Progeria Research Foundation®

WWW.PROGERIARESEARCH.ORG • SEPTEMBER 2017

news

Phase 1 Successful
Phase 2 of 2-Drug Clinical Trial Begins!

New Drug, New Hope for the Children

Over the past year, PRF funded a Phase 1 trial of a new 2-drug combination, everolimus plus lonafarnib. Seventeen children enrolled, and Phase 1 successfully determined the optimal drug doses for this treatment combination. Over the next two years, up to 63 more children will come to Boston Children's Hospital to enroll in Phase 2, where researchers will determine whether this 2-drug combination is effective in fighting heart disease and aging in children with Progeria.

Read more about the PRF-funded Progeria clinical trial – our best hope for treatment and cure – on pages 4-5.

On July 17th, Leticia, 9 years old from Brazil, came to Boston to enroll in the 2-drug trial. Children and their families are filled with courage and optimism as they travel from around the world to the PRF-funded Progeria trials.

Danielle Kim,
10 years old

PRF's Mission:

To discover treatments and the cure for Progeria and its aging-related disorders, including heart disease.

Progeria is a fatal, "rapid aging" condition that afflicts children, who die of heart disease at an average age of 14 years – the same heart disease that affects millions of normal aging adults.

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

A Message from the President and Executive Director

Dear Friends,

I am happy to report remarkable progress on many fronts in this newsletter. Progress that is the result of the generosity and commitment of our partners and financial supporters; the hard work and dedication of our staff and volunteers; and, of course, the courage and strength of our children and their families. Progress because of YOU.

I am honored to succeed Audrey Gordon, our founding Executive Director. Audrey's legacy of leadership is a tribute to her success and stability and her unwavering devotion to our mission. In this exciting time of growth and progress, I will strive to preserve what has made PRF successful. I will work with PRF's dedicated Board of Directors to bring hope to more children and their families, and bring us closer to curing Progeria.

It is amazing to reflect on the past year, as well as PRF's current and future activities – so much going on! Examples of PRF's steadfast determination in Progeria research, public awareness and fundraising are evident throughout these pages, including:

- Phase 1 of our new 2-drug treatment trial for the children was successfully completed and in July 2017, the first children travelled to Boston to enroll in Phase 2 – an important step toward discovering additional treatments for Progeria.
- Chapter and PRF special events abound, including our first-ever Cure Cup Classic golf tournament that introduced PRF and our mission to a new group of supporters.
- PRF is releasing a middle and high school curriculum-based on HBO's ***Life According to Sam*** and Sam Berns' popular TEDx talk, bringing awareness of Progeria and PRF's work, and Sam's legacy of inspiration, to students across the US.

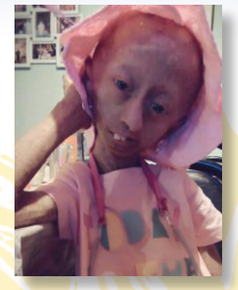
Thank you all for your enduring support. I hope you enjoy reading the pages that follow as much as we enjoyed writing them. And I hope you will share in my sense of accomplishment in all that we have achieved, and of hope in all that we will accomplish – together.

Together, we *WILL* find the cure!

Meryl Fink

Meryl Fink, Esq.

In Loving Memory...



Mariella
14 years old, from Peru

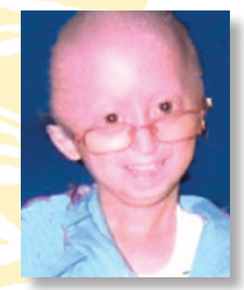
Gamze
17 years old, from Germany

Ontlametse
18 years old, from South Africa

Antonin
6 years old, from Czech Republic

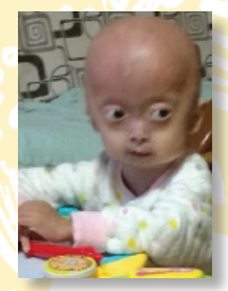
Gone from our sight, but never our memories ~ Gone from our touch, but never our hearts.

Francisco
11 years old, from Chile



Joao
14 years old, from Portugal

Devin
20 years old, from Canada



Xinyan
2 years old, from China

New Drug, New Hope for Children with Progeria

Phase 1 of New 2-Drug Trial is Complete!

Last year you helped PRF fund a new Progeria clinical trial: the drug **everolimus** (a form of the drug rapamycin) is being added to the drug that the children are already taking, **lonafarnib**. This new trial gives us hope that the two drugs together will be even more effective than lonafarnib alone.

Seventeen children participated in Phase 1 over a one-year period, and this crucial trial stage was completed in March 2017. *The purpose of a Phase 1 trial is to determine the safest maximum dosage of a drug.* With the appropriate dosage of the new drug set, Phase 2 has begun. Over the next 3 years, Phase 2 will tell us whether the new drug combination is effective in treating Progeria.

