FANTASTIC NEWS!
Study Published in JAMA Finds Treatment Extends Survival

In a spectacular development, a new study published in The Journal of the American Medical Association (JAMA) shows that treatment with lonafarnib extends lifespan in children with Progeria. This is the first evidence that lonafarnib alone improves survival for this fatal disease.

On the heels of the JAMA study, PRF and Eiger BioPharmaceuticals announced they will partner to pursue FDA approval of lonafarnib so that children may access the drug with a prescription instead of through a clinical trial.

Read about this groundbreaking study and the PRF-funded clinical trials that make this progress possible on pages 4-7.

Meghan, then six years old, was one of the first children to enroll in the clinical trial in 2007 that led to the recent breakthrough on lonafarnib. She is pictured on the left getting a lesson in how to take lonafarnib, holding the drug for the very first time. On the right, after ten years of taking lonafarnib, Meghan is finishing strong in PRF’s Annual Race for Research in 2017.
A Message from the President and Executive Director:

Dear Friends,

PRF’s mission is clear: to find life-changing treatments and the cure for Progeria. Every day, our research makes strides towards this goal – thanks to YOU, our steadfast and dedicated supporters.

The past year has been an incredibly active year for PRF, full of exciting progress. This newsletter highlights many of these notable achievements:

In April 2018, a study published in JAMA led by PRF’s Medical Director, Dr. Leslie Gordon, and funded by PRF found that lonafarnib extends survival in children with Progeria – a remarkable feat that demonstrate our work is resulting in longer, stronger lives for children with Progeria.

In May 2018, PRF and Eiger BioPharmaceuticals partnered to pursue FDA approval for lonafarnib as a treatment for Progeria, marking the first Progeria therapy to be submitted for FDA approval.

Our two-drug clinical trial is moving full speed ahead, with new children enrolling and some now coming back to Boston to complete their final trial visits.

We “Rocked the Cure” at Night of Wonder 2018, raising a record-breaking $580,000 for new research.

None of this progress would have been possible without all of you. Your donations, fundraising events and volunteer efforts help PRF raise the funds needed to fuel our research, allowing us to continue to strive for the next breakthrough in our race to cure Progeria.

As PRF’s Executive Director, I have the privilege of meeting children and families touched by Progeria. As I tell many people, this is the best part of my job. I meet extraordinary families filled with love, hope, optimism and trust in our mission. Families inspire us every day, and I am proud to be a part of this fight. I pledge to continue this progress, helping raise awareness of this rare disease and bringing together the people who can play a part in this fight.

Thank you all for your support,

Meryl Fink, Esq.
President and Executive Director

Meryl with 8 year old Aadiya from India during her trial visit to Boston Children’s Hospital in May 2018.

PRF’s Vision:
A world in which every child with Progeria is cured.

PRF’s Mission:
To discover treatments and the cure for Progeria and its aging-related disorders, including heart disease.

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Audrey Gordon, Esq.
Director of Development
Molly McDermott
Clinical Trial Coordinator/Family Liaison
Michelle Fino
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John Marozzi

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Meghan Waldron

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New Jersey, Barbara Batesko
Ohio, Maria & Tim Halio and Heather Kudzis
Pennsylvania West, Jim Schoonover and Stephanie Howard
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Progeria is a “rapid aging” condition that affects 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.
Progeria Research Drives Forward

PRF-Funded Study Finds Lonafarnib Increases Lifespan for Children with Progeria

Next step: seeking FDA approval.

The best news yet...
The study using lonafarnib, a type of farnesyltransferase inhibitor (FTI), shows extension of lifespan in children with Progeria. Authors compared children who received lonafarnib alone to those similar in age, sex and continent of residency who were not part of the clinical trial and therefore did not receive lonafarnib.

The results demonstrate that treatment with lonafarnib alone compared with no treatment was associated with a significantly lower mortality rate (3.7% vs. 33.3%). The study, which was funded by The Progeria Research Foundation, was published April 24, 2018 in The Journal of the American Medical Association* (JAMA), one of the most prestigious scientific journals in the world.

