation of this lipid bearing version of progerin have been postulated to be of therapeutic use in the treatment of HGPS. This project will test the hypothesis that progerin exhibits novelties in its molecular structure that are secondary to adding farnesyl, particularly the addition of phosphate. This hypothesis will be tested as will the effects of FTIs on these postulated additions of phosphate.

Dr. Sinensky is Professor and Chair in the Department of Biochemistry and Molecular Biology at East Tennessee State University's Quillen College of Medicine. His career-long, pioneering work in the LMNA field (the gene responsible for Progeria) has been key to our understanding of how Lamin A plays a role in Progeria, and how to go about finding new treatments.

**Read more "Research Grant" profiles on next page...**



**Susan Michaelis, PhD, speaks at the 2005 International Progeria Workshop. Dr. Michaelis is a PRF research grantee whose findings were published in PNAS.**



**Jan Lammerding, PhD**  
**Brigham & Women's Hospital**  
**Cambridge, MA**

*The Role of Nuclear Mechanics and Mechanotransduction in Hutchinson-Gilford Progeria Syndrome and the Effect of Farnesyltransferase Inhibitor Treatment*

Dr. Lammerding will conduct a series of experiments to evaluate if cells from Hutchinson-Gilford Progeria syndrome patients are more susceptible to damage through mechanical stimulation. In addition, Dr. Lammerding's experiments will test if treatment with farnesyltransferase inhibitors (FTI) can reverse mechanical deficiencies in HGPS cells and thus lead to a reversal of some of the tissue-specific disease phenotypes.

Dr. Lammerding is an Instructor at Harvard Medical School serving in the Department of Medicine at Brigham & Women's Hospital. His areas of interest include subcellular biomechanics and the cellular signaling response to mechanical stimulation. In particular, he is focusing on how mutations in nuclear envelope proteins such as lamin can render cells more sensitive to mechanical stress and affect their mechanotransduction signaling. Insights gained from this work can lead to a better understanding of the molecular mechanism underlying laminopathies, a diverse group of diseases including Emery-Dreifuss muscular dystrophy, HGPS, and familial partial lipodystrophy.



**Tom Misteli, PhD**  
**National Cancer Institute, NIH**  
**Bethesda, MD**

*Molecular Therapy Approaches for HGPS Via Correction of Pre-mRNA Splicing*

Dr. Misteli and his team are developing novel therapeutic strategies for Progeria.

His group's work focuses on interfering with the production of the progerin protein using highly specific molecular tools and to find novel small molecules to counteract the detrimental effects of the progerin protein in patient cells. These efforts will lead to a detailed cell biological understanding of Progeria cells and bring us closer to a molecularly-based therapy for Progeria.

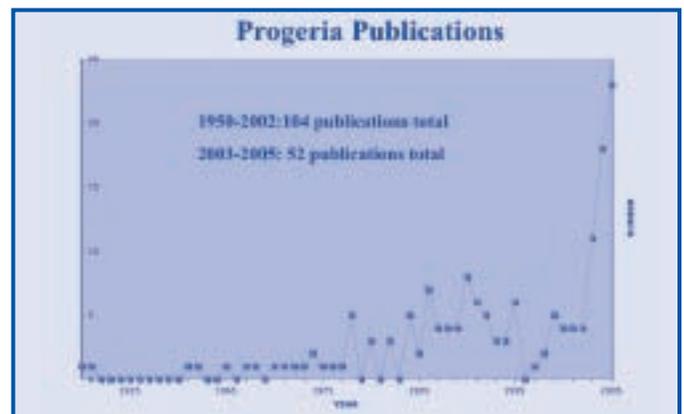
Dr. Misteli is a Senior Investigator at the National Cancer Institute where he heads the Cell Biology of Genomes Group. He is a member of the NCI Center for Excellence in Chromosome Biology. Dr. Misteli has pioneered technology to analyze the function of genes in living cells and his work has provided fundamental insights into genome function.

### About PRF's Research Grants...

A major part of our mission is to fund and promote basic science and clinical research on Progeria in order to accomplish our goal of developing treatments and a cure. PRF awards research grants (19 to date!) through peer review by our volunteer Medical Research Committee and approval of our Board of Directors. Awards of up to \$100,000 over a two-year period have allowed innovative new research in Progeria to thrive.

