

Website Privacy Statement (for this website)

Novartis Gene Therapies, a company owned by Novartis, focusses on bringing gene therapy from the laboratory and into clinical settings for patients and families affected by rare and life-threatening neurological genetic diseases.

This Privacy Statement describes the ways in which we, Novartis Gene Therapies (registered at Northwood, Santry, Dublin 9, Republic of Ireland) and all of its subsidiaries and branch offices collect, hold and use information about individuals who visit this website ("Personal Data").

We invite you to carefully read this Privacy Statement, which sets out in which context we are processing your Personal Data and explains your rights and our obligations when doing so.

Novartis Gene Therapies is responsible for the processing of your Personal Data as it decides why and how it is processing such data, thereby acting as the "controller". It may exercise this responsibility alone or jointly with other companies in the Novartis Gene Therapies or Novartis group.

1. Personal Data we collect about you and how we process the data

Most of our services do not require any form of registration, allowing you to visit our site without telling us who you are. However, some services may require you to provide us with Personal Data, which may include your direct identifiers, such as name, birth date, email address or telephone number. We may collect and use Personal Data to provide you with products or services, to bill you for products and services you request, to market products and services which we think may be of interest to you, or to communicate with you for other purposes which are evident from the circumstances or about which we inform you when we collect Personal Data from you. Unless otherwise specified, processing of this Personal Data is necessary for the legitimate interests described in this Privacy Statement and/or necessary to comply with our legal and regulatory obligations.

2. Personal Data used for website usage analytics

We may collect and process information about your visit to this website, such as the pages you visit, the website you came from and some of the searches you perform. Such information is used by us to help improve the contents of the site and to compile aggregate statistics using our site for internal, market research purposes. In doing this, we may install "cookies" that collect the domain name of the user, your internet service provider, your operating system, and the date and time of access. A "cookie" is a small piece of information, which is sent to your browser and stored on your computer's hard drive. Cookies do not damage your computer. You can set your browser to notify you when you receive a "cookie", this will enable you to decide if you want to accept it or not. , however, if you do not accept cookies, you may not be able to use all functionalities of your browser software.

We use Google Analytics to rationalize our portfolio of websites by (i) optimizing traffic to and between corporate websites, and (ii) integrating and optimizing web pages where appropriate. "Google Analytics" is a service offered by Google Inc. ("Google") that generates detailed statistics about a website's traffic and traffic sources and measures conversions and sales. Google Analytics uses "cookies" stored on your computer to help analyze how users use our website. The information generated by the cookies about your use of our website, including your IP address, will be anonymized by use of the appropriate settings prior to be transmitted to Google servers in the United States. For more information on how IP anonymization works, please see <https://support.google.com/analytics/answer/2763052>.

You may prevent or stop the installation and storage of cookies by your browser settings by downloading and installing the free Opt-out Browser Add-on available at <https://tools.google.com/dlpage/gaoptout>. If you do not accept cookies, you may not be able to fully experience all functions of our website.

3. With whom we share your Personal Data

Novartis Gene Therapies is an international organization with headquarters in the United States, Switzerland, and affiliates in Europe. We may share your Personal Data to those affiliates as well as to Novartis affiliates if this is reasonably required to pursue our legitimate business interest and as required by applicable laws.

Personal Data may also be transferred to third parties who act for or on our behalf, for further processing in accordance with the purpose(s) for which the data were originally collected or may otherwise be lawfully processed, such as services delivery, evaluating the usefulness of this website, marketing, data management, or technical support.

These third parties have contracted with us to only use Personal Data for the agreed upon purpose, and not to sell your Personal Data to third parties, and not to disclose it to third parties except as may be permitted by us, as required by law, or as stated in this Privacy Statement.

