Moving Ahead at Lightning Speed:
New Progeria ‘Triple Drug Trial’ Begins!

As the first Progeria clinical trial draws to a close, PRF is funding continued drug treatment at Children’s Hospital Boston.

In August, 2009, The Progeria Research Foundation and Children’s Hospital Boston began a three-drug combination treatment trial. Researchers have 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 FTI’s alone. See page 4 for details on this exciting and much larger trial that will include up to 45 children from 19 different countries.

Adalia, age 2, and Mom Natalia share a special kiss. Adalia was one of the first children to receive the new triple drug therapy.
PRF’s Mission:
To discover the cure and effective treatments for Progeria and its aging-related disorders.

Message from the President & Executive Director
On June 9th, 2009, I qualify celebrated ten years since PRF’s first board meeting. I found myself vividly remembering that gathering at my sister and brother-in-law Leslie and Scott’s house, my notes in hand and my nerves in turmoil. It was a magical meeting, full of hope, determination and, of course, infinite passion – all of which remain the vital ingredients driving PRF’s mission today.

Knowing this milestone will be shared later in 2009 with hundreds of supporters at the Night of Wonder and tens of thousands more through email blasts, press releases, Facebook and our web site, I took some time to reflect privately on the remarkable journey so many others and I have been part of.

In just ten years, since we founded PRF in the face of no resources and no hope for the children, we have gone from gene finding to the first clinical trial in Progeria, and now a second drug trial has begun. We are now being hailed as a model for disease-research organizations and a prime example of successful translational research, moving from the lab to treatments at a pace virtually unheard of in the scientific community. And along the roads towards helping to save the lives of children with Progeria, we’ve discovered brand new clues to heart disease and aging that affect us all. How absolutely astounding!

A mom recently wrote to me, “Sometimes I wonder how you continue to be motivated after 10 years… then I get a chance to talk to people who just want to help… and I get it.” She’s right on – compassion is tremendously inspiring!

My motivation comes from my nephew Sam and all children with Progeria, the families who put their trust in us to help their children, and the 10,000 of you who support PRF’s work in dozens of ways. It is all of that – all of YOU – who will lead us to the cure.

Happy Anniversary to us all,

Audrey Gordon
President & Executive Director
Announcing
The Progeria Triple Drug Trial

Scientific Basis for Treatment
Progeria is caused by an abnormal protein named progerin. The Progeria research team at Children’s Hospital Boston will add two drugs, called pravastatin and zoledronate, to the current treatment with FTI. Strategy: All three drugs will target different points along the pathway leading to production of the disease-causing progerin. In exciting laboratory studies presented by Dr. Carlos Lopez-Otin of Spain at the 2007 Progeria Research Foundation Scientific Workshop, the two new drugs improved disease in Progeria cells and extended lifespan in mouse models of Progeria. Goal: If the three drugs administered in this trial can effectively block the farnesyl group attachment, then progerin may be “paralyzed” and Progeria may be improved. We hope that the drugs will work as partners, to complement each other so that the progerin protein is affected more by combining the three drugs than using any one drug alone.

Who Will Enroll In The Triple Drug Trial?
The Feasibility Trial: The team has already conducted a mini-trial for 5 children with Progeria. The short, one-month “feasibility” trial asked whether the three-drug combination would be well-tolerated, prior to embarking on a larger international trial. Side effects were acceptable, and the team has moved ahead to the larger efficacy trial.

The Efficacy Trial: We anticipate up to 45 children will enroll in this trial, from 19 different countries, speaking 11 different languages. This includes children participating in the FTI-only trial, the 5 in the feasibility trial, and other children that were either too young to participate in the first trial or children that we’ve discovered over the past 2 years. Children currently enrolled in the FTI-only trial will have the opportunity to enroll in the triple trial when they arrive for their last visit for the current trial. This allows the children to continue taking FTI without any missed doses.

The Treatment/Progeria Relationship
How did we get from gene discovery to drug therapy for children with Progeria? Finding the gene for Progeria was the key. This gene is called LMNA, and it normally encodes a protein called prelamin A (this protein is further processed and becomes lamin A). Children with Progeria have a mutation in LMNA which leads to the production of an abnormal form of prelamin A called “progerin.” Many years’ worth of basic research on prelamin A and lamin A gave us the ability to understand that the drugs administered in this trial may affect disease in Progeria. Over the past six years, research has focused on systematically testing these drugs on Progeria cells and Progeria mice.