**Grant applications are accepted twice per year.**  
**For more information, please go to:**  
[www.progeriaresearch.org/grant\\_application](http://www.progeriaresearch.org/grant_application)

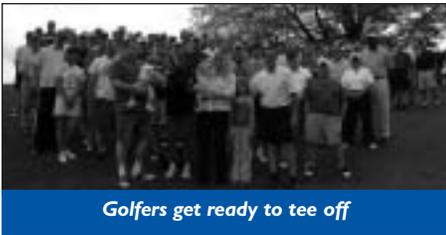
**Cells and tissues are also provided for research in Progeria:**  
[www.progeriaresearch.org/grant\\_application](http://www.progeriaresearch.org/grant_application)



*Funding research is the key to success. Every new research finding brings us closer to a cure! From 1950-2001, there were a total of 104 peer review publications on Progeria – an average of about two per year. From 2002-2005, 52 publications appeared – that's a 550% annual increase!*

## Family Events

More and more families from all over the world are joining in our mission to find a cure for their children, grandchildren, nieces, nephews, and siblings with Progeria. We are forever grateful for their growing support.



Golfers get ready to tee off

### 2nd Annual Sarah Kennedy Golf Tournament Raises Record Amount

Raising over \$17,000 – more than four times as much as last year! – Sarah’s grandfather Chris Kempf was overjoyed as 150 golfers teed off at Eagle Valley Golf Course in [Indiana](#). Joining Sarah again this year was her friend Kaylee Halko, and new to the event were National Mrs. representatives Raelee Toye (National Miss 2006) and Justine Kaldahl (Mrs. Indiana 2006). Chris was overwhelmed with the response and generosity of all who attended, and so are we!



Kaylee and “Big Dave”

### Halko Family and Red Hat Society’s Rowdy Rabbles Barbecue for PRF

The Halko’s and Rowdy Rabbles of [Ohio](#) are at it again! Led by Kaylee Halko’s great-great Aunt Carol, the ladies in red hats and purple clothes and other friends and family held a Chicken BBQ, raising \$1,900! Hundreds of hungry supporters grabbed a sandwich as

Kaylee’s brother Timmy gave them PRF brochures. Many thanks to the volunteers who ran back and forth all day, taking and delivering orders, and Dave the Bar-B-Q man for a job well done.

### Sibling Devotion

In loving memory of their brother Zachary Moore, Courtney and Derek held a bake sale for PRF in February with their friends at their [Oklahoma](#) elementary school. They sold homemade goodies and drinks, raising over \$300 in one day. We are honored that they chose to honor Zach in this way.



The Moore family and friends



Lindsay is all smiles at the race.

### Lindsay’s 2nd Annual “Miles for Miracles” Race a Huge Success

Thanks to the hard work and publicity surrounding the Flat Rock, [Michigan](#), race put on by Lindsay’s family and friends, they raised over \$35,000 and had over 400 people walking and running to help find a cure. Last year they raised \$7,000 and had 20 walkers – what a leap! “I am still reeling over this accomplishment!” says Lindsay’s grandma and race co-organizer Rosie, “Lindsay’s FOX-TV story touched hundreds of people and inspired them to want to help. It is truly amazing to see sponsors and people volunteering who we have not known before this.”



Steve and Sandy Nighbor share a laugh

### Ambassador Family Holds Series of Fundraisers

The Nighbor family has held several events in [Wisconsin](#), this year to help raise money for Progeria research, and they have been busy speaking to the media to raise awareness. A Texas Hold-Em Poker Tournament, BBQs at a local grocery store, and food and games at the Crossroads Bar raised over \$5,000, and more events are coming! Plans for a bowl-a-thon event in 2007 that includes raffles, an auction, and bake sale are in the works, so stay tuned for more details on when and where!

### Family Raises Money Through the “Italian Association For Progeria – Sammy Basso”

[Italy](#) has many PRF supporters, thanks to the family and friends of Sammy. They have organized a group devoted to raising money and awareness for Progeria research, and they have been busy holding several events that have raised over \$50,000 to date – amazing!



