In April 2010, The Progeria Research Foundation held its tenth anniversary scientific workshop, “From Bench to Bedside in a Decade.” A record 140 participants from ten countries gathered in Boston to share their progress in Progeria research, making this our largest and most diverse workshop yet. Highlights included a Progeria family panel led by Pulitzer Prize-winning journalist Amy Dockser Marcus, an inspiring plenary address from PRF Medical Director Dr. Leslie Gordon, and tremendous excitement about the breadth and depth of knowledge we now have for Progeria and its window into aging. Read more on pages 6-7.
Hello everyone,

I wish each of you could have been there to experience the 2010 workshop. From the first night’s family panel to the last day’s wrap-up, the excitement was palpable. I found myself reflecting on past workshops, excited about the progress we’ve made. I have no doubt that this latest conference will help push Progeria research as far and as fast as we had imagined — but hardly dared to hope for — 11 short years ago.

So much news to share with you!

• Thanks to our increased global awareness efforts, we’re finding more children.
• Progeria is getting lots of exposure through television and other media.
• PRF spokespeople are sought after to speak at conferences around the US.
• Fundraisers abound.
• We are now reporting on multiple Progeria clinical drug trials.

Lots of new people have joined in our efforts, too:
Staff member Donna Bertko has taken the place of Kyra Lotsof new people have joined in our efforts, too:

Message from the President & Executive Director

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

- Staff:
  - Audrey Gordon, Esq., Executive Director
  - Susan Rosenblatt, Executive Assistant
  - Donna Bertko, Clinical Trial Coordinator/ Administrative Assistant
  - Lynne MacKenzie, Administrative Assistant

- Volunteers:
  - Karen N. Ballack, Esq.
  - Sandra Bresnick, Esq.
  - Carl Alviti, CPA
  - Barbara F. Gordon, Esq.
  - Scott D. Berns, MD, MPH, FAAP
  - Audrey Gordon, Esq.
  - Carl Alviti, CPA
  - Rabbi Harold Kushner
  - Suzette Kushner, MS
  - Skip Wohlner, MD
  - Kim Paratore
  - John Seng
  - Robert K. Morrison
  - William Oh, MD
  - Mary Oh, MD
  - Dr. William F. Schulz
  - Dr. William F. Schulz
  - Mary Oh, MD
  - Board of Directors:
    - Karen N. Ballack, Esq.
    - Sandra Bresnick, Esq.
    - Carl Alviti, CPA
    - Barbara F. Gordon, Esq.
    - Scott D. Berns, MD, MPH, FAAP
    - Audrey Gordon, Esq.
    - Carl Alviti, CPA
    - Rabbi Harold Kushner
    - Suzette Kushner, MS
    - Kim Paratore
    - John Seng
    - Skip Wohlner, MD
    - Board of Advisors:
      - W. Ted Brown, MD, PhD
      - Robert N. Butler, MD
      - Monica Klemmend, MD
      - George M. Martin, MD
      - Robert K. Morrison
      - Mary Oh, MD
      - William Oh, MD
      - Dr. William F. Schulz
      - Mel Zuckerman
    - Medical Director:
      - Leslie B. Gordon, MD, PhD
    - Ambassador Family:
      - The Pickards participated in the 2010 workshop as one of their
        PRF Logo & Web Site Get a Facelift

APRIL Showers brought May flowers — and a new look for the PRF site. Visit www.progeriaresearch.org to see the sleek redesign and learn all about Progeria and PRF.