The research was led by PRF’s Medical Director, Leslie B. Gordon, MD, PhD, and conducted by PRF-funded investigators from Brown University, Boston Children’s Hospital, Harvard Medical School and Boston University.

*Gordon et al., “Association of Lonafarnib Treatment vs No Treatment With Mortality Rate in Patients With Hutchinson-Gilford Progeria Syndrome, JAMA, April 24, 2018 Volume 319, Number 16

A link to PRF’s press release about the study and more details of the findings and their impact can be found at www.progeriaresearch.org

“Study published in JAMA shows evidence that we can begin to put the brakes on the rapid aging process for children with Progeria. These results provide new promise and optimism to the Progeria community.”

- Leslie Gordon, MD, PhD, co-founder and Medical Director for PRF, and lead study author.

“My lab did some of the original research on cellular and mouse models that showed potential benefit of this class of drugs for Progeria. It was encouraging to see those results translated into a clinical trial. Yet demonstrating effectiveness of treatments in this small population of children with this rare fatal disease is a major challenge. Thus, I’m particularly encouraged by these latest findings.”

- Dr. Francis S. Collins, MD, PhD, National Institutes of Health Director

Zoey is an active 8 year old from New Jersey. She has been taking gymnastics for over 3 years and loves training, performing and competing with her fellow teammates. Zoey has been taking lonafarnib since joining the PRF-funded clinical trials 4 years ago.

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PROGERIA SYNDROME

Children with Progeria die at an average age of just 14 years.

1999
- Discovery of Progeria Gene
- The Progeria Research Foundation (PRF) was founded in response to the complete lack of progress being made to help children with Progeria

2003
- First-ever clinical drug trial for a potential treatment

2007
- Clinical trial with lonafarnib reveals improvement in cardiovascular disease

2012
- Ongoing new trial adds a drug that attacks progerin from another route

2016
- Study published in JAMA shows decreased mortality rate when using lonafarnib as a treatment option

2018
- PRF’s Unprecedented Progress Against a Fatal Disease
- The Journal of the American Medical Association
- Study demonstrates a link between drug therapy and increased survival
- Lower mortality rate after a median of 2.2 years follow-up
- Treatment with lonafarnib alone compared with no treatment was associated with a significantly lower mortality rate (3.7% vs. 33.3%)

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PROGERIA

Progeria, also known as Hutchinson-Gilford Progeria Syndrome (HGPS), is a rare, fatal genetic condition of accelerated aging in children.

GLOBAL STUDY

Finds Treatment with Lonafarnib Increases Survival in Children with Progeria Syndrome

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PRF and Eiger BioPharmaceuticals Partner to Pursue FDA Approval of Lonafarnib

On the heels of the study published in April 2018 in JAMA, PRF partnered with Eiger BioPharmaceuticals to pursue FDA approval of lonafarnib as a treatment for Progeria – the first therapy to be submitted to the FDA for this purpose. Lonafarnib is not currently approved for use outside of clinical trials. If approved, children may access this drug by prescription instead of having to do so through a clinical trial. This would allow PRF to devote more resources to new trials in order to explore additional treatment options and ultimately discover the cure.

This road towards FDA approval of lonafarnib, in partnership with Eiger, is made possible by the success of all of PRF’s research programs:

• The PRF International Progeria Registry identified children who went on to receive lonafarnib as part of our clinical trials.
• Only children with a definitive diagnosis of Progeria can enroll in the trials, and the PRF Diagnostics Testing Program provided the diagnosis for many trial participants.
• Analysis of medical records gathered through the PRF Medical & Research Database provided critical health data as children entered the lonafarnib trials.
• Cells from the PRF Cell & Tissue Bank were instrumental in the gene discovery and studies of lonafarnib as a potential treatment.
• PRF-funded research grants showed that lonafarnib had a positive effect on Progeria cells and in Progeria mouse models, paving the way towards clinical trials.
• Results from PRF-funded clinical trials showed that lonafarnib improved weight gain, bone structure, vascular disease, and increased lifespan in children with Progeria.

If approved, children may access this drug by prescription instead of having to do so through a clinical trial. This would allow PRF to devote more resources to new trials in order to explore additional treatment options and ultimately discover the cure.