Sammy with the A.I.Pro.Sa.B. Directors

Read more “Family Stories” on next page...

## More Family Events...

### Mateo's Aunt Luciana brings Awareness and Fundraising to Argentina

It started with selling PRF wristbands and has spread to her college. The aunt of four-year-old Mateo of [Argentina](#) has organized a group of 50 students of Profesorado Superior De Lenguas Vivas College in Salta to hold a raffle and plan other events. "I am so excited that so many people are helping me do this event for PRF, which is doing so much for Mateo," says Luciana.



### Hayley Sings for Progeria

The Okines family teamed up with [United Kingdom](#) singer/songwriter Jane Winiberg, songwriter and producer Mark Street, and Kids Choir 2000 to create and promote "Voices of Tomorrow," an inspiring song about Hayley. The Okines appeared at a CD release concert in March, have sold dozens of wristbands, and are often interviewed by UK media to raise awareness about Progeria.

(You can buy this CD at our store:  
[www.progeriaresearch.org/shop\\_in\\_our\\_store](http://www.progeriaresearch.org/shop_in_our_store))



Everyone released bright blue balloons into the sky as the walk began

### McGuinness Family Holds 1st Annual Walk in Honor of Son Kristian

Classmates, teachers, friends, and family of Kristian McGuinness gathered at his Lincoln D. Lynch

School in Middleboro, [Massachusetts](#), in September for a two-mile walk. Classmates wore special t-shirts with his picture on them, and loads of photos of Kristian – always with a huge smile on his face! – were on display for all to enjoy. "We wanted to organize something that would let those who knew Kristian do something for him," say mom and dad, Kathy and Tom. "It's also a great way to raise money for PRF to help others with this condition." Thanks to the many sponsors, donors, and walkers, \$15,000 was raised and everyone enjoyed a day in the bright sunshine, keeping Kristian close to their hearts and in their thoughts.

## So much to say, so little space...

We need to spend more money on research, and less on paper and postage!

You can get more details on these events and other news on our website at [www.progeriaresearch.org/events](http://www.progeriaresearch.org/events)

## Plans for NIGHT OF WONDER 2007 are UNDERWAY!



Save the date! **November 10, 2007**

PRF will host our biannual gala in Boston, MA.

Watch for details on our website, in email blitzes, and in the mail...

You will NOT want to miss this event!

## More events... More awareness... More money raised for Progeria research!



*Phil and Jodi Mitchell & family  
all ran the race*

### 5th Annual International Race for Research the Biggest and Best Yet!

With nearly 250 people (almost double the number from last year!) running, walking, and pushing children in strollers in PRF's hometown of Peabody, MA, dozens of sponsors, and a pre-race party at Champions Pub where comedian Gary Gullman stepped in as the celebrity bartender, we raised an astonishing \$25,000. With the other Races for Research held in Ohio, Michigan, and Middleboro, MA (see pages 11 & 12), the total raised in 2006 from races is \$111,000 – AMAZING! Every year our race gets bigger and more races are held in other cities and towns.

Heartfelt thanks to all who participated in these races, including our major sponsors: **NORTH SHORE BANK**, Peabody Track Foundation, Peter Albert - Northwestern Mutual Financial Network, Lew & Alice Berns, Champions Pub, Burt & Barbara Gordon, Eastman Gelatine Corporation, Gravoc Associates, the Keilty Family, North Shore Tile & Marble, and Total Entertainment.



*6-month old Lily Clare  
Paine was the youngest  
race participant!*



*Gary Gullman entertains  
the crowd at the pre-race  
party*



*The final table of remaining players  
competed for 1st place*

### PRF'S 1st Texas Hold'em Poker Tournament a Success!

What fun! Seventy-five people gathered at the Knights of Columbus in Norwood, MA, in May for this popular FUNdraiser which raised \$3,500. All enjoyed delicious food, raffles, and a silent auction, and plans for another tournament this winter in Peabody, MA, are already being made. Lisa Corcoran, a Night of Wonder 2005 attendee who was so impressed and taken with PRF's work that she wanted to help in some way, organized this event. Thank you, Lisa!