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It’s time for PRF’s Annual Campaign 2010: May 1st to June 15th. The cure starts with one - YOU.

onepossible
The Progeria Research Foundation

To donate, go to www.onepossible.org. Choose a team, write a note, and enjoy team leaders’ photos and stories of why they are involved in PRF’s work:

TEAM AARON’S PRIDE, led by Ariel Kushner Haber, in loving memory of her brother Aaron
TEAM BALLACK, led by PRF Board member Karen Ballack from California
TEAM FACEBOOK, for all those who have Facebook pages and want to show how powerful the social media world can be in making the dream of a cure POSSIBLE, ONE by ONE
TEAM FOOSE, led by Terry Foose from California, in loving memory of her daughter Amy
TEAM PARATORE, led by PRF Board member and campaign chair Kim Paratore from Massachusetts
TEAM PRF, led by PRF Chairman of the Board Scott Berns, for those who are not affiliated with any of the other teams but who want to contribute
TEAM SCHOONOVER, led by Cam’s grandparents from Pennsylvania
TEAM ZACH ATTACK, led by Zach’s parents from Kentucky
TEAM ZOEY, led by John Marozzi of New Jersey, the grandfather of 6-month-old Zoey who was recently diagnosed with Progeria

You can also send a check in the enclosed envelope and note “ONEpossible.”

What Your Money Goes To
• Drug trials
• PRF’s 6th scientific conference
• Testing undiagnosed children
• Creating standards of care for families and their doctors
• Family-to-family communication
• Funding at least 6 research projects
• Collecting cells and sending them to researchers around the world
• Spreading the word about Progeria and PRF’s work
• Advancing the quest for a cure

THANK YOU for being ONE who makes a cure POSSIBLE!
2010 Progeria Research Foundation Workshop:
From Bench to Bedside In a Decade

From April 11-13, PRF held its 6th Scientific Meeting at the Seaport Hotel and World Trade Center in Boston, MA. A record 140 attendees congregated from 10 different countries to hear expert oral presentations and view a record-breaking 36 poster presentations. Doctors and scientists—who often work in separate worlds, either in the clinic or in the lab—inspired one another as they came together to share cutting-edge findings and directions for future research. The depth and breadth of research into Progeria grows stronger with every meeting. Speakers included leading scientists in the fields of heart disease, aging, genetics, and lamins.

Workshop Organizers:
Leslie B. Gordon, MD, PhD, Medical Director; The Progeria Research Foundation
Frank G. Rothman, PhD, long-standing member of the PRF Medical Research Committee, and Professor and Provost Emeritus at Brown University.
Robert D. Goldman, PhD, Stephen Walter Professor and Chair of the Department of Cell and Molecular Biology at the Feinberg School of Medicine at Northwestern University, and former President of the American Society of Cell Biology.
George Martin, MD, Professor Emeritus of Pathology and Director Emeritus of the Alzheimer’s Disease Research Center at the University of Washington School of Medicine. Scientific Director of the American Federation for Aging Research and former President of the Gerontological Society of America.
Tom Misteli, PhD, Director of the Cell Biology of Genomes Group at the National Cancer Institute, NIH.

The stage was set during the first evening with a Progeria Family Panel, moderated by Wall Street Journalist Amy Dockser Marcus. Researchers had a unique chance to meet some of the people their work could help: Hayley Okines and her parents, Mark and Kerry, from England; Devin Scullion, along with his mom Jamie and step-dad Shawn, from Canada; and Zach Pickard, with his parents Tina and Brandon, from Kentucky. Hayley, Devin, and the adults talked about what it’s like to live with Progeria, and answered questions from the attendees who wanted to better understand how they can continue to help the children.

The family panel was followed by a plenary talk with Leslie Gordon, who brought us through a journey from obscurity, through gene discovery, to on treatment trials, and presented a vision of where the field is headed in the push towards new treatments and a cure.

Scientific Session Topics:
Clinical Trials in Progeria: The American and European teams conducting the world’s first Progeria clinical drug trials opened the scientific presentations. U.S. trial Principal Investigator Mark Kieran (Dana-Farber Cancer Institute, Boston) and trial co-coordinator Leslie Gordon presented an overview of trial design, baseline analyses, and toxicity, pharmacokinetics, and other aspects of the FTI clinical trial designed to create a comprehensive baseline and detailed clinical description of Progeria. Marie Gerhard-Heriman (Brigham and Women’s Hospital, Boston) described the dramatic vessel wall abnormalities in Progeria and Catherine Gordon (Children’s Hospital Boston (CHB)) presented growth and bone health as a distinct skeletal dysplasia which shows some unique abnormalities through testing during the clinical trial. Nicole Ulrich (CHB) reported her novel findings on the natural history of neurovascular disease and stroke in Progeria. Finally, Nicolas Levy (University of Marseille, France) presented exciting preliminary results from their Phase II treatment trial for Progeria and laminopathies with pravastatin and azelodecic acid, the two non-FTI drugs involved in the triple drug trial (see page 4).