The Clinical Trial Team
Since May 2007, a 28-member team has treated children with Progeria from around the globe. Members of the team have expertise not only in Progeria, but also in the three drugs administered in this trial.

Trial Medications At A Glance
Pravastatin (marketed as Pravachol or Selektine) is a member of the drug class of statins. It is usually used for lowering cholesterol and preventing cardiovascular disease.

Zoledronic acid is a bisphosphonate, usually used as a bone drug for improving osteoporosis, and to prevent skeletal fractures in people suffering from some forms of cancer. It is an anti-osteoclastic drug which increases bone density.

Lonafarnib is an FTI (Farnesyltransferase inhibitor), a drug that can reverse an abnormality in Progeria cells in the laboratory, and has improved disease in Progeria mice. All 3 drugs block the production of the farnesyl molecule that is needed for progerin to create disease in Progeria.

Timing
Patients will travel to Boston for testing and examinations lasting 4-7 days, every 6 months for a period of 2 years. For the FTI-only trial, Boston visits occur every four months.

Cost:
We estimate the trial will cost PRF nearly $1.7 million over a 2½-year period for drugs, clinical testing, translators, travel, food, lodging and staff.


This is the new generation of children PRF is helping...

“Paving the Way”
In March, 2009, these five children participated in a one-month feasibility study to determine if the side effects of the three drugs taken together were tolerable. The results were positive, paving the way for the full two-year Triple Drug Trial to enroll up to 45 children with Progeria.

“EVERYONE has been so wonderful. To us you are ALL GOD SENT and we APPRECIATE all that you do for these little angels. Our family is so overwhelmed with excitement and all sorts of emotions with Adalia’s trip to Boston this weekend, I can’t even begin to type the words of how we are feeling!”

- Adalia’s grandmother, just before Adalia’s first trip to Boston for the 1-month tolerability trial.

“Thank you all at PRF so much for all you have done! We would have been lost in a world of confusion and grief without you. Instead, we live in a world of hope and purpose. Thank you again and again! With much love and respect.”

- Family of Cam, another new triple trial patient.

To learn all about clinical trials, go to www.clinicaltrials.gov
Progeria mice tell us more about how hair and skin are affected in all stages of the hair cycle. Comparisons with normal and lamin A and B in different types of skin cells and during the hair cycle showed that normal skin cells make smaller amounts of progerin RNA as they age. Eriksson's result shows that the RNA signal for progerin decreases with diminishing vascular function in normal cells. These results established a direct link at the cellular level between Progeria and normal aging.

**Detailed Dental Analysis Emerges from NIH Natural History Study**

From 2005-2006, PRF collaborated with the National Institutes of Health on a natural history study of Progeria. Fifteen children flew to NIH for clinical examinations, as the research team studied all organ systems affected by the disease. Novel oral-craniofacial phenotypes and quantification of previously reported features were examined. This detailed analysis of dental characteristics of Progeria, led by Dr. Thomas Harcus's dental team, helps us to understand much more about how Progeria affects the mouth structure and function.


**Progeria, Gene Discovery, and Research Challenges**

One author of the Progeria gene discovery in 2003, Dr. Stephen Young's laboratory at UCLA has set up an experimental system in which the amount of progerin in normal cells can be increased or decreased. This method will allow investigators to sort out the direct effects of progerin from secondary ones, and better understand the damage caused by varying amounts of progerin in cells.


All proteins are synthesized in the cytoplasm, and those that end up in the nucleus have to get across the nuclear membrane. The transport is accomplished through channels in the nuclear membrane called "nuclear pores." Many proteins are too large to simply diffuse through the nuclear pores, but are "shuttled" through them by special proteins that have evolved for this purpose. Dr. Hubner's group shows that Progeria cells have globally decreased protein transport from the cytoplasm into the nucleus.


**Hutchinson-Gilford Progeria Syndrome**

**What's New in Progeria Research? Plenty!!**

**Swedish team's new findings strengthen our understanding of the connection between normal aging and Progeria**

Dr. Maria Eriksson, author of the Progeria gene discovery in 2003, has now invented a new, powerful technique to quantitatively measure the expression of the Progeria gene. Dr. Eriksson's laboratory at the Karolinska Institute in Sweden used the technique to measure the amount of progerin RNA in both normal and Progeria cells. RNA is the blueprint molecule in our cells for making protein. The Swedish group found that both normal and Progeria cells make larger and larger amounts of progerin RNA as they age. Eriksson's result shows that the RNA signal for progerin decreases with diminishing vascular function in normal cells. These results established a direct link at the cellular level between Progeria and normal aging.

