



## *The Progeria Research Foundation Medical and Research Database Information Sheet*

On behalf of The Progeria Research Foundation, I would like to introduce you to the Hutchinson-Gilford Progeria Syndrome Medical and Research Database project. The following information will describe this Database and how it will help children with Progeria. If you decide to participate, please see my contact information below and we will begin the process of enrolling you into this study.

There has never been a centralized childhood Progeria database from which to draw health care information. This has led to unintentional clinical maltreatment of patients, misdiagnoses and delayed diagnoses, simply because caretakers do not know which medical strategies have been successful with other progeria children and which have not. The goal of this project is to collect the health care records for children with Progeria and develop a centralized health database for use by health care professionals, medical researchers, and families of children with Progeria.

### **Aims of the Database**

1. To describe in detail what treatment strategies have been successful, and what treatments have failed for the medical issues faced by children with HGPS.
2. To provide health care recommendations to families in non-medical language about the issues that are important to quality of life for children with HGPS. Two of these recommendation sheets have been sent to you with this letter.
3. The database will be a resource for gaining new insights into the nature of HGPS and into the nature of other diseases such as heart disease which in turn will serve to stimulate the advancement of new research projects.
4. **The Weighing-In Program:** We have discovered that each child with Progeria has a consistent and slow weight gain. We plan to use this data to track baseline weight gain, and potentially to track improvements with treatment in the future. We send families a scale, log book, and instructions so that they can report weekly weights directly to us.

**Your privacy and confidentiality will always be protected.** We will remove your name and all other identifying information to protect your privacy.

**There is no cost to you or your health care providers.**

**You will be informed about new advances in Progeria.** This may help you and your doctors understand how to best care for children with Progeria.

If you decide to participate in this project, we will send you consent forms to read and discuss. Please know that signing the consent forms does not in any way bind you to doing this.

Thank you for considering participation in The PRF Medical and Research Database. Please feel free to email me at [lbgmdphd@aol.com](mailto:lbgmdphd@aol.com) or call with any questions at any time (978) 535-2594.

Sincerely,

Leslie B. Gordon, MD, PhD  
Medical Director, The Progeria Research Foundation