Thanks to all of this year’s workshop attendees for becoming part of the Progeria research community—you are an incredibly dedicated group of scientists. Your discoveries are our past, and will be our future.

- PRF Medical Director
Dr. Leslie Gordon

Aging, Cardiovascular Disease, and Progeria: George Martin (University of Washington) addressed unanswered questions regarding the pathogenesis of the vascular pathology associated with normative aging and Progeria. Elizabeth Nabel (Brigham & Women’s Hospital, Boston) described the commonalities between cardiovascular disease in Progeria and the aging population as demonstrated in both progeria mouse models and in human pathology specimens. Michael Goldman, (PRF grantee, Brigham & Women’s Hospital) described the importance of endothelial cell function on heart disease in Progeria and on normal aging. PRF grantee Thomas Wright (Beruva Research Institute at the Univ of Washington) presented his key findings on the Progeria extracellular matrix integrity. Finally, Yosef Gruenbaum, (Hebrew University Israel) talked about drug and genetic manipulations in a new lamin worm model.

Lamin Biochemistry and Pathophysiology:
Lamin is the normal protein counterpart to progerin, which causes disease in Progeria. The more we understand lamin, the better we can understand Progeria. In this session, former PRF grantee Robert Goldman (Northwestern U, Chicago) addressed lamins as essential building blocks of nuclear architecture. Ueli Asali (University of Basel, Switzerland) presented the structure and assembly of wild-type and disease variants of human lamins A/C. PRF grantee Kris Dahil (Carnegie Mellon University, PA) presented her work on the multi-scale mechanical changes in progerin-expressing cells. Maria Eriksson, (Karolinska Institute, Sweden) demonstrated the effects of stem cell depletion in a mouse model of Progeria. Finally, Bryce Paschal (U of Virginia) presented his discoveries on defects in the Ran GTPase system in HGPS.

Cutting Edge Strategies for Research and Discovery:
PRF grantee Tom Misteli, (National Cancer Institute, NIH) brought us a glimpse of the future, with a thrilling presentation on the status of drug development in Progeria. Fyodor Urnov, (Sangamo Biosciences, CA) then took us to the realm of genetic therapies for Progeria by proposing we apply human genetics with engineered zinc-finger nucleases to treat Progeria in the future. PRF grantee William Stanford, (Univ. of Toronto, Canada) then brought us to the cutting edge by developing induced pluripotent stem cells (iPS cells) in Progeria and Laminopathies, which will be invaluable for studying Progeria in the near future. Finally, PRF Medical Research Committee member Judy Campisi, (Buck Institute for Age Research and Lawrence Berkeley National Laboratory, CA) brought her expertise to bear with new insights and new targets for Progeria, aging and the inflammation that affects them both.

You investigators took the stage, with two poster abstracts elevated to oral presentations. Giovanna Lattanzi, (Institute for Molecular Genetics, Italy) presented data on prelin A in diverse tissues. What happens in health and disease? Yva Rosengraven, (Karolinska Institute, Sweden) presented her work on embryonic expression of the HGPS mutation in embryos.

The Poster session, boasting 36 cutting edge projects, displayed the many new directions Progeria research is headed in. Congratulations to John Grazziotto (Mass. General Hospital, Charlestown), who won best basic science poster on “Lamin A and Progeria Degradation: Influence of Farnesyl-transferase Inhibitors,” and to Kelly Littlefield (CHB) who won best clinical poster on “Progeria Clinical Trials: Patient Life at Children’s Hospital Boston.”

“This workshop clearly set a new bench-mark,” said Michael Goldman. “It was one of the most interactive and informative meetings of its kind I have ever attended. The spirit of the meeting was remarkably collaborative, upbeat and inspiring.

