

General Privacy Notice for Patients

This Privacy Notice is addressed to patients and/or patient advocacy groups.

BioMarin Pharmaceutical Inc., located at 770 Lindero Street, San Rafael, CA 94901, USA and its worldwide BioMarin group of companies (“BioMarin,” “we,” “us,” or “our”) respect the privacy of individuals and value the confidence of our customers, partners, patients, employees and visitors. BioMarin is responsible for the processing of your personal information as we decide why and how it is processed, thereby acting as the “**data controller(s)**”. We may exercise this responsibility alone or jointly with other company(-ies) in the BioMarin group, acting as joint controller(s).

This Privacy Notice sets forth BioMarin’s practices regarding the collection, use, and disclosure of information that you may provide to us that constitutes personal information either directly or indirectly through online or offline means (collectively, the “Services”).

Please carefully read this Privacy Notice that sets out in which context we process your personal information and explains your rights and our obligations.

1 WHAT INFORMATION DO WE COLLECT ABOUT YOU?

We may collect your general and identification information (e.g. name, first name, last name, gender, date and place of birth, email and/or postal address, fixed and/or mobile phone number).

Please note that we will not knowingly collect, use or disclose special categories personal data (e.g. health data) or personal data from a minor under the age of 16/18 (depending on country) without obtaining prior consent from you, or in the case of a minor, a parent or legal guardian.

2 WHY DO WE USE YOUR PERSONAL DATA AND WHY IS THIS JUSTIFIED?


2.1 Legal basis for the processing

We will not process your personal data if we do not have a proper justification foreseen in the law for that purpose. Therefore, we will only process your personal data if:

- we have obtained your prior consent;
- the processing is necessary to perform our contractual obligations towards you or to take pre-contractual steps at your request;
- the processing is necessary to comply with our legal or regulatory obligations;
- the processing is necessary to protect your vital interests or those of another person; or
- the processing is necessary for our legitimate interests and does not unduly affect your interests or fundamental rights and freedoms.

Please note that, when processing your personal data on this last basis, we always seek to maintain a balance between our legitimate interests and your privacy. Examples of such ‘legitimate interests’ are data processing activities performed:

- to benefit from cost-effective services (e.g. we may decide to use certain platforms offered by suppliers to process data);

- 
- to offer our products and services to our customers;
 - to prevent fraud or criminal activity, misuses of our services and products as well as the security of our IT systems, architecture and networks;
 - to sell any part of our business or its assets or to enable the acquisition of all or part of our business or assets by a third party; and
 - to meet our corporate and social responsibility objectives.

Where we rely on consent, you may withdraw your consent at any time by completing the Data Subject Request Form, [here](#). You acknowledge that where BioMarin has a regulatory obligation to retain your personal information, the withdrawal of your consent will not limit the ability of BioMarin to continue processing your personal information in line with that legal basis.


2.2 Purposes of the processing

We always process your personal data for a specific purpose and only process the personal data which is relevant to achieve that purpose.

- manage patients' data;
- for pharmacovigilance purposes (tracking of side effects);
- improve our products and services;
- research, development and commercialization of products;
- scientific research purposes or statistical purposes subject to appropriate safeguards such as pseudonymisation;
- training or educational purposes within or outside BioMarin;
- provide you with adequate and updated information about disease, drugs, as well as our product and services;
- organize patients support or assistance programs (including connecting you with health resources and patient associations upon your request) and patients testimonials;
- answer any questions or requests you may have;
- manage our IT resources, including infrastructure management and business continuity;
- preserve the company's economic interests and ensure compliance and reporting (such as complying with our policies and local legal requirements, tax and deductions, managing alleged cases of misconduct or fraud, conducting audits and defending litigation);
- manage mergers and acquisitions involving our company;
- archiving and record-keeping; and
- any other purposes imposed by law and authorities.

3 WHO HAS ACCESS TO YOUR PERSONAL DATA AND IS IT TRANSFERRED?

We will not sell, share, or otherwise transfer your personal data to third parties other than those indicated in this Privacy Notice.



We are committed to maintaining your trust, and we want you to understand when and with whom we may share the information we collect.

- *Corporate Parents and Affiliates.* We may share your information with personnel of our corporate headquarters and other subsidiary/affiliated entities for a variety of purposes, including business, operational, and marketing purposes (in compliance with consent). For more information on those entities, see www.biomarin.com/contact.
- *Service Providers.* We may share your information with independent agents, consultants or brokers (if any); service providers and their personnel that perform certain functions or services on our behalf pursuant to the purposes set out in this Privacy Notice (such as to host the Services, manage databases, perform analyses, or send communications for us); and business partners who offer products or services jointly with us or with our subsidiaries or affiliates. In these cases, BioMarin ensures adequate security is observed by third parties and affiliates processing personal information on behalf of BioMarin, subject to processing agreements in line with GDPR requirements.
- *Other Parties When Required by Law or as Necessary to Protect the Services.* We may disclose your information to third parties in order to: protect the legal rights, safety, and security of BioMarin, our corporate parents and affiliates, and the users of our Services; enforce our Terms of Use; prevent fraud (or for risk management purposes); and comply with or respond to law enforcement, or legal process, or a request for cooperation by a government entity, whether or not legally required.
- *In Connection with a Transfer of Assets.* If we sell all or part of our business, or make a sale or transfer of assets, or are otherwise involved in a merger or business transfer, or in the event of bankruptcy, we may transfer your information to one or more third parties (e.g. external lawyers, tax advisers, etc.) as part of that transaction.
- *Aggregate Information.* We may disclose to third parties information that does not describe or identify individual users, such as aggregate website usage data or demographic reports.

