



The Progeria Research Foundation

www.progeriaresearch.org

Summer 2004

PRF Co-hosts Bone Marrow Transplant Scientific Meeting: Forging Ahead by Exploring Potential Treatments

The Progeria Research Foundation, in partnership with the National Human Genome Research Institute and the National Heart, Lung and Blood Institute, sponsored an exciting meeting: "Exploring the Potential for Stem Cell Transplantation in Hutchinson-Gilford Progeria Syndrome", April 25-26, 2004 at the National Institutes of Health in Bethesda, Maryland.

This meeting brought together physicians and scientists with expertise in fields that are essential for a comprehensive assessment of the potential for stem cell and bone marrow transplantation strategies to treat children with Progeria.

Read more about the Workshop on page 4.

These are the
experts who came
together in April
to assess new
technologies and
strategies to treat
children with
Progeria.



Wisconsin Benefit Raises Over \$26,000 for PRF



PRF President Audrey
Gordon and Megan
Nighbor are all smiles.

Aunties are special, but few are as determined as Sue Giese – the aunt of Megan Nighbor, a 3-year old child with Progeria. This "Amazing Auntie" spent months planning and organizing a fun-filled **Bowl-a-thon Benefit** that was attended by hundreds of friends and family, Saturday, May 8, 2004 at Prairie Lanes in Markesan, Wisconsin.

The all-day, all-night fundraiser featured a silent and live auction, bake sale, sponsored bowling, raffles and much, much more! Hundreds of friends, family, and well-wishers who had heard of Megan's fight for a cure came together in a tremendous show of support for the Nighbor

family – and raised over \$26,000 for The Progeria Research Foundation.

In just the past two years, the Nighbor's hard work has generated more than \$40,000 to assist in funding our medical research work. We offer our sincere thanks and gratitude to Sue Giese, Steve and Sandy Nighbor, and to all of their loving family and circle of friends.

Read more about fundraising events on pages 10 & 11.

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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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Kathleen Cody, Executive Director
Susan Rosenblatt, Administrative Assistant



Message from the President:

I have written hundreds of pieces for PRF during my five years as Executive Director – grants, contracts, newsletter articles, volunteer program materials – just about everything you can imagine a non-profit needs to operate, but this is by far the most difficult one! How do I express my feelings on the incredible experiences I've had over the past five years, and about stepping down as Executive Director – in half a page?! I will try my best, and hope I can convey what PRF has meant – and will continue to mean – to me.

In November my husband and I adopted two toddlers, which keeps me very busy, so we decided it was the right time for me to step down from the position of Executive Director, yet maintain my role as President and be named Chairman of the Board of Directors so that I am still closely connected with PRF's activities. As the aunt of a child with Progeria and one of the founders of PRF, I am deeply committed to its mission, and am grateful for the opportunity to remain involved in this new way.

How lucky we are to have found Kathleen Cody! Kathleen has taken over the reigns of PRF for four months now, and she looks like she always belonged there. What impresses me most is that she has the passion for PRF's mission – the key ingredient for a successful leader. With that passion, combined with her impressive fundraising background, I know PRF is in good hands. The rest of the Board and I look forward to working with Kathleen and having her lead PRF to the next level – increasing the budget to pour more money into research and our programs so that treatments are developed and a cure found as soon as possible.

I have watched PRF blossom into a successful, well-respected organization, and have met thousands of people who have opened up their hearts to support our efforts. It is an experience like none other – to see the pure good in people who volunteer their time and expertise, send money, or otherwise give of themselves, many of them total strangers who learn of our work and just want to help – I'm talking about YOU! So from the bottom of my heart, I want to thank you for helping me bring PRF to the extraordinary place we are at today. I could not have done it without each and every one of you.

I hope you will join me as I continue to work with PRF, so that one day – soon, I hope and pray – we can turn out the lights together. Our slogan says it all: Together we WILL find a cure!

Fondly,

Audrey Gordon, Esq.
President, Chairman of the Board



Message from the Executive Director:

It is with a great sense of excitement and pride that I take the reins of The Progeria Research Foundation from Audrey Gordon. For those of you who have never met Audrey, she may have awfully small feet – yet she is leaving some very big shoes for me to fill. The accomplishments of PRF and the growth that we are now experiencing are a testament to her skill and devotion as PRF's first Executive Director.

Before coming to PRF, I managed my own nonprofit consulting firm and provided nonprofit management and fundraising services to organizations throughout the Pacific Northwest including the Court Appointed Special Advocates (CASA) program, the I Have a Dream® Foundation of Oregon, the Oregon Film & Video Foundation, and the State of Oregon Economic Development Department.

I have worked with over 40 nonprofits during the course of my career, yet I have never encountered someone with such fierce dedication to their organization's cause – commitment that is matched only by her compassion and concern for the children with Progeria. The good news is that Audrey will remain very active and involved with PRF as the President of The Progeria Research Foundation and Chairman of the Board.

