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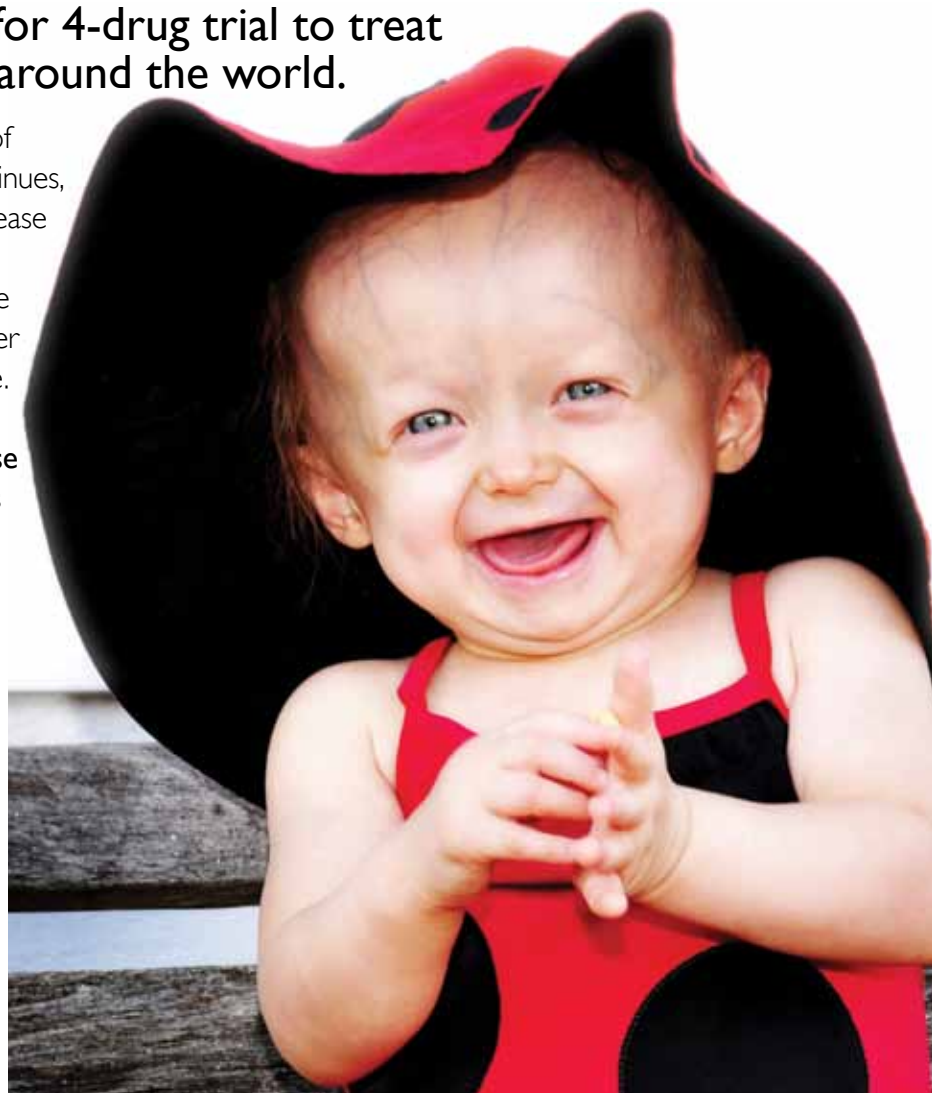
Groundbreaking Studies Identify New Potential Drug Treatment, Strengthen Progeria-Aging Link

**PRF prepares for 4-drug trial to treat
children from around the world.**

The spectacular pace of Progeria research continues, with the June 2011 release of two studies that put Progeria and PRF in the spotlight and ever closer to treatments and cure.

**Read more about these
exciting developments
on pages 6-7.**

One-year-old Carly from the US is the 80th and most recent child with Progeria to be identified. She and other children will have an opportunity to enroll in a new clinical trial planned for 2012.





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

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 Susan Rosenblatt, *Executive Assistant*
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 Donna Bertko, *Clinical Trial Coordinator*
 Lynne MacKenzie, *Donor and
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 Washington, DC

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Sandra Bresnick, Esq.
 Quinn Emanuel Urquhardt
 & Sullivan LLP, NY, NY
 Alan Jakimo, Esq.
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 Karen N. Ballack, Esq.
 and Jeffrey D. Osterman, Esq.,
 Weil, Gotshal & Manges, LLP,
 Silicon Valley, CA and NY, NY

Accounting:

Carl Alviti, Matrix Financial, LLC,
 Wellesley, MA

Web Site:

Karen Gordon Betourmay
Coordinator
 Useful Studios
Technical/Design

Graphic Designers:

Julie Pritchard
 JCR Design, Foxboro, MA
 Marie Migliaccio, Topsfield, MA
 Regina Printing, Belleville, NJ

Newsletter Editor:

Stephanie Dutchen

**Progeria is a fatal, "premature
 aging" disease that afflicts
 children, who die of heart
 disease at an average age of
 13 years - the same heart
 disease that affects millions
 of normal aging adults.**

**Because of Progeria's
 connection to general heart
 disease and aging, what we learn
 from Progeria research has the
 potential to benefit all of us.**

**Message from the President
 & Executive Director**

Hello everyone,

As I finalize the pages in this issue, I am so excited and grateful for all that is happening:

- Another potential drug treatment
- A third clinical trial
- New evidence for Progeria-aging link
- 80 children living with Progeria identified, from 31 countries
- New "Find the Other 150" partners to help discover more children
- Record media interest in and exposure of Progeria and PRF's work
- Expansion of our cell & tissue bank and grant funding programs
- More volunteers than ever helping PRF achieve our mission – the cure for Progeria!