The above third parties are contractually obliged to protect the confidentiality and security of your personal information, in compliance with applicable law.

Your personal information can also be accessed by or transferred to any national and/or international regulatory, enforcement, public body or court, where we are required to do so by applicable law or regulation or at their request.

The personal information we collect from you may also be processed, accessed or stored in a country outside the country where BioMarin is located, which may not offer the same level of protection of personal information.

BioMarin operates as a global entity and will be required to process and transfer personal information within BioMarin businesses. Some of these transfers may be outside the European Economic Area (EEA), United Kingdom (UK) or Switzerland (CH) to countries that may not provide the same level of data protection as the EEA, UK or CH such as to the United States of America (USA) and elsewhere. Transfers may also involve your personal information being sent to third party service providers outside of the EEA, UK or CH. Regardless of whether the transfers are to a third party, or within the BioMarin group, appropriate safeguards will be applied as required by applicable law, for example EU-approved “standard contractual clauses”, to ensure that any transferred personal information remains protected and secure. You may request additional information in relation to international transfers of personal information and obtain a copy of the adequate safeguard put in place by exercising your rights as set out below.



4 HOW DO WE PROTECT YOUR PERSONAL DATA?

We maintain reasonable security procedures to help protect against loss, misuse or unauthorized access, disclosure, alteration or destruction of the information you provide. These measures consider the state of the art of the technology; the costs of its implementation; the nature of the data; and the risk of the processing.

Moreover, when handling your personal information, we only collect and process personal information which is adequate, relevant and not excessive, as required to meet the above purposes; and ensure that your personal information remains up to date and accurate. We may request you to confirm the personal information we hold about you. You are also invited to spontaneously inform us whenever there is a change in your personal circumstances so we can ensure your personal information is kept up to date.

No data transmission over the Internet or stored on a server can be guaranteed to be 100% secure. As a result, while we strive to protect your information and privacy, we cannot guarantee or warrant the security of any information you disclose or transmit to us online and cannot be responsible for the theft, destruction, or inadvertent disclosure of your information. If we believe that the security of your information may have been compromised, we will endeavour to give you appropriate notice as quickly as possible, including by email, and in accordance with applicable laws.

5 HOW LONG DO 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.

Personal information collected and processed in the context of a dispute are deleted or archived (i) as soon as an amicable settlement has been reached, (ii) once a decision in last resort has been rendered or (iii) when the claim becomes time barred.

6 WHAT ARE YOUR RIGHTS AND HOW CAN YOU EXERCISE THEM?

You have certain rights to the personal information that BioMarin holds about you. Subject to certain legal limitations, these rights include the following:

- The right of access to your personal information plus additional ancillary information such as the origin of such data, the purposes for which it has been collected, processed and transferred and the recipients of such data.;
- The right to rectify or erase your personal information (right to be forgotten);
- The right to restrict the processing of your personal information;
- The right of data portability. i.e. the right to have your data returned to you or to a third party in certain cases;
- The right of objection where BioMarin is relying on its legitimate interests as explained above; and
- The right to withdraw consent at any time
- The right to object to automated decision making, including profiling (BioMarin does not carry out either of these practices)



To exercise any of the above rights, if you wish to stop receiving emails or other communications from us, you may make a request by either contacting us (refer to contact details below) or by completing the Data Subject Request form [here](#).

You will also have the option of removing your e-mail address from our database on each occasion that you receive an automated e-mail alert, by clicking on the unsubscribe link.

BioMarin will assess your request in accordance with its Data Subject Rights Request Policy, subject to applicable laws and exceptions, and will respond within the relevant legal time limits.

7 HOW WILL YOU BE INFORMED OF THE CHANGES TO OUR PRIVACY NOTICE?

This Privacy Notice may be revised from time to time as we add new features and services, as laws change, and as industry privacy and security best practices evolve. We display an effective date on the policy in the upper corner of this Privacy Notice so that it will be easier for you to know when there has been a change. If we make any material change to this Privacy Notice regarding use or disclosure of personal information, we will provide advance notice either through the Services or through our online websites. Small changes or changes that do not significantly affect individual privacy interests may be made at any time and without prior notice.

8 CONTACT INFORMATION OR COMPLAINTS

Should you have questions about the processing of your personal information, we invite you to contact:

Nicola Fowler, Global Data Privacy Officer
BioMarin International, Ltd.
6th Floor, 5 Earlsfort Terrace
Earlsfort Centre, Dublin-2 Ireland
Tel: +353 1 479 4300
E-mail: EMEAPrivacy@bmrn.com

If you feel your data protection rights have been infringed by BioMarin, you have the right to complain to your local data protection supervisory authority. The lead supervisory authority for BioMarin in Europe is the Irish Data Protection Commission (see www.dataprotection.ie).

[END OF DOCUMENT]