The Progeria Research Foundation has made tremendous strides within a relatively brief period of time – progress that is unlike any I have seen in my 20-year career in the nonprofit sector. The discovery in 2003 of the gene that causes Progeria has elevated the work of PRF to a new level of intensity and focus. To support this growth, fundraising will become even more critical than ever before and as Executive Director that is a responsibility which falls upon my shoulders.

My commitment to The Progeria Research Foundation, and the children with Progeria, is quite simple – find the funding! Whether it is through special events, corporate sponsorships, foundation grants, major gifts, volunteer projects, or personal contributions from friends and supporters just like you, my time and talent will remain focused on this goal. It is a challenge that I welcome and am prepared to meet on behalf of PRF. Exciting times are ahead and I feel both fortunate and blessed to have the opportunity to work for such a wonderful organization – with a brilliant Medical Director, passionate Board of Directors, amazing staff, dedicated volunteers, and steadfast supporters.

Together we WILL find a cure!

Kathleen Cody

Kathleen Cody
Executive Director

We have a new brochure!



We are pleased and proud to announce that PRF has a brand new brochure – with a whole new look! We've come so far since PRF was formed five years ago when our original brochure was made, and this new pamphlet really shows it! It informatively highlights the research-related programs PRF created – Cell & Tissue Bank, Medical & Research Database, Diagnostics, Testing – and describes our other activities such as the scientific workshops we coordinate, the research grants we fund, and how PRF is a valuable resource to the doctors and families of children with Progeria. Using a wonderfully colorful design with children's illustrations, the brochure also answers basic questions about Progeria and emphasizes that research on Progeria could help millions who suffer from heart disease and other aging-related conditions.

A heartfelt thanks to all those who provided pro bono services to make this new brochure a reality: Our friend Julie Pritchard, owner of JCR Design in Foxboro, Massachusetts, who without thinking twice, agreed to provide design and production services; skilled copywriter Joanne Maynard of QuillCopy in Chelmsford, Massachusetts; and Jon Buddington of Global Printing in Washington, DC.

You can view the color brochure by visiting our website at www.progeriaresearch.org and click on "About PRF".

PRF / National Institutes of Health Scientific Meeting: Exploring the Potential for Stem Cell Transplantation in Hutchinson-Gilford Progeria Syndrome

Pulling together 22 scientific experts in various fields essential to exploring this innovative research direction, this third PRF co-sponsored workshop was successful in addressing this challenging topic. Here is some background information on this topic and the results of the meeting:



What are bone marrow and stem cells?

In the center of our bones, we have marrow that contains special cells known as stem cells. Stem cells can divide to form more stem cells, or they can mature into cell types found in all of the organs of our bodies, such as those cells making up our blood vessels.

What is bone marrow transplantation?

Bone marrow transplantation (BMT) is a procedure in which a child's own bone marrow cells are replaced with new bone marrow stem cells (a transplant) from a healthy donor. While the ideal donor is an identical twin, Progeria children could potentially receive transplants from a relative with a close match to their own cells, or even someone who is unrelated.

For cancer treatment, doctors use radiation and chemotherapy before bone marrow transplantation. Would that be a part of this treatment for Progeria?

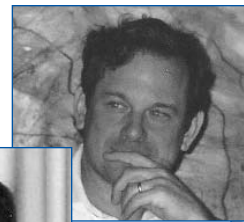
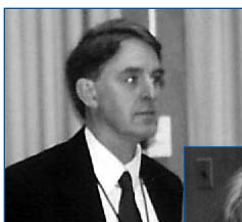
For cancer, this type of "pretreatment" is needed to kill off as many of the cancer cells as possible. We do not need to get rid of the Progeria cells, so we would not expect to use the same type of pretreatment for BMT in Progeria. However, there would be a milder form of pretreatment to help the child with Progeria to receive cells from the donor without reacting

against them. Therefore, there is some risk involved in this type of treatment. That is why it is very important to do as much research as possible before potentially moving to treatment in Progeria children.

Are we moving forward with bone marrow transplantation in children with Progeria, or are we going to work in animal models first?

Here's what the experts at our meeting recommended:

The first step for safe and effective treatment is to perform BMT in animals, such as mice, that have been created to mimic the disease process in Progeria as closely as possible. Many laboratories in the scientific community are working hard to create these animal models (some of which are funded by PRF.) The experts who attended this meeting all agreed that PRF needs to move as quickly as possible to test BMT as a treatment in Progeria mice. This will help to answer two key questions: 1) Is this procedure safe? and 2) Will the bone marrow/stem cells go to the organs in which they are most needed – the blood vessels, heart, fat stores, etc. – to replace unhealthy cells? In the coming months, PRF will promote the research that is essential to understanding whether BMT will improve the lives of children with Progeria. This workshop provided a great starting point.



