

Annex "A" to registered deed no. 4162

STATUTE

Article 1

A Foundation denominated "**FONDAZIONE TELETHON ETS**", with registered office in **Rome** is hereby established.

The Foundation has secondary offices in **Milan** and **Pozzuoli** (province of Naples).

The address of the registered office and of the secondary offices appear in the single national Third Sector Register, pursuant to Art. 48, paragraph 1 of Italian Legislative Decree No. 117/2017. A change of address in the same Municipality does not constitute an amendment to the Statute.

The Foundation is obliged to display the wording "Third Sector Entity" or the acronym "ETS" in its name, deeds, correspondence and any distinctive sign or communication directed to the public.

Article 2

The Foundation is a non-profit organization and only pursues civil, solidarity and social utility purposes, based on activities with the following aims:

1. the scientific research of particular social interest, pursuant to letter h) of Art. 5 under Italian Legislative Decree No. 117 of 3 July 2017;
2. the health-related interventions and services pursuant to letter b) under Art. 5 of Italian Legislative Decree No. 117 of 3 July 2017, needed to achieve the purpose referred to in this Statute;
3. the disbursement of money, goods or services to support patients and their families involved in scientific research projects and/or medical assistance aimed at providing the Foundation's innovative treatments or activities in the public interest pursuant to letter u) under Art. 5 of Italian Legislative Decree No. 117 of 3 July 2017;
4. the organisation and management of cultural, artistic, or recreational activities of public interest, including editorial activities, promoting and spreading the culture and the practice of volunteering and activities of public interest, pursuant to letter i) under Art. 5 of Italian Legislative Decree No. 117 of 3 July 2017, needed to achieve the purpose referred to in this Statute.

The purpose of the Foundation is:

- a. to promote, support and implement research and development activities, also on the basis of an opinion expressed by the dedicated Scientific Medical Committee, and translate the positive results of these activities,

when the appropriate conditions are met, into treatments, medicines and/or therapies to be made available to anyone affected by neuromuscular pathologies and rare genetic diseases, including those of an oncological nature;

- b. to disseminate knowledge to the public about the scientific research activities carried out, about the social issues inherent to genetic diseases, as well as about the results achieved;
- c. to promote and support technological research aimed at developing aids that promote the autonomy of patients affected by neuromuscular pathologies and genetic diseases.

The Foundation may carry out all activities in the public interest, in Italy and abroad, which are needed to achieve the purpose referred to in this article, as well as further activities in the public interest on condition that said further activities are secondary and instrumental in relation to the aforementioned public interest activities, pursuant to the criteria and limits stipulated under the Decree of the Ministry of Labour and Social Policies No. 107 of 19 May 2021. These activities shall be better identified by the Board of Directors based on the aforementioned Ministerial Decree.

The necessary activities also include fundraising ones, pursuant to Art. 7 of Italian Legislative Decree No. 117 of 3 July 2017.

Specifically, by way of example the Foundation can:

- promote fund raising by way of donations, subscriptions, bequests or any other means, also in conjunction with celebrations, annual events or public awareness campaigns;
- promote fund raising also in an organized and continuous g basis, also by public solicitation or through the sale or supply of goods and services of modest value, using its own or third party resources, including volunteers and employees, in compliance with the principles of truth, transparency and fairness in relations with supporters and the public, in accordance with the guidelines to be adopted pursuant to the Decree of the Ministry of Labour and Social Policies in terms of Art. 7 of Italian Legislative Decree No. 117 of 3 July 2017;
- conduct research activities also through universities, other entities, and other foundations. In this case, relations between the Foundation and such parties shall be governed by specific agreements that shall regulate, in particular, the guidelines for the activities to be carried out at the entities to which the research is entrusted and the terms between the foundation and the entity for the provision of collaboration, in addition to consultancy, assistance, service, support and promotion relating to the activities, as well as the procedures for the use of research, technical and

administrative staff. These arrangements will also determine the assignment of assets, structures and facilities necessary to carry out the research activities, and the forms of funding also through the contribution of other public and private institutions;

- manage research activities by organizing and administering laboratories and research centres in person, managing funding allocated to research projects, granting research and study scholarships to Italian and foreign doctors and researchers through public tenders, supporting very high-profile projects and carrying out any instrumental and/or related activities;

- subsidise, endorse, support, establish or participate in the establishment of any association, institution, foundation or entity, including corporate ones, with similar purposes.

