



**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 participant or his/her 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: 200 Lake Street, Suite 102, 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:	
<input type="checkbox"/>	Email
<input type="checkbox"/>	Phone
<input type="checkbox"/>	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: \_\_\_\_\_

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

Would you like PRF to contact you directly with information about current or future clinical treatment trials and other programs that may be of interest to you?

Yes \_\_\_\_\_

No \_\_\_\_\_

If the person registering is not the person with progeria or his/her parent or legal guardian:

Do the parents or legal guardians of the child with progeria, or the adult with progeria, want PRF to contact them directly with information about current or future clinical treatment trials and other programs that may be of interest to them?

Yes \_\_\_\_\_

No \_\_\_\_\_

**Information About Child or Adult with Progeria**

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

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

Gender: \_\_\_\_\_

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

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

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

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

Primary Language Spoken: \_\_\_\_\_ Other 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 if the condition is present, when it began, how it was or is treated, 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 of the person with Progeria:

<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?

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