Kaylee, 14 years old from Ohio, is looking good during her endurance testing through the hallways at Boston Children's Hospital.

Phase 2 Moving Full Speed Ahead!

The PRF office has been buzzing with excitement, as enrollment for Phase 2 of the 2-drug trial moved into full swing beginning this July. *The purpose of a Phase 2 trial is to determine whether the drugs are effective in treating Progeria.* Over the next 6-8 months, two children at a time will travel to Boston for their 1-week initial visits. The children will then return for their second and final end-of-study visits two years later. While at home, their doctors will oversee the children and submit periodic health reports to the Boston study team. After completion of the final visits, a rigorous review of the trial data will begin. Final analyses will determine if the two-drug combination is a more effective treatment than lonafarnib alone.

Jesper, 19 years old from Denmark, signing his consent to participate in the 2-drug trial.

Progeria clinical drug trials are the best hope to treat and cure children with Progeria. Through the **2017 ONEpossible** campaign, you helped raise $200,000 to kick-start Phase 2 of the 2-drug trial. THANK YOU for being ONE to make this new trial – and a cure for Progeria – POSSIBLE!

*The combination of the **only known treatment**, plus this new drug, may provide a "one-two punch" to Progeria.*

Each drug attacks progerin, the toxic, disease-causing protein, in different ways. Lonafarnib blocks progerin from developing, while everolimus allows cells to more rapidly clear progerin out of the cells.

We are hard at work arranging flights, lodging, interpreters, and testing at Boston Children's Hospital and Brigham & Women's Hospital, as children with Progeria from throughout the world come to Boston to participate. PRF covers all trial expenses for the families, so they can focus on caring for their children.

Siblings Amber, 11, and Michiel, 19, from Belgium holding their trophies as they finish their prior trial and enter the new trial – GO Michiel & Amber!

Logistics and Funding: It's up to us!

Involving a remarkable 80 children from over 30 countries, the 2-drug trial will cost an estimated $3.7 million over 4 years for clinical testing, travel, food, lodging, staff support and trial-related medical care. Your support makes it possible for PRF to fund the trial and coordinate all travel and lodging for the children and their families.

PRF's Latest Travel Partner: Massport

We are thrilled to be working with a new trial partner - Massport's Logan Airport Medical Patient Assistance Program (LAMPAP) – to welcome families arriving in Boston for their trial visits. Massport employees speak 24 languages! They escort the families from their arrival gate through baggage claim and customs and make sure they connect with our PRF Ambassador who takes the family to their lodging. They also help the families with their return journey, greeting them at the terminal entrance and helping them check in and get to their departure gate. This program is a wonderful way to ease the stress of travel. We are so grateful to Massport and our dedicated Ambassadors for making this possible.

Members of the LAMPAP Customer Service Supervisor staff who meet and assist the families with their arrival and departure in Boston. L-R: Elaine Young, Carlo Maffeo, Brenda Nocella, Bridget Accettullo, Sherry Ricupero, Brad Martin, Carmen Ferreira-Mzaoukk, Michelle Borriello, Maritza Sanchez and Mario Marathias.

PRF Awards Five More Research Grants

Since its inception in 1999, PRF has awarded 70 grants to researchers throughout the world to advance the field of Progeria research. The work produced by these scientists has led to important discoveries about Progeria, heart disease, and aging, as interest in Progeria research continues to thrive.

INNOVATOR AWARDS

Richard K. Assoian, PhD
Professor of Pharmacology, University of Pennsylvania Perelman School of Medicine, Department of Systems Pharmacology and Translational Therapeutics (Philadelphia, PA)

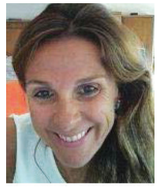
"Analysis and attenuation of arterial stiffening in HGPS: implications for lifespan"

The arteries of children with Progeria are abnormally stiff, and arterial stiffness is a risk factor for heart attacks. Blood vessel walls contain collagen and elastin for flexibility, as blood is pumped to and from the heart. This study will assess the roles of collagen and elastin in normal arterial stiffening with age versus premature arterial stiffening in Progeria. Dr. Assoian will also explore genetic and pharmacologic approaches that aim to improve arterial stiffening by targeting elastin and collagen, and assess the resulting effects of these approaches on lifespan.

Juan Carlos Izpisua Belmonte, PhD
Professor, Gene Expression Laboratories at The Salk Institute for Biological Studies (La Jolla, CA)

"Amelioration of premature aging phenotypes in HGPS"

Cardiovascular alterations are the leading cause of death among children with Progeria. Dr. Izpisua Belmonte's laboratory has demonstrated that cellular reprogramming can rejuvenate Progeria cells. His laboratory is now using cellular reprogramming to improve aging symptoms in mouse models of Progeria, with special focus on the cardiovascular system. These discoveries could lead to the development of novel treatments for children with Progeria.