- publish scientific related texts, documents, periodicals or journals, use channels of communication with the aim of disseminating and deepening scientific research and the social issues related to genetic diseases, as well as with the aim of offering a series of services that are useful to users, including in-depth answers regarding medicines, research, innovative treatments, hospitals of excellence and other related topics;

- provide training for students and refresher courses for teaching staff at schools at every level, more specifically, for example, by organising courses, seminars and conferences and producing information, teaching and educational material;

- in order to translate the positive research results into treatments, drugs and/or therapies that are accessible to patients, develop collaboration with public and private bodies and institutions, and the pharmaceuticals industries, according to the competencies and responsibilities of each, as well as eventually manage in autonomy the production and distribution of treatments, drugs and/or therapies in cases where it would not otherwise be produced and/or distributed by pharmaceutical operators;

- protect the intellectual property generated by the projects of funded research and enhance it also through technology transfer operations;

- acquire, own, manage, lease both movable and immovable assets, also, if necessary, in order to support the temporary residential needs of patients, and of their families, involved in scientific research projects, and/or supply with medical assistance aimed at providing the Foundation's innovative therapies;

- enter into contracts, understandings and agreements with institutes, entities, associations, bodies and commercial companies.

Article 3

The Foundation's assets consist of:

- a) the donated assets as it appears from the Memorandum of Incorporation;
- b) the contributions and bequests received from the Government, the European Union or other public or private entities, including non-profit ones, specifically assigned to increase the Foundation's assets;
- c) the funds collected from legal (public or private) or natural persons, including by way of public subscriptions duly authorised in terms of the law, and which are specifically assigned to increase the assets;
- d) the movable and immovable assets that are received by the Foundation as inheritances, bequests or donations or on whatever other basis and that are specifically assigned to the assets;
- e) the amounts drawn from income, referred to under Article 4 below, which the Board of Directors, by means of its own reasoned resolutions, resolves to assign to increasing the Foundation's asset.

The foundation is obliged to use its assets, including any proceeds, income and revenue, however denominated, to carry out its statutory activities for the exclusive pursuit of civic, solidarity and social utility purposes.

Article 4

For the fulfilment of its tasks, the foundation provides:

- a) income from the assets pursuant to Article 3;
- b) the amount of money received by the Foundation from other entities or private persons interested in the Foundation's mission;
- c) the amount of money collected through fund raising pursuant to Art. 7 of Italian Legislative Decree No. 117 of 3 July 2017;
- d) the amount of money resulting from the sale of its assets, which are assigned to be used for purposes other than increasing assets, on the basis of a motivated resolution taken by the Board of Directors;
- e) the amount of money received by the Foundation as a result of entrepreneurial or commercial activities, where income is assigned to statutory activities solely in pursuit of its civic, solidarity and social utility purposes.

In order to carry out its activities, the Foundation has income received for any reason, surplus of management, any profits and proceeds of its own patrimony, as well as any other asset, which for whatever reason, become part of its assets, expressly forbidding the distribution, of operating profits and surpluses, funds and reserves however referred to, albeit indirectly, to founders, employees and collaborators, directors and other members of corporate bodies.

Article 5

The bodies of the Foundation are:

- the President of the Foundation;
- the Vice President;
- the Board of Directors;
- the Secretary General, if appointed;
- the Supervisory Body.

All appointments are free, excluding the fees payable to the supervisory body, and without prejudice to the possible reimbursement of the out-of-pocket expenses incurred to carry out the appointment or based on a specific Board of Directors' resolution. This is further without prejudice to the powers vested with the Board of Directors to deliberate the allocation of remuneration for individual Board members in relation to specific tasks, after due consultation with the supervisory body.

Article 6

The Board of Directors comprises seven members and may be increased up to fifteen, by way of the Board of Directors co-opting members; in this regard, the Board approve this resolution with the presence and favourable votes of at least two thirds of its members.