Two-Drug Trial Continues

Progeria clinical drug trials are the culmination of years of research focused on discovering treatments and the cure for children with Progeria. Your support has allowed PRF to coordinate and fund our third experimental treatment in eleven years – a remarkable feat for a relatively small organization focused on a rare disease. Children in this trial take two drugs: lonafarnib, the medication that gives the children stronger hearts and longer lives; and everolimus, a drug that shows promise in laboratory studies. The trial has two phases. Phase 1, completed in June 2017, determined the best dose of everolimus to give the children. Phase 2 is occurring now, and will determine whether the combination therapy is more beneficial than lonafarnib alone.

It has been a busy year! Since last fall, more than 40 children have traveled to Boston from 20 countries, for a total of over 60 children currently enrolled in this trial. Enrollment will be completed this year – an amazing accomplishment!

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

Lucy
8 years old,
from the United Kingdom

Nova Mae
8 years old,
from the Philippines

Luis Javier
10 years old,
from Guatemala

Magaly
16 years old,
from Columbia

Rafaely
12 years old,
from Brazil

Elias
12 years old,
from Mexico

Natsuki
17 years old,
from Japan

In Loving Memory...

Eloysa
2 years old,
from Brazil

...and in memory of those who are
not able to share in our loss:

(Top row l to r): Tom Glover PhD, Vicente Andrade Garcia PhD, Tom Misteli PhD,
Maria Eriksson PhD, W. Ted Brown MD, PhD, Frank Rothman PhD (emeritus),
Bryan Tale PhD (chair)
(Front Row l to r): Monica Kleiman MD, Christine Harley-Berg PhD,
Judy Garapli PhD, Leslie Gordon MD, PhD, Marsha Moses PhD

PRF Announces Updated Grant Program

Since its inception in 1999, PRF has awarded 71 grants to researchers spanning 14 countries to
advance the field of Progeria research. The work produced by these scientists has shaped the field
and led to important discoveries about Progeria, heart disease, and aging.

Over this past year, PRF’s 11-member Medical Research Committee (MRC) held two meetings
to revise PRF’s grant program. Based on these discussions, PRF has implemented a two-step
granting process: a letter of intent, followed
by an invitation for selected full proposals. In addition, a member of the MRC will conduct
regular advisory meetings with each funded investigator, to discuss progress, pitfalls, changes
in project direction, and provide assistance in
any way possible to facilitate successful research. These changes will assure that PRF’s grant program
remains on the cutting edge of science and
continues to propel us towards new treatments
and the cure.

For more details on the application process and the grants PRF has funded please visit:
www.progeriaresearch.org/research_funding_opportunities

Researchers, Still Time to Register!

THE PROGERIA RESEARCH FOUNDATION PRESENTS
9TH INTERNATIONAL SCIENTIFIC WORKSHOP
September 20-22, 2018
Royal Sonesta Hotel, Cambridge, MA USA

Meeting Mission:
To promote collaboration between basic and clinical scientists
toward progress in Progeria, cardiovascular, and aging research

Featured Presentations:
Progeria Families Inspiring the Research Community
Plenary Session by Eric Lander: Broad Institute, MIT
Presentation by Francis Collins, NIH Director

Session Topics Include:
Disease Mechanisms in Progeria, Heart Disease and Aging
Therapeutic Approaches to Progeria
Spotlight on Genetic Therapies

Register at www.prfworkshop.org
Questions? Contact us at workshop@progeriaresearch.org
or call 978 535-2594
REVENUE 2017

- INDIVIDUAL GIVING (includes in-kind donations) $1,497,241
- SPECIAL EVENTS (includes PRF’s gala, chapter events, other volunteer fundraising, and ONEpossible campaign) $1,123,766
- PRIVATE FOUNDATIONS $279,005
- OTHER (interest, Store Items) $58,315
- TOTAL REVENUE $2,958,327

EXPENSES 2017

- RESEARCH PROGRAMS Clinical Trials, Diagnostic Testing Medical & Research Database, Cell & Tissue Bank $1,847,965
- RESEARCH GRANTS $626,671
- ADMINISTRATIVE $303,134
- PUBLIC AWARENESS $242,106
- FUNDRAISING $154,027
- TOTAL EXPENSES $3,173,903

NET ASSETS: $4,178,941*

*Much of these funds are designated for future clinical trials and drug development costs

PROGRAM RATIO SUMMARY

- 85% PROGRAMS
- 15% ADMINISTRATIVE AND FUNDRAISING

Night of Wonder 2018: A Rockin’ SUCCESS!