And as I struggled with having to choose from the many Miracle Makers and Special Events on our web site to include in this newsletter because they wouldn't all fit, I was struck by the growing number of people raising funds and awareness – two vital ingredients to keep our progress going at the phenomenal rate it has enjoyed for the past 12 years.

Fall will bring road races, our Night of Wonder gala, preparation for our biggest and most costly clinical trial yet, and the continuation and expansion of all of PRF's other activities. I hope you will attend one or more events, and look forward to updates on research progress that your kind and generous support makes possible.

Audrey Gordon
 President & Executive Director

In Loving Memory...



Vasile, 12 years old,
from Romania



Theo, 9 months old, from Sweden (pictured here with his big sister)



Luci, 12 years old, from Mexico



Leon, from South Africa, the
day after his 26th birthday

*They are gone
from our sight,
but never our memories*

*Gone from our touch,
but never our hearts.*

Progeria Research Pushes Forward

With Broader Applications Than Ever Before

Telomere Study Reinforces Connection Between Progeria and Aging

The National Institutes of Health research group of **Francis Collins (NIH Director)** has discovered a new and crucial link between Progeria and aging in all of us. Collins shows a direct effect of a key aging ingredient called telomeres on progerin, the enemy protein that causes Progeria. The laboratory found this link not only for Progeria, but for normal aging cells.

Telomeres are tiny pieces of DNA which protect the ends of chromosomes. When telomeres wear away over time, cells die. If telomere length is preserved, cells live longer.

Hence, the strong link between telomeres and aging. Now we know that telomere dysfunction causes cells to make progerin. When this happens, cells stop growing and die.

The study* was reported on the CBS Evening News (watch the video at www.progeriaresearch.org/cbs-monday-night) and in the Wall Street Journal and other print and online media.

“For the first time, we know that telomere dysfunction

A normal cell, grown from a person without Progeria, making progerin and showing signs of aging. The blue cloud shows the cell nucleus, where DNA, progerin and telomeres are found. Reds dots show telomeres.

influences the production of progerin,” says PRF Medical Director **Leslie B. Gordon, MD, PhD.** **“Thus these two processes, both of which influence cellular aging, are actually linked.”**

Prior research has shown that progerin is not only produced in children with Progeria, but is produced in smaller amounts in all of us—and progerin levels increase with aging. Independently, previous research on telomere shortening and dysfunction has been associated with normal aging. Since 2003, with the discovery of the Progeria gene mutation and progerin, research has focused on understanding whether and how Progeria and aging are linked.

“Connecting this rare disease phenomenon and normal aging is bearing fruit in an important way,” said Dr. Collins. **“This study highlights that valuable biological insights are gained by studying rare genetic disorders such as Progeria. Our sense from the start was that Progeria had a lot to teach us about the normal aging process.”**

* Kan Cao, Cecilia D. Blair, Dina A. Faddah, Julia E. Kieckhafer, Michelle Olive, Michael R. Erdos, Elizabeth G. Nabel and Francis S. Collins, “Progerin and telomere dysfunction collaborate to trigger cellular senescence in normal human fibroblasts.” *J Clin Invest.* 2011;121(7):2833–2844.

New Study Identifies Rapamycin as Possible Treatment for Progeria

Rapamycin is an FDA-approved drug that has previously been shown to extend the lives of non-Progeria mouse models. A study† by researchers at the NIH in Bethesda, MD and Massachusetts General Hospital in Boston demonstrates that rapamycin decreases the amount of the disease-causing protein progerin by 50%, improves abnormal nuclear shape, and extends the lifespan of Progeria cells. This study provides the first evidence that rapamycin may be able to decrease progerin’s damaging effects in children with Progeria.

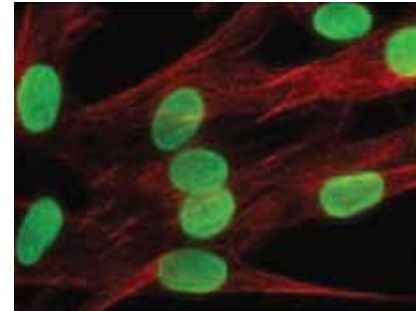
The Progeria Research Foundation provided cells for this project from the PRF Cell & Tissue Bank and helped fund the research through our grants program.

This exciting new study has provided the basis for a new clinical drug trial with a rapamycin-like drug – the fourth drug to be identified as a possible treatment for children with Progeria. How fortunate we are to have multiple treatment possibilities!