PRF would like to thank all of the participants on the BMT / stem cell workshop for providing us with their expertise in order to help us to find a cure.

PRF / National Institutes of Health Scientific Meeting: Bone Marrow Transplant Workshop Agenda & Speakers

Session One: Clinical and Genetic Aspects of HGPS

Chair: Leslie B. Gordon, MD, PhD

Clinical overview of HGPS and longitudinal assessment strategies: How will we know if the treatments are improving disease?

Leslie Gordon, MD, PhD
Medical Director, The Progeria Research Foundation; Assistant Professor, Tufts University School of Medicine, Boston, MA; Assistant Professor of Pediatrics, University School of Medicine, Brown University, Providence, RI

Elizabeth Nabel, MD
Scientific Director of Clinical Research and Head of Vascular Biology Branch, National Heart, Lung and Blood Institute (NHLBI), Bethesda, MD

The HGPS gene defect and what it means: Putative disease mechanism and senescence characteristics

Francis Collins, MD, PhD
Director of the National Human Genome Research Institute, Bethesda, MD

Session Two: Why Might BMT Work for HGPS? Learning from BMT in Other Diseases

Chair: Jennifer M. Puck, MD
Senior Investigator and Chief, Genetics and Molecular Biology Branch, National Human Genome Research Institute, Bethesda, MD

Metabolic correction of Mucopolysaccharidosis Disorders by bone marrow transplantation and gene therapy

Chester B. Whitley, MD, PhD
Professor, Gene Therapy Center, Department of Pediatrics and Professor, Institute of Human Genetics, University of Minnesota, Minneapolis, MN

BMT strategies in osteogenesis imperfecta: Clinical trials and lessons learned

Edwin Horwitz, MD, PhD
Associate Member, Department of Hematology–Oncology, Divisions of Stem Cell Transplantation and Experimental Hematology, St. Jude's Children's Research Hospital, Memphis, TN

Transplantation experiences with storage diseases that may apply to HGPS

William Krivit, MD, PhD
Emeritus Professor, Department of Pediatrics, University of Minnesota, Minneapolis, MN

Session Three: Evidence For / Against Vascular Repopulation Leading to Clinical Improvement

Chairs: Elizabeth Nabel, MD and Donald Orlic, PhD
Associate Investigator, Genetics and Molecular Biology Branch, NHLBI, Bethesda, MD

Vascular wall cell recruitment and BMT: How might transplant affect vascular plaques?

Richard Mitchell, MD, PhD
Associate Professor of Pathology, Harvard Medical School, Staff Pathologist, Brigham & Women's Hospital, Boston, MA

Potential for cardiovascular repopulation with BMT in Progeria – evidence from human and mouse studies

Richard Cannon, MD
Clinical Director of the Division of Intramural Research, NHLBI, Bethesda, MD

The state of funding for Hutchinson-Gilford Progeria Syndrome from the National Institute on Aging

Huber Warner, PhD
Director, Biology of Aging Program, National Institute on Aging, National Institutes of Health, Bethesda, MD

Session Four: Complications and Assessment of Risks and Benefits

Chair: William A. Gahl, MD, PhD
Clinical Director, National Human Genome Research Institute, Bethesda, MD

Early and late risks of hematopoietic cell transplants vs disease control

Armand Keating, MD
Chief of Medical Services, Epstein Professor and Head of Department of Medical Oncology and Hematology, Princess Margaret Hospital/Ontario Cancer Institute, Toronto, Ontario, Canada

What can we learn from stem cell transplants to correct other genetic disorders?

John Barrett, MD
Director, Bone Marrow Transplantation Unit of Hematology Branch, NHLBI, Bethesda, MD

Umbilical cord blood transplantation; results from prior studies and assessment of this strategy for Progeria

John Wagner, MD
Scientific Director of Clinical Research Blood and Marrow Transplant Program, Department of Pediatrics, Division of Bone Marrow Transplantation, University of Minnesota School of Medicine, Minneapolis, MN

Gene therapy for HGPS: Strategies, targets, and timeline

Cynthia Dunbar, MD
Head of the Molecular Hematopoiesis Section, Hematology Branch, NHLBI, Bethesda, MD

PRF / National Institutes of Health Scientific Meeting: Bone Marrow Transplant Workshop, continued

Additional BMT Workshop Attendees

Scott D. Berns, MD, MPH, FAAP
Vice President, Chapter Programs, March of Dimes,
White Plains, NY

Fabio Candotti, MD
Genetics and Molecular Biology Branch, National Human
Genome Research Institute, Bethesda, MD

Kathleen Cody
Executive Director, The Progeria Research Foundation

Michael Erdos, PhD
Staff Scientist in the laboratory of Dr. Francis Collins,
National Human Genome Research Institute, Bethesda, MD

