

## Privacy Notice

1. **This Privacy Notice tells you** how we process your Personal Data in accordance with the EU General Data Protection Regulation (**GDPR**). **Personal Data** is any information processed under this activity that identifies, or that, together or in connection with other information, can be uniquely linked to an individual. Any operation performed on Personal Data, including collection, structuring, storage, adaptation, consultation, disclosure, dissemination or otherwise making available, or erasure is **processing**. This Privacy Notice should be read in conjunction with the Cookie Notice which you can read on the [www.getrareaware.ie](http://www.getrareaware.ie) website or be otherwise provided with it.
2. **What data we process and why:** You acknowledge that Roche Products (Ireland) Limited of 3004, Lake Drive, City West, Naas Road, Dublin 24 and Rare Diseases Ireland, Carmichael House, North Brunswick St., Dublin 7 (joint **controllers**, or **we, us** or **our**), may collect, use, store and disclose your Personal Data (**Your Data**) for the purposes (**Permitted Purposes**) and on the basis set out in the table below.

Your Data	Permitted Purposes	Legal basis under the GDPR
<p><i>If you are a public representative:</i> first and last name, constituency, email address, link to health region and whether you are a TD, a Senator or a Minister (<i>note public representative political affiliations or opinions are not being processed</i>)</p> <p>Details of the emails which have been sent to you by users of the <a href="http://www.getrareaware.ie">www.getrareaware.ie</a> website (e.g. volume, time and date of sending, sender)</p>	<p>To enable the recording on the <a href="http://www.getrareaware.ie">www.getrareaware.ie</a> website the details of those public representatives located in a particular health region; to provide visibility to the user of the <a href="http://www.getrareaware.ie">www.getrareaware.ie</a> website of those public representatives that will receive the email the user will send</p> <p>To provide visibility of the effectiveness of the <a href="http://www.getrareaware.ie">www.getrareaware.ie</a> website</p>	<p>The legal basis for processing Your Data is that it is necessary for the purposes of our legitimate interests and those of patients with rare diseases</p>
<p><i>If you are a user of the <a href="http://www.getrareaware.ie">www.getrareaware.ie</a> website:</i> your first and last name and your email address</p> <p>Details of the emails which have been sent by you (e.g. volume, time and date of sending, recipient)</p>	<p>To include your name in the email you send to the listed public representatives</p> <p>Your email address is included in the email sent to the listed public representatives to allow for a public representative to respond back to you</p> <p>To provide visibility of the effectiveness of the <a href="http://www.getrareaware.ie">www.getrareaware.ie</a> website</p>	<p>The legal basis for processing Your Data is that it is necessary for the purposes of our legitimate interests and those of patients with rare diseases</p>
<p><i>If you are a visitor to the <a href="http://www.getrareaware.ie">www.getrareaware.ie</a> website:</i> data (including your device's IP address) collected from our use of cookies on the website</p> <p>Your consent to accept the use of cookies associated with the <a href="http://www.getrareaware.ie">www.getrareaware.ie</a> website</p>	<p>To enable us to operate the website – please see our Cookie Notice for more information</p> <p>To record your agreement with the use of cookies associated with the <a href="http://www.getrareaware.ie">www.getrareaware.ie</a> website</p>	<p>The legal basis for processing Your Data is that it is necessary for the purposes of our legitimate interests and those of patients with rare diseases</p> <p>Any non-essential cookies that we deploy on your devices will be done on the basis of your consent – please see our Cookie Notice for more information</p>

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3. **Legitimate interests.** We rely upon the legal basis of “legitimate interests” under the GDPR to process your personal data as described above. We have conducted a separate legitimate interests assessment to make sure we consider and balance any potential impact on you (both positive and negative) and your rights before we process your personal data for our legitimate interests. We will review this assessment on a regular basis and update it where necessary. We do not use your personal data for activities where our interests are overridden by the impact on you (unless we have your consent or are otherwise required or permitted to by law). You can obtain further information about how we assess our legitimate interests against any potential impact on you in respect of specific activities by contacting us.
4. **Data sources.** We obtain Your Data from internal and external sources and from you directly.
5. **How we share Your Data.** Your Data will be shared with and seen by a 3<sup>rd</sup> party service provider to ensure successful operation of the website. Your Data may possibly be seen by regulatory bodies, individuals acting as auditors for or on behalf of Roche Products (Ireland) Limited or the wider Roche Group or individuals providing legal advice to Roche Products (Ireland) Limited be they external providers of legal services or employed within the broader Roche organisation. The personal data of visitors to and users of the [www.getrareaware.ie](http://www.getrareaware.ie) website will not otherwise be seen by Roche Products (Ireland) Limited or Rare Diseases Ireland.  
Your Data may be located in countries that do not provide the same level of protection for Your Data as Ireland. However, we will still ensure that Your Data is processed only for Permitted Purposes and in accordance with our policies and data protection laws that apply to Your Data. Where appropriate, we may rely on European Commission adequacy decisions about certain countries, as applicable. Safeguard measures for transfers of Your Data outside the EEA, which we may rely on from time to time include having standard clauses approved by the European Commission in our contracts, using Binding Corporate Rules, approved Codes of Conduct, Certifications or, in exceptional circumstances, permissible statutory derogations using other acceptable data transfer mechanisms. You can learn more about the safeguards we use to transfer Your Data from the Roche Products (Ireland) Limited Data Protection Officer.
6. **How long we keep Your Data.** Your Data will be processed and stored by us (or on our behalf) for as long as is necessary to fulfil the purposes of this activity or to comply with legal obligations or requirements of any applicable code of practice.
7. **Security of Your Data.** We have put in place measures to protect the security of Your Data. Details of these measures are available from the Roche Products (Ireland) Limited Data Protection Officer.
8. **Automated decision-making.** Our processing of Your Data will not involve automated decision-making.
9. **Requirement to provide personal data to us.** You are not contractually obliged to provide personal data to us. As a user of the [www.getrareaware.ie](http://www.getrareaware.ie) website, if you do not provide your name and email address, you will not be able to send any emails to the listed public representatives.
10. **Your Rights.** You have the right to know about, access and receive a copy, rectify, request deletion or restrict the processing of Your Data to the extent permitted by applicable laws. If data processing is based on consent, kindly note that you have the right to withdraw your consent at any time, however, without affecting the lawfulness of processing based on consent before its withdrawal. You can exercise these rights and ask questions about the processing of Your Data by contacting the Roche Products (Ireland) Limited Data Protection Officer. You also have the right to make a complaint to the competent supervisory authority about the processing of Your Data, which in Ireland is the Data Protection Commission.
11. **Data Protection Officer.** You can contact the Roche Products (Ireland) Limited Data Protection Officer by email at [pat.lennon@roche.com](mailto:pat.lennon@roche.com).