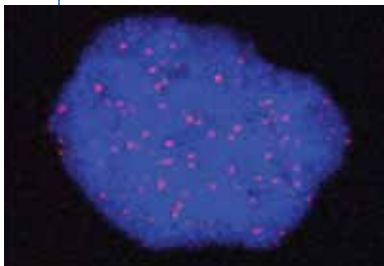
† K. Cao, J.J. Graziotto, C. D. Blair, J. R. Mazzulli, M. R. Erdos, D. Krainc, F. S. Collins, “Rapamycin Reverses Cellular Phenotypes and Enhances Mutant Protein Clearance in Hutchinson-Gilford Progeria Syndrome Cells.” *Sci. Transl. Med.* 3, 89ra58 (2011).

Media interest soared at the news that a drug, already FDA-approved for other uses and linked to extending life in a mouse model, could be used to treat children with Progeria. From the front page of the *Boston Globe*, to CNN Health, to *US News & World Report* and many others, the recognition of the importance of Progeria research continues.

This photo of 4-year-old Zach was featured in the July 1, 2011 CNN Health article on the rapamycin study. Links to this and many other articles can be found at www.progeriaresearch.org/study-id-rapamycin.



Progeria cells treated with rapamycin become normalized.



Introducing the Progeria 4-Drug Clinical Trial

With 65* children from 30 countries and a cost of over \$3 million, PRF prepares for its largest endeavor yet in the pursuit of treatments and cure.

PRF is thrilled to announce the planning of a third clinical trial, involving the three drugs currently being tested plus **everolimus**, a form of rapamycin (see page 4 for related story). While **lonafarnib**, **pravastatin**, and **zoledronic acid** may block progerin from developing, rapamycin appears to increase cells' own recycling system to clear out the toxic progerin more rapidly. Thus with rapamycin targeting a different pathway than the other three drugs, the combination may prove to be a "one-two punch" to Progeria.

Medications to be administered include:

- **Lonafarnib**, an FTI (Farnesyltransferase inhibitor) also given in the first Progeria drug trial
- **Pravastatin**, a statin drug usually used for lowering cholesterol, which was added to FTIs for the Triple Drug Trial
- **Zoledronic acid**, a bone drug typically used for improving osteoporosis, also included in the Triple Drug Trial
- **Everolimus**, a derivative of the immune-suppressing drug rapamycin

This new trial is a collaborative effort that will build upon the knowledge gained from the previous two Progeria trials (see page 8 for an update on them). The children will be seen by virtually the same team of physicians from Children's Hospital Boston, Dana-Farber Cancer Institute and Brigham and Women's Hospital, all of whom now have world-renowned expertise in Progeria.

The Progeria 4-Drug Clinical Trial will be considered a success if the children achieve certain pre-selected clinical characteristics, such as rate of weight gain and improvement of blood vessels. Such success would deem the 4-drug combination an effective treatment for Progeria.

Logistics and Funding: It's up to us!

Involving an astonishing 65 children from 30 countries, the trial will cost an estimated \$3.5 million for clinical testing, travel, food, lodging, staff, translation and certain trial-related medical care costs. PRF is responsible for funding the trial and coordinating travel and lodging for all children and their parents, who will journey to Boston multiple times over two years for testing and to receive their new drug supply.



Please help us raise the funds to support this trial – make a donation, hold a fundraiser, connect us with people you know that may want to support our efforts. Your combined efforts are needed now more than ever!

*We anticipate that 65 of the 80 children will participate in the trial.

7-year-old Lindsay from the US, pictured here with mom Kristy, has been involved in the first two Progeria clinical trials (see page 8 for details) and plans to continue with the new 4-Drug Trial.

What's News in Progeria Research?

From the laboratory to the bedside, research holds the keys to treatments and cure.

Basic laboratory science using cells grown in a dish and animal models of disease give us crucial information about how the body works. Without basic science, we would not be zooming along towards treatments and the cure for Progeria. PRF supports scientists in their quest to understand Progeria by funding research and supplying crucial scientific materials such as cells to aid in new discoveries. One way that PRF measures its success towards supporting basic "preclinical" progress is by looking at the productivity of our funded scientists.

Before PRF was created, there were about 2 Progeria scientific publications per year. Today, there are 30-40 original scientific works per year, plus 10-15 review articles and commentaries in the scientific literature. More than 60% of new articles are published by scientists who have been funded by PRF. This means that our grantees are discovering new information on Progeria using PRF funds, and using that success to gain funding from larger organizations such as the National Institutes of Health.

When I look back on PRF's strategic plan in our first year, 1999, I see a page dedicated to exactly this goal. **Congratulations to all of our grantees. You are changing the landscape of Progeria research. You are giving the world ever-increasing hope for treatments and cure.**

Sincerely,



Leslie B. Gordon, MD, PhD - Medical Director

PRF's Grant Program Undergoes Major Changes!

In an effort to further propel research progress, PRF increases and expands funding.

Since its inception in 1999, PRF has awarded grants to investigators at a maximum of \$50,000 per year for up to two years. The funding was intended to allow researchers to produce enough preliminary data to be competitive for greater, longer-term funding by NIH or other large agencies. PRF's Grant Program served Progeria research very well, yielding major advances that have propelled Progeria from a disease about which virtually nothing was known at the cellular and molecular levels, to one that was understood well enough to begin clinical drug trials.

