



## Progeria Connect Terms of Use

### Introduction

*Progeria Connect* (PC) is a new and exciting Progeria Research Foundation (PRF) program, created in partnership with Sciensus Pharma Services Limited (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.

Please read these PC Terms of Use (the Terms) and the PC Privacy Policy [<https://www.progeriaresearch.org/pcprivacy/>] carefully before using the PC platform, as they set out the basis on which services are provided to you. By using the PC platform, you acknowledge your agreement to the Terms of Use, along with the terms of the PC Privacy Policy.

The Terms are 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.

PRF reserves the right to monitor your use of PC and to disable any user access at any time, if in our reasonable opinion you fail to comply with any of the provisions of these Terms.

If you have any questions relating to these Terms, 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

We may contact you by email, telephone, WhatsApp, through PC, or by written communication to your postal address.

#### 1. EMERGENCIES

**PC must NOT be used to assist in a medical or other emergency.** IF YOU BELIEVE THAT YOU OR ANY PERSON YOU ARE ASSISTING IS IN AN URGENT OR EMERGENCY SITUATION, YOU SHOULD IMMEDIATELY DIAL THE EMERGENCY ASSISTANCE NUMBER FOR YOUR COUNTRY.

#### 2. WHAT DOES PC OFFER?

The PC platform provides a range of communication tools that enable members of the Progeria community to connect with one another in a secure and confidential way. For example, subsequent to successful registration and authentication, patients, family members, researchers and clinicians will be able to:

- ✓ Monitor the latest news and upcoming events
- ✓ Post messages and connect with fellow members (subject to certain restrictions)
- ✓ Join secure groups based on their eligibility
- ✓ Participate in online events such as group Zoom calls

### 3. USE OF PC

To ensure you can use PC safely and in accordance with these Terms, you must:

- a. comply with our **Fair Usage Policy** (see Appendix, below) at all times
- b. follow instructions given to you
- c. represent and warrant that you:
  - i. are at least eighteen (18) years of age; and
  - ii. have capacity to accept and agree to these Terms.

If you are under 18 and wish to use PC separately from your parent or guardian, you must obtain the consent of your parent or guardian, who must contact PRF directly to provide their written consent to your use of PC.

### 4. CONNECTIVITY

The secure PC platform contains all current available features, and is designed to be easy to use and work on most tablets and smart phones. Your device (defined as the smartphone or tablet computer that you use to connect to PC) will need to be internet enabled to use some features. PC should work on the following:

- ✓ Tablet devices: Apple iPad (iOS v10 or later) and Android tablet (v7 or later)
- ✓ Mobile devices: iOS (v10 or later) and Android (v7 or later)

### 5. TEMPORARY USE LICENSE GRANTED

You are hereby granted a limited license, and you may not sell, assign, sublicense, grant a security interest in or otherwise attempt to transfer any right in PC, create any works based on PC or commercially exploit PC. This includes (but is not limited to) selling, reselling, reproducing, duplicating or copying any PC content, including images and logos, and the use of any data mining, gathering or extraction tool. Any of these uses will result in your membership being terminated and you will no longer be authorized to use PC.

### 6. DISCLAIMERS

**Medical and Other Content Disclaimers:** You should always seek the advice of a doctor or other qualified healthcare provider regarding any medical concerns (and before starting, pausing, stopping or modifying any treatment or medication) even if you have read relevant material on PC or received medical advice from a PC member. Such information should not be relied upon as a substitute for seeking appropriate individual medical advice or services.

*In an emergency, you should contact your nearest emergency services center immediately.*

PRF and Sciensus recognize that the connections made through PC among families and other PC members is an important way to connect and inform each other of particular methods, treatments or other medical-related issues that members recommend or have otherwise experienced. However, PRF and Sciensus are not responsible for such recommendations, advice, or other information given by PC members. Any information on PC, either generated by PC members, PRF or Sciensus, is for general educational and informational purposes only, and is not intended to amount to advice on which you should rely. By agreeing to these Terms,

you hereby release from any and all liability, and shall indemnify, defend and hold harmless PRF, Sciensus and each of their officers, directors, employees and agents from and against any and all claims, losses, liabilities, damages, settlements, costs and expenses of any kind, as incurred, including reasonable attorneys' fees resulting from any suit, action, claim, demand or proceeding of any kind or nature arising from such recommendations, advice, or other information.

### **General Disclaimers:**

Sciensus will take all reasonable precautions to protect against failure of the PC-related equipment and software, and will perform regular back-ups of all data stored. You acknowledge and accept that in the event restoration of data from backup is necessary, it may take several days to complete such restoration of data and resume operation of PC.

