



**THE PROGERIA RESEARCH FOUNDATION  
INTERNATIONAL PROGERIA REGISTRY**

Hutchinson-Gilford Progeria Syndrome (Progeria) is a very rare condition. This International Registry has been established to provide services and information to families of children with Progeria, treating physicians, and researchers, and to better understand the nature and natural course of Progeria. This serves to improve communication of ideas among interested researchers, and assures rapid distribution of any new information that may benefit patients and/or their families. Your cooperation in registering and in helping to contribute information on Progeria individuals to the Registry is greatly appreciated.

**PRF considers confidentiality a high priority. The personal identifying information you submit on these forms will not be distributed in any way without explicit consent from the Progeria subject or their parent or guardian.**

You may email the completed forms to [info@progeriaresearch.org](mailto:info@progeriaresearch.org) or  
Return completed forms directly to Registry Headquarters:

The Progeria Research Foundation, Inc.  
PO Box 3453  
Peabody, MA  
01961-3453  
USA

FedEx or other delivery address: 2 Bourbon Street, Suite 208, Peabody, MA 01960

Website: [www.progeriaresearch.org](http://www.progeriaresearch.org)

Telephone: (978) 535-2594

Fax: (978) 535-5849

**PRF OFFICE USE ONLY**

Date contacted: \_\_\_\_\_

By whom: \_\_\_\_\_

Method of contact:

Email

Phone

Other: \_\_\_\_\_

PRF International Progeria Registry  
Registration of Progeria Subject

Who is registering this Progeria Subject?

Name: \_\_\_\_\_

Title: \_\_\_\_\_

Specialty: \_\_\_\_\_

Address: \_\_\_\_\_

Telephone: \_\_\_\_\_

Email: \_\_\_\_\_

The information I have provided may be summarized and communicated to other health care professionals if there is proper acknowledgement and the patient's identity remains confidential.

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

Today's Date: \_\_\_\_\_

Progeria Subject's Name: \_\_\_\_\_

Birth Date: \_\_\_\_\_

Address: \_\_\_\_\_

Telephone: \_\_\_\_\_

Language(s) Spoken: \_\_\_\_\_

Age diagnosis was made: \_\_\_\_\_

Diagnosis made by whom?:

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Subject's personal physician or family doctor:

Name: \_\_\_\_\_

Address: \_\_\_\_\_

What was diagnosis based on? \_\_\_\_\_

Was genetic testing done? \_\_\_\_\_ If so, where? \_\_\_\_\_

Test Result: \_\_\_\_\_

What is subject's Weight: \_\_\_\_\_

Height: \_\_\_\_\_

Medical problems: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Signs or Symptoms:	Yes/ Present	No/ Absent	Ages of Onset
Hair	_____	_____	_____
Skin Changes	_____	_____	_____
Teeth Delay	_____	_____	_____
Diabetes	_____	_____	_____
Chest pain	_____	_____	_____
Cardiovascular symptoms	_____	_____	_____
Hip problems	_____	_____	_____
Other joint problems	_____	_____	_____
Other pain	_____	_____	_____

What specific tests have been done?

\_\_\_\_\_

\_\_\_\_\_

Family:

Mother's name: \_\_\_\_\_

Birth date: \_\_\_\_\_

Father's name: \_\_\_\_\_

Birth date: \_\_\_\_\_

Brothers and Sisters:

<u>Name</u>	<u>Sex</u>	<u>Birth date</u>	<u>Medical Problems</u>
1. _____	___	_____	_____
2. _____	___	_____	_____
3. _____	___	_____	_____
4. _____	___	_____	_____
5. _____	___	_____	_____
6. _____	___	_____	_____

Are parents cousins or related in any way? If yes, how?

\_\_\_\_\_

Has subject been reported in medical literature? If so, where and when.

\_\_\_\_\_

\_\_\_\_\_

How did you learn about Progeria?

\_\_\_\_\_

How did you learn about The Progeria Research Foundation?

\_\_\_\_\_

Other history you may consider relevant:

\_\_\_\_\_

\_\_\_\_\_

What are your needs/the child's needs at this time?

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_