Our signature gala and auction rocked the house, raising a record-breaking $580,000! This year’s theme was Rock the Cure, with 450 PRF supporters celebrating the historic “hits” PRF has achieved, while seeking to ensure we keep “climbing the charts” to the cure. PRF’s Youth Ambassador 17-year-old Meghan Waldron stole the show with her speech, sharing the importance of PRF’s work and urging everyone to contribute to the Circle of Hope so that the hope of a cure can become a reality:

“I want you all to know that I believe I wouldn’t be able to do all the things I love if it weren’t for the treatment. I feel that it’s given me a healthier and longer life, and for that I am truly thankful!”

PRF will use the funds raised at Night of Wonder 2018 to find new treatments that may help the children even more than lonafarnib alone. Thank you to our sponsors, auction donors, advertisers, volunteers and guests – We sure do make beautiful music together!

This phenomenal event is held every two years, so we hope to see you at Night of Wonder 2020!

A special thank you to our major sponsors:

The Morrison Family
Leslie Gordon & Scott Berns
Debbie Mendelson Ponn (pictured above on the far left, with family and friends)
PT Sanders

Andrea Hayward is all smiles as she places the winning bid on one of the many fantastic auction items.

Gala co-chairs Martha Holden (seated, front) and Mary Bellavance (directly behind Martha) enjoyed the evening – and the culmination of all their hard work – with their spouses and friends.

Science and Medicine (SAM) Award winner John Song celebrates on the dance floor with his wife Christine.
Chapter, Family and Annual PRF Events

Special events are the community glue that holds together thousands of people each year, all of whom have one goal: to help cure Progeria. They participate in road races, tournaments of all kinds, car shows, pool parties, and more for children with Progeria. THANK YOU ALL for your special support.

Another strong finish for Team PRF at the Falmouth Road Race
You could see TEAM PRF from a mile away in their neon orange shirts at the 2017 Falmouth Road Race. PRF’s largest team to date (18 runners – wow!) ran past thousands of spectators along the 7-mile rigorous race route, raising awareness and funds for Progeria research. Congratulations, team!

16 Years Strong: Race for Research continues to inspire our local community
The Annual International Race for Research is the biggest team effort to inspire our local community. Every year, we’ve added a fall date of October 19th. Thanks to the many people involved in this event – participants, sponsors, donors, volunteers, and t-shirt purchasers – everyone had a great time and raised awareness and funds for Progeria research. It takes a (fishing) village!

HatsON for Progeria is now in its 6th year!
In our widest-reaching year yet, students and companies in 27 states and 21 countries donned their favorite hats in April for PRF’s annual version of Dress Down Days. We love to see them sharing photos on Facebook, too! This event is so popular, we’ve added a fall date of October 19th – contact Lynne at lamackenzie@progeriaresearch.org to join in on the fun, or next year on March 9th!

The Falcone family is all smiles posing poolside!

Make A Splash! Always a fun event for both kids and adults, the 7th annual Make-a-Splash pool party in support of our PA East Chapter was the biggest yet! Costume characters, log rolling, magic, games, music, amazing auction items and more, this event is a great way to end the summer and support Nathan and Bennett.

PPG employees with Cam and his dad Jason. PPG participates in HatsON every year and doubles their impact by matching all gifts!

1st Annual Team Zoey - Verona Cornhole Tournament a sellout!
It began as a conversation at the gym and escalated to a charitable tournament that sold out in under two hours – wow! “We saw a Cornhole tournament on ESPN and said ‘hey, we could do that for charity,’” said one of the organizers, Shawn Luftglass. With 32 teams and dozens of sponsors, he describes the event as a “true team effort” from residents and the business community. We can’t wait for next year’s event!