Thank you to our co-funders
American Federation for Aging Research
THE MAX AND VICTORIA DREYFUS FOUNDATION, INC.
What's News in Progeria Research?

Here is just a sampling of the many recent publications on Progeria that now appear on a regular basis. The average annual number of articles since 2002 is 25, whereas in the previous 50 years it was just 2 — now that’s progress!

Prior PRF Grantees Provide More Evidence that FTIs Act on Farnesylated Progerin

Researchers believe FTIs help alleviate Progeria symptoms because the drug prevents the protein progerin from becoming farnesylated. But what if FTIs actually work because they’re preventing the farnesylation of other proteins? Researchers from UCLA and the University of Kentucky set out to find the answer. The team created mice that made only unfarnesylated progerin. As expected, the mice developed Progeria-like symptoms. When treated with FTIs, they didn’t improve. If FTIs work by acting on proteins other than farnesylated progerin, the authors reasoned, then the mice would have improved. So the key to FTI benefit must be in the mice’s missing biochemical step.


Art Meets Science in ‘Benjamin Button’ Story

If you’ve ever wondered about the connection between Progeria and the movie The Curious Case of Benjamin Button, this paper may interest you. In the movie and the F. Scott Fitzgerald story that inspired it, Button is born looking elderly and then ages backwards. Dr. Maloney argues that Fitzgerald based this fictional madly on Progeria. After outlining Progeria’s dental, jaw, head and neck symptoms, the author wonders whether Progeria offers “a rare and precious opportunity” to study natural aging on fast-forward.


Progeria’s Link to Normal Aging: An Impressive Detailing of the Evidence

Progeria is caused by a genetic mutation in the gene called LMNA, pronounced “lum’s-uh.” Studies of the worm C. elegans and the fruit fly D. melanogaster have provided more evidence that lamin is involved in aging. Because these organisms have short lifespans and can be studied in large quantities, researchers can more easily study how changes in the nuclear lamina — of which lamin is major component — affect lifespan. The author’s detailed review of the evidence that lamin is involved in aging also includes their own original results. Eriksson is the co-discoverer of the Progeria gene, along with PRF, and her laboratory at the Karolinska Institute in Stockholm remains a major research lab working on Progeria.


Progeria Research a Hot Topic at Conferences Nationwide

Many organizations now seek PRF’s participation in their conferences, where PRF spokespeople share their success stories so others may learn from them, and describe exciting new ventures to prospective partners. Here are the latest presentations given:

- Arlington, VA: PRF Medical Director Dr. Leslie Gordon and PRF Board Chairman Dr. Scott Berns were featured speakers at the Pharmaceutical Research and Manufacturers of America (PhRMA) annual meeting in March. In addition to Progeria being mentioned by other featured speakers

- Kris Noel Dahl, PhD, Carnegie Mellon University, Pittsburgh, PA: “Quantification of progerin recruitment to membranes

The devastating structural and functional cellular changes associated with Progeria, appear to be caused by the protein named progerin. Progerin maintains its lipid properties and therefore remains embedded in the nuclear membrane, where it can be extremely damaging. Dr. Dahl’s work will quantify and characterize the membrane interactions of progerin, compared to its normal counterpart protein, lamin A. With a better understanding of the role of these protein-membrane interactions, we hope to develop strategies for treatment through lipid mediators, such as cholesterol.

Dr. Dahl is an Assistant Professor in the Departments of Chemical Engineering and Biomedical Engineering at Carnegie Mellon University. In Dr. Dahl’s lab, they study the biophysical and mechanical properties of the nucleus at the molecular and tissue levels.

PM Project Collaborator: Mathias Lüeche, Professor of Physics and Biomedical Engineering, Carnegie Mellon Project Postdoctoral fellow: Peter Yaron.

- Kris Dahl

Project Postdoctoral fellow: Dr. Kohta Ikegami.

Tom Misteli, PhD, National Cancer Institute, NIH, Bethesda, MD: “Identification of small molecule modulators of LMNA splicing.”