Although PRF and Sciensus make reasonable efforts to update the information on PC, we make no representations, warranties or guarantees, whether express or implied, that the content on PC is accurate, complete or up to date. Sciensus and PRF make no warranty that PC will meet your requirements or that PC operations will be uninterrupted, 100% secure or error-free, or that defects, if any, will be corrected. Sciensus and PRF are not responsible for transmission errors or any corruption or compromise of data carried over local or interchange telecommunication carriers.

Sciensus and PRF do not guarantee that PC will be secure or free from bugs or viruses. You are responsible for configuring your devices to access PC, and should use your own virus protection software.

By using PC, you may encounter content or information that might be inaccurate, incomplete, delayed, misleading, illegal, offensive or otherwise harmful. While PRF regularly reviews and deletes inappropriate content, this misuse of PC cannot always be prevented or deleted immediately, and you agree that PRF and Sciensus are not responsible for any such misuse.

Similarly, PRF may help you register for and/or attend events organized by users and connect with other users who are attendees at such events. You agree that (1) PRF and Sciensus are not responsible for the conduct of any of the users or other attendees at such events, and (2) that you will adhere to these Terms that apply to such events.

PRF and Sciensus do not assume any responsibility or liability for the accuracy of information contained on any third-party web sites.

## **7. RESPONSIBILITY FOR LOSS OR DAMAGE**

PRF and Sciensus do not exclude or limit in any way their liability to you where it would be unlawful to do so.

PRF and Sciensus are responsible to you for foreseeable loss and damage caused by failure to comply with the Terms or failure to use reasonable care and skill.

**Liability for damage to your device or digital content.** If defective digital content which Sciensus has supplied damages your device or digital content belonging to you, and this is caused by Sciensus' failure to use reasonable care and skill, Sciensus will either repair the damage or pay you compensation. However, Sciensus will not be liable for damage which you could have avoided by following their advice to apply an update offered to you free of charge or for damage which was caused by you failing to correctly follow installation instructions or to have in place the minimum system requirements advised by Sciensus.

**No liability for inability to use PC / reliance on any content.** Subject to the language above that 'PRF and Sciensus do not exclude or limit in any way their liability to you where it would be unlawful to do so', PRF and Sciensus will not be liable to you for any loss or damage,

whether in contract, tort (including negligence), breach of statutory duty, or otherwise, even if foreseeable, arising in connection with:

- a) inability to use PC; or
- b) use of or reliance on any content displayed on PC, including medical advice or any other medical information.

**No liability for business losses.** PC is for private use only and not for any commercial, business or re-sale purpose. PRF and Sciensus are not liable to you for any loss of profit, loss of business, business interruption, or loss of business opportunity.

## 8. CIRCUMSTANCES OUTSIDE OUR CONTROL

Sciensus and PRF shall not be responsible if PC access is delayed or prevented by circumstances outside our reasonable control. If this happens, PRF will contact you as soon as possible to let you know and steps will be taken to minimize the effect of the delay or failure.

## 9. TERMINATION OF PC USAGE

**Your right to terminate.** You may cease using PC at any time.

**Our right to terminate.** Terminating your right to use PC is possible if:

- you do not provide information that is necessary for inclusion in PC, for example valid contact details; and/or
- you breach any of these Terms or our **Fair Usage Policy** (see Schedule 1, below).

**Termination or Suspension of the Platform.** While we anticipate that Progeria Connect will be available for the foreseeable future, it may terminate or suspend operations due to as yet-unknown, unanticipated, or other reasons. In addition, there is no guarantee that PC, or any content on it, will always be available or be uninterrupted. PC operations may be suspended or restricted in whole or part for business and operational reasons, including (without limitation) for technical or security reasons. PRF will inform you as soon as possible of any suspension or withdrawal of PC operations.

## 10. INTELLECTUAL PROPERTY

PRF and Sciensus reserve all their respective intellectual property rights in PC. Trademarks and logos used in connection with PC are the trademarks of their respective owners.

You own the content and information that you submit or post to PC, and you are only granting PRF, Sciensus, and Sciensus' affiliates the following non-exclusive license:

Subject to the terms of the Privacy Policy, a limited, worldwide, transferable and sublicensable right to use, copy, modify, distribute, publish and process information and content that you provide through PC and the services of others, without any further consent, notice and/or compensation to you or others. These rights are limited in the following ways:

- a) You can end this license for specific content by deleting such content from PC, except (a) to the extent you shared it with others as part of PC and they copied, re-shared it or stored it and (b) for the reasonable time it takes to remove from backup and other systems.
- b) While we may edit and make format changes to your content (such as translating or transcribing it, modifying the size, layout or file type, or removing metadata), we will not modify the meaning of your expression.
- c) Because you own your content and information and we only have non-exclusive rights to it, you may choose to make it available to others.