Audrey Gordon, Esq.
President, The Progeria Research Foundation

Monica Kleinman, MD
Senior Associate of Critical Care Medicine,
Medical-Surgical Intensive Care Unit, Medical
Director of the Transport Program & Associate in Anesthesia
Children's Hospital, Boston, MA

Felipe Sierra, PhD
Head of the Extramural Portfolio on Cell Structure and
Function of the Biology of Aging Program at the National
Institute on Aging, Bethesda, MD

Lino Tessarollo, PhD
Head, Neural Development Group and Gene Targeting
Facility, Mouse Cancer Genetics Program
National Cancer Institute, Frederick, MD

Rene Varga, PhD
Post-doctoral candidate in the laboratory of Dr. Francis Collins
National Human Genome Research Institute, Bethesda, MD



"A very impressive group of experts was assembled, and the quality of the scientific discussion was very high. I learned a lot about the pros and cons of bone marrow transplantation for other genetic disorders, and how that experience might extrapolate to Hutchinson-Gilford Progeria Syndrome."

Francis Collins, MD, PhD, Director of the
National Human Genome Research Institute



"I thoroughly enjoyed participating in this workshop. The greatest strength was that the diverse group enabled us to address most aspects of Progeria in a concise and informative manner. My congratulations for assembling such an outstanding group."

Edwin Horwitz, MD, PhD
St. Jude's Children's Research Hospital



"A virtually unique experience—tackling a serious medical problem with individuals of different expertise was stimulating, humbling, and provided a fascinating glimpse into a complex disorder that may serve as a valuable model of disease management and understanding well beyond its impact on a very small number of patients."

Armand Keating, MD
Princess Margaret Hospital/Ontario Cancer Institute



"I thought the workshop was extremely helpful in bringing together experts in multiple disciplines that all tie into Progeria, educating each other about related fields that we don't directly work in and focusing specifically on bone marrow transplantation and other therapeutic approaches for Progeria."

Elizabeth Nabel, MD
National Heart, Lung and Blood Institute

PRF's Medical & Research Database in Action: Keeping Our Promise to Make the Lives of Children with Progeria Better Through Proper Medical Care

All children with Progeria develop tight joints all over their bodies, an often dramatic and painful condition that can significantly limit their activities. Physical Therapy and Occupational Therapy (PT and OT) can dramatically improve the quality of life for these children, keeping them active and more flexible so they can run and play with their friends.

Thanks to the PRF Medical and Research Database project, we have recently created **Treatment Recommendations for PT and OT**.

Why did we do it? We have received many phone calls and emails from doctors, school nurses, therapists, and families of Progeria children stating that they are not sure how best to treat Progeria children when it comes to physical activity and physical therapy. Many times therapists are afraid they might injure the children, who look quite frail to them, and want to understand how to optimize quality of life without causing any harm.

How did we do it? Through the PRF Medical & Research Database that YOU helped support! Here's how it works: We've gathered the records of children with Progeria from all over the world, reviewed the PT and OT used by each of them, extracted what has worked best, and had our medical experts analyze the information for creation of our treatment recommendations.

This is the third such medical piece – the first two address medical care for the heart and nutritional supplements – and many more are planned as the Database project progresses. With your support, PRF will continue its commitment to help the children, their families, and health caretakers with the medical issues they face on a daily basis.

A big thank you goes out Lisa Macdonnell, physical therapist, for donating her time and expertise to help PRF in its mission to help children with Progeria!

To see this and the other recommendations in their entirety, please go to our web site at www.progeriaresearch.org/db_guidelines.shtml

New Published Studies Advance the Drive for Treatments and Cure for Progeria

A major goal of researchers is to publish the results of their work in scientific journals for others to learn about it and perhaps use the data for their own research. This is one way we move towards treatments and a cure for Progeria. We are proud to announce the publication of two studies supported by PRF:

Accumulation of mutant lamin A causes progressive changes in nuclear architecture in Hutchinson-Gilford progeria syndrome

Authors: Robert D. Goldman, Dale K. Shumaker, Michael R. Erdos, Maria Eriksson, Anne E. Goldman, Leslie B. Gordon, Yosef Gruenbaum, Satya Khuon, Melissa Mendez, Renée Varga, Francis S. Collins

"Although it is a rare disease, Progeria has long been considered to be a model for studying the mechanisms responsible for normal aging" said Dr. Goldman, "This study highlights the importance of the Lamin A gene in the maintenance of cell structure and function." Key findings relied on cells from the PRF Cell & Tissue Bank.

Published in Proceedings of the National Academy of Sciences (PNAS), June 2004.

