

The Progeria Research Foundation Selected as an Official Charity Partner in 2024 Boston Marathon

PRF's 10 Marathon Runners Raise Funds to cure Progeria, all connected to Sam Berns

PEABODY, MA – March 26, 2024 – The Progeria Research Foundation (PRF), the only nonprofit solely dedicated to finding treatments and the cure for Progeria, celebrates its first year as an Official Charity Partner of the Boston Athletic Association's 128th Bank of America Boston Marathon®. Represented by a team of 10 passionate runners, this partnership will bring vital funds for Progeria research endeavors, while casting a light on this ultra-rare disease and PRF's progress toward the cure.

Progeria is an ultra-rare, fatal "rapid-aging" disease. Without treatment, children with Progeria die of heart disease at an average age of 14.5 years old. PRF is making extraordinary progress, including the discovery of one FDA-approved treatment, development of genetic and other drug therapies, and creation of healthcare guidelines - all of which are giving these special children longer, healthier lives while the work toward the cure diligently continues.

All ten PRF runners are personally connected in some way to Sam Berns, son of co-founders Drs. Leslie Gordon and Scott Berns and the inspiration behind the creation of PRF. "What is so amazing is that every runner has a connection to our son Sam, and that means the world to us," said Drs. Gordon and Berns. "From Foxboro neighbors, to middle school classmates, to athletes who got to know Sam at PRF's annual 5K *Race for Research* – it's heartwarming to know they're now representing The Progeria Research Foundation at the Boston Marathon, in Sam's honor."

Sam Berns grew up in Foxboro, MA, and by his teenage years, he had inspired millions around the world with his resilience and positive attitude. In 2013, Sam starred in HBO's Emmy Award-winning documentary, "<u>Life According to Sam</u>," which features him realizing his dream of playing the snare drum in the Foxboro High School marching band. That same week, he delivered his iconic TEDx talk, "<u>My Philosophy for a Happy Life</u>," which is the 7th most viewed TED talk of all time and recently exceeded 100M views across the TED and TEDx platforms.

Runner Paul Michienzie said, "I do this for the kids (and now young and thriving adults thanks to PRF) with Progeria and in memory and honor of Sam Berns, who was our Foxboro neighbor and close family friend. He inspires me every step of the way from the Hopkinton start to the finish line on Boylston Street, just near my office where Sam, his parents, Leslie and Scott, and our friends and families have watched other marathoners make their way to the finish line. When I cross that line again, I will be looking high and thinking of Sam!"

"This is a tremendous honor to be invited to join the Bank of America's Official Charity Program in the 2024 Boston Marathon," said Audrey Gordon, President and Executive Director of The Progeria Research Foundation. "PRF's partnership with this prestigious organization will help us spotlight our mission to cure Progeria, while bringing in the necessary funds to propel our research endeavors to new heights."

For more information on PRF's runners or to support their fundraising campaigns directly, click <u>here</u>.

ABOUT THE PROGERIA RESEARCH FOUNDATION

The Progeria Research Foundation (PRF) is a nonprofit organization established in 1999 by the family of Sam Berns, a child with Progeria. PRF funds and conducts research-related programs, including the clinical trials and studies that led to approval of the first-ever FDA-approved drug for Progeria, lonafarnib (Zokinvy®). PRF is the only organization in the world solely dedicated to finding treatments and the cure for Progeria and its aging related conditions, including heart disease. Due to the discovery of the biological connection between Progeria, heart disease and aging, finding the cure for one of the rarest diseases on earth could provide keys for treating millions of adults with heart disease and stroke associated with the natural aging process, as well as help the entire aging population. The organization fills a void, taking these children out of the background where they had been for more than 100 years and putting them and Progeria at the forefront of scientific efforts. For more information, and to support PRF's mission, please visit www.progeriaresearch.org.

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