





Prior to the launch of the campaign, PRF's Medical Director said that finding even one child would make the campaign a success.

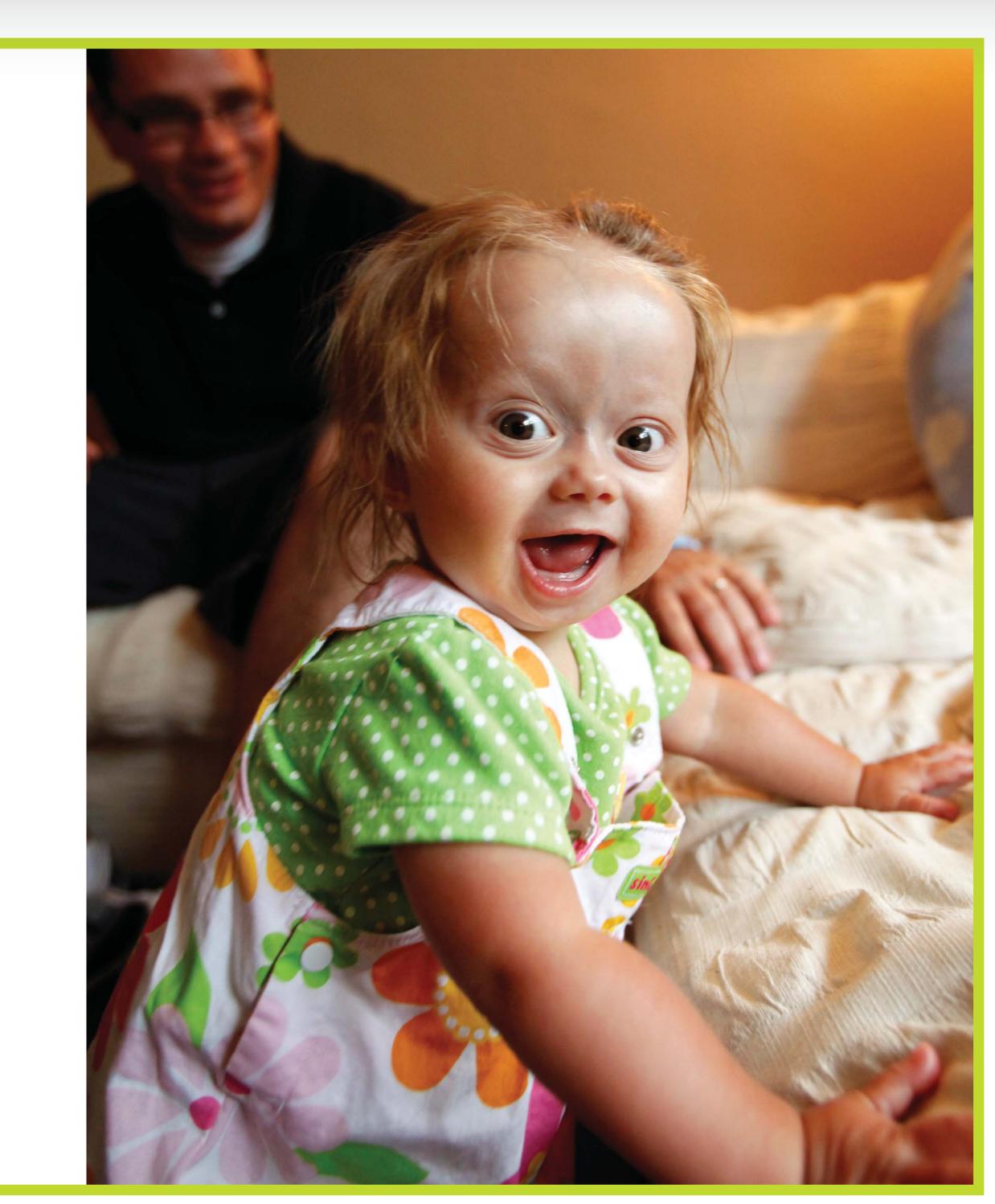
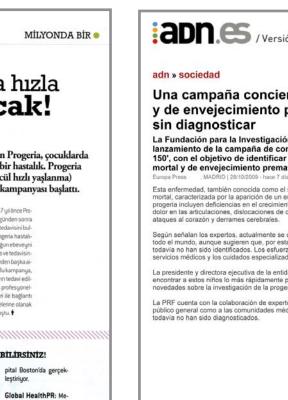


Photo Credit: David Gard/NJ Local News Service









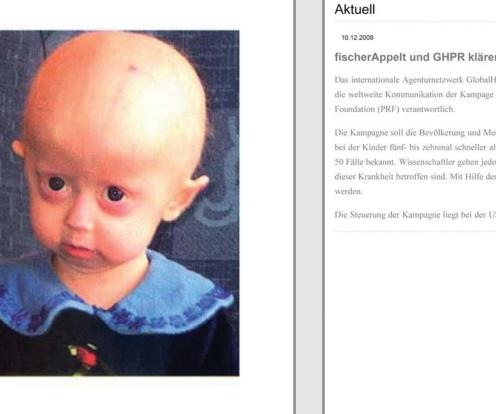


The Power of ««« Global Collaboration to Find a Needle in the Haystack

Introduction

Progeria, also known as Hutchinson-Gilford Progeria Syndrome (HGPS), is a rare, fatal genetic condition characterized by an appearance of accelerated aging in children. All children with Progeria die of the same heart disease that affects millions of normal aging adults (arteriosclerosis), but instead of occurring at 60 or 70 years of age, these children may suffer strokes and heart attacks even before age 10, and the average age of death is 13 years.

The Progeria Research Foundation (PRF) is the only non-profit organization solely dedicated to finding treatments and the cure for Progeria. As of October 2009, only 54 children in **30 countries** living with Progeria had been identified, but experts believe that there are another 150 children worldwide with Progeria who have not yet been diagnosed or identified.



Objective

GlobalHealthPR, a partnership of international health care communications specialists, approached PRF to:

- Launch a global awareness campaign to drive the search for unidentified children with Progeria worldwide.
- Identify additional children with Progeria in order to provide them the unique medical services and care they need, and to further medical research to develop treatments and a cure.
- Since all children with Progeria die from the same heart disease that affects millions of older people, finding a cure for Progeria may give us clues to the heart disease that affects millions of people, as well as other conditions associated with the natural aging process.

How do you find

150 children among

Methods

GlobalHealthPR and PRF launched, "Find the Other 150." The campaign website, www.findtheother150.org, was developed to serve as an international resource, with images of children with Progeria and information about the disease. Informational materials were translated into several languages and distributed to media outlets worldwide. The campaign requested that anyone who knows or treats a child with Progeria-like characteristics visit the "Find the Other 150" website to contact PRF.



Results/Conclusions

- Within just 6 months of launching the campaign, PRF received more than 20 inquiries regarding potential children with Progeria from countries around the world.
- 13 new children with Progeria from 7 different countries have been identified, including several from developing countries, bringing the total number to 67 children worldwide (a 24 percent increase).
- The results of this campaign—which have successfully identified children with a disease affecting less than .01% of the global population—demonstrate that this model could be successfully applied to other initiatives focused on more prevalent diseases throughout the world.
- Stretching across language and geographic barriers, the campaign's results to date are a true testament to the power of global collaboration with culturally-knowledgeable local communicators.