Genome-scale expression profiling of Hutchinson-Gilford progeria syndrome reveals widespread transcriptional misregulation leading to mesodermal/mesenchymal defects and accelerated atherosclerosis

Authors: Antonei B. Csoka, Sangeeta B. English, Carl P. Simkevich, David G. Ginzinger, Atul J. Butte, Gerald P. Schatten, Frank G. Rothman and John M. Sedivy

In this PRF-funded project, Dr. Sedivy's team explored the downstream changes in the molecules in the LMNA gene, to better understand which molecules are involved in disease process in Progeria.

Published in the journal "Aging Cell" August, 2004.

PRF Funding of Research Grants Continues...

PRF has awarded its 12th grant – funding Stephen Young, PhD, Professor of Medicine at the University of California at Los Angeles. The project is entitled "Genetic Experiments in Mice to Understand Progeria". The aim of this research project is to use mouse models to build an intellectual foundation for designing appropriate therapies for Hutchinson-Gilford Progeria Syndrome. Dr. Young's laboratory will create a mouse model of Progeria and use that model to understand how the genetic change in Progeria leads to heart disease. As concluded from the BMT workshop, the study of mouse models is a critical next-step in the process to discover treatments and the cure for Progeria.





Remembering Our Dear Friend John M. Tacket

February 9, 1988 – March 3, 2004

John Tacket, The Progeria Research Foundation's first Youth Ambassador, passed away March 3, 2004, at the age of 16. At the time of his death, John was the oldest known child with Progeria living in the United States and this fact alone would have made him special.



But, John was more than special—he was an extraordinary young man who never let his condition get in the way of living his short life on his terms. Everyone who ever met John was touched by his uplifting spirit. “Life is a gift,” he once said, “and I’m going to live it to the fullest.” Unlike so many of us, John never complained about anything, even as his failing health led to painful conditions of angina and arthritis. He was a role model for how to live a life of joy and optimism instead of wasting energy wishing for something he didn’t have.

John was an excellent student, popular in school, and had a job as a cashier at Rally’s restaurants in his hometown of Bay City, Michigan. Active and outgoing, he loved ice hockey and playing pool. But John’s real passion was playing the drums – so much so that he was planning to go to drum college after high school graduation.

As Youth Ambassador for The Progeria Research Foundation, John was an exceptional representative for our organization. His attitude and presence at the 2003 gene discovery news conference in Washington, DC were admired by many and touched the hearts of everyone who met him. Although John’s passing created a deep sense of loss, we still think of him often and feel his spirit behind us as we continue our fight to find the cure for Progeria.

A Message from John’s Family:

To Our Friends at PRF,

John once told us, “I don’t know if what we are doing will help me, but it might help kids in the future.” He was speaking about The Progeria Research Foundation, which he felt a part of. He was honored to be the Youth Ambassador for PRF. He told everyone about the work that is being done. Most of it over my head, but you know John, he seemed to understand what the medical people were talking about.

What is really cool for me to witness is that the love people have for John is being shown through the support of what he believed in, his faith in God, and his works like PRF. Through these people, John is still hard at work.

Thanks for everything you are doing.

Troy, Lynn and Megan Tacket





PRF in the News!

To receive any of these articles in their entirety, please contact us at info@progeriaresearch.org



TIME Magazine Profiles the Efforts of PRF Co-Founders Dr. Leslie Gordon & Dr. Scott Berns

In the May 10 issue of TIME magazine, PRF Co-founder and Medical Director Dr. Leslie Gordon and her husband Dr. Scott Berns are highlighted for their efforts towards finding the cause, treatment, and cure of Hutchinson-Gilford Progeria Syndrome. The article also presents the moving stories of two other parents whose lives were also transformed when their children were diagnosed with serious genetic diseases.

Excerpt from “Saviour Parents”:

“Somebody called me a barracuda once, and I said thank you,” Dr. Gordon says. “You can’t hand a child a paper saying we found the gene, and here, you’re cured. Isolating the gene was the end of Chapter One. We now have a gene that leads to a protein defect that researchers can sink their teeth into. Fantastic labs can ask fantastic questions. We can pull in a lot more terrific researchers, ask better questions and start moving toward treatment.”

PRF Featured by Healthy Mothers, Healthy Babies Coalition



National Healthy Mothers, Healthy Babies Coalition



Healthy Mothers, Healthy Babies Coalition is devoted to improving the health and safety of mothers, babies and families through education and collaborative partnerships, of public and private organizations. Each month the HMHB website features a personal Question & Answer interview with experts in the fields of maternal and child health. PRF Medical Director Leslie Gordon shared PRF’s story in the April edition.

Excerpt from “Learn About Progeria”:

“We identified the ingredients that were critical – funding for researchers, the Cell and Tissue Bank, the Clinical and Research Database, scientific meetings, and workshops that pull in researchers, the consortium, and the diagnostics program. The discovery of the Progeria gene has catapulted us forward, and now we are moving towards treatment and cure, but there is a long way to go. We’ve got all the ingredients that we need, plus a lot of hard work and a lot of volunteers.”