**Progerin is the abnormal protein causing Progeria.** In recent years, several research groups have found that normal cells also produce progerin, but at lower rates than the cells of a child with Progeria. Moreover, the amount of progerin present in normal cells increases with age. These results established a direct link at the cellular level between Progeria and normal aging.

**Article breaks new ground on HGPS on cellular functions**

Progeria has previously been shown to affect many fundamental cellular functions including replication, gene expression, and DNA repair. Dr. Hubner and coworkers from Germany's University of Würzburg, Institute of Anatomy and Cell Biology have added the transport of proteins from the cytoplasm (outside of the nucleus) into the nucleus (which contains our DNA) to this list.

**PRF Research Grantees Devise New Method to Study Progerin in Cells**

Dr. Stephen Young's laboratory at UCLA has set up an experimental system in which the amount of progerin in normal cells can be increased or decreased. This method will allow investigators to sort out the direct effects of progerin from secondary ones, and better understand the damage caused by varying amounts of progerin in cells.


**Progerin is the abnormal protein that causes Progeria. Its normal protein counterpart is lamin A. Both progerin and lamin A go through a series of processing steps in order to function.** Current treatment trials for progeria are based on an understanding of how we can affect progerin processing.


**Italian Researchers Study Lamin A Biochemistry**

Progerin is the abnormal protein that causes Progeria. Its normal protein counterpart is lamin A. Both progerin and lamin A go through a process of processing steps in order to function. Current treatment trials for progeria are based on an understanding of how we can affect progerin processing.

Word of the impressive advancements in Progeria research continues to spread throughout the scientific and general community. As a result, speaking invitations from prestigious organizations to PRF’s leadership have helped reach thousands who attend to learn more about Progeria and PRF’s work.

PRF’s Chairman Dr. Scott Berns Speaks at Milken Global Conference

Beverly Hills, CA: This annual event brings together 3,000 extraordinary people – Nobel laureates, CEOs from the world’s top companies, first-rate journalists, and leaders in education, health care and philanthropy – to discuss today’s most pressing challenges. Dr. Berns participated in a fascinating panel discussion on longevity, bringing a scientific perspective of the link of Progeria research to normal aging. He received a rousing applause from the audience after describing PRF’s progress toward a cure for Progeria.

Many thanks to panel moderator and Milken Institute senior fellow Howard R. Soule, PhD, for inviting Dr. Berns to speak. “Nothing that I am aware of in the history of modern medicine comes close to a trial of this complexity, with children coming from all over the world”, Dr. Soule remarked toward the end of the presentation, “Hats off to you and your foundation.”

PRF’s Medical Director Speaks at ASCB Meeting with NIH Director Nominee Dr. Francis Collins and Progeria Trial Investigator Dr. Mark Kieran

San Francisco, CA: The American Society for Cell Biology (ASCB) is the world’s largest professional organization advancing cell biological research. At its 48th annual meeting in December 2008, this prestigious panel of Progeria researchers conducted a special session detailing the story of Progeria research advances. The one hour session, entitled “Translating Progeria: A Bench-to-Bedside Story” was chaired by ASCB President and pioneering nuclear lamin researcher Dr. Robert Goldman. It was attended by 1,000 scientists.

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April 2010:
PRF To Hold Its 6th International Workshop on Progeria “From Bench to Bedside in a Decade”

With the expected presentation of the first-ever Progeria clinical trial results, this 6th Progeria scientific meeting promises to be the most exciting and informative conference yet.

The meeting will promote scientific discussions within formal and informal settings. The main focus is to bring basic and clinical science together, to promote collaboration and progress in Progeria research.

Organizers:
• Leslie Gordon, MD, PhD, Warren Alpert School of Medicine, Brown University
  Medical Director, The Progeria Research Foundation
• Frank Rothman, PhD, Brown University
• Christine Harley-Berg, PhD, Brown University

Advisory Committee:
• Robert Goldman, PhD, Northwestern University
• George Martin, MD, University of Washington
• Tom Misteli, PhD, National Cancer Institute

Location and accommodations: Seaport Hotel, Boston, MA

Dates and times: Sunday evening, April 11, 2010 through Tuesday late afternoon April 13, 2010

Agenda: Plenary Session, Oral Presentations, Posters and a Progeria Family Panel
Poster presentations are encouraged. Several posters will be elevated to oral presentations.