Dr. Misteli and his team are bringing drug development to the field of Progeria. In collaboration with the NIH Chemical Genomics Center, Dr. Misteli has created a high throughput assay to discover chemicals that interfere with progerin production. This assay has the power to reveal drugs and chemicals that actually rid the cell of progerin altogether. It is the first step in drug discovery that could lead us to treat Progeria and provide clues towards new treatments which may target pathways that FTIs do not affect.

Dr. Lieb is an Associate Professor in the Department of Biology and Carolina Center for Genome Sciences. The projects in his laboratory are united by the scientific goal of understanding relationships between DNA packaging, transcription factor targeting, and gene expression.

Project postdoctoral fellow: Dr. Kohta Ikegami.

Sara Snyder, PhD, The National Organization for Rare Disorders: “Educating the Medical Community about Progeria in the Medical Textbook.”

Dr. Lieb is contributing author for the 7th edition of the Brocklehurst’s Textbook of Genetics and Clinical Genomology. Popular with generations of practitioners, this textbook is an authoritative reference in the field of geriatric care.

PRF Awards Three More Research Grants!

As of May 2010, PRF has funded 29 grants — over $2 million for Progeria-related research projects performed in 4 countries and 13 U.S. states! We continue to solicit proposals worldwide, in our ongoing effort to support the research that will bring us to a cure. All projects are carefully evaluated by our Medical Research Committee and Board of Directors.

Kris Noel Dahl, PhD, Carnegie Mellon University, Pittsburgh, PA: “Quantification of progerin recruitment to membranes

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PM Project Collaborator: Mathias Lüeche, Professor of Physics and Biomedical Engineering, Carnegie Mellon Project Postdoctoral fellow: Peter Yaron.

Jason Lieb

Dr. Lieb is a Senior Investigator at the National Cancer Institute where he heads the Cell Biology of Genomes Group and the NCI Cellular Screening Initiative. He is a member of the NCI Center for Excellence in Chromosome Biology and has pioneered technology to analyze the function of genes in living cells. His team was recently awarded to Dr. Misteli for drug development in Progeria.

Project Participants: Douglas Auld, PhD; Paola Scaffidi, PhD; Sara Snyder, PhD; and Pilar Saladores, BSc.
Mission: To discover the cause, treatment, and cure for Hutchinson-Gilford Progeria and its aging-related disorders.

PRF BY THE NUMBERS:

- **Children living with Progeria:** 63 children in 30 countries
- **Children tested through the PRF Diagnostic Program:** 85
- **Grants funded since PRF was established:** 2299
- **Cell lines in the PRF Cell & Tissue Bank:** 133
- **Children participating in the PRF Medical & Research Database:** 92

**Total Dollars Raised**

- **From 1999 to March 2010:** $8,323,581

85-90% of PRF’s annual expenses are consistently dedicated to its programs and services. The support we have received made the Progeria gene discovery, the Progeria clinical trials and all of our other extraordinary progress possible. With the continued help of our supporters, we will win this race against time and find treatments and the cure for these special children — and perhaps also help millions who suffer from heart disease and other, aging-related conditions.

**PRF’s Programs & Services**

**First-Ever Progeria Clinical Drug Trials for Progeria:**

- PRF funded and co-coordinated a $2 million, first-ever clinical drug trial for Progeria that took place in Boston with partners Children’s Hospital Boston (CHB), Dana-Farber Cancer Institute and Brigham & Women’s Hospital. The trial drug is called a farabeufin-beta inhibitor, or FTI, a drug that has shown great promise in the laboratory and in animal models. The trial enrolled 28 children from 16 countries, ages 3 to 15 years. Trial results are expected to be published in 2010. If the drug proves effective, it will be a remarkable step forward in the pursuit of a cure.

- Since the start of the first trial, researchers identified two additional drugs that, when used in combination with the current FTI drug being tested, may provide an even more effective treatment for children with Progeria than the single drug. PRF moved quickly to explore these additional treatment options. PRF and CHB began a second clinical trial for Progeria in August 2009. The “Triple Drug Trial” is much larger than the first, involving 45 children from 24 countries, speaking 17 different languages.

