



## Appendix 1 – PRIVACY NOTICE

**Fondazione Telethon ETS's** primary institutional purpose is to promote, support and carry out medical-scientific research into neuromuscular diseases and genetic disorders, including those of an oncological nature, based on the opinion of a Scientific Committee. To do so Fondazione Telethon ETS uses a platform called "Smart Simple" (hereinafter the "Platform") in the context of the following phases of the funding process:

a. **Application – Participation in calls for proposals**

The Platform enables interested organisations wishing to apply for financial contributions (hereinafter "**Contributions**") to submit their projects through researchers affiliated with them (such researchers are referred to as "**Applicants**"), in accordance with the specifications set out in the relevant research call and guidelines published by Fondazione Telethon ETS. Within the scope of the projects, Applicants may include personal references to other researchers involved in the project in various capacities (such researchers are referred to as "**Researchers**").

b. **Evaluation**

The submission of projects by Applicants triggers the selection and review process, carried out by researchers selected by Secretariat of the Clinical Trial Call (S-CTC) hosted by Fondazione Telethon ETS as members of a the Clinical Trial Scientific Committee (CTSC), who may also be identified on an ad hoc basis for the specific nature of the project (such researchers are referred to as "Reviewers"). The evaluation process takes place within the Platform, through which Reviewers directly access the submitted projects. The selection and review process carried out by Reviewers is aimed at identifying, from a scientific standpoint, the projects worthy of receiving Contributions.

c. **Disbursement of Contributions**

The Contribution shall be awarded by ERDERA through Fondazione Telethon ETS, subject to the availability of funds, to the Organisation under a funding agreement signed between the Parties and managed in paper format outside the Platform. Following the award of the Contribution, Applicants shall be referred to as "**Funded Researchers**".

The Contribution shall be managed by Fondazione Telethon ETS under a mandate without representation granted by the Organisation upon acceptance of the Contribution.

d. **Reporting**

The administrative reporting of the awarded Contribution, as well as the final scientific report of activities carried out by Funded Researchers at the Organisation, shall be submitted in accordance with the procedures indicated by Fondazione Telethon ETS in the contribution Award Agreement, and in particular through the Platform. Both are deemed to be carried out by the Organisation, albeit through the Funded Researcher, who acts as guarantor in this regard towards Fondazione Telethon ETS, with all legal effects.

In light of the foregoing, Fondazione Telethon ETS, in the context of the contribution award process, will process, among others, the personal data of the following individuals:

- I. Applicants
- II. Researchers

hereinafter collectively referred to as "**Users**".

Fondazione Telethon ETS, in order to ensure fair and transparent processing of Users' personal data, provides the following notice in accordance with Article 13 of EU Regulation No. 679/2016.

### **Identity and Contact Details of the Controller and the Data Protection Officer**

Users' personal data will be processed by the Data Controller, identified as Fondazione Telethon ETS, with registered office in Rome, Via Varese 16/B (hereinafter the "**Controller**").

The DPO is identified as Avv. Francesco Giorgianni, reachable by writing to the Controller's registered office or at the following contact: email [dpo@fondazionetelethon.it](mailto:dpo@fondazionetelethon.it).

#### **A. Personal Data Processed**

In the context of this initiative, the Controller will mainly process personal data of Users that may be classified as identification and personal registry data.

#### **B. Purposes and Legal Basis for Processing**

The Controller identifies the following legal bases that make the processing lawful, and the corresponding purposes:

1. **Purposes based on compliance with a legal obligation (Art. 6(1)(c) of EU Regulation 2016/679):**
  - management of preliminary activities preparatory to the Controller's institutional functions, and in particular to the formal and substantive evaluation of projects submitted under the research call;
  - disclosure of data in fulfilment of general transparency obligations.
2. **Purposes necessary for the performance of a contract or pre-contractual measures (Art. 6(1)(b) of EU Regulation 2016/679):**
  - to enable the Controller to complete registration and any subsequent access to the Platform;
  - to enable the Controller to carry out the evaluation of the research project to be funded by the Reviewers in implementation of the research call;
  - to enable the management of operational activities aimed at ensuring the possible disbursement of contributions in implementation of the research call;
  - to enable the management of administrative, accounting and fiscal processes in implementation of the contribution award agreement, where a Contribution is granted in favour of the project submitted by Applicants;
  - to enable the Controller to evaluate the administrative and scientific report in implementation of the contribution award agreement, where a Contribution is granted in favour of the project submitted by Applicants.
3. **Purposes pursued on the basis of the Controller's legitimate interests (Art. 6(1)(f) of EU Regulation 2016/679):**
  - archiving the data strictly necessary for monitoring, analysis and research activities, including historical and statistical purposes;

- communication and promotional activities relating to the Controller's institutional mission.

