

# EURORDIS-Rare Diseases Europe Personal Data Consent for Multimedia Submissions

## Data Controller\*:

EURORDIS – Rare Diseases Europe  
La Plateforme Maladies Rares, rue Didot 96, 75014 Paris, France  
Registered in France under SIRET number 413 459 066 00036

## Purpose of processing:

By consenting to this document and signing the submission form, you agree to allow EURORDIS to use your story, images, or other personal data\*\* to raise awareness about rare diseases on behalf of all subjects featured in the photo, of all legal parents or guardians of any subject featured who is under the age of 18, on behalf of the holder of the [Intellectual Property Rights](#), and on behalf of the photographer.

It may be shared via EURORDIS' websites, social media platforms, printed materials, podcasts, videos, and other communication channels to promote advocacy and awareness.

## Personal data to be collected:

This consent applies to the following types of personal data:

- Name
- Age
- Contact information (email address, phone number)
- Photograph(s)
- Video(s)
- Voice recordings (e.g. for a podcast)
- Details of rare disease diagnosis and related health information
- Any other information shared in submitted stories

## Scope of consent:

1. I grant EURORDIS the right to collect, process, and publish the personal data described above.
2. I understand that the data may be shared publicly, including online and in printed materials, and that it may be accessed globally.
3. I give explicit consent for the processing of health-related data, including details about my/the Data Subject's rare disease.
4. I acknowledge that the data may be transferred across borders, including to jurisdictions outside the EU, which may not provide the same level of data protection.

## Rights of the Data Subject:

### 1. Withdrawal of consent\*\*\*\*:

- I may withdraw this consent at any time by contacting EURORDIS at [communications@eurordis.org](mailto:communications@eurordis.org).
- Upon withdrawal, EURORDIS will cease using the data and will remove previously published materials where feasible.
- I understand that EURORDIS cannot control third-party use of the data already accessed or shared publicly.

### 2. Access and correction: I have the right to access and correct the personal data held by EURORDIS.

### 3. Retention period: I understand that the data will be retained until consent is withdrawn or the data is no longer necessary for the purposes outlined above.

## Special provisions for minors:

If the person (Data Subject) is under 18, consent must be provided to the signatory by all parents or legal guardians.

If the person is aged 14 to 17, they must also provide their own consent to the signatory in addition to their parent(s)/guardian(s).

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\*Data Controller: The organisation or entity responsible for determining how and why personal data is collected and processed. In this case, EURORDIS is the Data Controller and manages your personal data responsibly in line with legal requirements.

\*\*Personal Data: Any information that can identify a person, either directly (e.g., name or photo) or indirectly (e.g., information about a health condition).

\*\*\*Data Subject: The individual whose personal data is collected and used. If consent is provided for someone under 18, the child is the Data Subject, and their parent(s)/guardian(s) are providing consent on their behalf.

\*\*\*\*Withdrawal of Consent: You can revoke your consent at any time by contacting EURORDIS. However, previously published materials may remain accessible outside EURORDIS' control.