**Cell & Tissue Bank:**

The PRF Cell & Tissue Bank provides medical researchers with genetic and biological material from Progeria patients and their families, so that research on Progeria and other aging-related diseases can be performed to bring us closer to finding the cure. PRF has collected an impressive 83 cell lines from affected children worldwide (with ages ranging from 2 months to 17 years), and 50 lines from their immediate relatives.

**Who’s Who at PRF?**

Audrey Gordon, Eqp., President and Executive Director, Co-Founder

Audrey Gordon, Eqp., oversees all administrative aspects of The Progeria Research Foundation, including the Board of Directors’ activities, fund-raising events, grant writing, medical research projects administration, and volunteer programs.

Leslie B. Gordon, MD, PhD, Medical Director, Co-Founder

Dr. Gordon co-founded The Progeria Research Foundation with friends and family after her son, Sam, was diagnosed with Progeria. As PRF’s medical director, Dr. Gordon oversees the Diagnostics Testing Program, Cell & Tissue Bank, and Medical & Research Database, and is a co-chair for the Progeria clinical drug trials. She is Associate Professor of Pediatrics Research at the Alpert Medical School of Brown University and Hasbro Children’s Hospital in Providence, RI, and a staff scientist at Children’s Hospital Boston and Harvard University Medical School.

Scott D. Berns, MD, MPH, FAAP, PRF Chairman of the Board, Co-Founder

Dr. Berns, Sam’s father, is a co-founder of The Progeria Research Foundation, and serves as the Chairman of the Board. He is a Board-Certified Pediatrician and Clinical Professor of Pediatrics at the Alpert Medical School of Brown University. He is also Senior Vice President of Chapter Programs at the March of Dimes.

Tina, Brandon, Britanny, and Zach Pickard, PRF’s Ambassador Family

In January 2010, the family of 3-year-old Zach Pickard was named PRF’s Ambassador Family. The Pickards live in Lexington, Kentucky, and are an integral part of PRF’s efforts to raise public awareness, offer information in our programs, and raise funds for research. We appreciate the time and effort they put into these important activities.

**The Quick Facts are updated every few months and are available at www.progeriaresearch.org/quickfacts**

**Medical & Research Database:**

The Database is a centralized collection of medical information from Progeria patients worldwide. The data is rigorously analyzed to help us understand more about Progeria and devise treatment recommendations. Database analysis was critical in determining the primary clinical outcome parameter for the first-ever Progeria clinical drug trial, and in 2010, this analysis contributed to PRF’s comprehensive recommendations handbook on Progeria aimed at optimizing quality of life.

**Diagnostic Testing:**

PRF developed a diagnostic testing program for Progeria in the wake of the 2003 gene discovery so that children, their families and medical caregivers can get a definitive, scientific diagnosis. This can translate into earlier diagnosis, fewer misdiagnoses and early medical intervention to ensure a better quality of life for the children.

**Scientific Workshops on Progeria:**

PRF has organized six scientific conferences that have brought together scientists and clinicians from all over the world to share their expertise and cutting edge scientific data, and foster collaboration on the fight against this devastating disease.

**Research Grants:**

PRF has awarded 28 research grants totaling over $2 million through peer review by our volunteer Medical Research Committee. Awards of up to $100,000, for up to two years, have allowed innovative new research in Progeria to thrive.

**Website/Public Awareness:**

Progeria Research Foundation provides visitors with access to the latest information on Progeria research, support, and education for families and caregivers, and enjoys an average of 10,000 visitors per month. PRF’s newsletters reach nearly 10,000 people in 52 countries. PRF’s story has appeared on CNN, The Dr. Oz Show, Primetime Live, Dateline, and The Today Show, and in Time and People magazines, The New York Times, The Wall Street Journal (front page) and dozens of other widely-read media outlets.

PRF and its partner GlobalHealthPR recently launched a global awareness campaign called **Find the Other 150**, to drive the search for unidentified children with Progeria worldwide by raising awareness of the disease among both the general public and medical communities. The campaign has already helped PRF to discover new families and children with Progeria who need our help.