### National Mrs. Pageant Organization Teams up with PRF!

PRF's Executive Director Audrey Gordon and Ambassador Family members Sandy, Steve, Michaela, and Megan Nighbor traveled to Tennessee to attend the National Mrs. pageant in July, and were warmly greeted with energetic offers of support. Many state delegates are holding fundraisers and raising awareness in their communities. "The Progeria Research Foundation is our charity of choice for raising funds and awareness to find a cure for children with Progeria," said pageant co-owners Sherry Strother and Djuana Stump. Thank you, ladies, you are beautiful inside and out!

Congratulations to National Mrs. Indiana's Justine Kaldahl, winner of the "Megan Nighbor Inspiration Award" for actively promoting Progeria research. Justine has appeared at several fundraisers and has been a tremendous source of support for PRF.



*National Mrs. 2007, Paula Folkers  
of Nebraska, with Megan*

# WOW

The number of PRF chapters has grown from ONE to FOUR in less than a year!

## PRF Chapter News . . . .

### CALIFORNIA

#### **YearOne Braselton Bash**

YearOne owner Kevin King and his team, along with California chapter board member Chip Foose and the Overhaulin' crew raised \$90,000 as a record crowd came to this popular annual car show in June in Georgia. A VIP poker tournament, silent auction, Best in Show contest, raffles, and autograph session all contributed to this incredibly successful fundraiser. "We're doing this again next year," said Kevin. "We want to help in any way we can." Thank you to Kevin, Marci Stephens, and all who helped make this a phenomenally successful event.



*Audrey with Chip Foose and Overhaulin' co-stars AJ and Chris, who signed autographs all day as fans waited for hours to talk to the popular crew*

#### **Wheels and Waves Show in Santa Barbara**

In April, PRF's CA chapter raised \$5,000 at the Wheels and Waves Show, with the help of Foose family friends Dick and Eileen Howett. Lots of people donated to our collection cans and bought PRF wristbands and raffle tickets for a set of Foose wheels and a custom Real Fire Flames paint job by the talented Kurt Grimes.

#### **Bobco Party in Lake Elsinore**

This year Bobco Auto of California teamed up with PRF's CA chapter for their annual F-100 Super Tour kickoff party, making it a fundraiser for PRF and raising \$24,000! Many thanks to the event sponsors and organizers: Pickups Limited's Bonnie and Bill Lee, Bobco's Bob and ShirI Carvajal, Dan and Cathy Cangro of Vintage Vinyl, and dozens of vendors who donated items for the auction and raffle. "We are hoping to make this our first annual event and to top our donations in the coming years" said Bob and Shirley. "It was a true pleasure being a part of the miracle that is happening in your research."



*Sam and Terry Foose are presented with a "check" from one of the generous Bobco event supporters*

#### **Teaming up with Sioux Falls Ford and Rydell Management Company**

Hundreds helped "Drive the Cure for Progeria" in Sioux Falls, SD, in June, raising over \$50,000 for Progeria research! The day included a private luncheon with Chip Foose, the introduction of the new Foose Stallion Mustang, and donations for Overhaulin' items autographed by Chip.



*Randy Nehring (Sioux Falls Ford dealer) Heidi Lea-Nehring Bloom, and Debbie Nehring present Chip Foose and mom Terry with "the big check"*

#### **Back to the 50's Show**

In St. Paul, MN, Chip signed autographs on his signature FOOSE Design and Overhaulin' t-shirts, hats, and posters; and money was collected through our signature PRF Coins to Cure Progeria® drive, raising over \$8,400 and pleasing hundreds of fans.

**See page 19 for the most recent California Chapter event: Unique PerformanceFest!**



## MICHIGAN

**The Michigan Chapter of PRF officially opened** with its first meeting on September 29, 2006, led by Lindsay Ratcliffe’s parents, Kristy and Joe. The group plans to continue to hold its annual “Miles for Miracles” race (see page 11), and now with the added support from chapter board members and other volunteers, the group is excited to plan additional events in 2007 and beyond.