Isabella Saggio, PhD
Associate Professor of Genetics and Gene Therapy, Sapienza University (Rome, Italy)

"The lamin-interacting telomeric protein AKTIP in HGPS"

The causative mutation of Progeria affects the protein lamin A. AKTIP, a protein that Dr. Saggio's team recently characterized, is a lamin-interacting factor essential for cell survival. This study will test the hypothesis that AKTIP acts as a checkpoint for DNA damage in Progeria. The team will extensively analyze AKTIP function in cells and in Progeria mice. This research will give new insights into the role of this new protein in driving disease in Progeria, including progerin function, telomere dysfunction, and DNA damage. Discovering a new key protein in disease could provide a new target for future treatment.

SPECIALTY AWARDS

Ricardo Villa-Bellosta, PhD
Team Leader, Fundación Jiménez Díaz University Hospital Health Research Institute (Madrid, Spain).

"Therapeutic strategies to recover the normal pyrophosphate homeostasis in HGPS"

Like children with Progeria, Progeria mice exhibit excessive vascular calcification and this contributes to their premature atherosclerosis. Pyrophosphate (PPi) is needed to prevent calcifications, but is impaired in Progeria mice. Dr. Villa-Bellosta will conduct experiments to restore PPi balance in Progeria mice, and test whether this prevents the calcifications that contribute to disease in Progeria. If successful, this strategy may give us new pharmacological agents to develop for the treatment of Progeria.

Tom Misteli, PhD
NIH Distinguished Investigator and the Director of the Center for Cancer Research at the National Cancer Institute, NIH (Bethesda, MD)

"In vivo testing of candidate HGPS therapeutics"

The goal of this study is to test new RNA-based therapeutic agents in mouse models of Progeria. Dr. Misteli previously received a PRF grant to discover RNA therapeutics by testing them on Progeria cells, where the treatments were able to prevent most of the progerin from being made by the cells. Successful in this endeavor, he now moves the treatments into Progeria mouse models, where the goals are to improve cardiac disease and lifespan. If successful, human trials may follow.

Researchers, Register Now!

THE PROGERIA RESEARCH FOUNDATION PRESENTS

9TH INTERNATIONAL SCIENTIFIC WORKSHOP

September 20-22, 2018
Royal Sonesta Hotel, Cambridge, MA USA

Register at *www.prfworkshop.org*

Questions? Contact us at *workshop@progeriaresearch.org* or call 978 535-2594

We look forward to your participation. Together, we *WILL* find the cure!

Grantee Research Highlights – The Big News!

PRF Grantee **Tom Misteli, PhD** (Director, Center for Cancer Research, National Cancer Institute, NIH) and his research team have discovered that disease in progeria is tightly linked to a protein called NRF2. This work, published in the world's leading basic science journal *CELL*, determined that the interaction of progerin and NRF2 is a key contributor to premature aging in Progeria. This finding gives us a new target for treating Progeria, and a new way to link Progeria with cellular aging. (Kubben, et al, Repression of the Antioxidant NRF2 Pathway in Premature Aging. *Cell*. 2016; 165: 1361-74.2016)

PRF Grantee **John P. Cooke, MD, PhD** (Distinguished Chair, Houston Methodist Research Institute, TX) and his research team inserted telomerase, a key aging-associated enzyme, into Progeria cells. This lengthened the cells' telomeres, resulting in a substantial, positive effect on the lifespan and function of the cells. Telomeres are shorter in children with Progeria, so reversing the process of the telomere shortening in their cells may improve disease. (Li, et al, Telomerase mRNA Reverses Senescence in Progeria Cells. *Journal of the American College of Cardiology* 2017; 70: 804-810)

"We all have telomere erosion over time, and many of the things that happen to these children at an accelerated pace occur in all of us," Dr. Cooke said. "We markedly improved the ability of cells to multiply and reversed the production of inflammatory proteins. These findings have the potential not only to help children with Progeria, but also to reverse some problems associated with normal aging."

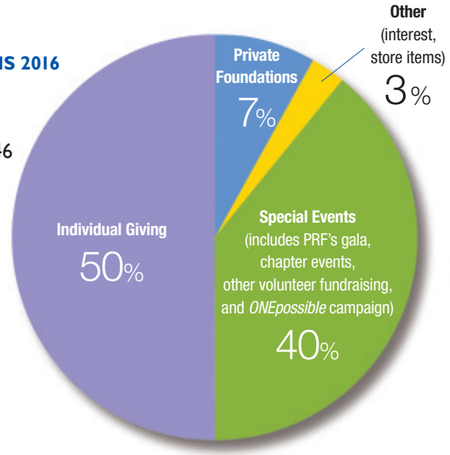
PRF continues to invest your generous contributions by funding dedicated researchers who are working intensely every day to find new treatments and the cure for Progeria.