**Progeria Family Outreach-The PRF Family Chat Room:**

To further provide valuable resources for families of children with Progeria, PRF has created a private Web site to help the families get to know each other and develop a support network where they can share concerns and ideas on how best to care for their children.

**Publications & Research:**

A major goal of PRF is to promote awareness about Progeria and the progress being made in the field of Progeria research. Both clinical and basic scientists have accessed the PRF grants, cells and tissues, and database; their discoveries are published in top-notch scientific journals. The average annual number of scientific publications on Progeria since 2002 is more than 12 times that of the previous 50 years.
Hundreds RIDE THE WAVE at PRF’s signature “Night of Wonder” gala!

In Cambridge, Massachusetts, nearly 400 people celebrated THE WAVE of progress and the tremendous advancements PRF is making toward our ultimate goal of a cure for Progeria.

Mary Thanks to our Generous Sponsors…

Alice & Lew Berns
Leslie Gordon & Scott Berns
Sandra Bresnick & Peter Armenio
Fran & David Elovitz
The Flynn Family
Barbara & Burt Gordon
Elliot and Maryanne Hilbick Foundation
Lori & John Ledoux
Therese & Kurt Melden
Robyn & Tom Milbury
Grechen & Bob Morrison
Kim & Joe Paratore
Debbie & David Ponn
Elaine & Skip Wohlner
Galaco-chairs Vickie Robbin and Debbie Michienzie were all smiles at the evening’s success.

A huge crowd from Foxboro, MA attended.

Rabbi and Suzanne Kushner and friends.

Jim Goh flew in from Colorado and brought his daughter Lauren, who attends Harvard.

Debbie Ponn is surprised and thrilled to be this year’s Amy Award recipient, in recognition of her all-around support of PRF.

Kim and Kevin King enjoy the opening reception with the Gordon-Berns family: Sam, Leslie and Scott.

4th Annual Walk in Honor of Kris McGuinness Filled with Massachusetts Sunshine

How wonderful that Kris is honored every September by family and an ever-growing number of friends who join in a 2-mile walk around Kris’ hometown of Middleboro, Massachusetts. Hundreds enjoyed the sunny morning, refreshments, raffles, music, and the company of others, all to support Progeria research.

Over $260,000 was raised – how WONDERful!

More details and photos at www.progeriaresearch.org/ridethewave2009

Annual & Chapter Special Events Abound!

So many people now look forward to annual PRF events in their communities, thanks to our dedicated families, chapters and other steadfast supporters. Visit our web site to see if there are any upcoming events in your area.

Another Amazing Year at Year-One in Georgia!

For the 4th year in a row, the Year-One Hot Rodders Children’s Charity teamed up with automotive design guru Chip Foose at the Braselton Bash car show. Year-One has raised hundreds of thousands of much-needed dollars to help find a cure for Progeria.

We hope to see you at this year’s event on September 18th!

Kaylee’s 5K Course in Ohio Breaks All Records!

Raising an astonishing $58,000, last year’s race was the biggest yet. On a sunny day in October, hundreds of people – including three other families – came out to support the Hakala family and children with Progeria around the world.

Kaylee gives the “peace” sign as she and her friends Zach, Cam and Lindsay hang out after the race. The families of all 4 children hold races in their communities – amazing!

Rain Doesn’t Dampen PRF’s 8th Annual International Race for Research in Peabody, MA

It’s official: PRF supporters are so committed, they’ll show up no matter what the weather is! What a day - hundreds braved the rain to make this race a memorable one. The after-party inside City Hall kept everyone dry and cheerful; we had more participants, sponsors and donors than ever; and PRF’s executive director met her goal of a first-time 5K run. This year’s race is September 11th – see you at the finish line!

Over 260,000 was raised – how WONDERful!