*The Michigan Chapter Board of Directors and Lindsay*

## OHIO

**It was a busy weekend for the Ohio Chapter of PRF**, as they kicked off their first event and held their first meeting on September 30, 2006. Led by Kaylee Halko’s parents, Tim and Marla, this group organized “Kaylee’s Course,” a 5k run/3-mile walk at Monclova Primary School where Kaylee’s siblings attend school. Nearly 400 people participated and the race raised almost \$40,000 – what a great start!



*The Ohio chapter Board of Directors with Audrey Gordon*

## ENGLAND

**PRF Chapters are spanning the globe**, with Hayley Okines’s family starting the first international chapter of PRF. Called “Hayley’s Hope – Progeria Research Support in the UK,” the group, led by parents Mark and Kerry Okines, is a registered UK charity and plans to kick things off in December for Hayley’s 9th birthday. Mark and Kerry have held fundraisers for PRF in the past, and also devote time to media interviews to help raise awareness of Progeria.



*And they’re off! Hundreds participate in “Kaylee’s Course” in Ohio*

**Congratulations to all our new PRF Chapters! You can read Chapter updates at our website. If you would like to learn how you can start a local chapter in your community, please call the PRF office at 978-535-2594.**



*The Okines: Mark, Hayley, brother Louis, and Kerry*

## PRF On the Move: Public Awareness Reaches New Heights!

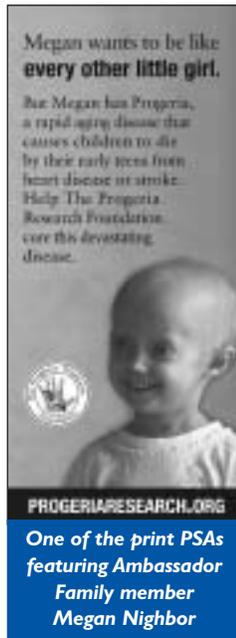
*In 2006, stories about PRF and Progeria have reached an estimated audience of more than 114 million people through print, broadcast, and internet coverage.*



### Celebrities Continue to Support PRF with Public Service Announcement

The recognizable voices of Ted Danson and Mary Steenburgen are featured in a public service announcement (PSA) campaign launched this summer by The Progeria Research Foundation. Proud supporters of PRF since 2003, the couple lend their time and talent to help raise awareness of Progeria and highlight the need for more research of this disease. The TV PSA alone has already reached more than 60 million viewers! You can view all versions of the PSA at [www.progeriaresearch.org/public\\_service\\_announcements](http://www.progeriaresearch.org/public_service_announcements)

Thank you Mary and Ted, and **CVS/pharmacy** for sponsoring the costs for copying and distribution of the PSA to hundreds of media outlets throughout the country, and to In Five Productions, TV Access, and Spectrum Science Communications for donating time, talent, and materials to create and launch the PSA.



### Dateline NBC, Primetime, FOX 25, Discovery, and TLC among TV media Airing Pieces on Progeria and PRF

It's been quite a year for PRF's public awareness activities! A special thank you to Spectrum Science Communications for their tireless work on our behalf, and to the many families who have participated in interviews to raise awareness and gain new PRF supporters.

### In Other News...

#### PRF's Medical Director Receives Working Mother of the Year Award

Looking for "gutsy go-getters whose innovative thinking, intrepid spirit, and influential lives make you feel as if anything is possible," *Working Mother* magazine selected Dr. Leslie Gordon as a 2006 Working Mother of the Year. She was honored at an awards ceremony in New York City on May 16, along with actor Susan Sarandon for her work as a UNICEF ambassador and activist, the first female fire chief in Arizona, and an aspiring corporate manager. Leslie received a standing ovation for her tireless work as PRF's founder and medical director.



Susan Sarandon with Sam, Leslie Gordon, and her husband, PRF Chairman of the Board Scott Berns

#### Executive Director Receives Mary Upton Ferrin Award

In March, the Peabody, MA, Chamber of Commerce awarded the 2006 Mary Upton Ferrin Community Service Award to Audrey Gordon for her role in the creation of PRF. This award recognizes "someone in the Peabody community who has been a leader and role model, conquering unique challenges and overcoming obstacles to effect change and achieve success for the good of the people."



