

## Privacy Policy

The Progeria Research Foundation (“PRF”) believes that addressing concerns about privacy is critical. PRF takes steps to protect the personal information provided by visitors to PRF’s website and information included on our electronic mail lists. A more detailed explanation about how we care for your personal information follows. Certain forms and agreements available on our website may be governed by separate policies and terms, as further discussed in such forms and agreements.

By using our website, you consent to our collection, storage, use, sharing and disclosure of your personal information and other information as described in this Privacy Policy.

### Collection and Use of Information:

*Voluntary E-Mail Lists:* Visitors to the PRF website are invited to sign up to receive news and information that may be of interest to them. We collect personal information (such as, for example, name, address, phone number and e-mail address) only if you provide it to us voluntarily through e-mail, registration forms, information request forms or otherwise. Your personal information that you provide to us or that we collect will not be shared with third parties except as provided in this Privacy Policy. **We do not sell, rent, loan, trade or lease your personal information to anyone except as provided in this Privacy Policy.** Details on how to correct, change or remove subscription information from our email lists are provided in the text of each email list distribution to the subscriber.

*Browser Information Collected on the Website:* You can view many portions of our website without actively providing us with your personal information. However, like most websites and applications, we collect certain information from your computer or mobile device by automated means when you visit our website (such as, for example, IP address, geographic location, referral website data, domain server, software and hardware attributes, type of web browser, usage data and pages accessed) that provides us with information such as, for example, page views, unique views, unique visitors, repeat visitors, frequency of visits and peak-volume traffic periods. This data helps us to analyze and improve our website.

*Use of Flash and Cookies:* We may use “cookies,” “web beacons,” Flash and similar technologies on our website. A cookie is a small file that is stored on your computer by a browser and allows us to recognize you when you return to our website using the same computer or web browser. We use cookies for various reasons, such as, for example, monitoring website traffic, customizing your experience on our website and displaying relevant and timely content. You can adjust your browser settings to block cookies; however, if you do, you may not be able to take full advantage of our website. In addition, we may use tracking pixels or web beacons, which are clear graphic images that can be placed on websites or emails to convey information about whether a page has been visited or an email has been opened, and can be used for performance monitoring.

*Other Uses of Your Personal Information:* In addition to using information about you for the specific purposes set out above, from time to time we may also use your personal information to send you news about our organization and promotional materials about PRF initiatives, provided that you have not opted out of receiving such information as described below.

### **Sharing and Disclosure of Information:**

*No Resale of Personal Information.* Other than as described in this Privacy Policy, PRF does not sell, rent, loan, trade or lease personal information collected on our website, included on our e-mail lists or collected offline to any third party.

*Disclosure of Information to Third Parties.* PRF respects the privacy of its financial supporters, and we will not send donor mailings on behalf of other organizations.

However, PRF relies on consultants and other third parties to provide various services (such as, for example, transactions card processing, sign-up forms, advocacy actions, infrastructure hosting, performance monitoring, site maintenance and website analytics), and we may share information with these service providers to enable them to perform their respective services.

*Donation Processing.* Certain sections of our website allow you to make donations. Online donations are handled by a third-party payment processor, Donor Perfect, that has its own privacy policies. If you require more information please see the following links: <https://www.donorperfect.com/fundraising-software/online-fundraising-security/> and <https://www.donorperfect.com/company/privacy-policy/>. Only the third-party payment processor will handle your transaction card or financial account information, but we may obtain certain information about you, such as, for example, your name, date of donation, donation amount and the last four digits of the card used in connection with the donation. We will not share this information with third parties except in the limited circumstances described in this Privacy Policy or in PRF's donation page or forms.

### **Copyright and Photo Use Policy:**

All information and pages are Copyright © 2017 The Progeria Research Foundation, Inc., P.O. Box 3453, Peabody, MA 01961-3453. All rights reserved. Contact PRF for permission to reprint any portion of this website or any materials displayed on this website for purposes other than personal, non-commercial use. **No works or photos displayed on this website may be reproduced in any way or form without specific written permission from PRF.** All such requests for permission must be made in writing and submitted to [info@progeriaresearch.org](mailto:info@progeriaresearch.org).

### **Our Commitment to Data Security:**

PRF implements physical, electronic and managerial procedures to protect the personal information we collect through our website. However, we cannot ensure or warrant the security of any information you transmit to the website or to us. Donor databases are password protected; information submitted through our website is encrypted in transit through Secure Sockets Layer (SSL) software; physical documents are stored in secure

locations; and our employees, volunteers and contractors are limited to necessary access to said documents.

**External Links:**

This website provides links to various websites that PRF does not control. When you click on one of these links, you will be transferred out of our website and connected to the website of the organization or company that you selected. Even if an affiliation exists between our website and a third party website, we exercise no control over linked sites. Each of these linked sites maintains its own independent privacy and data collection practices and procedures. If you visit a website that is linked to our site, you should consult that site's privacy policy before providing any personal information.

**Children's Privacy:**

This website includes certain information for review and use by children. We hope that children and parents will visit our website together so that they can jointly learn about Progeria and PRF's mission. We do not knowingly collect, either online or offline, personal information from individuals under the age of 13 years old. If we learn that we have received information pertaining to children under 13 years old, we will promptly obtain parental consent or otherwise delete the information from our servers. If you want to notify us of our receipt of information in relation to children under 13 years old, please do so by emailing us at [info@progeriaresearch.org](mailto:info@progeriaresearch.org).

**International Information Transfers:**

Any personally identifiable information that you provide to PRF will be collected directly on servers located in the United States and maintained on servers located in the United States or other countries. If you are located outside the United States, this means that any information you provide will be transferred abroad. While PRF is committed to protecting your information, you should know that the general level of protection for personal information in the United States may not be the same as that provided in other countries.

**Terms and Modifications to Privacy Policy:**

By using this website, you acknowledge your agreement to the terms of our Privacy Policy.

We reserve the right to, at any time, modify this Privacy Policy or any of our terms of service ("Terms of Service"). We will notify you about significant changes in the way we treat your personal information by sending a notice to the email address you have provided to us or by placing a prominent notice on our website. Changes will be effective immediately upon posting of the updated Privacy Policy or Terms of Service on our website. Your use of our website after such effective time will constitute acceptance by you of such changes.

**Data Quality and Access:**

You have the opportunity, by contacting us as set forth below, to know about the information that PRF holds about you and to correct, amend or delete, as appropriate, any such information that is incomplete or inaccurate.

Although most visitors to the PRF website indicate that they welcome details of PRF's initiatives and educational efforts and other PRF materials, we acknowledge that individuals should have the right to choose. If you choose to provide us with your contact information, but later decide that you do not wish to receive future PRF communications, you can notify us at [info@progeriaresearch.org](mailto:info@progeriaresearch.org) or by following the "unsubscribe" or "opt out" instructions/link provided in PRF's email communications.

Please note that, despite any indicated email marketing preferences, we may send you administrative emails regarding our website, including, for example, information you requested, invitations and notices of updates or modifications to our Privacy Policy or Terms of Service.

**Enforcement/Contact Us:**

If you have any questions or concerns regarding this Privacy Policy, or if you believe that PRF has not adhered to this Privacy Policy, please notify us by e-mail at [info@progeriaresearch.org](mailto:info@progeriaresearch.org), or write to us at P.O. Box 3453, Peabody, MA 01961-3453. Please use the words "Privacy Policy" in the Subject line.

This policy was last updated on October 26, 2020.