M ore details and photos at www.progeriaresearch.org/ridethewave2009
More Special Events

PRF Leaders and Special Guest Sam Berns Appear on SpikeTV

PRF Executive Director Audrey Gordon, Chairman of the Board Dr. Scott Berns, and Scott’s son Sam appeared in a segment about Progeria and PRF during SpikeTV’s show MuscleCar in February. The piece was filmed in September at the CA chapter’s YearOne event. MuscleCar is an automotive how-to program that airs every weekend and reaches more than 4 million viewers. Thanks to steadfast supporters YearOne, Chip Foose and RTM Productions for helping to drive awareness!

Everyone’s a Winner at PRF’s 5th Annual Poker for Progeria Game

(left to right) Brittany Carnegie (who helped sell tickets of raffle tickets), Boston Bruins player Milan Lucic, and former NHL player and current Director of Development for the Boston Bruins Foundation Bob Sweeney all come to support Sam, helped sell loads of raffle tickets!)

Chairman of the Board Dr. Scott Berns, and muscle car thanks to long-time popular event. Many socializing in Peabody, Jack, bidding on playing Texas Hold ‘em Poker and Black Jack, bidding on fabulous auction items, eating, drinking, and socializing in Peabody, MA at this increasingly popular event. Many thanks to long-time event chair Maura Smith, the many sponsors, volunteers and food donors, and everyone who came— you helped raise nearly $9,000.

AAA: Another Amazing Aunt!

Congratulations to Cameron’s great-aunt, Jody, who ran her first half-marathon in November and raised nearly $7,000! “I was awe-inspired by everyone’s generosity. Yes, we knew we could count on our friends and family, but the outpouring from complete strangers was so touching,” said Jody. And so is her dedication to her grand-nephew …

Blogging About Progeria

Amanda, a junior broadcast journalism major at Quinnipiac University in Hamden, CT, produced a blog called “Ensure a Cure” as a school project. It includes photos, podcasts and a video interview with PRF’s Director. Check it out at ensuresurcure.wordpress.com. Great job, Amanda, and remember to feature us when you’re a famous news anchor!

Teen Devises “Crafty” Way to Support PRF

Thirteen-year-old Alie from Melville, NY, learned of Progeria when she saw “Hayley’s Story” last spring. That summer at camp, while making bracelets, Alie decided to turn the craft into a fundraiser. She raised $200 from selling her colorful bracelets, and sent PRF several to give to the children to “put a smile on a child’s face.” We’re lucky to have such a talented, generous and thoughtful young lady!

Our Latest Miracle Makers - Helping to Make the Miracle of a Cure Happen

A Miracle Maker is a volunteer who raises awareness and money for PRF by running a fundraiser or other activity to help PRF carry out its mission. Enjoy these wonderful stories of creative and generous people who are making a difference in the lives of children with Progeria.

Aunt Emily’s Endless Devotion

Motivated by her nephew Cam, Emily Howard is one of the family’s hardest-working fundraisers. She has set up collection cans, hosted bake sales and poker games, collected race sponsorships and much more. How wonderful to have such close family ties!

Third Graders Show the Spirit of Giving

Students at Temple Beth Shalom in Peabody, MA collected 50000+ (“charity”) money, and chose to donate the funds to PRF. “The kids were moved by the fact that someone’s age could have this disease,” said teacher Barr. And we are moved by their kindness and generosity.

October 2009: Student Holds Bake Sale and Volunteers with California Chapter

Aidan, from Santa Barbara High School in California, is a friend of the Foose family. She has volunteered to help with several CA Chapter events and has raised money on her own as well as a bake sale at the show grounds where she rides her horse— running back and forth between the show arena and the bake sale table! Thank you Aidan, for being such a great volunteer!

Please join our ever-growing group of heroes. Working together in a variety of ways, we WILL find the cure!
Happy Mother’s Day

Hot off the Presses!
Progeria Handbook Now Available
PRF is proud to present the first handbook dedicated to the care of children with Progeria. With contributors from Brown University, Hasbro Children’s Hospital, and Harvard University Hospitals, the 100-page handbook contains a wealth of information for families and medical caretakers. From basic health facts to daily care recommendations to extensive treatment guidelines, the handbook will help answer many questions for children with Progeria throughout the world.

The handbook is also available to download at www.progeriaresearch.org/patient_care

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