PRF's Medical Research Committee recently held a 1-day summit to revise our granting structure. Proposals will now be accepted in three categories:

- **Innovator Awards:** 2-year awards that are a continuation of the former program, except award amounts will increase to up to \$75,000 per year.
- **Established Investigator Awards:** for senior investigators established either in the field of Progeria or a field that can be directly applied to Progeria. Grants up to 3 years duration and up to \$100,000 per year.

1999 strategic plan for basic science research success in Progeria

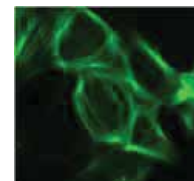
- **Specialty Awards:** for smaller, more technology-driven projects, e.g., drug screening, preparation of antibodies, and new cell and animal models. Funding amounts and lengths will vary.

For further details, contact us or go to www.progeriaresearch.org/grant_application



PRF keeps scientists on the cutting edge by adding a new branch to its Cell & Tissue Bank: Induced Pluripotent Stem Cells (iPSCs)

Stem cells are "immature" cells that have not yet committed to becoming any one cell type. Researchers now have a strategy for reprogramming mature Progeria cells such as skin cells to become stem cells called Induced Pluripotent Stem Cells ("iPSCs"). Progeria iPSC can then be directed to become mature cells such as blood vessel and heart cells. PRF funded William Stanford, PhD at the University of Toronto, Canada to generate Progeria iPSCs. PRF will provide these iPSCs to the research community worldwide.



Newly-created mature Progeria blood vessel cells

Why is this so important? Researchers can now use these previously unavailable Progeria stem cells in order to ask key questions about the heart disease that leads to early death in Progeria, or to discover and test new treatments. These discoveries can then be compared with the heart disease and aging in the general population, and tell us more about what influences aging in all of us.

For ordering information and additional details, please visit www.progeriaresearch.org/induced-pluripotent-stem-cells

PRF Awards Five More Research Grants

To date, PRF has provided over \$2.5 million* to fund 34 grants for Progeria-related research. We applaud these dedicated scientists and encourage others to submit proposals to help us reach our goal of developing treatments and the cure for Progeria. The following have been funded over the past 12 months:

Robert D. Goldman, PhD,
Northwestern University Medical School,
Chicago, IL

“A Role for B-type Lamins in Progeria”



The A- and B-type nuclear lamins form separate but interacting structural networks in a cell's nucleus. Although Progeria is caused by mutations in the lamin A gene, Progeria patients' B-type lamin networks are also abnormally altered. B-type lamins are known to be important in regulating many nuclear functions. Dr. Goldman's lab will determine the effects of the expression of progerin and other lamin A mutations on the expression, structure and function of the B-type lamins in Progeria patient cells. He will also investigate the effects of farnesyltransferase inhibition on B-type lamins.

Dr. Goldman is the Stephen Walter Ranson Professor and Chairman of the Department of Cell and Molecular Biology at Northwestern University's Feinberg School of Medicine in Chicago. He is widely recognized as an authority on lamins and the impact of lamin A mutations that give rise to Progeria.

Yue Zou, PhD,
East Tennessee State University,
Johnson City, TN

“Molecular Mechanisms of Genome Instability in HGPS”



Dr. Zou's project aims to define on a molecular level how progerin causes replication abnormality and genome instability in HGPS cells, which may lead to early cell senescence.

Revealing the cause of defective activities at replication forks, and investigating whether progerin interacts with the factors involved, may help researchers better understand the causes of HGPS symptoms, which could lead in turn to new treatments.

Dr. Zou is a professor in the Department of Biochemistry and Molecular Biology of Quillen College of Medicine at East Tennessee State University.

* This does not include clinical trials expenses.

John Graziotto, PhD,
Massachusetts General Hospital (MGH),
Boston, MA

“Clearance of Progerin Protein as Therapeutic Target in Hutchinson-Gilford Progeria Syndrome”

Because the HGPS mutant disease protein progerin accumulates over time, determining how it is degraded is important from a therapeutic standpoint. The focus of Dr. Graziotto's work is to determine the cellular clearance pathways responsible for degrading progerin. Using this information, he hopes to be able to manipulate those pathways to facilitate progerin clearance, with the goal of enhancing current or future Progeria therapies.

Dr. Graziotto is a Postdoctoral Fellow in the Department of Neurology at MGH working in the lab of Dr. Dimitri Krainc

Kan Cao, PhD,
University of Maryland,
College Park, MD

“Rapamycin Reverses Cellular Phenotype and Enhanced Mutant Protein Clearance in Hutchinson Gilford Progeria Syndrome”



Dr. Cao's study is featured on page 4; her investigation of the effect of rapamycin on HGPS cells formed the basis for a new clinical trial that will test the therapeutic potential of the drug (see page 5 for details).

Dr. Cao is an Assistant Professor in the Department of Cell Biology and Molecular Genetics at the University of Maryland. Her lab is focused on studying cellular mechanisms in Progeria and normal aging.