Personal Data collected from you may also be transferred to a third party in the event that the business of this site or a part of it and the customer data connected with it is sold, assigned or transferred, in which case we would require the buyer, assignee or transferee to treat Personal Data in accordance with this Privacy Statement. Also, Personal Data may be disclosed to a third party if we are required to do so because of an applicable law, court order or governmental regulation, or if such disclosure is otherwise necessary in support of any criminal or other legal investigation or proceeding here or abroad.

The Personal Data we collect from you may also be processed, accessed, or stored in countries outside Ireland and the EEA. Such countries may offer a different level of protection of Personal Data. If we transfer your Personal Data to companies in other jurisdictions, we will make sure to protect your Personal Data by applying the level of protection required under applicable data privacy laws, such as entering into Standard Contractual Clauses as approved by the EU Commission. For further information about these safeguards or to receive a copy, please contact us as described in section 8 "How to contact us".

4. How we safeguard your Personal Data

To ensure the security and confidentiality of Personal Data that we collect online, we use data networks protected, inter alia, by industry standard firewall and password protection. In the course of handling your Personal Data, we take measures reasonably designed to protect that information from loss, misuse, unauthorized access, disclosure, alteration or destruction and against other unlawful forms of processing.

5. How long we store your Personal Data

We will only retain your Personal Data for as long as necessary to fulfil the purpose for which it was collected or to comply with legal or regulatory requirements.

6. Your rights concerning your Personal Data

Subject to applicable laws and specific conditions, you have the right to request access to and rectification or erasure of your Personal Data or restriction of processing, and to withdraw your consent at any time, when processing is based on your consent. You further have the right to object to the processing of your Personal Data where we rely on our legitimate interest. Where processing is based on your consent or on a contract with you, you may have the right to data portability.

To exercise your rights, please contact us as described in section 8 "How to contact us". Please note that these rights are not absolute, and we reserve the right to enforce the restrictions imposed by law.

You have further the right to lodge a complaint about the processing of your Personal Data with your local data protection authority.

7. Changes to this Privacy Statement

We reserve the right to change this Privacy Statement at any time. The current version published on this website applies.

8. How to contact us

If you have a question or would like to exercise your privacy rights, please contact us via e-mail at dataprotectionEMEA@avexis.com or at

Novartis Gene Therapies

c/o Regus, Block B
The Crescent Building
Northwood, Santry Dublin 9
Republic of Ireland
Tel.: +353 (0) 1 893 4141

Privacy Notice for Healthcare and Medical Professionals

Novartis Gene Therapies is a company with its primary focus on bringing gene therapy out of the lab and into the clinical setting for patients and families devastated by rare and life-threatening neurological genetic diseases.

Novartis Gene Therapies (registered at Northwood, Santry, Dublin 9, Republic of Ireland) (“Novartis Gene Therapies” or “we”), the controller of the processing activities as described in this Privacy Notice, is committed to secure and handle personal data of Healthcare Professionals and other medical professionals such as employees and representatives of healthcare organizations such as pharmacies responsibly and in accordance with applicable data protection laws and regulations, and this Privacy Notice.

This Privacy Notice explains what personal data we collect about you, for what purposes and how we process such data and the rights you may exercise concerning the processing of your personal data. For further information on how we process your personal data that we collect online, please consult our Website Privacy Statement.

1. Personal data we collect about you, the source and the legal basis

Subject to applicable laws, we collect personal data about you which is necessary to manage our relationship with you:

- General information including your name, gender, academic title, position, and communication preferences, language, contact details including your work address, telephone number and e-mail;
- Educational and professional information such as your job title, educational and professional qualifications, graduate school and year, specialty, experience in the relevant fields, organizational or institutional affiliations, participation to conferences and events;
- Financial information, such as payment related information, where necessary;
- Further information including feedback and evaluations, classifications of your professional activities, territory fields, and information related to payments and services provided, invoices and tax-related information

We may collect personal data directly from you as well from public sources such as websites, social media and other digital platforms, journals, and from third-party information sources including healthcare professional databases, e.g. Veeva that provides data based on publicly available information.

