



Lifespan



BROWN
Alpert Medical School

The Progeria Research Foundation Medical and Research Database Information Sheet

On behalf of The Progeria Research Foundation (PRF), I would like to introduce you to the Medical and Research Database program for children and adults with Progeria. The following information will describe this Database and how it will help those with Progeria. Please feel free to share the enclosed information with your family physician. If you decide to participate, please see my contact information below and we will begin the process of enrolling you into this study.

The goal of the Medical and Research Database is to collect the health care records worldwide for those with Progeria, remove identifying information such as names, and use the medical information to conduct research that will assist health care professionals, medical researchers, and families of children and adults 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 those with Progeria.
2. To provide health care recommendations to families and medical professionals about the issues that are important to quality of life for children and adults with Progeria. This database research program has helped us create The Progeria Handbook – a guide for families and healthcare providers who care for those with Progeria. If you haven't received this handbook, please request one to be mailed to you. It is also available at www.progeriaresearch.org.
3. The Database is a resource for gaining new insights into the nature of Progeria 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 person with Progeria has a consistent and slow weight gain. We use the data collected to track baseline weight gain, and in some instances we may track improvements with treatment. Families receive a scale, log book, and instructions so that they can report monthly 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 and adults with Progeria.

If you are interested in participating in The PRF Medical and Research Database, we will send you consent forms for your review and follow this with a consenting process.

Thank you for considering participation in The PRF Medical and Research Database. Please feel free to email me at Leslie_Gordon@brown.edu or call with any questions at any time (978) 535-2594.

Sincerely,

A handwritten signature in black ink, appearing to read "Leslie B. Gordon", with a long, sweeping underline.

Leslie B. Gordon, MD, PhD
Medical Director, Principal Investigator