10 Core PRF Activities That Support Our Mission

2016 ACTIVITY	PRF PROGRAM	ACTIVITY FROM 1999 through 12/31/16
18 children from 13 countries	International Patient Registry	241 children from 57 countries and all continents
4 children tested positive from Guatemala, India, the Phillipines & Romania	Diagnostic Testing Program	127 children diagnosed
143 cell lines sent to 28 teams in 8 countries	Cell & Tissue Bank	723 cell lines sent to 122 teams in 20 countries
5 children enrolled; 8 treatment guidelines sent to 3 countries	Medical & Research Database	152 enrolled; 501 treatment guidelines sent to 42 countries
Phase 1 trial initiated 15 patient visits	Clinical Trial Funding & Co-coordination	3 clinical trials funded since 2007
6 grants awarded	Basic Research Grant Funding	69 grants to 41 labs in 13 countries; funding total >$7 million
2016 International Workshop held	International Scientific Meetings	11 meetings: 8 general workshops and 3 subspecialties
40 events & over 150 new volunteers	Volunteer Program	Nearly 4,600 volunteers worldwide have helped raise awareness and funds
1 language added: Pashto	Translations Program	32 languages
19 new children identified	Public Awareness & Find The Other 150 Campaign	146 living children from 46 countries

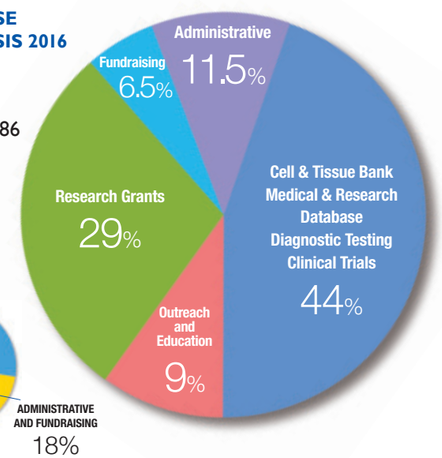
INCOME ANALYSIS 2016

TOTAL REVENUE
$3,189,046

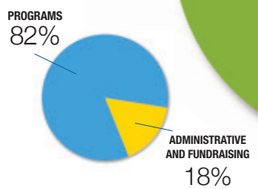


EXPENSE ANALYSIS 2016

TOTAL EXPENSES
$2,660,386



PROGRAM RATIO

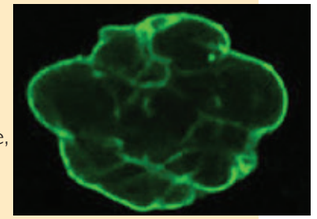


12/31/16 Net Assets: $4,402,872*
*Much of these funds are designated for future clinical trials and drug development costs

Spectacular Milestones Reached for 3 PRF Programs: Propelling Progeria Research Forward

1. PRF Cell & Tissue Bank Distributes over 1,000 Samples

Science can only advance if scientists have the cells and tissues that are essential for their studies. Since its inception, the PRF Cell & Tissue Bank has supplied Progeria basic scientists with over **1,000** cell lines and biological materials, at **135** laboratories in **20** different countries. With the Bank's precious biological materials readily available, these researchers have led the charge toward future advances in Progeria research, giving the world ever-increasing hope for treatments and a cure.



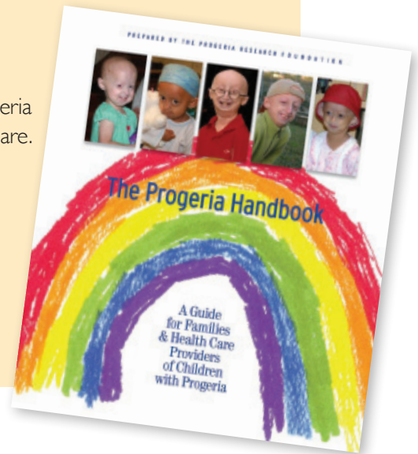
Progeria cell

2. PRF Programs Have Supported 100 Progeria Publications

As of July 2017, scientists have published **100** peer-reviewed scientific studies utilizing support from PRF programs such as research grants, cells, tissues, and clinical information. These publications include the full range of breakthrough discoveries, such as testing new potential drugs in the laboratory, new connections between Progeria, heart disease and aging, and clinical trial results that have shown us how Progeria can be treated and someday cured. You can access information on the latest scientific publications on Progeria at ***https://www.progeriaresearch.org/whats-new-in-progeria-research/***.