Registration information and Abstract forms: http://www.progeriaresearch.org/workshop2010.html

Workshop coordinator: Susan Rosenblatt, workshop@progeriaresearch.org or 978-535-2594

2007 Workshop attendees
PRF’s 1st Annual Campaign Surpasses $100,000 Goal!!

With just 6 months left until the first-ever Progeria clinical drug trial was to be completed, our goal was to raise $100,000 to help fund it. Mission accomplished! From February 1 to March 31, over 800 people donated anywhere from $10 to $5,000, raising an astonishing $107,000 — amazing!

We know these are tough financial times, so it is especially heartwarming that so many donated. It all made a difference — $25, $30, $50 or more — every ONE of you and your donations got us to goal. Thank you to campaign chair Kim Paratore, and to all the teams who worked so hard to make this event a success.

Thank you for being ONE who will make a cure POSSIBLE

TEAM BALLACK, led by PRF Board member Karen Ballack from California

TEAM BRESNAHAN, led by PRF Board member Chuck Bresnahan and his daughters from Ohio

TEAM FACEBOOK, for all those who have Facebook pages and wanted to show how powerful the online world can be in making the dream of a cure POSSIBLE.

TEAM FOOSE, led by Terry Foose from California, in loving memory of her daughter Amy

TEAM KUSHNER, led by Arieh Haber Kushner in loving memory of her brother Aaron

TEAM NEIGHBOR, led by PRF’s Ambassador family with Megan Neighbor

TEAM PARATORE, led by PRF Board member and campaign chair Kim Paratore from Massachusetts

TEAM PONN, led by long-time PRF supporter and former Night of Wonder chair Debbie Ponn from MA

TEAM SCHOONOVER, led by Cam’s grandparents from Pennsylvania

TEAM ZACH ATTACK, led by Zach’s parents from Kentucky

TEAM BOSTON MARATHON, led by the committed athletes who ran in this year’s marathon

Thank you for being ONE who will make a cure POSSIBLE

onepossible
The Progeria Research Foundation

Surf’s Up!

for PRF’s 10th anniversary night of wonder 2009!
it’s time once again for PRF’s amazing signature gala – you won’t want to miss it
Saturday, November 14, 2009 at 6:30 pm
The Royal Sonesta Hotel, Cambridge, Massachusetts

Tickets are now available at $200 participant level and $500 benefactor level...
be a corporate or individual sponsor – levels from $2,500 to $20,000 and come with great “perks”...
place an ad in our beautiful and well-distributed program book – ads range from $100 to $1,000...
donate an auction item... so many ways to ride the wave!

this beach party promises...
top-down cruising through silent and live auctions with paul zekos, auctioneer...
surfside picnic with gourmet food and umbrella drinks – try our special “bikini-tinis”...
dancing “inside the curl” to music by the zaitchik brothers... and much, much more!
call 978-335-2594, email prfnow09@yahoo.com or visit progeriaresearch.org today!

Wendy Nelson and Paula Kelly smile triumphantly after completing the 2009 Boston Marathon and raising nearly $10,000 for PRF! They are surrounded by their children, and in the middle is their neighbor Sam Berns.

Check out these statistics!

Number of Donors: 845
New Donors to PRF: 636
Average Donation: $96.21
Most Common Donation: $25

Wendy Nelson and Paula Kelly smile triumphantly after completing the 2009 Boston Marathon and raising nearly $10,000 for PRF! They are surrounded by their children, and in the middle is their neighbor Sam Berns.
PRF ON THE MOVE!

PRF Comes to Chicago!
It was a night to remember in the windy city on June 8th, with 85 guests attending a champagne reception for the Progeria Research Foundation at the home of hosts Linda and Bob Mendelson. Linda and Bob learned of PRF’s work through attending the most recent two Night of Wonder gala co-chaired by their daughter Debbie Ponn, and wanted to do something to bring awareness to their hometown of Chicago.

