



**The Progeria Research Foundation
International Progeria Registry**

The PRF International Registry has been established to provide services and information to families of children and adults with Progeria and their treating physicians. After receiving this registry form, we will contact you about opportunities for participating in programs and services that we offer individuals with Progeria. In addition, the Registry information 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 individuals with Progeria 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 his/her parent or guardian.

You may email the completed forms to 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: 200 Lake Street, Suite 102, Peabody, MA 01960

Website: 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 Individual with Progeria

Who is registering this child or adult with Progeria?

Name: _____

Title: _____

Specialty (for Physicians): _____

Relationship to child or adult with Progeria: _____

Address: _____

Telephone: _____

Email: _____

Languages Spoken: _____

There may be instances where we would like to get outside expert medical opinion. Please check below as to whether the information provided here may be summarized and communicated to other health care professionals if the patient's identity remains confidential (no name, address, or other identifiers given).

Yes _____

No _____

Information About Child or Adult with Progeria

Today's Date: _____

Name: _____

Gender: _____

Date of Birth: _____

Address: _____

Email: _____

Telephone: _____

Language(s) Spoken: _____

Age diagnosis was made: _____

Diagnosis made by whom?

Name: _____

Address: _____

Personal physician or family doctor:

Name: _____

Address: _____

What was diagnosis based on? _____

Was genetic testing done? _____ If so, where? _____

Test Result: _____

What is the individual's current

Weight: _____

Height: _____

Medical problems: _____

Signs and Symptoms

The following are common with Progeria. For each item below, please describe

- a. if the condition is present
- b. when it began
- c. how it was or is treated
- d. how it has progressed and describe the condition as it is currently (today)

• Poor Weight Gain _____

• Hair Loss _____

• Skin Changes _____

• Delayed Tooth Eruption _____

• Cardiovascular problems such as chest pain, heart attacks _____

• Headaches _____

• Strokes _____

• Hip Problems or Other Joint Problems _____

• Bone fractures _____

• Other Pain or problems _____

What specific tests have been done? _____

Family Information:

Mother's name: _____
Date of Birth: _____
Father's name: _____
Date of Birth: _____

Brothers and Sisters:

<u>Name</u>	<u>Gender</u>	<u>Date of Birth</u>	<u>Medical Problems</u>
1. _____	_____	_____	_____
2. _____	_____	_____	_____
3. _____	_____	_____	_____
4. _____	_____	_____	_____
5. _____	_____	_____	_____
6. _____	_____	_____	_____

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

Has this child or adult 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 or the needs of the child or adult with Progeria at this time?