The members of the Board of Directors hold office for three financial years or for any different period as established upon their appointment. Their assignment expires on the date of the Meeting convened to approve the balance sheet for the last financial year of their term; they may be reappointed.

In any case, the outgoing Board members retain their administrative powers until the date of appointment of the members of the new Board of Directors.

Should the number of Board members fall below seven, the Board shall be convened by the President, or in his/her place, by the Secretary General if appointed, or by the eldest Board member for integration.

The term of office of the new members shall coincide with that of the members already in office, so that the entire Board can be reappointed at the same time.

If, due to resignations or any other reason, the number of Board of Directors members is reduced to fewer than five, the entire Board shall be deemed to have lapsed, and the President, or in his/her place, the Secretary General if appointed, or the eldest Board member shall immediately convene the Board to appoint a new Board of Directors. Until the new Board has accepted its appointment, the lapsed Board shall only have powers to perform ordinary administrative actions.

If an appointed member should not accept the appointment in writing, within fifteen days of the news received from the Foundation President, it is understood that he/she has

rejected.

At least one Board member shall be selected from among people who have gained experience in entities involved in muscular dystrophy; if the board comprises nine or more members, at least one other member shall be selected from among people who have gained experience in entities involved in rare genetic diseases.

The Board of Directors has full powers to carry out the ordinary and extraordinary administration of the Foundation.

In particular, the Board of Directors may:

- prepare the programmes and guidelines for managing the Foundation;
- where deemed appropriate, through the office of the President, invite experts to its meetings (including those not part of the Scientific Medical Committee) in the field of biomedicine, who can provide non-binding guidelines and opinions for the Board of Directors, as well as representatives from organisational and administrative offices to provide clarification and information on the management activities or external consultants deemed appropriate for the work of the Board of Directors.
- deliberate on the acceptance of gifts, donations and bequests;
- deliberate on contributions, grants and collaboration to be provided to the initiatives of other entities, which correspond with the objectives pursued by the Foundation;
- enter into agreements relating to the use of contributions;
- verify the utilisation of the contributions granted;
- ratify the deeds of extraordinary administration carried out by the President or anyone delegated by the latter in cases of mandatory and urgent needs;
- set the guidelines and signing powers for managing current account and banking transactions;
- set up temporary or permanent advisory boards, to support the Board of Directors' strategic decisions with non-binding opinions, determining their composition, which may also include external members, the scope of their activities, the purpose, and possibly, the rules for their functioning;
- delegate all or part of its powers and functions, including those having and exclusively advisory nature, to one or more of its members, even severally, except for the powers specified below;
- appoint managers and representatives to carry out certain acts or categories of acts, by determining the pertinent duration and powers.
- based on the Decree of the Ministry of Labour and Social Policies No. 107 of 19 May 2021, identify the activities other than those of public interest that can be carried out by the Foundation.

In the aforementioned cases, the mandated Board members,

managers and representatives duly represent the Foundation within the limits of the powers they have been conferred.

The following issues fall within the exclusive competence of the Board of Directors and cannot be delegated under any circumstances: amendment of the Statute and/or the Memorandum of Incorporation, the dissolution of the Foundation, the establishment of a Scientific Medical Committee and the appointment of its members, the approval of the budget, balance sheet and social report.

The Board must be convened at least twice a year (the first, to approve the balance sheet and social report, and the second, to approve the budget), and, in addition, at any time the President shall deem it appropriate, or he/she is requested to do so by at least one third of the Board members.

Regarding resolutions referring to ordinary administration, the Board of Directors is validly constituted with the presence of at least half of its members, and the resolution is valid if taken by a majority of those present, provided that the Statute does not require a qualified majority; in the event of a tie, the President's vote shall prevail.

For acts of extraordinary administration, the resolution is valid if passed by a majority of at least two thirds of Board of Directors' members.

Resolutions extraordinary administration include those related to the appointment of the President; to the appointment of Board of Directors' members; amendments to the Statute and/or Memorandum of Incorporation; the assignment of assets; the dissolution of the Foundation should the purpose of the latter become impossible or of little relevance or if the assets should become insufficient, or generally, if the causes for dissolution pursuant to Art. 27 of the Italian Civil Code should apply.