2nd Deallaney Hudson King Mackerel Tournament makes it official: another fantastic annual event for PRF!
Thanks to the many people involved in this event – participants, sponsors, donors, volunteers, and t-shirt purchasers – everyone had a great time and raised awareness and funds for Progeria research. It takes a (fishing) village!

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!

13th MILES FOR MIRACLES
The rain couldn’t dampen the spirits of steadfast supporters of this fantastic event that features a walk, raffles, music, food and loads of love! A huge turnout of local firefighters and other first responders joined Lindsay, her parents, friends and family to raise money for the clinical trial Lindsay is enrolled in.

Zach Attack Bowl-a-Thon
Every lane was full of Zach fans wearing their red “Keep Calm and Zach On” t-shirts! This sold-out Kentucky Chapter event is a blast that bowlers look forward to each year: “We are so grateful to everyone who shows up, year after year, as the research they help fund brings more and more good news for Zach”, says mom Tina.

Miles for Miracles... and fun!
The annual Make-a-Splash pool party in support of our PA East Chapter was the biggest yet! Costume characters, log rolling, magic, games, music, amazing auction items and more, this event is a great way to end the summer and support Nathan and Bennett.

First-rate support from first responders at MI Chapter’s 13th MILES FOR MIRACLES
The rain couldn’t dampen the spirits of steadfast supporters of this fantastic event that features a walk, raffles, music, food and loads of love! A huge turnout of local firefighters and other first responders joined Lindsay, her parents, friends and family to raise money for the clinical trial Lindsay is enrolled in.

Lindsay with her firefighter friends.
Volunteers making a difference in the lives of children with Progeria.

This very special group of people raises awareness by sharing our mission, helps defray costs by donating their time and talents, and raises critical funds through handmade craft sales, wedding and birthday fundraisers, and lots of other creative ways. You can become a Miracle Maker, too – visit progeriaresearch.org/miracle_makers to learn how!

Friends Forever
Enzo’s schoolmate Charlotte is a determined 6 year-old with a huge heart. Charlotte started her own fundraising project, selling hand-made bracelets. Her project went viral and she raised over $400 for Team Enzo – now that’s what friendship is all about!

A Selfless Act of Friendship
Birthdays are special, especially for kids who look forward to the presents. But for Chloe’s 9th birthday, it was an opportunity for her to do something for her friend, Bennett. Instead of gifts, Chloe asked people to make donations to PRF’s PA West Chapter. Thank you Chloe and friends for raising $250 for The Progeria Research Foundation!

Talented Photographer Takes Aim for PRF
For the past year, Gleb Budilovsky has volunteered his time and talents to PRF to photograph dozens of children who are in Boston for the clinical trials. Gleb is always eager to help, and his photos capture the special personalities of the children!

DMB Fans Unite for PRF
Back in 2014, a group of Dave Matthews Band (DMB) fans designed and sold hundreds of Kit Kat Sam shirts after seeing Sam Berns’ special relationship with band members in the HBO documentary “Life According to Sam.” All t-shirt sale proceeds were donated to PRF, and to this day, you can see the blue Kit Kat Sam shirts in the crowd at many DMB shows! This year, to further honor Sam and celebrate the shows taking place at Sam’s and one of the band’s favorite venues – the Gorge – they designed another t-shirt to benefit PRF. Many thanks to organizer Nathaniel Shoshan and all who have bought, and proudly wear, these t-shirts. 

A group of Kit Kat Sam fans at the Gorge in Washington, and this year’s t-shirt.

Executive Director Presents at Broad Institute’s 2018 Rare Disease Day Seminar
Rare Disease Day takes place each year in February and events are held around the world, providing a forum where the community of children and families affected by rare diseases join together to raise awareness and garner support for their research efforts. PRF Executive Director Meryl Fink spoke in Cambridge, Massachusetts at the Broad Institute’s Rare Disease Day seminar, which also featured the traveling art exhibit “Beyond the Diagnosis” showcasing portraits of children with rare diseases.

Meryl Fink next to the beautiful portrait of Meghan Waldron, PRF Youth’s Ambassador, on display at the Broad Institute.

