

PRIVACY INFORMATION
FOR PUBLICATION OF PATIENT IMAGES
ON THE UDNI NETWORK WEB SITE
(UE 2016/679 Regulation and Privacy Code D. Lgs. 101/2018)

the **ISTITUTO SUPERIORE DI SANITÀ**, Viale Regina Elena n. 299 – 00161 Rome, fiscal code 80211730587 – V.A.T. 03657731000 (hereinafter referred to as “ISS” or “Istituto”, together “co-owners” or “parties”)

and

the **WILHELM FOUNDATION SANDBACKEN**, 186 97 BROTTBY, SWEDEN – WILHELM FOUNDATION, (hereinafter referred to as “Wilhelm” or “Foundation”, together “co-owner” or “parties”)

INFORM THAT

According to art. 13 UE regulation n. 679/2016 (defined as “GDPR”) and Privacy Code D. Lgs. 101/2018, personal data will be treated as follows:

1. Purpose and Legal Basis of the Processing

The personal data, processed by the co-owners through the production and subsequent publication on the website www.udninternational.org of photographic surveys of the interested parties, are collected exclusively for purposes of study and scientific research as well as for the assistance of Rare Patients. The ISS and the Foundation intend, in fact, to disseminate the aforementioned photos among researchers around the world in order to help those suffering from a rare disease to find a diagnosis.

The co-owners process the data referred to in point n. 2 only insofar as they are indispensable for the achievement of the purposes of study and scientific research as well as treatment and diagnosis.

The **legal basis** for the processing of personal data referred to in point n. 2 of the following privacy information is found in art. 9, par. 2, lett. a) GDPR, as "*the interested party has given his explicit consent to the processing of such personal data for one or more specific purposes (...)*".

The interested party has the right to revoke his consent to participation, previously given, at any time and with the ease with which he has given it, pursuant to art. 17, paragraph 1, lett. b) GDPR.

However, this revocation does not affect the lawfulness of the processing carried out on the basis of the consent previously given and will have the sole effect of terminating the processing of the data subject's personal data for the future.

2. Categories of Personal Data

For the purposes referred to in point n. 1 and through the UDNI network website, the following categories of personal data may be collected and subsequently processed:

- Health and health data;
- Photographic surveys
- Genetic data

3. Processing methods

The processing of personal data is carried out by means of the operations indicated in art. 4, par. 1, no. 2 GDPR and more precisely: collection, registration, organization, storage, consultation, processing, modification, selection, extraction, comparison, use, interconnection, blocking, communication, cancellation and destruction of data.

4. Retention period

Personal data will be kept for a period congenial to the realization of the purposes of assistance to Rare Patients referred to in point n. 1 of this privacy information, as well as for scientific research purposes.

5. Access to personal data

Data will be accessible by scientist and researchers involved in UDNI activities

6. Rights of the interested party

The owner of the personal data, in his capacity as an interested party, has the rights referred to in art. 15 GDPR et seq., More precisely right of access, right of rectification, right of cancellation, right of limitation of treatment, right to data portability, right of opposition, as well as the right to lodge a complaint with the Guarantor Authority (art.77 GDPR and 141 of the Privacy Code, as amended by Legislative Decree 101/2018).

The interested party has the right to revoke his consent, previously given, at any time and with the ease with which he has given it, pursuant to art. 17, paragraph 1, lett. b) GDPR, without compromising future medical care.

However, this revocation does not affect the lawfulness of the processing carried out on the basis of the consent previously given and will have the sole effect of terminating the processing of the data subject's personal data for the future.

7. How to exercise rights

The interested party may at any time exercise the rights by sending a specific communication to the PEC addresses of the co-owners:

- the **ISTITUTO SUPERIORE DI SANITÀ**, Viale Regina Elena n. 299 – 00161 Rome, fiscal code 80211730587 – V.A.T. 03657731000 (protocollo.centrale@pec.iss.it)
- the **WILHELM FOUNDATION SANDBACKEN**, 186 97 BROTTBY, SWEDEN – WILHELM FOUNDATION (info@wilhelmfoundation.org)

8. Identity and contact details of:

- **ISTITUTO SUPERIORE DI SANITÀ**

President: Prof. Silvio Brusafarro E-mail: (presidenza@iss.it) PEC: protocollo.centrale@pec.iss.it Phone.: +39 06 4990 1
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- **RPD – SCUDO PRIVACY S.r.l.**

Legal Representative: Dr. Carlo Villanacci E-mail: responsabile.protezionedati@iss.it
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- **WILHELM FOUNDATION**

President: Helene Cederroth E-mail: helene@wilhelmfoundation.org

**CONSENT TO THE PROCESSING OF PERSONAL DATA
FOR THE PURPOSE OF THE PUBLICATION OF PATIENTS 'IMAGES
ON THE WEB SITE OF THE UDNI NETWORK**

I, the undersigned

born in the/...../..... in

resident

POSTAL CODEstreet n°Phone.....

- on their own, as a subject affected by a pathology defined as "Rare Disease":

yes

no

OR

- as

- Tutor / Curator / Support Administrator
- CareGiver
- Exercising parental responsibility

- and on behalf of:

- Son / daughter
- Parent
- Relative
- Assisted

DECLARES

to have read and fully understood the information document regarding the collection, storage and use, even in the future, of personal data.

Furthermore, he declares to have read and understood the purposes and methods of the processing of personal data and to have had sufficient time to decide, freely and voluntarily, whether or not to give consent.

AGREE

to the processing of their personal data for the purposes indicated in the privacy information in point n. 1 by the ISS and the Wilhelm Foundation and specifically for the assistance to the so-called "Undiagnosed Rare Patients" and for scientific research purposes

YES

NO

Furthermore, he/she **agrees** to the processing of personal data in the manner set out in the privacy information in point n. 3 and specifically through the production, collection and subsequent publication of photographic reliefs depicting the subject concerned.

YES

NO

Place and date

Signature

_____, __/__/____
