

## Managed Access Programs / Post-Study Drug Supplies

### Patient Privacy Notice/Consent Template

Dear Parent/ Patient,

Your treating physician is submitting a request to Novartis for your treatment or your child's/ward's treatment. This privacy notice describes how Novartis Pharma AG, at Lichtstrasse 35, 4056 Basel, Switzerland (hereinafter referred to as "Novartis"), uses and otherwise processes your data as controller.

Novartis Pharma AG designated Novartis Pharma S.A.S., 8-10, rue Henri Sainte-Claire Deville, 92563 Rueil Malmaison, France as its representative in the European Union

In this privacy notice, references to "we" or "us" mean Novartis. "You" means the patient whose data is processed as described in this document. If you receive this document because your treating physician has submitted a request for access to treatment for your child or ward, the term 'you' refers to your child or ward for whom the request is being made.

#### **What data do we collect and what happens with it?**

When submitting the request for access to your treatment, your treating physician is required to share certain data about you with Novartis (hereinafter referred to as "your data").

Novartis solely receives information about your gender, month and year of birth and information about your health, such as your medical condition and the information about the treatment you have received so far. In case your treating physician requests a re-supply of the treatment for you, additional information about the treatment efficacy may also be requested. Novartis does not receive your directly identifiable information such as your name or address.

Novartis needs your data to:

- manage the request, e.g., evaluate your eligibility for the treatment,
- comply with legal or regulatory requirements, for example, in case of safety events.

Novartis may also further anonymize your data, which means that the data can no longer be linked back to you. Anonymized data may be used by Novartis for other purposes such as writing scientific publications and educational papers and may share it with others including external partners or health authorities.

#### **Who can see your data?**

Your data can be seen by:

- Institutional review boards or ethics committees,
- Novartis and their representatives,
- Third parties hired by Novartis to provide services related to the management of the request and other purposes outlined in this document,
- Health Authorities.

The people and organizations listed in the section above are required to keep your data confidential.

Novartis representatives and third parties hired by Novartis may be located in countries that do not provide the same level of data protection, however Novartis will protect the privacy of your data by applying safeguards required by law.

Novartis collects and uses your data based on your consent and to meet its legal obligations. Novartis will keep your data for 15 years.

### **What are your privacy rights?**

Subject to applicable laws and regulations, you have the right to:

- Ask to review and correct or erase your data
- Ask for a copy of your data
- Ask to get your data in a standard electronic format so you may transfer it to another organization (the law calls it 'right of portability')
- Oppose the use or the use of part of your data
- Withdraw your consent, without affecting the lawfulness of our use of your data prior to such withdrawal

Novartis may be restricted by law in following requests related to your privacy rights, it may e.g. not be possible to erase certain data, where data needs to be available for health authority purposes.

If you have any questions about your data or want to exercise the above rights, please contact your treating physician.

You can also contact the Novartis data protection officer at the email address **global.privacy\_office@novartis.com** or writing per post mail to "Global Data Privacy Office, Novartis Pharma AG, Lichtstrasse 35, 4056 Basel, Switzerland". If you reach out directly to Novartis, and not through your physician, Novartis may know your identity. In addition to the rights above, you may have the right under applicable law to file a complaint with the competent supervisory authority.

This form will be retained by your physician.

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*The following section should be used in those countries where consent should be used or can be adapted /deleted in countries where this document is used as a privacy notice to the legal basis for the processing of personal data used as per the country specific regulations.*

*Option for the countries relying on the **consent** for the processing of personal data*

By signing below, I agree to the sharing and use of my data, as described in this privacy notice.

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Typed/printed name of  
**Patient / Parent/Guardian**

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Signature

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Date