



## Progeria Connect Privacy Notice

### **Introduction**

*Progeria Connect* (PC) is a new and exciting Progeria Research Foundation (PRF) program, created in partnership with Sciensus Pharma Services Ltd. (Sciensus). PC provides a private platform for families, caregivers, clinicians, researchers, and children and young adults with Progeria (“PC members”) to communicate without language barriers, and to access a variety of information in a safe and secure environment.

All communications with PC members, forums, live feeds, content, and overall site monitoring are conducted and managed by PRF. Sciensus, the creator of the site’s intricate design, provides technical support and training, and manages data analytics and performance monitoring to ensure the site is running optimally.

PRF and Sciensus believe that addressing concerns about privacy is critical. Below is a more detailed explanation about how the personal information you provide as part of the PC platform is used, processed and cared for.

### **Privacy Policy**

By using the PC platform, you acknowledge your agreement to the terms of this Privacy Policy, along with the Terms of Use available here [<https://www.progeriaresearch.org/pcterm sandconditions/>]. This Privacy Policy is regularly reviewed, and changes may be made from time to time. You will be notified about significant changes by notice to the email address you have provided, or by posting a prominent notice on the PC website. Changes will be effective immediately upon posting. Your use of the Progeria Connect platform after such effective time will constitute acceptance by you of such changes.

If you have any questions relating to this notice, please contact the Progeria Connect administrator, Marianna Castro Florez

- by email at [PC@progeriaresearch.org](mailto:PC@progeriaresearch.org)
- by telephone at: country code + 1 + 978-535-2594
- through WhatsApp at: country code + 1 + 551-202-1199
- by postal mail at: PRF, PO Box 3453, Peabody, MA, USA 01961

#### **1. Collection and Use of Information:**

By using the PC platform, you consent to the collection, storage, and use of your personal information as described in this Privacy Policy.

Your personal information that you provide 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.*

The PC platform also uses Google translation services. These translation services will be provided for all information you provide. To the extent you do provide any personally identifiable information, that information may be translated by the Google translation services and read by other users of the PC platform. For further details, please see Google’s privacy [here](#).

## **2. Where your information comes from, and how your information is used:**

The information PRF obtains for the PC platform is solely information you provide through the platform. This personal information is primarily used in the following ways, by PRF and/or Sciensus, in accordance with their respective roles described above:

- To create and maintain a record of your profile for the platform
- To improve and optimise the platform's performance in order to enhance the user experience
- To deploy and target member communications
- To moderate the platform to ensure its safety and security
- For statistical and monitoring purposes

## **3. How Sciensus keeps your information safe:**

As a member of Progeria Connect, personal and sensitive information about you is collected. To ensure your data is safe, Sciensus has expert teams and a high-level information security management system to ensure your data will be treated appropriately and securely from unauthorized third parties. To achieve this, Sciensus uses a number of technology systems to control how your data is accessed and secured. Their technology covers multiple levels of their systems to ensure they can control your data from end to end. All of their users are trained in the best ways of handling personal data and confidentiality, and follow strict policies and procedures to ensure security is kept to a high level. Sciensus will:

- Keep your information confidential
- Use it lawfully, fairly and in a transparent way
- Protect your data and keep it secure
- Have contractual obligations for data management and protection when outsourcing functions to third parties to process your personal information on their behalf
- Carry out periodic security and cyber security checks

For the avoidance of doubt, Sciensus will never use or share your personally identifiable information outside of the PC platform without first seeking your express, explicit written consent to share that information.

## **4. Who your information will be shared with by Sciensus:**

Sciensus wants to maintain your trust and protect your personal information, and in the limited circumstances in which Sciensus shares your personal information with third parties, they are doing so because it is essential to enable Sciensus to provide the technical platform services to you. These third parties are the following:

- Companies in the Sciensus Group who carry out functions on Sciensus' behalf.
- Sciensus' Professional IT service providers and website hosts who help run the platform
- Third Party-Processor "Hivebrite" to manage the platform

## **5. Who your information may be shared with by PRF or Sciensus:**

You agree to allow PRF and Sciensus to share *your non-identifying and de-identified* data with third parties for purposes of promotion of the Progeria Connect program. For example, PRF may include an announcement in its newsletter about PC that includes the number of PC members and a general description of platform activity, and Sciensus may market the PC platform in order to create similar sites for other rare disease-research organizations.

When PRF or Sciensus collaborate with partner organizations, the data is shared in a manner that does not identify you or any member on the site, and the partner is contractually forbidden from making any attempt to re-identify the data.

If there is ever a time PRF or Sciensus would like to share data that does or could reasonably identify you, PRF will seek your express, explicit written consent to share that data with a specific partner for a specific purpose.

#### **6. How long your information is kept for:**

PRF and Sciensus will only hold your information for as long as it is needed to enable each to provide their respective services to you and the Progeria community. Your personal information is held on the platform and will be immediately deleted upon request or account closure. PRF and/or Sciensus may hold onto your data for longer due to the following:

- It is necessary or required to meet legal or regulatory requirements
- To resolve disputes
- To prevent fraud and abuse
- To enforce terms and conditions

PRF and/or Sciensus may keep an anonymised form of your personal data, which will no longer identify you, for statistical, research and analysis purposes without time limits, to the extent either PRF or Sciensus has a legitimate and lawful interest in doing so.

#### **7. Your rights:**

You own your personal data, and have a number of rights regarding how PRF and Sciensus use your data, including the right to:

- access your data by requesting copies of the personal information being held
- delete all or part of your personal information
- restrict access to your personal information beyond the standard PC protocol
- share as much or as little about yourself on the site as you choose.
- correct or amend information you think is inaccurate or incomplete

To exercise these rights at any time, have a complaint, or just have a question, please contact the Progeria Connect administrator, Marianna Castro Florez at [PC@progeriaresearch.org](mailto:PC@progeriaresearch.org)  
Telephone number: country code +1+ 978-535-2594

This Privacy Policy was created on January 4, 2023