

PRIVACY INFORMATION ON THE PATIENTS AREA ON THE UDNI NETWORK WEB SITE

(General Conditions of Use and Site Consultation)

the **WILHELM FOUNDATION, SANDBACKEN**, 186 97 BROTTBY, SWEDEN –
WILHELM FOUNDATION, (hereinafter referred to as “Wilhelm Foundation”

INFORM THAT

pursuant to art. 13 EU Regulation 2016/679 (hereinafter "GDPR") and the Privacy Code, as amended by Legislative Decree 101/2018, that the processing of personal data of users who consult the site www.udninternational.org will take place in the manner and for the purposes described below.

The privacy information is provided only for the website www.udninternational.org and not for other websites that may be consulted by the user via link.

Following consultation of this site, data relating to identified or identifiable persons may be processed.

The privacy information also takes into account Recommendation no. 2/2001 that the European Authorities for the protection of personal data, gathered in the Group established by art. 29 of Directive no. 95/46 / EC, adopted on 17 May 2001 to identify some minimum requirements for the collection of personal data online, and, in particular, the methods, timing and nature of the information that the data controllers must provide to users when they connect to web pages, regardless of the purpose of the link.

Furthermore, the following privacy information takes into account the provisions of the internal legislator - Legislative Decree 196/2003 (Privacy Code), as amended by Legislative Decree 101/2018, and is updated according to the new European directives referred to in EU Reg. 2016/679.

The purpose of the privacy information is to provide maximum transparency regarding the information that the site collects and how it uses it.

1. Object of the Treatment

Following consultation of this site, data relating to identified or identifiable persons may be processed.

Personal data is processed when the user visits the website www.udninternational.org.

2. Purpose of the processing

The processing of personal data of those who consult the site indicated above will take place for different purposes depending on the category of data processed.

- The processing of "navigation data" is carried out, in an automated way, in order to obtain anonymous information and statistics on the use of the site and to check its correct

functioning and are stored in the database of Google Analytics. The data could be used to ascertain responsibility in case of hypothetical computer crimes against the site: except for this possibility, the data on web contacts will currently be deleted from the system following a direct request by the interested party.

- The processing of "data provided voluntarily by the user" is necessary to evaluate and subsequently respond to the applications that the user submits on the site, by:

- a) the application form as a patient with an undiagnosed disease;
- b) photographic surveys relating to undiagnosed patients.

The data thus collected will be deleted from the system after following a direct request by the interested party.

3. Legal basis of the processing

The legal basis of the processing is found in the legitimate interest of the Data Controller in an efficient and safe navigation on the website, also of an interactive nature, based on the provisions of art. 6, par. 1f).

Furthermore, the legal basis of the processing lies in the consent expressed by the data subject to the processing of their personal data, pursuant to art 9, par. 2). By using or consulting this site, visitors and users explicitly approve this privacy information and consent to the processing of their personal data in relation to the methods and purposes described above, including any disclosure to third parties if necessary, for the provision of a service.

The provision of data and therefore consent to the collection and processing are optional, the User can deny consent and can revoke a consent already provided at any time. However, denying consent may make it impossible to provide the services requested or for which you want to apply on the website.

4. Categories of data processed

Website navigation data

The computer systems and software procedures used to operate this website acquire, during their normal operation, some personal and non-personal data, the transmission of which is implicit in the use of Internet communication protocols (log files).

This information is not collected to be associated with identified interested parties, but which by their very nature could, through processing and association with data held by third parties, allow users to be identified.

This category of data includes the IP addresses or domain names of the computers used by users who connect to the site, the addresses in the Uniform Resource Identifier (URI) notation of the requested resources, the time of the request, pages viewed, average time spent on the site, the method used to submit the request to the server, the size of the file obtained in response, the numerical code indicating the status of the response given by the server

(successful, error, etc.) and other parameters relating to the operating system and computer environment of the user.

Data provided voluntarily by the undiagnosed patients.

For the purposes referred to in point n. 2 and through the application form as an undiagnosed patient the following categories of personal data may be collected and subsequently processed:

SYMPTOMS / SIGNS
CURRENT TREATMENTS
PRIOR TREATMENTS
CONSIDERED TREATMENTS
PREVIOUSLY CONSIDERED DIAGNOSES
TESTED
GENETIC VARIANTS OF INTEREST
SIBLINGS, AGE & GENDER
BIO
PICTURES

5. Provision of data

Apart from that specified for navigation data, the user is free to provide the Joint Controllers with the personal data contained in the application forms as a member or as a patient.

Nonetheless, failure to provide them could make it impossible to obtain the performance or service you want to request.

For the sake of completeness, it should be remembered that in some cases (not subject to the ordinary management of this site) the Authority may request news and information regarding the protection of personal data, for the purpose of monitoring the processing of personal data. In these cases, the reply is mandatory under penalty of an administrative sanction.

6. Places and methods of treatment

The processing related to the web services of this site takes place at the forementioned headquarters of the Istituto Superiore di Sanità and is only handled by technical personnel in charge of processing.

The processing of personal data, for various reasons, is however carried out according to the indications of art. 4, par. 1, no. 2 GDPR: collection, registration, organization, storage, consultation, processing, modification, selection, extraction, comparison, use, interconnection, blocking, communication, cancellation and destruction of data.

Personal data are processed with automated tools for the time strictly necessary to achieve the purposes for which they were collected and are deleted from the system following a direct request by the interested party.

This site processes user data in a lawful and correct manner. Specific technical and organizational security measures are observed to prevent data loss, illicit or incorrect use and unauthorized access (data breach).

7. Access to personal data

For the purposes described above, personal data may be accessible:

to the collaborators of the Data Controller in their capacity as persons authorized to process, subject by these delegates and / or system administrators;
to third-party companies that carry out outsourced activities on behalf of the Data Controller in their capacity as Data Processors pursuant to art. 28 GDPR.

8. Transfer of personal data

The personal data processing activities are carried out and managed mainly in house; nevertheless, the Joint Data Controllers reserve the right to transfer the data to third party operators and / or suppliers for the purpose of pursuing the forementioned purposes.

Any transfer of personal data to a third country or to an international organization will take place on the sole condition that they have obtained a positive assessment of the protection standards through an adequacy decision by the European Commission pursuant to art 45 GDPR or, alternatively, adequate guarantees are recognized pursuant to art. 46 GDPR.

In the event that the communication and / or transfer of personal data is foreseen to a third country not considered adequate by the Commission or which does not present adequate guarantees, a further informative appendix is required containing all the legal requirements that allow specific exceptions pursuant to art. 49 GDPR. In the absence of this information and your subsequent explicit consent, no communication and / or transfer of your data will be arranged.

9. 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).

10. How to exercise rights.

The interested party may at any time exercise the rights by sending:

- to WILHELM FOUNDATION, SANDBACKEN, 186 97 BROTTBY, SWEDEN –
WILHELM FOUNDATION a certified e-mail at the following email address
info@wilhelmfoundation.org

11. Identity and contact details of:

Co-owners – **WILHELM FOUNDATION**

legal representative: Helene Cederroth

E-mail: helene@wilhelmfoundation.org

Phone: +46 8 512 418 94