

“My Rare Life Campaign” Privacy Notice

Effective Date: 1 February 2022

BioMarin has created the “My Rare Life Campaign” for the development of a film to mark Rare Disease Day on 28 February 2022 (the “Campaign”) which will be distributed on select social media channels, such as Facebook and Instagram. A supporting Facebook page has been set up for the Campaign, which will be used to encourage people to post using the #MyRareLife about the person/people who has supported them throughout their rare disease journey.

A live social feed page has also been set up on which posts using the hashtag are pulled through and publicised. We will launch the film and supporting materials to the rare disease community and the general public in 2022.

BioMarin’s relationship with you as a participant will be managed through PORTLAND PR LIMITED (hereinafter, the “Agency”), Portland PR LTD - Bankside 2 90-100 Southwark Street London SE1 0SW.

Your submission and any other information we receive from you as part of the Campaign (the “Content”), including personal information will be stored securely in line with BioMarin’s sensitive data processing policies by the Agency.

This Privacy Notice provides you with information about how BioMarin, as the controller of any personal information that you provide, will use your Content.

The personal information we collect about you and how we use it

As part of the campaign we may collect and process the following information:

Information you provide to us in your submission, which may include:

- Information about your health and medical condition;
- Your image or videos of you and your thoughts and opinions;
- Your contact information including your name and email address; and
- Your country of residence.

We will use this information to process your submission and evaluate its suitability for inclusion in the Campaign. We also may use the information you provide in your submission on the live social feed page as well as other related Campaign resources, to be used in connection with Rare Disease Day 2022. If we decide to use your Content for the Campaign, we may share it with a general audience, including healthcare professionals, media outlets, politicians and senior health officials as well as social media companies. Because your Content will be distributed online it will be accessible worldwide.

With your prior consent, we may also use your contact information to provide you with updates about the project and further information if we decide to use your submission.

Under the General Data Protection Regulation 2016/679 (“GDPR”) our lawful basis for processing this information is your consent. You are able to withdraw your consent at any time (although it may not be possible to remove your Content from Campaign materials already in circulation over which BioMarin has no control). You can do this by contacting us using the contact information supplied in the “Contact us” section below.

How long we store your personal information

We will keep the information you provide for the duration of the Campaign. Afterwards, we will dispose your information by deleting all Content you had shared with us from any database.

Your data protection rights

Data protection laws provide you with rights that you may exercise in certain circumstances. These include:

- Right of Access – You have the right to ask us for copies of your personal information.
- Right to Rectification – You have the right to ask us to rectify personal information you think is inaccurate. You also have the right to ask us to complete information you think is incomplete.
- Right to Erasure – You have the right to ask us to erase your personal information in certain circumstances.

- Right to Restriction of Processing – You have the right to ask us to restrict the processing of your personal information in certain circumstances.
- Right to Object to Processing – You have the right to object to the processing of your personal information in certain circumstances.
- Right to Data Portability – You have the right to ask that we transfer the personal information you gave us to another organisation, or to you, in certain circumstances.

We will not charge you a fee for exercising your rights.

Refer to <https://www.biomarin.eu/privacy-policy> if you wish to make a request or exercise your rights.

How to contact us

If you have any questions about this Privacy Notice, you may contact our European Affiliate Data Protection Officer:

Global Data Privacy Officer
EMEAprivacy@bmrn.com
5 Earlsfort Terrace
6TH Floor
2 Grand Canal Square
Dublin 2
Ireland

You can also lodge a complaint with the Irish Data Protection Commissioner if you are unhappy about how we have used your information, at <https://www.dataprotection.ie/>.

If you have any further questions about the Campaign, please contact Shivani Choda or Lucy Rodrick via email at: shivani.choda@portland-communications.com or lucy.rodrick@portland-communications.com.