3. Handbook Distribution reaches 500 copies

Because Progeria is so rare, most caregivers have never treated a child with Progeria and need expert advice on how to give these children the best possible clinical care. To date, over **500** hard copies of The Progeria Handbook have been distributed to families of children with Progeria and their caregivers. Many more have been downloaded from the PRF website. From basic health facts to daily care recommendations to extensive treatment guidelines from the world's leading experts on Progeria, this 100-page handbook helps doctors, school nurses, parents and other caregivers to provide the best possible care for the children.



PRF By The Numbers

PRF's programs are the cornerstone of our progress.

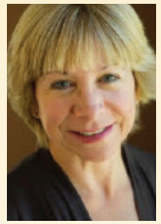
For more details on all of PRF's programs and services, check out **PRF By The Numbers**, a 68-page presentation of charts and graphs that illustrate PRF's progress, at *progeriaresearch.org/prf-by-the-numbers*

Your support makes all of these remarkable milestones possible!

PRF *ON THE MOVE!*

PRF Welcomes New Board Members

Three new members have joined PRF's volunteer Board of Directors. These renowned leaders bring their fresh and unique perspectives, as they help guide PRF's mission.



Paula Kelly is an Assistant Professor of Accounting at Dean College, teaching Financial and Managerial Accounting. Paula is a certified public accountant with an MBA from Providence College, and is a member of the American Institute of Certified Public Accountants. In addition to joining our Board, she will also serve as PRF's Treasurer.

Liza Morris is a 20-year veteran of health and science communications. As a strategy and communications consultant, she works with organizations to build strategic partnerships; raise awareness in global markets about important science, education and human development issues; create programs to drive fundraising; and establish new programs to measure results. Liza has been involved in PRF's media and awareness efforts since 2003, and will continue to serve as Chair of our Public Awareness Committee.

Tom O'Brien is an economist with interests in urban economics and public finance. He is Professor Emeritus of the Isenberg School of Management at the University of Massachusetts/Amherst where he was Dean for 19 years. Prior to that he worked at Harvard University, serving as Vice President of Finance from 1977 until 1987. He has been on the boards of three public corporations, several not for profit organizations, and has worked in federal, state, and local government in appointed positions.

PRF Achieved Highest 4-Star Rating For a Fourth Consecutive Year

For the fourth year in a row, we are incredibly proud to have been awarded the coveted four star rating from Charity Navigator, America's premier independent nonprofit evaluator. Charity Navigator bases its ratings on non-profits' financial health and commitment to accountability and transparency. **Only 11% of evaluated charities share this 4-year distinction.**

Thanks to YOU - PRF's dedicated staff, talented Board, passionate volunteers and generous supporters – for making this honor possible.

PRF Medical Director Presents at Milan, Italy Workshop

In October 2016, The Center for Complexity & Biosystems in Milan, Italy held a Workshop highlighting Progeria research. The meeting was organized by PRF funded researcher, Dr. Catherine LaPorta, and Sammy Basso. PRF's Medical Director Dr. Leslie Gordon presented **"The Progeria Research Foundation and its Global Role."**

PRF Board Chair Dr. Scott Berns, Dr. LaPorta, Sammy and Dr. Gordon (l-r).

PRF Youth Ambassador is a Published Author!

Meghan Waldron, our talented Youth Ambassador, celebrated the publication of her new children's book ***Running on the Wind*** on July 8, 2017 at a book signing party at Barnes & Noble in Hadley, MA. Attended by dozens of friends, family and fellow book lovers, it was the store's largest signing! You can read about the book at *www.redfredproject.com/*

Many thanks to Dallas Graham and his Red Fred Project for helping to raise awareness of Progeria, and enabling Meghan to express her creative writing talents.

Meghan signs one of her books for a fan.

Curriculum Based on Lessons from Sam Berns and PRF will Inspire Generations

In partnership with leadership development organization GearUp2Lead, PRF has released a middle and high school curriculum based on the award-winning HBO documentary ***Life According To Sam***, and Sam Berns' extraordinarily popular TEDx Talk, ***My Philosophy for a Happy Life***.

The TEDx Talk and HBO film are used throughout the curriculum as examples of how we all have the ability to learn and grow as individuals and overcome life's challenges. With Sam's use of a positive mindset to create changes within himself and the people around him, his legacy of inspiration will continue, affecting generations of students through the teachings of this curriculum. Since its release, the curriculum has garnered interest from schools across the country.

TEACHERS AND STUDENTS: To learn more about bringing this exciting program to your school, please visit *www.gearupcurriculum.org* or call (978) 535-2594.

New Year, New Look

PRF's staff has been hard at work redesigning our website!

The new site offers a fresh look, streamlined menus and easier navigation. The site is also mobile-friendly, so you'll find the same information and look whether you're using your desktop, tablet or smart phone. If you haven't visited recently, check out ***www.progeriaresearch.org*** to see the sleek redesign and easily find everything you need to know about Progeria and PRF.

