

## **“The Progeria Research Foundation: The Power of Passion, Partnerships, Programming and Public Awareness”**

Progeria is a rare genetic condition characterized by accelerated aging in children, who die of heart disease at an average age of 13. The Progeria Research Foundation (PRF) is the only international non-profit organization solely dedicated to finding treatments and a cure for Progeria. Where there was previously no help for children with Progeria, PRF has facilitated tremendous progress in just 6 years – worldwide outreach, discovery of the Progeria gene, first-ever clinical studies, and movement towards a potential new drug treatment. PRF's success is attributed to several key elements:

- **Passion:** Everyone involved with PRF – from researchers to volunteers to families of the children – is exceedingly dedicated to the children and our mission. This dedication has driven our accomplishments and will carry PRF through to finding treatments and a cure for Progeria, which will also result in a better understanding of heart disease and aging.
- **Partnerships:** PRF partners with Progeria families, academic institutions, and scientists to accomplish its programmatic and scientific goals. PRF has brought together scientists in an international collaboration to find the gene for Progeria, partnered with the National Institutes of Health (NIH) to conduct research that led PRF to our first goal, and is now leading the way to treatments and a cure.
- **Programming:** PRF runs its own Cell & Tissue Bank, Diagnostics Testing and Medical & Research Database. PRF sponsors scientific workshops, is collaborating with NIH on clinical studies and a potential treatment, and funds basic science research throughout the world. Through this multi-pronged structure, PRF provides all the tools necessary to help Progeria families and their physicians to understand how to care for Progeria children, while simultaneously promoting forward movement in Progeria research.
- **Public Outreach:** With so few children affected by Progeria, worldwide outreach is essential to our mission, and we have reached Progeria families and physicians in over 20 different countries. We have also reached millions throughout the world who care about Progeria and the link between Progeria and the heart disease and aging that affects us all.

**Presented By:** The Progeria Research Foundation, [www.progeriaresearch.org](http://www.progeriaresearch.org), [info@progeriaresearch.org](mailto:info@progeriaresearch.org)

**For more information, see Audrey Gordon's abstract presentation at the “Individuals Seeking Cures” keynote session, November 11, 2005, at 1:00 pm.**