Work of The Progeria Research Foundation Highlighted on Medical Research Website



The Progeria Research Foundation was featured in the June 23 issue of SAGE KE – an online resource for researchers who are working in the field of aging. The article, “Racing Against Time,” featured The Progeria Research Foundation’s journey to drive the research behind the Progeria gene discovery.

Excerpt from “Racing Against Time”:

“Through PRF’s efforts, Dr. Leslie Gordon says with a proud smile, hundreds of people are now working on behalf of children who have the syndrome: I don’t think you ever do anything important alone. Grain by grain, the scientific beach of knowledge about Progeria is growing.”



Don't Miss PRF's

3RD ANNUAL

International Race for Research

5K ROAD RACE and
2-MILE FUN RUN & WALK

T-shirts! Refreshments!
Post-Race Party!

Saturday,
September 11, 2004

9:00 am

Peabody City Hall
24 Lowell St., Peabody, MA



Get a team together to help
find the cure for Progeria!

Race Applications available at
www.progeriaresearch.org
or call 978-535-2594

Join PRF and North Shore Bank: Team Up for the 3rd Annual Road Race for Research September 11th!



*Stu Robbins and daughter Caroline
agree that the Road Race is
a great family event!*

It's hard to believe that this is the third year for The Progeria Research Foundation International Road Race! Thanks to the generous sponsorship of North Shore Bank, this year's race will be bigger and better than ever – and raise even more money for Progeria research. Gather a team of

your friends or family and

run in the **5K Road Race**, or take it a bit easier by entering in the **2-Mile Fun Run & Walk**. Prizes will be awarded, including running shoes donated by our friends at Saucony.

This year's race is dedicated to two boys who had Progeria: John Tackett, PRF's former Youth Ambassador, who passed away this year at the age of 16 and Andrew, a Massachusetts boy who passed away at the age of 9 – and whose family has run the race every year, in his memory. Please join us in honoring these exceptional young people and for a special dedication and moment of observance for those who lost their lives on September 11, 2001.

The pre-entry fee is \$15 for the Road Race, and \$7 for the Fun Run/Walk. Post-entry (received after September 3) is \$20 for the Road Race and \$10 for the Fun Run/Walk. Raise \$100 in pledges and your entry into the race or fun run is free!

T-shirts will be given to the first 150 pre-entries and those who raise more than \$100 in pledges. Awards will be given to the 1st place male and female runners, 1st and 2nd place in seven age categories for both the Race and Fun Run/Walk, the entrant that raises the most money through sponsorships, and all kids! Additional highlights include a post-race party with free refreshments, and children's favorite costumed characters. Computerized timing for runners will be provided by North Shore Striders.

One of the best things about the PRF Road Race is that you don't even have to live near Peabody to participate – you can run or walk in your own hometown! Just call 978-535-2594 or email info@progeriaresearch.org for more information. Our race application can also be downloaded from our website at www.progeriaresearch.org.

NORTH SHORE BANK



Sports fan Sam – working on his swing before the tournament!

Celebrity Golfers Scramble to Help Find the Cure for Progeria

Every year, Playboy holds a series of golf tournaments around the country, with the winners moving on to the semi-finals in Las Vegas – then the finals at the Playboy Mansion in Los Angeles. On Thursday, June 24, the Georgetown Club hosted Boston's 2004 Golf Scramble, under the capable direction of CMT Entertainment of Winchester, Massachusetts.

For each tournament, Playboy Golf generously chooses a local charity to receive a portion of the proceeds generated. This year The Progeria Research Foundation was the lucky one! Celebrities Seth Meyers from Saturday Night Live, Survivor sweetheart "Boston Rob" Mariano, and a host of sports celebrities attended the Wednesday night pre-party and benefit auction at the FELT nightclub in Boston. The next day, a sold-out crowd of 144 golfers enjoyed a picture perfect day on the course, a fabulous dinner, and an awards ceremony that was highlighted by speeches from Dr. Leslie Gordon and PRF President Audrey Gordon. On hand to help give out the awards was Sam Berns, a 7-year-old child with Progeria – a diehard sports fan who captured the hearts of all who attended.

PRF extends our sincere gratitude and thanks to: Carla, Kristin, and Lisa from CMT Entertainment; Ajay Pathak, President of Playboy Golf; all of the Playmates; and each of the golfers and auction winners who contributed to making this generous fundraiser such a huge success.

Peabody Alumni Pull Together Raising \$5,000 from "A Night at the Elks"

Lisa Holmes Masella and friends of the Peabody High School Class of 1982 sponsored a "Fun"raiser April 10th at the Peabody Elks Club to support PRF and their fellow classmate, PRF Medical Director Dr. Leslie Gordon. Familiar faces created some great new memories as everyone danced the night away. And not only was the event fun – it also raised \$5,000 for The Progeria Research Foundation.