New York's Team Brennen - Now an Official PRF Chapter!

PRF's NY Chapter Board of Directors and Volunteers

When Brennen Maddox was diagnosed with Progeria, his small upstate New York community of Brocton rallied around his family, holding fundraisers to support Progeria research. Now this devoted group is a full-fledged PRF chapter. Led by Brennen's mom Erin, the board plans to organize an annual signature race and other events throughout the year.

"We are so excited to start this new adventure in our lives as a PRF NY chapter!" says Erin, "We have been discussing this for years and now it's finally a reality. We have such a great community rallying behind us and can't wait to get started to help PRF find the cure!"

Lots of Birdies and Eagles seen at PRF's Inaugural Cure Cup Classic

With the rain ending just before tee time on a chilly May morning, dozens of committed golfers took to the greens for PRF's very first Cure Cup Classic Golf Tournament. Held at the beautiful Ipswich Country Club, players enjoyed a challenging round of golf, great food and a Hot Toddy on the first hole!

Thank you to our terrific golf committee – Michele & Tom Mathers, Debbie Mendelson Ponn and Robyn & Tom Milbury – for their enthusiasm and guidance. It was a terrific day!

Chapter, Family and Annual PRF Events

Each year, the number of dedicated volunteers and participants involved in community special events increases – we are amazed, delighted and SO grateful! Thanks to everyone who came to one or more events this past year, to those who brought others who are now PRF supporters, and to all of you for committing to continue helping these special children.

PRF finishes strong with biggest team yet at Falmouth Road Race It was a perfect day last August for the **2016 Falmouth Road Race,** as the 15 members of TEAM PRF ran past thousands of spectators along the 7-mile rigorous race route in their neon green shirts, raising awareness and funds for Progeria research. Way to go, runners!

The FORCE was poolside with Nathan and Bennett The 6th annual **Make A Splash** was fun for kids and kids at heart. Swimming, dancing, silent auction, bake sale, balloon artist and special guest appearances by Star Wars characters made for a perfect day to support PRF's Pennsylvania East chapter.

YearOne and Chip Foose in Georgia – Ten years of car shows and tremendous support

Last September marked the 10th **Chip Foose-YearOne Braselton Bash** car show to support PRF. Organized by YearOne's Kevin King and his phenomenal staff, this event draws hundreds of people from around the country who come to display their classic auto gems and see the famous Overhaulin' star, whose sister Amy had Progeria. Chip enjoyed a very special bond with Sam, who visited him at his shop in California in 2010 (pictured here).

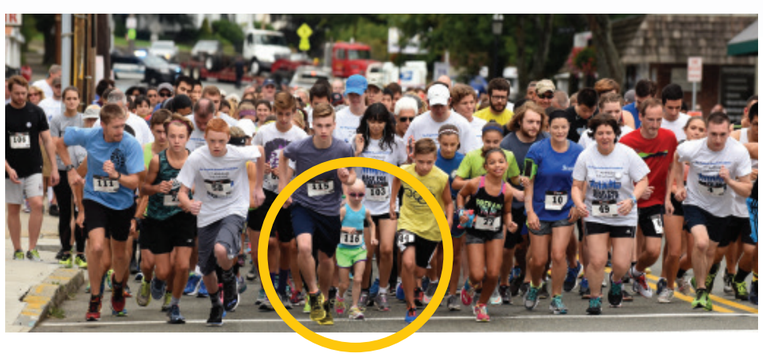
Miles for Miracles goes nationwide

12th year's a charm, as, for the first time, donations poured in from all 50 states for the Michigan chapter's signature event – Incredible! Sporting original t-shirts designed by Lindsay, hundreds enjoyed a day of walking, running, raffles, music, food, and all-out FUN.

Lindsay leads everyone in a big cheer at the start of the race in Flat Rock, MI.

15 years of Racing for Research

Last September marked the **15th Annual International Race for Research**, the biggest and most well-known road race in PRF's hometown of Peabody, MA. The 2016 race was especially exciting, with the top 2 runners finishing within one second of each other! Thanks to all our steadfast local supporters!



With Meghan out in front, hundreds are off and running.

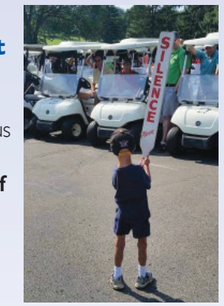
Enzo has a smile on his face start to finish!

Team Enzo hits the streets down under

Since 2014, Team Enzo fans have participated in the **City to Bay Fun Run** in Adelaide, Australia. Co-workers, friends of the family, and Enzo's schoolmates ran or walked the course holding colorful signs and balloons. The Team has grown from 10 the first year to 50 this year – SO awesome!

