



## **Search begins for approximately 60 unidentified Progeria children in India**

**Researchers announce Global Program to find and help children living with rare, fatal rapid-aging condition**

India, June 15, 2015: **The Progeria Research Foundation** (PRF) has initiated a global campaign, '**Find the Other 150**,' to identify, connect with and help an estimated 60 children living today in India with Progeria, a fatal rapid-aging disease. Locating and assisting these children; providing them with access to PRF's programs, including diagnosis, medical recommendations, and research-based treatment, is the goal of [Find the Other 150](#).

An investigational treatment has been shown to increase the estimated lifespan of children with Progeria beyond the previous average of 14 years. A team of doctors including Dr. Leslie Gordon, co-founder & Medical Director at PRF, succeeded in identifying the first drug, called lonafarnib, shown to improve cardiovascular function and life span of these children.

The Progeria Research Foundation (PRF) is funding the participation of children from around the world, who will come to Boston Children's Hospital in Boston, MA, USA where they will have access to the only known treatment for Progeria.

Nihal Bitla, a 14 year-old boy from Mumbai with Progeria, was diagnosed with Progeria at the age of nine. According to his doctor and parents, before the treatment, Nihal's health was deteriorating, he was consistently growing weak and tired, and his heart and lungs couldn't take exertion. He has recently returned from Boston where he received treatment and his family reports that he is feeling well and hopeful.

All children with Progeria die of the same heart disease affecting millions of normal aging adults (arteriosclerosis), but instead of occurring at 60 or 70 years of age, Progeria children may suffer strokes and heart attacks before age 10. The intellect of children with Progeria is unaffected, and despite startling physical changes in their young bodies, these remarkable children are intelligent, courageous, and full of life.

**Audrey Gordon, President and Executive Director, PRF said,** “Our search for more children with Progeria continues. There are an estimated 300-350 children living with Progeria worldwide at any one time, but right now we only know of 125. That is why we call the campaign “Find the Other 150.” Statistically, about one third of the unknown children live in India – undiagnosed and untreated. We at PRF are here to help. So far three children from India have been identified and helped by The Progeria Research Foundation. We need to continue to find as many children as we can. All children with Progeria must have the opportunity to benefit from our efforts to find treatments and a cure.”

**Dr. Parag Tamhankar, medical geneticist and Divisional Head at Genetic Research Center, National Institute for Research in Reproductive Health, Mumbai, India said,** “Heart problems or strokes are the eventual cause of death in most children with Progeria. The average life expectancy for a child with Progeria is about 14 years, but some with the disease die younger and some live 20 years or longer. Progeria signs include growth failure, loss of body fat and hair, aged-looking skin, stiffness of joints, hip dislocation, generalized atherosclerosis, cardiovascular (heart) disease and stroke. The children have a remarkably similar appearance, despite different ethnic backgrounds”.

He further added, “Children with Progeria generally appear normal at birth. During the first year, signs and symptoms, such as slow growth and hair loss, begin to appear. There is no complete cure for this disease but with the new drug treatment the life expectancy of these children can get extended and quality of life may improve.”

### **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 and a treatment for the same. To learn more about Progeria and what you can do to help, please visit [www.progeriaresearch.org](http://www.progeriaresearch.org).

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### **Note to the Editor**

#### **How you can assist**

The Progeria Research Foundation invites global media outlets to cover and feature children with Progeria who will be traveling to the United States to receive treatment. Media, physicians and families around the globe can follow updates from PRF through [Facebook](#) and [Twitter](#), and can encourage others to use these social media outlets as resources for information about Progeria and ways to provide additional assistance.

Images of children with Progeria can be found in PRF's [gallery](#). If one of your readers or viewers knows of a child with Progeria-like characteristics, please ask the person to contact The Progeria Research Foundation at [info@progeriaresearch.org](mailto:info@progeriaresearch.org) and visit [www.findtheother150.org](http://www.findtheother150.org) for resources that will help to provide children with Progeria with the medical resources they need.

**For Media Contacts –**

**MediaMedic Communications Pvt. Ltd.**

Purnima Shrinivasan – 9833100866 @ [purnima.mediamedic@gmail.com](mailto:purnima.mediamedic@gmail.com)