Audrey Gordon with Peabody Mayor Michael Bonfanti and Chamber President Deanne Healy

## Our Latest Miracle Makers

Now more than ever, PRF relies on its volunteers to help spread the word and raise funds for medical research and the clinical drug trial. As you can see from this latest list of Miracle Makers, the possibilities are limitless!



### Wedding Bells Chime for Katie, Rory, and PRF!

Congratulations and thank you to newlyweds Katie and Rory Bloom of Attleboro, MA,

who were married in May. In lieu of giving wedding favors to their guests, they made a generous donation to PRF. They also gave each guest a card explaining what Progeria and PRF were all about, and why they gave this donation in their honor. "I hope that in getting the word out to our 200 guests, we in some way inspired others to donate to your organization," says Katie. "We were so happy to have been able to share our special day with PRF in this way!"

### "Hats Off" to the Senior Class of Gackle-Streeter School!

Every year, Kristi Anderson, a teacher in Gackle, ND, has each student in her Senior English class present a persuasive speech about his or her favorite charity. After the speeches, the students vote to support one of the charities, and the class works together on a fundraiser. PRF won the class vote and they raised over \$400 with a "Hat Day" and contribution from the Senior class account. Thank you, Class of 2006, and good luck to all of you!



### Mary Rose Raises Awareness, Personally Donates to PRF!

Mary Rose, an 8th grader from Butler, NJ has wanted to help PRF since she saw a show about the children. So she bought a wristband and has done school projects on Progeria. She also wants to help raise money, so she is planning a bake sale at her gymnastics school. In the meantime, she sent PRF \$75 of her own money! Thanks, Mary Rose!

### New York High School Faculty Dresses Down for PRF!

Many thanks to Principal Phil Lima and faculty at Suffern High for choosing PRF to receive money raised from their "dress down" Fridays during October. They raised \$442 and got to wear casual clothes – so everybody wins!

### Temple Beth El's "Keren Ami" Collection Helps PRF!

Many thanks to the student committee, faculty, and children of Temple Beth El's Religious School in Newark, DE, for choosing PRF as a recipient of the children's Keren Ami collection, which means "Fund for Our People," this year. Each week the children bring money to class in the spirit of helping others, and charities are chosen at the end of the school year. PRF received almost \$500 – WOW!

### Fourth Graders Choose Progeria for Class Project and PRF for Fundraiser Proceeds!

Kaylee Halko's brother Timmy and his Monclova, OH, elementary school classmates complete a community service project every year. They raise money and donate it to a charity they have researched and chosen. This year the class overwhelmingly picked The Progeria Research Foundation, and held a bake sale that raised over \$250 – wow! They also asked Kaylee's parents to come and talk to them about Progeria. The local news station filmed the event and the story was shown on the local ABC News. Kaylee enjoyed meeting and giving high fives to all the students!

*There are thousands of schools and religious groups whose students collect money and/or hold fundraisers for charities throughout the school year. Please nominate PRF to receive these donations!*

### PRF Spirit (and Our Wristbands) Takes Over an Ohio Elementary School!

Allie, a 4th grader and neighbor of Kaylee Halko's family, was wearing her PRF wristband at school in early 2006 when her teacher noticed and asked about it. Not only did he buy some wristbands, but he also allowed Allie to tell her classmates about Progeria and sell wristbands to them. When Kaylee's brothers Timmy, 8, and Brendan, 6, heard the story, they got excited and wanted to sell the wristbands in their classes. So far, the children have made over \$350 and sold 40 youth bracelets in just two days, WOW! Way to go kids!

**Do we have your email address?** There's lots of exciting news happening at PRF and we want you to be the first to know! Learn about breaking news of scientific advancements, TV appearances, events in your area, etc.

Sign up through [www.progeriaresearch.org](http://www.progeriaresearch.org) or email us at [info@progeriaresearch.org](mailto:info@progeriaresearch.org) and we'll put you on our email blitz list TODAY!

**More Miracle Makers...****Rising Star Megan Meets Lindsay at Benefit Concert!**

Young Tejano singer-songwriter Megan Leyva and her mom, Hilda, of Croswell, MI, saw a news story on Lindsay, who stole their hearts and motivated them to help PRF. So in July they organized a concert and donated the proceeds from her CD sales that night. Megan sold almost \$500 worth of CD's at the sold out show, WOW!