In addition to heartfelt speeches by PRF’s Chairman of the Board Scott Berns, Executive Director Audrey Gordon, Linda, Bob and Debbie, the captivated audience listened to two honored guests:

• Dr. Robert Goldman, distinguished researcher from around the corner at Northwestern University’s Feinberg School of Medicine, and
• Rabbi Harold Kushner, founding PRF board member and renowned writer of inspirational books, the most famous being “When Bad Things Happen to Good People” written in 1981.

“I wrote that book because I made a promise to my son that he would be remembered.” said Rabbi Kushner, “Who would have imagined the couple that started PRF 22 years later would live 20 minutes from my wife and me, and we would be so deeply involved in their efforts to find a cure.”

“Many thanks for including me in such a wonderful event! The good spirits and warm camaraderie were infectious. It was an inspiring event, and such an opportunity to share the facts about Progeria.”

Public Service Announcement

Viamedia, the leading independent provider of Cable TV advertising sales, donated $500,000 in advertising time for PRF’s Public Service Announcement this spring. The PSA ran nationwide over a 3-month period on networks such as TLC, Discovery and Fox News.

Raising awareness about Progeria and PRF’s work is one of our major goals, as we strive to find all children with this rare disease throughout the world, so we can help each and every one. Thanks to partners like Viamedia, we will accomplish that mission!

PRF Keeps Up with the “Social Media” Times

“We’re on Facebook and Twitter! Visit our Cause and Group pages on Facebook, featuring PRF’s logo and named: Support Progeria Research. The Official Cause / Group for the Progeria Research Foundation. Combined, the pages have nearly 2,000 friends following discussions, events and the latest PRF news – Join in at http://apps.facebook.com/causes/183613?m=92eea645&recruiter_id=39018947

We’re also Tweeting under the name “Progeria”, so log in and Tweet us, too!

PRF is “Smarter than a 5th Grader” charity

On July 24, 2009, millions tuned in to the FOX channel as professional wrestler Bill Goldberg bravado the classroom to test his knowledge of elementary school subjects on ARE YOU SMARTER THAN A 5th GRADER? - Celebrity Charity Edition.

Bill learned about Progeria and PRF’s work through car designer guru Chip Foose and YardOne President Kevin King at the 2007 Braselton Bash car show supporting PRF. Shortly thereafter, he was approached by FOX and generously chose The Progeria Research Foundation to benefit from his appearance. How exciting to hear PRF’s name on a national TV show!

ARE YOU SMARTER THAN A 5th GRADER? is an award-winning, unique game show measuring adults’ lack of knowledge as they tackle school subjects learned decades ago. They can “cheat” through advice from real grade-schoolers. Contestants compete for cash that is then donated to their chosen charity. PRF received $25,000 - Thank you Bill, we think you made the SMART choice to support PRF!

New Charity Donate Games Supports PRF

In March, Donate Games was launched, its mission to support orphan disease research through “gamers” - players of video games. It was started by seasoned technology executive Jim Carol after his son Taylor was diagnosed with a rare form of Leukemia.

Taylor made a full recovery but he and his family were left with an unshakable urge to make a difference in the lives of others.

Donate Games collects and resells used video games from gamers, then donates the proceeds to organizations promoting research on rare diseases. The Progeria Research Foundation was chosen as one of the first to receive funding.

“Their thoughtful, planned vision of what is needed to propel the research forward. The Progeria Research Foundation has set the gold standard for what can be done when a family faces a rare disease,” says Jim. “We hope by spreading the word to the gaming community, it will inspire others to support their work and promote research for rare diseases.”

Thank you, Jim and Taylor - this is one game PRF is guaranteed to win!
Annual Events
They get better and better every year

Our chapters, families and other volunteers continue to devote their time and energy to events that help support PRF’s work, and new events start up each year. These FUNraisers make it possible for us to forge ahead toward a cure – THANK YOU ALL!

Dozens Deal In for 4th Annual Poker for Progeria Tournament
One hundred Texas Hold ‘em players gambled the night away in PRF’s hometown of Peabody, Massachusetts, while dozens more came to enjoy the silent auction, raffles and Black Jack, raising nearly $9,000.

In keeping with the gambling theme, our signature “Pocketbooks for Progeria” auction was a hit, where the high bidders on designer purses receive a surprise inside: lottery tickets, gift certificates, or start one of your own!

Labs, gift certificates, or start one of your own!

Lots more events planned for 2009 – go to www.progeriaresearch.org for the latest listings, or start one of your own!