Evgeny Makarov, PhD,
Brunel University,
Uxbridge, United Kingdom

“Identification of the LMNA Splicing Regulators by Comparative Proteomics of the Spliceosomal Complexes”



Dr. Makarov is currently studying the pre-mRNA splicing (a cellular process that cuts out non-coding sequences and stitches together the remaining coding sequences) of the LMNA gene, especially the incorrect (alternative) splicing that causes Progeria. His aim is to identify the proteins that affect such splicing and are therefore likely to affect the speed of the cellular ageing process. Drugs could potentially then be developed to target those proteins and slow the aging process.

Dr. Makarov is an expert in pre-mRNA splicing. He is a lecturer at the Division of Biosciences, Brunel University, London.

The First Two Clinical Trials:

Where We Are, How Far We've Come!

Progeria Trials by the Numbers

	Children	Countries	Languages	Visit Frequency
Trial #1 (First Ever Progeria Trial)	28	16	14	7 visits over 2 years (every 4 months)
Trial #2 (Triple Drug Trial)	45	23	16	5 visits over 2 years (every 6 months)

Trial #1: Begun in May 2007, the First-Ever Progeria Clinical Drug Trial marked an historic moment in Progeria research history. After only 7 years in existence, PRF and its partners became scientifically ready to begin a trial using FTIs, drugs that show great promise to effectively treat children with Progeria by blocking the function of progerin, the "enemy protein" that causes Progeria.

With an average of two families flying to Boston each week, all patients completed their visits in December 2009. The trial team has been hard at work since then, analyzing thousands of pieces of data that were collected over the 2 ½-year trial. As a PRF supporter, you will be among the first to know the results!

Trial #2: While the first trial was underway, researchers identified two additional drugs that, when used in combination with FTIs, may be even more effective for Progeria than FTIs alone. We swiftly prepared for a second trial so that FTI treatment could proceed uninterrupted. The "Triple Drug Trial" was launched in August 2009, and children have since completed four of their five Children's Hospital Boston visits. Many of the new children were either too young to participate in the first trial or were discovered after enrollment was complete, so we were delighted to be able to increase the number of participants in the second trial by 50%!

Meghan from the US and Sumaira from Pakistan, both 10 years old, get creative with spring flowers during their April 2011 trial visit. Both girls have been involved in the first two Progeria clinical trials.

A Difficult Journey...

It has been a tremendous challenge arranging travel to Boston for all the families. Soaring transportation costs, volcanic ash, airline strikes and political unrest are just some of the obstacles we have had to overcome to achieve our goal of getting children from around the world to Boston for their hospital visits. Whether the children came from Pakistan, Japan, South Africa, the US or elsewhere, hard work and determination brought them all to Boston for treatment. The wonderful partnership with the families, clinical trial coordinators, physicians, translators, ambassadors, housing staff and donors, all working together, has been the key to making these trials a success. Thank you, ALL!



PRF ON THE MOVE!

PRF and Boston Bruins Team Up to “Find the Other 150”!

In an exciting expansion of PRF's global campaign to find all children with Progeria, players from the Boston Bruins hockey team have recorded public service announcements (PSAs) to air in Europe, Canada and the U.S.

Recorded in both English and the players' native languages, the PSAs are being distributed in the Czech Republic, Finland, Serbia, Slovakia and Canada, as well as to U.S. outlets with ties to those countries. Go to PRF's YouTube site at www.youtube.com/user/progeria123 to view the English versions of the PSAs.

Players participating in this campaign include **Zdeno Chara** from Slovakia, **David Krejci** from the Czech Republic, **Milan Lucic** from Serbia and Canada, and **Tuukka Rask** from Finland.

The “**Find the Other 150**” campaign* has been remarkably successful in the countries where PRF has been able to penetrate, with an astonishing 48% increase in the number of children identified over the past 20 months. However, central and eastern Europe remain a challenge.

Partnering with Bruins players from these countries gives PRF the unique opportunity to raise awareness about Progeria and find more children to help.



Bruins Captain Zdeno Chara and Sam Chara recorded PSAs that are now airing in Slovakia. We hope this will raise awareness of Progeria, and that families and physicians of children in the area will reach out to PRF for help.

Thank you, Boston Bruins organization and players. You're not only the 2011 Stanley Cup Champions, but also champions for children with Progeria!

*Visit the campaign's dedicated website at www.findtheother150.org

“Find The Other 150” Helps Our Numbers Continue to Soar...

The number of known, living children with Progeria is now 80 worldwide. The children span five continents, and range in age from 5 months to 21 years. Stretching across language and geographic barriers, the campaign's results to date are a true testament to the power of global collaboration. Our thanks to campaign partners **Spectrum** and **GlobalHealthPR** for their dedication to finding all children with Progeria throughout the world.



There is a direct correlation between media exposure and identification of children, as evidenced by the tremendous success in Brazil, where the number of children increased from 1 to 10 as awareness of Progeria penetrated the entire country through TV and newspapers.

And the Art of Reporting Award Goes To...

Congratulations to John Seng, PRF Board member and CEO of Spectrum, for receiving The Art of Reporting Award at the Genetic Alliance's annual conference in Bethesda, MD for his creation of the "Find the Other 150" campaign. The award acknowledges "a media professional whose reporting contributes to public awareness and understanding about genetic advancements or advocacy organizations and their impact on real people's lives."