Cam's Course on par to be the biggest tournament yet

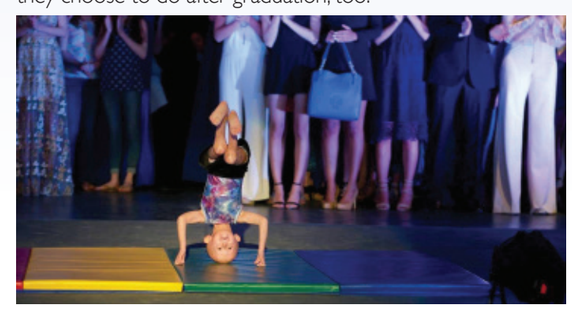
As this newsletter goes to print, Cam's tireless aunt Brooke Howard is gathering a large group of generous sponsors, golfers, and volunteers for the 9th Annual **Cam's Course Golf Tournament,** once again led by Title Sponsor Robert McCarthy. The event is a summer highlight in Cam's hometown of Butler, Pennsylvania for his family, friends, and local businesses and clubs, all rooting "fore" Cam and a cure!



Golfers wait in their carts for Cam to give the signal to hit the links

NJ's Mountain Lakes High School Fashion Show now a school tradition

For the past 7 years, the senior class has organized this event for Team Zoey. The students have a blast modeling the latest fashions, while fundraising through admission fees and an ad book, with a goal of matching or beating the amount raised by the previous class. They always succeed in doing so – and we're sure this industrious group will succeed in whatever they choose to do after graduation, too!



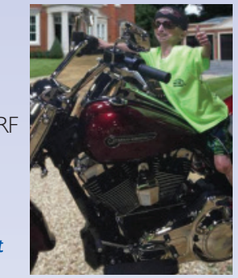
Fashion show student-models cheer for gymnast Zoey as she ends the show with a headstand.

Do we have your email address? We send notices of special events in your area so you don't miss out on all the fun.

Do you want to start your own PRF event tradition? Contact us at info@progeriaresearch.org to sign up for our mailing list and get more involved TODAY!

Harley lovers continue to ride for Progeria

It was a perfect day for the **6th Annual Zach Attack Poker Run**, as over 50 bikers hit the road for PRF in Zach's hometown of Lexington, Kentucky. Such a great group!



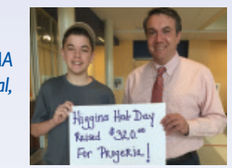
Zach gives a thumbs up to all the riders as they put their kick stands up and start the run.

HatsOFF to our HatsON supporters

An impressive 16 countries and 25 states were represented, as hundreds worldwide donned their favorite hats for PRF's **5th HatsON for Progeria Day**. Join the fun next April or any time – contact us at *volunteers@progeriaresearch.org*.

Adalia Rose and her family joined the fun!

All of our hometown schools in Peabody, MA participated. Chris, shown with his Principal, organized the middle school event.



First-time HatsON participants at Flagship Pioneering in Cambridge, MA got creative with a kids-themed lunch and Best Hat /Wig contest!

1st Annual Deallaney Hudson King Mackerel Tournament Reels in Funds for PRF

The fish were biting last October in Atlantic Beach, NC, as 38 boats participated in this fun event organized by Deallaney's family and friends. If you missed the tournament, you can "catch" the next one on October 28, 2017. Check our website home page events listings for details.

The Sea Dub team with their 21.7 lb and 17.5 lb King Mackerels!

Miracle Makers

PRF's Miracle Makers Continue to Inspire and Engage Their Communities

Each year we are inspired by and impressed with the students, companies, volunteer groups and more, who selflessly devote their time and energy to helping children with Progeria. Although we can only include a few stories here, we thank you ALL for making the miracle of a cure possible.

Ella Stark and Sarina Margolin – longtime supporters and only in high school!

They began their journey with PRF as middle school students at Sidwell Friends School in Washington, DC, running bake sales and attending the opening night of PRF's 2010 Scientific Workshop. Since that time, Ella and Sarina have grown to be passionate supporters of PRF, holding a school Community Night, speaking about their involvement as student leaders of PRF's curriculum at a national conference, and creating our 2017 **ONEpossible Campaign** video. Such talented and dedicated students – we are so grateful to have them on our team.

Olivia from New York started supporting PRF last year, when she asked her family to donate. This year she involved her school, giving a presentation about Progeria to her fellow 6th graders and placing **handmade donation jars** (pictured here) in the teacher's lounge.

Such a powerful message from a special person. Wow!

This is what the jars say:

"Change means growth…

Change means new experiences…

Change can make all things new…

Will you share YOUR loose change to help us find a cure for Progeria?

You could CHANGE a young person's LIFE."