**British Company Holds Casual Day for PRF!**

Many thanks to the employees of Hampshire's Winterthur Company, who raised over £328 (US \$585) from their Casual Dress day in March. They join the growing list of companies who devote a day where they allow their employees to come to work in jeans and other casual wear in exchange for a donation to charity. It's a win-win for the employees, the companies and PRF!

*Ask your employer to hold a Casual Day for children with Progeria!*

**New York Girls Raise Money Selling Handmade Jewelry!**

Eleven-year old Kim from Port Washington, NY, has always donated money to PRF from her piggy bank, and wanted to

raise money for Progeria research in another way. So this talented young lady, who has been making and selling beaded jewelry "by a tween for tweens" this year, had a jewelry sale on May 6.

Kate, Lucie, and Alyssa, friends of Kim and Kim's younger sister Sammy, helped out all day. Sammy made and sold refreshments and raffle tickets for prizes and helped hand out brochures and newsletters to spread the word about PRF. Together the sisters and their friends raised over \$1,100! Congratulations to the girls and to the lucky folks who now own an original piece of jewelry made by Kim!

**Walking for a Cure!**

Teacher David Kenigsberg and the students of Santa Teresa High School in San Jose, CA, held a Walk-a-Thon in April 2006 as a class project. They collected almost \$300, and chose PRF to donate the money to. Now *THAT's* class spirit!

**"Brewin' Up" a Cure!**

Ashley, a college student at California Polytechnic State University in San Luis Obispo, had been thinking about planning a benefit concert for months, but wasn't sure who to raise money for. Then she saw a program featuring Progeria on TLC, and knew PRF was the one! Within days she recruited lots of people to help out, including Speech Communications classmates, her Professor Nina Truch, and friends. The concert was held at the Downtown SLO Brewery in February and featured Seattle native musician Dan Purser and other bands. The event was a great success, raising awareness of Progeria and over \$3,000! Thanks to Ashley and friends for brewin' it up for Progeria!

**2nd Annual Charity Hog Roast Raises £1000 (US \$1,785) for Progeria!**

The Connell Family in the Essex village of Little Yeldham joined together for a day of fun, good food, and giving at their second

annual fundraiser for PRF. Over 100 people feasted on delicacies donated by local businesses. The two-day event included raffles, "sumo" wrestling (see photo), a bouncy castle, and a garden tent sleepover. Thank you to Jenny, Brenda, Amy, and Dan for your tireless efforts in organizing such a fun and successful event!

**Student Raises over \$1,200 During "Progeria Awareness Week"!**

In February 2006, high school student Kristen, of Moon Township, PA, held a "Progeria Awareness Week". She hung her original hand-painted posters around the school; made daily announcements; set up a table outside the lunch room to sell wristbands, collect donations, and hand out brochures; and did a letter writing campaign and candy drive. Thank you, Kristen, for all your hard work on behalf of children with Progeria.

**Candy Wreath Raffle Scores Big at Bowling Alley!**

In December 2005, Meagan of Zion, IL raffled off home-made candy wreaths for PRF. Meagan, an aspiring pediatric physician, has always been interested in Progeria. The raffle was held at the bowling alley where she works. With the help of her professor and bowlers from the men's and women's team clubs, she collected \$500 for PRF! "I don't know anyone with Progeria, but the stories touched my heart and inspired me to help," she said. Thanks, Meagan. We are lucky to have you on OUR team!

**More Miracle Makers...**



**Parachuting for Progeria!**

Just when we think our Miracle Makers have thought of every way possible to raise money for research, along comes Mike Brody with an idea that takes us to new “heights”: Mike, a firefighter who lives on Staten Island, NY, and sky diving friends David Bauer and Max Cohn

jumped from 3,000 feet not once but 38 times, floating to the ground carrying a PRF banner – AMAZING!

The men raised \$2,000 from people sponsoring their jumps, with all proceeds benefiting PRF. “We got to jump out of planes and raise money to help kids. It’s a win-win situation,” says Mike. It certainly is, guys, thanks so much! They plan to do this again in 2007, so watch for details on our website events section.

