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PRF re-ignites ‘Find the Children - 60 in India with Progeria’ Campaign

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

The Progeria Research Foundation, the organization dedicated to discovering treatments and the cure for children with Progeria has 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.”

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 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.

Dr. Leslie B. Gordon, Medical Director of PRF, "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. 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.