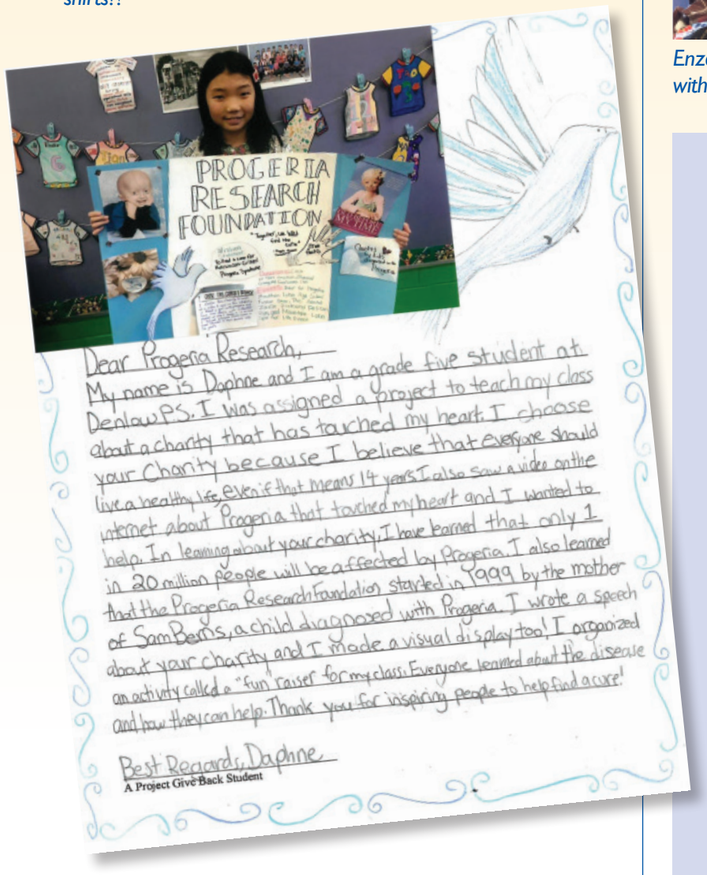
Cruise-In For Progeria

Since 2008, Classic Auto Restoration Specialists (CARS) in N. Fort Meyers, Florida, has hosted **'Cruise-In for Progeria'** open houses at the CARS shop, where people eat delicious BBQ, tour the museum, and see a wide array of classic cars – all for a small donation to PRF. Thank you, car lovers, for *driving up* donations to PRF!

CARS owner Mike Case speaks to Cruise-In attendees.

*The Kentucky **'Girls on the Run'** team at Rosa Parks Elementary raised funds for PRF in honor of Zach, who accepted the check from the group in person. "It was inspiring watching the girls meet Zach and be proud of their accomplishment. We hope to have Zach back to our school again. He's the best!"*

Zoey's Forest Avenue Elementary class of 2020 participated in the 2016 Turkey Trot. Could they be any cuter in their "Super Z" shirts?!



Daphne, from Ontario, Canada, thanks PRF for inspiring people to help find a cure. Thank YOU, Daphne, for the time and effort you put into this creative way to raise awareness of Progeria and PRF!

A Sweet Idea

Since she learned about Progeria in 2014, "Tia Lili" has become a very important part of Team Enzo in Australia. Most recently, she created a **Chocolate Box** stuffed full of candy she sells to her co-workers, with all funds donated to Enzo's ONEpossible team. Thanks to Lili and all her special customers – keep on snacking!

Enzo – showing off his "strong" pose – with Lili and the "sweet" fundraising box!

Donate Your Birthday to PRF on Facebook!

Now there's a simple and brand new way to be a Miracle Maker –

In lieu of presents, friends and family can now donate to PRF in honor of your special day. Watch for the "Donate Your Birthday" message on your personal home page as the date nears.

Join **Paula, Elaine, Kathryn, Gary, Kimberley, Leigh-Ann, Lynn,** and **Kathryn,** all of whom selflessly donated their birthdays, shared the event with their Facebook friends, and raised over $3,000 in total!

Many thanks to our first PRF Birthday Boys & Girls, for giving children with Progeria the best gift imaginable: hope for a cure.

You can also go to the PRF Facebook page *(www.facebook.com/ProgeriaResearch/)*, click on Fundraisers, then on Raise Money, and customize any other type of event you like.

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To learn more about how you can help, contact us:
info@progeriaresearch.org or call 978-535-2594

Jeanezharette hopes you had a great summer!

NIGHT OF WONDER 2018 will be music to your ears!

Tickets, ads and sponsorships now available for PRF's signature gala and auction.

Please join us Saturday, April 28, 2018 in Boston, MA for festive food, distinctive drink and an astounding auction...

This is your chance to be "instrument-al" in helping us cure Progeria.

Visit **prfnow.org** today to reserve your front row seat!

For more information, email **prfnow@gmail.com** or call 978-535-2594.