**Luck of the Irish and for PRF!**

Congratulations to Chas Newkey-Burden, who ran the Dublin Marathon in October and, despite a cold and strong winds for large parts of the race, finished with a terrific time of 4 hours, 20 minutes. Chas has raised almost \$500 to date.

If you’d like to make a donation in his honor, go to: [www.firstgiving.com/ChasNewkey-Burden](http://www.firstgiving.com/ChasNewkey-Burden)



**Ohio Hospital Holds Bake Sale for Progeria Research!**

In October 2006, staff from Mercy Hospital of Defiance and Defiance Clinic raised \$500 for PRF at a bake sale and raffle. In addition to baked goods, Tami Cupp made breakfast burritos (yum!) and donated home decorating items for the raffle. Many thanks to Tami, Tammy Olivo, and Cindy Wiles for coordinating the effort.



**PerformanceFest Raises \$30,000 for PRF!**

Chip Foose and PRF’s California chapter are at it again, raising awareness and funds for Progeria research at car shows

throughout the country. Unique Performance held their show in October in Farmer’s Branch, TX, where about 10,000 people admired 325 of the finest vehicles on display, and enjoyed an autograph session with Chip Foose, raffles, entertainment, food, and moving speeches from Chip and host Sam Pack. Originally estimates came in at \$20,000 (see the check presented to PRF’s President Audrey Gordon!), but later tallies have it at \$30,000 – incredible!

Many thanks to Miracle Makers Doug and Jennifer Hasty, Sam Pack, Tess Neilson, and the dozens of people who helped make this event possible.



**Janet Raises Money with Cans in UK!**

Moved to help because of England’s Hayley and Michaela, Janet Thomas has placed cans in local shops, inns, and banks in Sidley and Bexhill, and in just two months they have collected £132.40 (US \$250).

“I have two boys and if I ever needed help with them I wish that someone would be there for me, so I want to be there for others,” explains Janet. “Next year I hope to raise a lot more.” Thank you, Janet, and thanks to all the owners and workers in the stores who are helping as well.

The collection cans are a wonderful example of how “Together, we WILL find the cure!” Thank you, Janet! And thank you, Nick Highfield, boss at the Candy Corner.

*Do you know about the COINS TO CURE PROGERIA® Challenge? Over 100 volunteers have committed to fill 400 cans with their personal change or through store customers in the US, England, Canada, Sweden, Hong Kong, Italy, and Australia! You, too, can accept our “challenge” – call or email today!*

**Please visit PRF at [www.progeriaresearch.org/get\\_involved](http://www.progeriaresearch.org/get_involved) for lots of others ways you can help make the miracle of a cure happen.**



**PRF strives to raise awareness.** There are many ways in which you can help, and some require little effort or money on your part. Every word, every dollar helps. Please tell all your friends and family about these opportunities, and together we WILL find the cure!



**Search the Internet for Progeria through Goodsearch.com**

GoodSearch.com is a search engine that donates half its revenue to the charities its users designate. The site is powered by Yahoo!, so you'll get the same quality search results that you're used to. Go to [www.goodsearch.com/toolbar](http://www.goodsearch.com/toolbar) to add the GoodSearch toolbar to your browser, and type in PRF in the "my charity" box (you must reenter PRF if "cookies" are deleted). It takes less than 30 seconds to set up, and you will be raising money for PRF doing searches you'd do anyway and at no cost!

**Federal Employees: Donate to PRF through the CFC**

PRF is part of this year's Combined Federal Campaign, the federal government employees' charitable giving program. Please select PRF, listing number 9289.



**PRF Gets Ad Council Endorsement, PSA Airing in Times Square**

We're thrilled about PRF's Public Service Announcement (PSA) airing on the Astrovision in New York City's Times Square twice an hour during the month of November.

More great news: the PSA (see story on page 16) has been endorsed by the Ad Council, a highly respected organization whose endorsement is considered the "seal of approval" for PSA campaigns. This fantastic opportunity brings increased exposure for PRF, which will be featured in the Ad Council's November/December PSA Bulletin, distributed to 18,000 media outlets nationwide.



*The Progeria Research Foundation*

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