John's team has worked tirelessly for nine years on numerous PRF media projects.



John Seng (center, holding his award with Sam), with family, Spectrum staff, PRF representatives, and Genetic Alliance CEO Sharon Terry and husband Pat Terry (2nd and 3rd from the left).

Barbara Walters Reports on Progeria Awareness of Progeria spreads with the airing of "When Seven Looks Like 70"



Hayley from England meets Barbara Walters at the studio.

Last September, ABC's 20/20 aired a wonderful portrayal of Lindsay, Kaylee and Hayley and their families, and we thank Barbara Walters for bringing Progeria into the homes of millions of viewers. The one-hour special has been nominated for an Emmy Award and re-aired in July due to its popularity.

PRF Leaders Participate in Rare Disease Day - "Rare Diseases are Common"

Rare diseases affect over 250 million people worldwide, approximately 75 percent of whom are children. Like children with Progeria, they all have unique needs, but many have little or no research activity due to the rarity of their conditions. We celebrate the progress in Progeria research, but we know there is still much to do for Progeria and other rare diseases.



PRF Exec. Dir. Audrey Gordon (center) with NIH Director Francis Collins, rare disease advocate Nancy Goodman (l), and Global Genes Project President Nicole Boice (r).

The 4th Annual Rare Disease Day took place in February. Virtual and in-person events were held at the National Institutes of Health and other places around the world, providing a forum where the community of affected children and families joined together to garner support for their efforts. PRF's Medical Director Leslie Gordon spoke in Boston at Pfizer's Orphan & Genetic Disease Summit, while PRF's Executive Director Audrey Gordon attended a full-day conference at NIH.

Executive Director Joins RARE Board of Advisors



Audrey Gordon has joined the Board of Advisors for the RARE Project, a leading nonprofit rare disease advocacy organization that educates the public about the prevalence of rare diseases worldwide, and the importance of developing treatments and cures for them. Visit www.rareproject.org to learn more.

PRF's Social Media Sites - Join Us and Hear the Latest News First!

With over 5,000 members on our "Cause" page and 1,400 following our "Group" page, Progeria's presence on Facebook is strong and growing as more join every day. Several have participated in the Cause's Birthday Wish program, asking friends to support PRF in honor of their birthday - including Jody Slesser, who raised over \$4,000!

You can also subscribe to our **YouTube Channel (progeria123)** to watch the latest videos and follow us on **Twitter (@progeria)** for tweets on breaking news.



Please join us!



You complete the picture

now2011

Join us for a color-full celebration at

Night of Wonder 2011

6:30 pm on Saturday, November 12, 2011

Boston Marriott, Cambridge, Massachusetts

PRF is making tremendous advances toward a cure for Progeria.
You can help complete the picture by supporting Night of Wonder,
our signature gala featuring silent and live auctions, fabulous food & drink,
live entertainment, dancing & much, much more!

Come colorfully dressed! Tickets now available.
\$200 participant / \$300 benefactor

Be a Sponsor - Levels from \$2,500 to \$20,000 with great perks!

Place an ad in the Event Program book! Ads range from \$100 to \$1,500!

Donate an Auction item! Call 978-535-2594 today!

See you there!

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www.progeriaresearch.org/now-2011

Chapter & Annual Events

A Record-Breaking Year!!

Golf scrambles, bowling tournaments and run/walk road races are fun community events that bring people together to support Progeria research. The results of the hard work our chapters and other volunteers poured into these events have been exceptional this year. Enjoy reading these highlights, and **let us know if you want to organize an event – we can show you how!**



Chris and his granddaughter Sarah enjoy the day.

Golfers at the beautiful Eagle Valley Golf Course enjoyed the challenging course, great food and lots of camaraderie while raising awareness and funds for PRF. "We're just doing what we can to help Sarah and the other kids," says organizer Chris Kempf. This event has raised over \$100,000 to date – **AMAZING!**

3rd Annual Cam's Course Golf Scramble - Butler, PA

In loving honor of their 4-year old nephew Cameron Howard, Jeff and Brooke Howard held the 3rd Annual Cam's Course golf scramble. Thanks to dozens of sponsors, participants and volunteers, the event exceeded all expectations, raising almost double what was raised last year - **WOW!**

1st Annual Team Zoey Golf Outing - Wayne, NJ

In honor of Zoey, who turned one year old last September, Team Zoey held their first golf outing and dinner/auction at the Preakness Hills

Country Club. The event, organized by Zoey's grandfather John Marozzi and friends, was spectacular and raised over \$180,000 – **GO TEAM ZOEY!**



Zoey's family, and PRF's Board Chair Scott Berns (far left) and Director Audrey Gordon (far right) enjoy the cocktail hour.

Cam, with parents Stephanie and Jason and big sister Riley, having a blast by the carousel ride.

1st Annual Lindsay Ratcliffe Golf Outing - Monroe, MI

The 1st Annual Lindsay Ratcliffe Golf Outing organized by PRF's Michigan Chapter and Ellen Dulecki was a rousing success! 100 golfers enjoyed a day on the links as they played in a friendly, 4-person scramble format. Even more people came out to join Lindsay and her family at the post-golf dinner and raffle – **All "FORE" PRF!**



Lindsay during putting practice.

