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‘Find the Children - 60 in India with Progeria’ Campaign Re-Ignites the Search for Children with Progeria in India

The program, developed by The Progeria Research Foundation (USA), aims to find and assist children living with the rare, fatal rapid-ageing condition

INDIA, Mumbai, September 18, 2019: The Progeria Research Foundation (PRF; www.progeriaresearch.org), the only organization in the world dedicated to discovering treatments and the cure for children with Progeria, today announced the launch of **‘Find the Children - 60 in India with Progeria’** campaign. The campaign is designed to create awareness among the general public and healthcare providers, in order to locate and assist children with this rare and fatal rapid aging condition. The India search calls for the public’s help in finding undiagnosed children with Progeria, so they can have access to treatment and healthcare guidelines that can give them longer, more active lives.

Progeria, also known as Hutchinson-Gilford Progeria Syndrome (HGPS) is a rare, fatal genetic condition characterized by the appearance of accelerated ageing in children. Children with Progeria die of heart disease at an average age of 14 years – the same heart disease that affects millions of normal aging adults. Other symptoms of Progeria include stiffness of joints and hip dislocation, growth failure, loss of body fat and hair, and aged-looking skin that gives children with Progeria a unique and similar appearance, despite differences in ethnic backgrounds.

Audrey Gordon, President and Executive Director of PRF said, “In order to help the children, we have to find them. Locating and assisting them is the goal of our international ‘Find the Children’ campaign. Progeria is a very rare disease that many people don’t recognize. And in a vast, diverse, and multilingual country like India, many of these children come from smaller towns and remote villages; so this outreach is vital to finding them.” For more from Audrey Gordon, watch this video: <https://www.youtube.com/watch?v=FdxEveYaO8g&feature=youtu.be>.

Today, experts estimate there are approximately 350-400 children living with Progeria worldwide, but only 161 children are identified by The Progeria Research Foundation as of September, 2019. Thus, approximately 200 children remain undiagnosed. Statistically, about one third, or **60** of the unknown

children live in India— untreated and in need of help. Over the last ten years, 18 children have been identified in India. People living in India can help find more Indian children with Progeria so that PRF can provide the unique support they need.

PRF (www.progeriaresearch.org), has developed programs and services to aid those around the world affected by Progeria, including diagnosis and treatment recommendations, so the children may have a better quality of life. This includes access to lonafarnib, which has been shown to give the children stronger hearts and longer lives. Lonafarnib is currently available to qualifying children through the ongoing PRF-funded clinical drug trial taking place at Boston Children’s Hospital in Boston, Massachusetts, U.S.

In India, PRF’s local representative office for this campaign is MediaMedic Communications, an agency which specializes in health care and public relations. MediaMedic has more than a decade of experience working with the Indian public, Progeria families and medical professionals.

The Progeria Research Foundation has collaborated with MediaMedic Communications Pvt.Ltd. through its exclusive status as India partner in GLOBALHealthPR. In the past, MediaMedic helped find Nihal Bitla from Bhivandi, Mumbai, and several others, including children from Chhattisgarh, Bihar, and Madhya Pradesh. Follow the FB page [Team Nihal](#) for updates, and watch [‘Illuminating Progeria.’](#) a short film on the life of the late Nihal Bitla, a courageous boy who campaigned for Progeria awareness.

“We have connected with over a dozen families of children with Progeria in India, and they have become part of the PRF International Progeria Registry, received treatment recommendations, and joined clinical treatment trials. Our goal is to provide these opportunities to every child with Progeria in India. Finding these children and their families is the essential first step to helping them,” said Dr. Leslie B. Gordon, Medical Director of PRF. “All children with Progeria must have the opportunity to benefit from our efforts to find treatments and a cure, so please help us find children with Progeria in India.”

According to an April 2018 study published by Dr. Leslie Gordon in *The Journal of the American Medical Association (JAMA)*, children with Progeria who received lonafarnib showed an extension of lifespan. This was the first evidence of any treatment benefiting survival for this fatal disease.

“The earlier campaign in India built some awareness about Progeria amongst the Indian population, helping to change their outlook towards my child, and PRF’s help with medicine has improved her daily life.” said Mr. Vikas Sahoo, father of Prachi Sahoo, a child living with Progeria.

Mr. Uttam Sahu, father of another child living with Progeria, Aditya Sahu said “With the support of Progeria Research Foundation, we have been able to successfully provide our child with medical assistance and supervision. Over the past few years, the support and care for our child has helped him physically as well as emotionally.”

How you can assist:

The Progeria Research Foundation invites Indian media outlets to feature children with Progeria in their coverage (photos can be made available upon request), and to interview representatives from PRF. Media, physicians and families around the globe can connect with PRF through [Facebook](#) and [Twitter](#). PRF encourages use of these social media outlets as resources for information about Progeria and as a channel for additional assistance.

If you see or know of a child who may have Progeria:

Images of children with Progeria are available (permission needed) on [PRF's website](#). If one of your readers or viewers has Progeria-like characteristics, please contact The Progeria Research Foundation at info@progeriaresearch.org and visit www.progeriaresearch.org/find-the-children/ for resources and a toolkit that will help to provide more information.

About The Progeria Research Foundation

The Progeria Research Foundation (PRF) was established in 1999 to find the cause, treatments and cure for Progeria - a rapid aging disease that causes children to die from heart disease or stroke at an average age of 14 years. Research conducted in partnership with PRF has identified the gene that causes Progeria, a treatment and other possible treatment candidates for which clinical drug trials are in progress or being planned. To learn more about Progeria and what you can do to help, please visit www.progeriaresearch.org.

About MediaMedic Communications Pvt..Ltd.

MediaMedic Communications is an integrated Health Communications agency, servicing the healthcare, pharmaceutical and health foods segment. MediaMedic Communications has cutting edge expertise in providing health, medical, nutrition science support for brand development, digital marketing, public relation and creative services. Further information on the company can be found at www.mediamedichealth.com

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