We send our special thanks to Lisa, Jeannine Collela, Kim Paratore, Lucas Paratore, Lisa Masella-Babin, Maura Craig, and the rest of the wonderful group of Peabody classmates who continue to show their support for PRF – we are lucky to have such a devoted group of friends!



This table of ten – and hundreds of other Peabody Alumni – had a great time at the recent fundraiser at the Peabody Elks Club.

Colne Primet High School Does It Again! Year 10 Students Have Raised Over \$2,600 for PRF!



In 2003 it was the "Fame Academy" event that raised \$1,148! And this past May the energetic Year 10 students from Colne Primet High School in Lancashire, England, hosted another fundraiser, called

"Big Brother." This event brought another \$1,538 to The Progeria Research Foundation.

Held March 19-20th, this event involved 14 students staying at school (and awake!) for 24 hours carrying out tasks designed to "weed out the weakest," who were then voted out of the competition. Radio Lancashire aired an interview with event organizer and Year 10 Head, Debra Harrison, and an article about the event appeared in the local newspaper.

Great publicity for The Progeria Research Foundation and accolades for these hard-working young people as well!

We once again thank Debra and her classmates for their commitment to helping PRF and their ongoing creativity in finding new ways to raise money!

"Big Brother" Participants:

Jamie Afsar, Ninamarie Barlow, Lauren Barton, Bianca Bennett, Thomas Bennett, Aiden Bridge, Calum Christie, Sally Ann Eyre, Annaliese Lamb, Jason Olive Karl Phillips, Marcus Singleton, Lauren Taylor, and Katie Walls.



Miracle Makers

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

THANK YOU to Class 10-A at Colston's Girl School in Bristol, England! They raised £343 for PRF – that's over \$600 here in the US! The story is best told in their own words: "Having watched a documentary on Progeria, we all agreed to raise money for these children in need. We organized days of non-uniform, made cakes to sell to staff, collected pennies, and had a great book sale. We hope this donation brings lots of happiness." Yes, girls, PRF is very happy to have friends like you and we appreciate your hard work on our behalf.



THANK YOU to CIBC's Miracle Day.

One of PRF's most ardent supporters, CIBC Oppenheimer has once again contributed a portion of the funds raised through their incredibly generous Miracle Day program. The total amount donated to PRF to date is over \$52,000!

THANK YOU to Melissa Glaser Altman of Brookfield, CT who raised \$200 for PRF at her Bat Mitzvah Saturday, May 12, 2004. Marissa saw a program on TV about our founders Dr. Scott Berns and his wife Dr. Leslie Gordon and was so taken with their story that she decided she would ask guests at her Bat Mitzvah to make contributions to benefit PRF. Marissa has shown herself to be a bright, sensitive, and warm young lady – we thank her and wish her the very best!

THANK YOU to Nikki Monks and Geoff Griffiths of Cheshire, England for raising \$776 through sponsorships of their running in The Great North Run, a half-marathon road race. We also wish to acknowledge their two main sponsors, Desirable Fish Market and TalbotMalone, for showing their support of Nikki and Geoff – who tell us they already have plans underway for another fundraiser in 2004.

THANK YOU to David Lester, a long-time PRF supporter who donated a brand-new digital camera and all the accessories we need to put it to good use. One of the nicest things about David's generous gift was that it came as a complete surprise and arrived at a time when we really needed to add a camera to our office equipment.

THANK YOU to Lorraine Lifton for displaying a PRF coin collection can on her desk where she works at Affiliated Agency in Plainview, New York. The Affiliated Agency bosses and cafeteria and coffee shop owners located in the same building were very supportive – Lorraine's fundraising effort raised \$100 and she is also redeeming bottles and cans for PRF. Way to go, Lorraine!



Merchants Limited "BBC Children in Need Day," an annual event in the UK that raises funds for various charities.

THANK YOU to Merchants Limited who chose PRF as their charity of choice for "BBC Children in Need Day," an annual event in the UK that raises funds for various charities. Inspired by a documentary about a local child with Progeria, they raised \$720. The staff really got into the spirit of the "children's TV characters" dress-up theme. "We hope this donation will go some way in helping to find a cure." It certainly will, and we thank you!

THANK YOU to Rose Raymond, owner of Foto Werks, Danvers, MA. We love Rose! She has been a longstanding friend of PRF's and continues to come thorough for us whenever we call on her.

She recently designed a special candy bar wrapper for our recent Playboy golf event and created a wonderful DVD that tells the PRF story. If you would like a copy to share with others, just let us know!

THANK YOU to Kim Estes and the employees at Avnet, Inc., in Peabody, MA for raising \$260 through their monthly "Jeans For Charity Day." On March 5th, 40 employees participated and Avnet, Inc. generously matched their gift to PRF.