Zach Attack Bowl-a-Thon - Lexington, KY

232 bowlers, 45 teams and too many spectators to count made this 1st annual event a striking success! "We were bowled over by how many people came and how much fun they had," said KY Chapter leader Tina Pickard. "So we've decided to make this an annual event as part of our chapter activities." Now that's a **PERFECT SCORE!**

Strike Down Progeria Bowl-a-Thon - East Hanover, NJ

Bowlers from across the state of New Jersey participated in TEAM ZOEY'S first bowl-a-thon, filling up every lane for an entire afternoon and raising nearly \$14,000 – **WAY TO KNOCK 'EM DOWN FOR PRF!**

Zoey shows us how to do it – while eating a cookie!



3rd Annual Kilometers for Cam Road Race - St. Joseph, MI

The Howard family and their fellow Southwest Michigan chapter members were "blown away" by the largest race group yet – over 500! With a carnival-like atmosphere featuring face painting, games and a carousel, families now come from near and far to enjoy the day and support Cam



and all children with Progeria. **Now THAT's the way to PARTY for PROGERIA!**

4th Annual Zach Pickard Pelican 5k Run/Walk - Brownstown, IN

The weather was perfect and hundreds of people came out to enjoy this fun-filled day. Thank you to the Brownstown Electric Company team, including owner Carl Shake, Diana Beedie, Brittany Darlage, Greg Deck, Clay Fritz, Brett Turner, Rob Sipe and Debbie Sweeney for their time and tremendous effort in organizing this terrific event.



"I hope the paparazzi don't recognize me!"

5th Annual Kaylee's Course - Monclova, OH

With sunny skies and over 1,000 participants, the Ohio chapter raised over \$58,000 at the 2010 Kaylee's Course run/walk – its **BEST EVER!**



(l to r) Lindsay, Zach, Kaylee and Cam enjoy a special moment together after the race. The families live within driving distance of each other and attend each other's events whenever possible.

5th Annual Walk in Honor of Kristian McGuinness - Middleboro, MA

Every September for the past 5 years, family and friends of Kristian McGuinness honor this wonderful boy's memory with a 2-mile walk. Drawings for prizes and the popular WZLX van are always on hand to make it a day of family fun and rejoicing in Kristian's honor.

Long-time walk supporters Melissa (left) and Susan, with the youngest participant baby Kayle and walk organizer Kathy McGuinness (below)



6th Annual Miles for Miracles - Flat Rock, MI

PRF's Michigan chapter did it again - congratulations to Kristy and Joe Ratcliffe and all their supporters for achieving their phenomenal fundraising goal of \$50,000 – their biggest race yet! "With a great turnout, beautiful weather and record-breaking funds raised, I can't thank everyone enough for their steadfast support", said Kristy, who posted daily on Facebook to thank people and encourage attendance.



Lindsay designed the t-shirt herself!



Jesper, Sarah and Sam proudly hold their trophies at the 2010 race. This year's race will take place as the newsletter goes to press – go to our web site to read of its success!

9th Annual Race for Research - Peabody, MA

Imagine going from 250 participants to almost 400 in one year - outstanding! With support from hundreds of runners, walkers, sponsors and volunteers, and mild fall weather, \$25,000 was raised in PRF's home town.



The Pittsburgh "Miles for Miles" team. Stephanie appears in the center.

"Miles for Miles" Expands from Pittsburgh to Sweden!

"Miles for Miles" was created by Stephanie Bunt in honor of Miles from Sweden, whose mother is a dear childhood friend. Last year, members ran the Pittsburgh Marathon and the Lidingoloppet (the world's biggest cross country run), raising lots of funds and awareness along the way – **MANY "MILES" OF THANKS TO ALL!**

As PRF prepares for the biggest and most costly drug trial yet, doubles its research grant funding, and continues to run its other research-related programs, we are grateful to everyone who is raising funds to support all this work. It is only Together that we WILL find the cure!

Other Special Events

Celebrating the Support of Progeria Research in Lots of Fun Ways!

Here is just a sampling of the many types of other events that have taken place over the past year. We hope they inspire you to organize a bike ride, poker tournament or other fundraiser in your area – we'll put you in touch with the organizers so they can share their experiences and tell you how FUN it was! Visit our website at www.progeriaresearch.org/events to read about others, including upcoming events.



Sam and Brian McHugh of major sponsor Cranney Companies doubled down at the Black Jack table.

Another FULL HOUSE at Poker for Progeria Tournament

Players showed up in spades to participate in the 6th Annual Texas Hold 'Em Tournament in Peabody, MA. Everyone was feeling ace high as the evening started. There were no losing hands at this tournament - you can bet everyone had a great time!

Zach Attack Ride Against Progeria

This July event in Lexington, Kentucky was a roaring success! 70 motorcyclists rode their bikes 90 miles to support PRF's KY chapter. Everyone enjoyed the day, especially Zach who got a custom painted power wheels motorcycle... awesome!!!



Born to Ride

Spin-for-Life Has Dozens Pedaling for Progeria

On a chilly Sunday in January, Team Zoey held a spinning fundraiser at the Lakeland Hills YMCA in New Jersey, raising over \$25,000 through sponsors of committed participants. The four hour event, split into eight 30-minute sessions, was full to capacity.