Highest 4-Star Rating Achieved For a Fifth Consecutive Year!
We are thrilled and honored to be among the top 9% of evaluated charities to reach this 5-year distinction. This highest possible rating from the leading charity evaluator in America verifies that PRF exceeds industry standards and executes our mission in a financially efficient way. Thank you all for helping us achieve this impressive milestone!

Board of Directors Holds Strategy Summit in Boston
This dedicated group met in the fall of 2017 to drive PRF’s strategic planning. The Board developed a comprehensive plan that will be the blueprint for future organizational and program growth, all to propel us towards fulfilling our mission to cure Progeria. The day was made extra special by a visit with Sammy Basso and his parents from Italy, who were in Boston for Sammy to participate in the two-drug clinical trial.

Executive Director Meryl Fink; Paula Kelly, Karen Ballack, PRF supporter Miss Skoom, John Marozzi; Kim Paratore, Liza Morris, PRF Development Director Audrey Gordon, Tom O’Brien. (Bottom row l-r) Amiegeno Basso, Laura Bassa, Sammy Basso, PRF Board Chair Scott Berns, PRF Medical Director Leslie Gordon.

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This dedicated group met in the fall of 2017 to drive PRF’s strategic planning. The Board developed a comprehensive plan that will be the blueprint for future organizational and program growth, all to propel us towards fulfilling our mission to cure Progeria. The day was made extra special by a visit with Sammy Basso and his parents from Italy, who were in Boston for Sammy to participate in the two-drug clinical trial.

Executive Director Meryl Fink; Paula Kelly, Karen Ballack, PRF supporter Miss Skoom, John Marozzi; Kim Paratore, Liza Morris, PRF Development Director Audrey Gordon, Tom O’Brien. (Bottom row l-r) Amiegeno Basso, Laura Bassa, Sammy Basso, PRF Board Chair Scott Berns, PRF Medical Director Leslie Gordon.

A Selfless Act of Friendship – Birthday’s are special, especially for kids who look forward to the presents. But for Chloe’s 9th birthday, it was an opportunity for her to do something for her friend, Bennett. Instead of gifts, Chloe asked people to make donations to PRF’s PA West Chapter. Thank you Chloe and friends for raising $250 for The Progeria Research Foundation!

Talented Photographer Takes Aim for PRF
For the past year, Gleb Budilovsky has volunteered his time and talents to PRF to photograph dozens of children who are in Boston for the clinical trials. Gleb is always eager to help, and his photos capture the special personalities of the children!

DMB Fans Unite for PRF
Back in 2014, a group of Dave Matthews Band (DMB) fans designed and sold hundreds of Kit Kat Sam shirts after seeing Sam Berns’ special relationship with band members in the HBO documentary “Life According to Sam.” All t-shirt sale proceeds were donated to PRF, and to this day, you can see the blue Kit Kat Sam shirts in the crowd at many DMB shows! This year, to further honor Sam and celebrate the shows taking place at Sam’s and one of the band’s favorite venues – the Gorge – they designed another t-shirt to benefit PRF. Many thanks to organizer Nathaniel Shoshan and all who have bought, and proudly wear, these t-shirts.

Meryl Fink next to the beautiful portrait of Meghan Waldron, PRF Youth’s Ambassador, on display at the Broad Institute.

Highest 4-Star Rating Achieved For a Fifth Consecutive Year!
We are thrilled and honored to be among the top 9% of evaluated charities to reach this 5-year distinction. This highest possible rating from the leading charity evaluator in America verifies that PRF exceeds industry standards and executes our mission in a financially efficient way. Thank you all for helping us achieve this impressive milestone!
Enzo hopes everyone has a great school year!

Don’t Miss an Update!

Enjoy reading news from PRF?
Get the latest updates by connecting with us on Facebook, Twitter, and Instagram.

Already “Like” us on Facebook? Be sure to “Follow” us too!

Facebook recently changed the way your news feed is created, so many of you aren’t seeing all the fantastic posts about the children, fun events, and our progress towards the cure. To see PRF’s posts, be sure to “LIKE” AND “FOLLOW” us from the main PRF page.

facebook.com/ProgeriaResearch

twitter.com/progeria

Other ways to connect with us:

instagram.com/progeriaresearch