THANK YOU to Andrew McCreanor, Head Chef, University of Hertfordshire, England for turning his passion for running into a way to raise money for PRF. Andrew completed the 2004 London Marathon and raised over \$2,200 from sponsorships.

THANK YOU to Beth Mantueffel and her students from Freedom High School, whose coin can collection drive brought in \$265 for The Progeria Research Foundation.

You too can join PRF's team!



University of Miami Hurricanes cheerleaders gather around Sam Berns at a University of Miami vs. Boston College football game, along with Dr. Donna E. Shalala, President of U of M, former Secretary of the Department of Health and Human Services, and a "friend" of Sam and PRF.



Merci...Danke...Gracias...Abrigado!

We are very pleased to report that our June fundraising appeal raised over \$6,000 to help cover the costs of translating important medical documents and Progeria fact sheets into foreign languages such as French, Spanish, German, Italian, Dutch, and Korean – to name just a few. Children with Progeria live around the world and now PRF will be able to better communicate with their families and medical caregivers.

To all of you who responded to this special appeal, we once again say ...Thank You!

Thank You to These Foundations & Corporations for Their Generous Gifts to PRF

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The John W. Alden Trust
The Leslie Charitable Trust
The York Children's Foundation
Unlimited Auto & Truck Repair
Wells Fargo Community Fund

Help Us To Achieve PRF's Mission:

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

Name: _____

Address: _____

City: _____ State: _____ Country: _____

Zip: _____ Home Phone: _____

Work Phone: _____ Email: _____

- ☐ Enclosed please find my donation of \$ _____ to help find a cure.
☐ I am interested in volunteering. Please contact me.
☐ I no longer wish to receive this newsletter. Please remove me from your list

♥ Make a donation in honor of someone: Donation: \$ _____

♥ In honor of _____

♥ Donate on line at **www.progeriaresearch.org** ♥

The Progeria Research Foundation, Inc.

P.O. Box 3453 ♥ Peabody MA 01961-3453 ♥ 978-535-5294



To Our Friends and Supporters Who Have Generously Donated*...

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*From January 1, 2004 through July 1, 2004



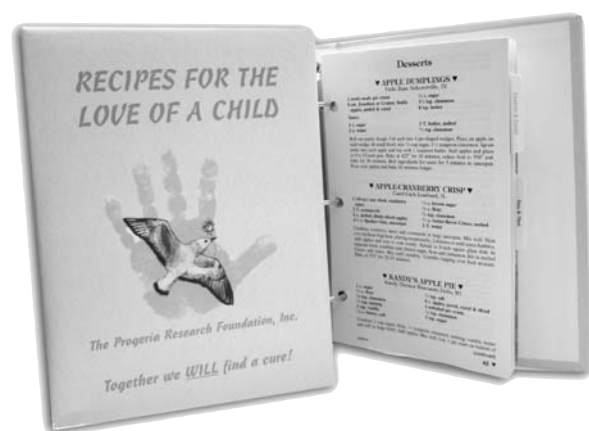
...Our Heartfelt Thanks and Sincere Appreciation!

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We have tried our best to insure that this list is accurate. We apologize if we have inadvertently omitted your name – should you find an error, please contact us at 978-535-2594 or through info@progeriaresearch.org. We also want to thank all of you who have supported PRF over the past five years and prior to January 1, 2004 – we'd need another whole newsletter to list you all!



**Order your PRF
cookbook today
while supplies last!**

Now We're "Cooking for the Cure" With Our New Cookbook

Recipes for the Love of a Child

We are pleased and proud to announce that we now have our very own cookbook, full of delicious recipes donated by the friends and families of children with Progeria, and other PRF supporters. On a cold day back in January we received an email from Lesa Biesiadecki of Romeoville, Illinois, offering to coordinate a cookbook project as a way to raise money for PRF. Thanks to her energy and creativity, the finished book is beautiful and offers recipes for some of the tastiest goodies we've ever eaten.

The cookbooks are \$15 each, including shipping and handling. You can order yours today by visiting our website at **www.progeriaresearch.org** or by calling the PRF office directly at 978-535-2594.

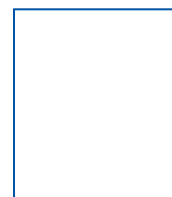
A Message from Lesa:

I would like to thank each person who took the time to donate their special recipes to make this cookbook possible. I would also like to thank each person for purchasing this cookbook – the money raised from the sale of this book will be used for a very important cause. Together we will find the cure for Progeria and these children will be able to live the long and happy lives that they deserve! Thank you for your support.

Lesa Biesiadecki,, Cookbook Chairperson

The Progeria Research Foundation

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



Together we WILL find a cure!



To learn more about how
you can help, contact us:
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