Karen Carolonza spun for 3 hours – whew!

Congratulations to organizer Barbara Batesko and the enthusiastic supporters who spun for multiple sessions!



Boston Bruins 6, Dallas Stars 3, Progeria Research Foundation \$5,000!

In February, 20 PRF volunteers descended upon the TD Garden for the Bruins vs. Stars game. Their mission: raise awareness of Progeria and sell as many 50/50 raffle tickets as possible, with proceeds going to PRF as the charity chosen by the Boston Bruins Foundation for that night. Sounding like old fashioned carnival hawkers and carrying a huge poster of 4-year-old Zach Pickard. It was a win for all!

5th Annual YEARONE-FOOSE Braselton Bash a Record-Breaking Show

Last September, the YearOne Hot Rodders Children's Charity and automotive design guru Chip Foose held the 5th annual car show in Georgia to benefit PRF. The action-packed day included best-in-show winners and hundreds of classic cars on display for the enjoyment of the biggest crowd yet. Thanks to Chip, Kevin King and everyone at YearOne for DRIVING the cure!



Sam and Chip check out the fabulous cars



3rd Annual Ride for Progeria with Amanda Lynn & Friends

On a sunny Saturday in June, Amanda Lynn Mayhew-Hare and friends held their annual motorcycle ride in Ontario, Canada. Riders enjoyed the journey through Elmira, live entertainment, door prizes and refreshments, all while raising funds and awareness for Progeria. SO COOL!

PRF Miracle Makers

From a Book-a-thon to a Fashion Show, our volunteers find creative ways to make a difference in the lives of children with Progeria.

One 9 year old + 2 months + 16 books = huge fundraising success!



9-year old Jaimee from Livingston, NJ combined her love of reading with her desire to help by holding a Book-a-thon fundraiser. She read 16 books over 2 months, raising \$700 by asking family and friends to sponsor her for each book she read. Thanks so much, Jaimee - *what a novel idea!*

6th Grade Chefs Cook for a Cure

Kelly Thompson's CCD class from Mountain Lakes, NJ had a great idea for a service project: cook chili, shells and enchilada dinners for family and friends to raise money for PRF. 90 orders later, the group of junior chefs raised \$1,685! Thank you, students, for reminding us that there are never too many cooks in the kitchen, especially when it comes to helping kids with Progeria.



The Key (club) to Success in the Bronx, NY

DeWitt Clinton High's Key Club educated the entire student body about Progeria for their school project, speaking to classmates and placing newsletters, and **Coins to Cure** cans throughout the school. "Kids actually stopped to read them," stated organizer Lendita, "It was amazing because they don't usually stop in the hall to read what's posted." *If YOU have a school project to complete, why not choose one like this?*



Mountain Lakes High Rocks the Runway for a Cure!

Led by Brianna Goodwin, the March fashion show benefit in Boonton, NJ was a huge success. This energetic group of young adults raised over \$5,000 through ticket sale and raffles. Thanks to the students at Mountain Lakes High School for organizing,



planning and modeling – *you are all models for others to follow!*

"Nothing but net" for Ohio's Boys Basketball Team

8th grade basketball players at Anthony Wayne Jr. High School are outstanding athletes AND philanthropists in the making! The team sold t-shirts and donated the proceeds to PRF and the ASPCA. *Thank you, boys, for your generosity.*



Music, Fashion and Food - A Great Combination for Success!

Karoly De La Rocha hosted a networking event for her family, friends and community in Woodland Hills, CA, raising awareness and close to \$200 for PRF by providing informational materials, selling jewelry and holding a gift basket raffle. The evening ended on a high note (literally!) with a special musical performance by Karoly and friends. *Thank you, Karoly, for using your talents and connections to benefit PRF.*

Senior Project: "Class of 2011 Can Cure Car Show"

Amberly Oltmer organized this event in Lompoc, CA as part of her high school senior project. Featuring over 100 cars and hot rods, attendees had a great time looking at the cool vehicles and meeting other car enthusiasts like Amberly's uncle, well-known car designer Chip Foose. *Chip and Amberly* Congratulations not only on your graduation, Amberly, but for *putting the pedal to the metal* for kids with Progeria!



We wish we could include all these Miraculous people in the newsletter – please visit www.progeriaresearch.org/miracle_makers to read about many more. We hope their stories inspire you to become a Miracle Maker, too!



**P.O. Box 3453
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Zoey hopes you had a great summer!



Now on Sale! “When I Grow Up” 2012 Calendar

“Every child has a dream of what they want to be when they grow up, and Nathan and Bennet are no different. Hence the theme of the drawings in our ‘When I Grow Up’ calendar. It represents what we all want for our children and what PRF is working so tirelessly to ensure.”

- **Phyllis Falcone,**

Nathan and Bennett’s mother

Featuring drawings by children, this calendar is an inspiring piece of art and a reminder that every day is a gift. Many thanks to Phyllis and her team of friends, for creating this beautiful calendar and donating the proceeds to PRF.



Please go to www.progeriaresearch.org/shop_in_our_store for purchasing details.