**4. Purposes pursued on the basis of consent (Art. 6(1)(a) of EU Regulation 2016/679):**

to enable the Controller to disseminate the personal data of Applicants, regardless of whether a Contribution has been received, through institutional channels, mass media and at scientific events in order to: (i) support the development of analysis, research and monitoring activities aimed at deepening and improving the Controller's scientific research funding activities; (ii) promote the dissemination of scientific content promoted by the Controller.

Users' personal data will be processed in digital format and stored in the Platform, with the Controller having the option to export certain data or reports and archive them in its own database or in one held by the Controller under a licence granted by third parties.

**C. Recipients or Categories of Recipients and Scope of Data Disclosure**

Users' personal data may be communicated to:

- I. the Controller's staff, with particular reference to employees and collaborators who handle the specific activities in connection with which data processing takes place, and who have been authorised to process data under the direct authority of the Controller pursuant to Article 2-quaterdecies of Legislative Decree 101/2018; third parties involved in the development and maintenance of IT tools or who provide services instrumental to the specific purposes indicated above (including, by way of example, companies that manage and/or participate in the management and/or maintenance of the Platform), who will operate under specific confidentiality clauses or, where required, under specific appointments as data processors, with the option to appoint sub-processors on a case-by-case basis, in accordance with the applicable data protection legislation;
- II. third parties in fulfilment of disclosure obligations arising from legal provisions, or where this is necessary for accountability purposes related to the institutional activities carried out, or for representation purposes, or in connection with the operational procedures adopted to pursue the Controller's institutional objectives;
- III. third parties entrusted with tax/legal advisory or statutory audit activities, who will acquire the data as independent data controllers;
- IV. competent authorities and/or public bodies and supervisory and control organisations for the possible fulfilment of legal obligations; research centres, communication agencies and companies; and other parties who, in any capacity, collaborate with the Controller in pursuit of its institutional objectives;
- V. Reviewers who have been identified, on the basis of their scientific expertise, as qualified to evaluate the research projects submitted under the research call and who have been appointed as authorised processors. Data will be communicated through the Platform, which hosts the evaluation process.

**D. Duration and Period of Processing**

Users' personal data will be retained for the period necessary for the execution of the project, and in any event for no longer than 10 years from its conclusion. Personal data may be further retained for archiving purposes in view of the ongoing and long-term nature of scientific research falling within the Controller's institutional objectives, which may require re-accessing project data for monitoring, analysis and research purposes, in compliance with the principle of data minimisation.

#### **E. Users' Rights**

In relation to the processing described above, Users may exercise the rights referred to in Article 13 of **EU Regulation No. 679/2016**, as further specified in Articles 15, 16, 17, 18, 20, 21 and 22 of **EU Regulation No. 679/2016**, and in particular shall have the right to:

1. obtain confirmation as to whether or not personal data concerning them are being processed;
2. request access to their personal data from the Controller, as well as the right to data portability;
3. obtain the updating and rectification, or, where in their interest, the completion of their data;
4. object, in whole or in part, on legitimate grounds, to the processing of personal data concerning them, even where such data are relevant to the purpose of collection;
5. obtain the erasure and anonymisation or blocking of data processed in violation of the law, including data whose retention is no longer necessary in relation to the purposes for which it was collected or subsequently processed;
6. withdraw consent (only for processing based on consent as the legal basis) at any time, without prejudice to the lawfulness of processing based on consent given prior to withdrawal;
7. lodge a complaint with a supervisory authority.

#### **F. Nature of the Communication of Personal Data and Consequences of Refusal**

Any refusal and/or the provision of inaccurate and/or incomplete personal data in relation to processing carried out on legal bases other than consent will make it impossible to pursue the corresponding purposes or to carry out pre-contractual and contractual activities.

The provision of data in connection with processing for which consent is requested is voluntary; if consent is withheld, it will not be possible to use the data for the disclosure and communication purposes specified above.

#### **G. Data Transfers**

The personal data processed through the Platform owned by Fondazione Telethon ETS are stored in data centres located within the European Union.

Furthermore, Users' personal data present in the Platform may also be processed by Reviewers who may occasionally be located in countries outside the European Union for which the European Commission has not issued an adequacy decision regarding the protection of personal data, for the sole purpose of evaluating projects in implementation of the call and, therefore, to the extent necessary, for the purpose of performing the contract to which the data subject is a party. In such cases, the transfer of personal data shall take place in accordance with Article 49(1)(b) of EU Regulation 2016/679; moreover, the Controller shall take measures to ensure the highest level of security for the data received, in compliance with applicable law, by requiring that the entire selection and review process be carried out by Reviewers with adequate guarantees.

The Data Controller  
**Fondazione Telethon ETS**

**Milan, July 1<sup>st</sup> 2026**