You agree to only provide content or information that does not violate the law nor anyone's rights (including intellectual property rights). You also agree that your profile information will be truthful. PRF and/or Sciensus may be required by law to remove certain information or content in certain countries.

#### 11. OTHER IMPORTANT TERMS

- a) **Nobody else has any rights under these Terms.** No other person shall have any rights to enforce any of these Terms apart from you, PRF and Sciensus.
- b) **If a court finds part of these Terms illegal, the rest will continue in force.** Each of the paragraphs of these Terms operates separately. If any court or relevant authority decides that any of them are unlawful, the remaining paragraphs will remain in full force and effect.
- c) **Even if there is a delay in enforcing these Terms, they can still be enforced.** If PRF does not insist immediately that you do anything you are required to do under these Terms, or if PRF delays in taking steps against you with respect to your breaching these Terms, such inaction or delay will not prevent PRF from taking steps against you at a later date.
- d) **Which laws apply to these Terms and where you may bring legal proceedings.** The Terms that apply to PRF only are governed by the laws of the Commonwealth of Massachusetts, USA and that is where legal proceedings must be brought. The Terms that apply to Sciensus only, or to both PRF and Sciensus, are governed by English law and you can bring legal proceedings in the English courts; If you live in Scotland you may alternatively bring legal proceedings in Scotland; If you live in Northern Ireland you may alternatively bring legal proceedings in Northern Ireland.

## APPENDIX

### Fair Usage Policy

The Fair Usage Policy is designed to prevent fraud and abuse of Progeria Connect (PC) memberships.

**Unlawful, prohibited or unusual activities (non-exhaustive list):** You are not permitted to (or permit anyone else to):

- a) use PC in any unlawful or fraudulent way and/or for any unlawful, fraudulent or inappropriate purpose;
- b) use PC for the purpose of harming or attempting to harm minors in any way;
- c) post or transmit a message (written, verbal or via video) under a false name or use PC's network resources to impersonate another person or misrepresent authorization to act on behalf of others. All messages transmitted via PC should correctly identify the sender and you may not attempt to alter the origin of email messages or postings;
- d) allow another person or entity to use your personal sign-on information (unless a permitted minor);
- e) attempt to undermine the security or integrity of computing systems or networks of Sciensus, the PC platform or any sites or platforms accessed through or via PC;
- f) harvest or collect data about any other individual who uses PC;
- g) post or transmit any data, materials, content or information which is threatening, false, misleading, abusive, defamatory, derogatory, pornographic or profane, or that contains or promotes any virus, worm, Trojan horse, time bomb or other

computer programming or code that is designed or intended to damage, destroy, intercept, download, interfere, manipulate or otherwise interrupt or expropriate PC;

- h) tamper, hack, spoof, copy, modify, use robots or scripts, or otherwise corrupt or attempt to gain unauthorized access to the administration, security or proper function of PC, or the server on which PC or related materials are stored or any server, computer or database connected to PC;
- i) attempt to reverse engineer, reverse assemble, reverse compile, decompile, disassemble, translate or otherwise alter, defraud or create false results from any executable code or information on or received by PC. You agree that you have the ability to override the Internet browser's cookie setting;
- j) upload or provide any information to PC in breach of any third party's intellectual property rights and/or any obligation of confidentiality or contractual duty owed to any third party; or
- k) reproduce, duplicate, copy or sell any part of PC in contravention of the provisions of these Terms.

### **Breach of this Fair Usage Policy**

Failure to comply with this Fair Usage Policy constitutes a material breach of the Terms upon which you are permitted to use PC, and may result in all or any of the following actions:

- deletion of any information provided by you that is deemed in PRF's sole discretion to be fraudulent, abusive, defamatory, obscene or in violation of any third-party intellectual property right; and/or
- suspension or termination of the Services and your membership in PC. You may be provided with a notice of improper behavior before suspension or termination, if PRF in its sole discretion deems appropriate; and/or issue a warning that any future or continuation of the improper behaviour will result in suspension or termination of PC membership.
- legal action against you, including reimbursement of all costs on an indemnity basis (including, but not limited to, reasonable administrative and legal costs) resulting from the breach;
- disclosure of such information to law enforcement authorities if reasonably necessary or as required by law; and/or
- Any other action reasonably deemed appropriate by PRF, in consultation with Sciensus, if applicable.

END OF DOCUMENT

These Terms of Use were created on January 4, 2023