Holy Cow – I mean Pelican! Pickard Pelican Run Raises $24,000
Indiana’s Brownstown Electric Supply Company (BESCO) once again organized the 2nd Annual Zach Pickard Pelican Run in May. 180 walkers and runners participated and Zach was on hand to meet every one of them. The highlight of the race was when Zach crossed the finish line while everyone cheered him on.

Determined to raise more than last year, they did so with some outstanding side events selling angel food cakes and shaving their heads! “It seems in many ways the whole town is behind our efforts,” says race organizer Brett Turner. “We’re not surprised, BESCO — your passion for children with Progeria is evident and contagious — we CAN’T WAIT TO SEE WHAT YOU COME UP WITH NEXT YEAR!”

More and more athletes are running for Progeria!
In addition to our Boston Marathon runners, this spring two dedicated women ran marathons in their communities, raising thousands for PRF: Now THAT’S racing for a cure!

Kira Brady ran the Newport Beach, CA Avis OC Marathon — a “Marathon for Miles” — for her 2-year-old god-nephew, raising over $5,000. “It is Miles’ wonderful spirit, kindness, sense of humor and joy that define him in a way that his disease never will,” she says. We applaud Kira’s own spirit!

Patti Tanaka ran her very first marathon in Colorado, in loving memory of her daughter Rachel. Patti’s shirt read “This is a true work of art!”

PowerBlockTV Sells its Unique Cars for Progeria
The PowerBlock is a series of four automotive how-to programs: Horsepower, Truckin’ MuscleCar and Extreme 4×4. They made room for the 2009 projects by auctioning six favorites. The fans went wild — bids for the one-of-a-kind vehicles totaled $10,000!

RPM Productions’ owners Joe and Patty St. Lawrence (pictured here) donated 20% of the proceeds to PRF after learning of Progeria through PRF supporter Chip Foose.

Now THAT’S Power!

Our Latest Miracle Makers – PRF’s Pride and Joy!
Many schools, clubs and religious organizations require students or members to perform community service—why not choose PRF to benefit from it?

Hot Wheels are Hot for PRF
Car enthusiast Craig Pike held a “Home Runs, Hot Dogs and Hot Rods” show in Mesa, Arizona to benefit PRF. For a donation, dozens rained their toy cars on 50-foot tracks. Craig, inspired by the story of Amy Foose, held this event in her honor; raised $365 for Team Foose and the ONEpossible campaign. Thanks for helping drive the cure, Craig!

Our First Miracle Makers from China!!!
Another example of how finding a cure for Progeria is truly a global effort: 8th graders at Shanghai Community International School, quite moved when they learned about Progeria, held a dance with games, raffles and a bake sale, raising $1,130!

They used their free time during lunch and after school organizing the event”, said teacher and event advisor Hung Tuurum. “These generous students represent the community spirit and outreach that is important to the school.”

We agree completely!

Senior Bakes to Make a Cure POSSIBLE
Another successful bake sale — and for the first time, at a Tae Kwon Do school! Lauren of Green River, RI raised $350 and handed out brochures to help educate her classmates about Progeria. Thanks to Jennifer and all the students who enjoyed the goodies for a good cause.

Student “kicks butt” to raise money and awareness for PRF!
Another successful bake sale — and for the first time, at a Tae Kwon Do school! Lauren of Green River, RI raised $350 and handed out brochures to help educate her classmates about Progeria. Thanks for demonstrating your skills and in out of the dojo, Lauren, and showing that bake sales can be held in all kinds of places!

Who else wants to join in and bake for a cure?!

Kentucky Go-Cart Racers Go Wild for PRF!
J & M Motorsports Park in Columbia hosted a Benefit Race for Progeria. After brief Campbell met Zach, he and his family wanted to support PRF by organizing the event. With sponsors, raffles, entry fees and concession sales, they raised over $3,000. “Way to go, Campbell family!”

Many people comment on how fun this section is to read and be inspired by — see even more photos and events at www.progeriaresearch.org
In Loving Memory of Ashley...

Ashley, from Canada, passed away in April, one month before her 18th birthday. Ashley’s popular YouTube video was viewed by millions who enjoyed seeing her bright personality and insightful advice to other children with Progeria: “when people stare at you, don’t let it bother you…you’re one of a kind”.

Ashley is gone from our sight, but never our memories. Gone from our touch, but never our hearts.