Unless we ask for your separate explicit consent to process your personal data, such as for electronic marketing communications or for publishing transfers of value where required, we collect and process your personal data for our legitimate business interest in communicating with you about our products and services, and about our area of expertise while ensuring that appropriate safeguards are established to protect your personal data. We may further process your personal data to comply with a legal obligation to which Novartis Gene Therapies is subject or for the performance of a contract with you.

2. How we use your personal data

We only process your personal data that is necessary for maintaining our relationship with you and as far as permitted by applicable laws:

- To manage our interaction with you including contacting you to arrange visits or to invite you to meetings or events, enabling you to access our resources, fulfilling product orders, and processing medical information requests, adverse events information and complaints;
- To support our internal business operations such as tracking our interactions with you;
- To engage in market research;

- To deliver information about our area of expertise, our products and the rare diseases for which they are indicated;
- To fulfill our contractual obligations including managing payments for engagements;
- To meet our regulatory and legal obligations in respect to compliance, in particular to ensure transparency on transfers of value and to ensure or to meet our drug safety obligations as well as security reporting. Please note, that Novartis Gene Therapies discloses annually payments and other transfers of value in line with the European Federation of Pharmaceutical Industries and Associations (EFPIA) Disclosure Code and its local transposition. Where consent for such a disclosure is required and we do not obtain such a consent, information is disclosed aggregated.

To better understand the needs of the medical communities, we may carry out internal assessments, evaluations, classifications or ratings of your activities. This may include understanding diagnosis and disease management including treatment approaches and how they correspond to related pharmaceutical products. Before conducting such analysis, we will seek your explicit consent.

3. With whom we share your personal data

Novartis Gene Therapies is an international organization with headquarters in the United States, Switzerland, and affiliates in Europe. We may share your personal data to those affiliates if this is reasonably required to pursue our legitimate business interest and as required by applicable laws.

We may further share your personal data with:

- third parties such as public or regulatory authorities or governmental bodies, if and as required;
- service providers that process personal data on our behalf to perform activities related to the purposes as described in this Privacy Notice such as for IT support and the administration of our CRM system. Before sharing your personal data, we will contractually ensure that these service providers protect your personal data and keep it confidential in alignment with applicable data protection laws;
- business partners and collaborators, such as external scientists or other third parties in the case of a merger or divestiture subject to appropriate confidentiality commitments

Some of the third parties with whom we may share your personal data, including the Novartis Gene Therapies headquarter in the US, may be located in countries that do not ensure the same level of data protection like in your country. Before disclosing your personal data to persons in those countries, we take appropriate safeguards, such as entering into Standard Contractual Clauses as approved by the EU Commission. For further information about these safeguards or to receive a copy, please contact us as described in section 8 "How to contact us".

4. How we safeguard your personal data

We take appropriate technical and organizational measures to secure your personal data from unauthorized access, loss and misuse. These measures include instructions to employees, access regulations and restrictions as well as the encryption of data carriers.

5. Your rights concerning your personal data

Subject to applicable laws and specific conditions, you have the right to request access to and rectification or erasure of your personal data or restriction of processing, and to withdraw your consent at any time, when processing is based on your consent. You further have the right to object to the processing of your personal data where we rely on our legitimate interest. Where processing is based on your consent or on a contract with you, you may have the right to data portability.

To exercise your rights, please contact us as described in section 8. Please note that these rights are not absolute, and we reserve the right to enforce the restrictions imposed by law.

You have further the right to lodge a complaint about the processing of your personal data with your local data protection authority.

6. How long we store your personal data

We store your personal data as long as necessary for the purposes for which it was collected and described in this Privacy Notice subject to local laws and regulations and our legitimate interest such as for the defense of legal claims.

7. Changes to this Privacy Notice

We reserve the right to change this Privacy Notice at any time. The current version published on this website applies.

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