

INFORMATION NOTICE

REF. ART 13/14 EU 2016/679 (GDPR)

The following information is provided by AriSLA ETS, Fondazione Italiana di ricerca per la SLA – Sclerosi Laterale Amiotrofica ETS (in brief AriSLA ETS or the Foundation) in accordance with art. 13/14 of the EU 2016/679 (General Data Protection Regulation, GDPR) to protect natural persons as to personal data processing.

DATA CONTROLLER

The CONTROLLER of your personal Data is AriSLA ETS - Fondazione Italiana di ricerca per la SLA – Sclerosi Laterale Amiotrofica ETS, based in Via Poerio 14 – 20129 Milano (C.F.: 97511040152), under the temporary Legal Representative, with the following contact data:

- email: privacy@arisla.org
- Tel. 02.20242390

The Data Controller has appointed a Data Protection Officer (DPO), lawyer Michela Maggi, with the following contact data: michela.maggi@milano.pecavvocati.it and mmaggi@maggilegal.it.

PURPOSE OF DATA PROCESSING

The processing of your personal data (such as name, surname, email, telephone number, address, Iban) by the Data Controller is specifically intended for the following purposes:

- A) MANAGEMENT OF THE DONATION** you have made and for the completion of all phases connected and consequent to the provision of the contribution such as, for example, the operations relating to the collection and issuing of receipts;
- B) ACCOUNTING** for the charitable initiative;
- C) LOYALTY** or to contact you, also by automated methods (such as telephone, sms, email, etc in order to inform you on the progress of scientific research and the charitable initiatives promoted by AriSLA ETS. This may involve sending communications of informative and promotional nature relating to projects, activities and fundraising initiatives, participation in events as well as research reserved for donors.

LEGAL BASIS OF PROCESSING

The legal basis of the processing carried out by the Data Controller referring to in the points A) is the execution of the contract pursuant to ex art. 6, paragraph 1, letter b) and letter c) GDPR.

The legal basis of the purpose referring to in the point B) is the pursuit of the legitimate interest of the Data Controller pursuant to ex art. 6, paragraph 1, letter f) GDPR.

The legal basis of the purpose referring to in the point C) is the consent of the interested party pursuant to art. 6, paragraph 1, letter a) GDPR.

NATURE OF THE PROVISION OF DATA AND CONSEQUENCES OF REFUSAL TO REPLY

The provision of personal data is essential for the Data Controller to carry out the activities referred to by the previous point A) and B). As a result, failure to provide aforesaid Data will make impossible to

establish and finalize the contract with AriSLA ETS, and to manage of the donation and of accept your request to make the donation.

Consent for purposes C) is optional. You can therefore decide not to give any Data or to subsequently deny the possibility of processing data already provided: in this case, your refusal will have as affect the impossibility by AriSLA ETS for update you on scientific progress and fundraising initiatives.

MODALITIES OF PROCESSING

Your personal data will be processed in both paper and electronic formats, to the extent and in the manner required to achieve the aforementioned purposes, and with the adoption of data breach protection measures provided by Art 32 of GDPR – EU 2016/679 Regulation, by the Data Controller and by subjects such as employees, collaborators or third parties designated for this purpose by written act, authorised persons or external Data processors. All these subjects will be required to operate within the limits and in compliance with the instructions given by the Data Controller.

Therefore, the processing will be carried out directly by the Data Controller, with the collaboration of authorized subjects and any external managers, appointed, where necessary, for specific operations.

RECIPIENTS OF PERSONAL DATA

The Data Controller will not disseminate your particular Data for a purpose other than that for which they were collected/obtained and may be communicated:

- i) to the staff of the Data Controller, with particular reference to employees and collaborators who deal with the specific activities within which the processing of data is carried out, designated as authorised for processing by written act;
- ii) to third parties, independent owners or appointed Data Processors or sub-processors, with whom specific confidentiality agreements are concluded, such as, but not limited to, partners, lawyers, tax advisors or consultant, third parties involved in the development and maintenance of IT tools or providing services or services related to the above purposes.

The complete and updated list of Data Processors, as well as other subjects to whom personal data may be communicated is available at the headquarters of the Data Controller and may be freely consulted upon request. AriSLA ETS staff can only access information strictly needed to accomplish their own functions.

LOCATION AND DATA TRANSFER

Data processing is carried out at the aforementioned headquarters of the Data Controller and in authorized third-party offices.

Personal Data are stored within the Controller's headquarter and on servers located within the European Union. The Data Controller, if necessary, will have the right to transfer personal Data also to non-EU countries. In this case, the Data Controller hereby ensures that the transfer of data outside the EU will take place in accordance with the applicable legal provisions. In the absence of a decision of adequacy from the European Commission, any processing of personal Data in non-EU countries will be possible only in the presence of adequate contractual guarantees, including binding company rules and contractual clauses of data protection, by the Controllers and Managers involved.

In the absence of a decision of adequacy or other appropriate measures as described above, the transfer and processing of personal Data outside the European Union will be carried out only with the consent of the Data subject.

DATA RETENTION PERIOD

Your data will be kept for the period of time strictly necessary to achieve the above-mentioned purposes and in any case no later than 10 years from the conclusion of the assignment and all the activity related to the management of the selective procedure, and for a longer time if required by defence requirements.

In order to fulfil the loyalty purpose, your data will be stored for a period of 24 months from the donation, in order to contact you again in the 24 months following the donation for other charitable and fundraising initiatives. In any case, your data may be deleted even before this period, if you revoke your consent to the processing.

RIGHT OF ACCES TO DATA AND OTHER RIGHTS

You may, at any time, exercise your rights under Articles 15, 16, 17, 18, 20 e 21 of the GDPR, as set forth below, by sending an email to privacy@arisla.org (or by writing to the Controller, Fondazione ArisLA ETS– Via Poerio, 14, 20129 Milan, Italy).

Particularly you will be informed about the following rights:

- obtain confirmation of the existence or otherwise of personal data concerning you, regardless of whether or not such data have been registered, and communication of such data in intelligible form;
- obtain the updating, rectification or, when interested, the integration of incomplete data and the limitation of processing in the cases provided for by art. 18 GDPR;
- obtain the deletion of personal data and the transformation into anonymous form or the blocking of data processed in violation of the law, including those whose retention is not necessary in relation to the purposes for which the data were collected or subsequently processed;
- object, at any time, for reasons related to your particular situation, to the processing of personal data concerning you pursuant to Article 6, paragraph 1, letters e) or f), to the processing of data for direct marketing purposes, including profiling;
- receive the data provided to the Controller in a structured, commonly used and machine-readable format, as well as, if technically feasible, transmit them to another Controller without impediments;
- revoke the consent given at any time without prejudice to the lawfulness of the processing based on the consent given before the revocation, in the cases provided for by law; lodge a complaint with the competent supervisory authority;
- obtain certification that the erasure, rectification and limitation operations have been brought to the attention, also with regard to their content, of those to whom the data have been communicated or disseminated, unless such fulfillment proves impossible or involves the use of means manifestly disproportionate to the right protected;
- not to be subject to a decision based solely on automated processing, including profiling, which produces legal effects concerning you or similarly significantly affects you.