Board of Directors' meetings may also be held by teleconference and videoconference

In this case, the President or in his/her absence, the Vice President shall verify that the legal number for a quorum has been reached, personally and unequivocally identifying all the participants linked via teleconference and videoconference, and ensure that all audio-visual tools allow them, in real time and continuously to follow the discussion and intervene in the discussion of the topics.

In the call notice it can be established that the meeting is held exclusively by means of telecommunications, thus omitting to specify a physical place for the meeting. In this case, the principles of collegiality, good faith and equal treatment shall be respected when conducting the meeting, without it being necessary for the President and Secretary or Notary to attend in the same place.

Board of Directors' meeting may also be held outside the Municipality where the Foundation has its registered office,

but must in any case take place with the simultaneous presence in the same location of President, or in his/her absence, the Vice President, and the secretary responsible for taking the meeting minutes.

The Board of Directors is convened by the President by means notice containing the day, time and place for the meeting and a list of the topics to discuss, to be sent by any means that can ensure proof of receipt, with at least 8 (eight) days' notice, and in urgent cases, the Board of Directors is convened using the same procedures, with at least 24 (twenty-four) hours' notice. Meetings minutes are prepared by the Secretary in charge, and signed by the Secretary and President, unless a Notary's intervention is required.

Article 7

The Foundation's President is appointed by a majority of two thirds of the Board of Directors' members; holds office for three financial years, or for a different term that may be established upon appointment and may be re-appointed. In any case, the President's term of office shall coincide with that of the members of the Board of Directors already in office, so that the entire Board and its President shall renewed at the same time.

If the person as President is not already be a Board member, he/she must first be co-opted to the Board of Directors.

The President of the Foundation is also the President of the Board of Directors.

The President has all powers pertaining to the ordinary administration. Within the scope of the powers conferred, the President may appoint representatives, determine their powers and delegate to persons within the Foundation's organisational and administrative offices.

The President is the legal representative of the Foundation both vis-à-vis third parties and in legal proceedings.

The President:

- convenes and chairs the Board of Directors, proposing the agenda for the respective meetings;
- oversees the smooth administrative management of the the Foundation;
- ensures that resolutions taken by the Board of Directors are executed, also with the assistance of the General Secretary, if appointed, or special attorneys;
- when urgent and in cases of need, undertakes deeds of extraordinary administration within the competence of the Board of Directors, without prejudice to the latter, subject to ratification by the latter at at its next meeting. The President's signature certifies that it is urgent and necessary to adopt a deed of extraordinary administration, in place of the Board of Directors.

The Vice President is appointed by a majority of the Board of

Directors' members from among its members, serves for three financial years, or for a different term that may be established upon appointment and may be re-appointed.

In any case, the Vice President's term of office shall coincide with that of the members of the Board of Directors already in office.

The Vice President is responsible for acting in place of the President in all cases where the latter is temporarily unavailable or absent.

The Vice President's signature attests the impediment (unavailability and absence) of the President.

The President and the Vice President are domiciled for office at the Foundation's headquarters.

Article 8

If deemed necessary to better manage the Foundation, the Board of Directors may appoint a General Secretary from among its members, based on a resolution taken by an absolute majority of the members in office; the latter is responsible for executing and complying with the resolutions taken by the Board of Directors.

For these tasks he/she has fully delegated authority, including the power to appoint attorneys for individual acts or categories of acts.

Within the scope of the guidelines from the Board of Directors, the General Secretary is vested with all powers referring to the ordinary administration and oversees all the activities of the Foundation's administrative and organisational structures.

Should the General Secretary leave office, the successor shall be appointed by the Board of Directors, with a resolution taken by an absolute majority of the members in office.

Article 9

With reference to all the opinions referred to in Art. 2 of these Statute, The Foundation avails itself of the Scientific Medical Committee, appointed by the Board of Directors, which defines the criteria for selecting its members and for its operation.

Members are appointed by the Board of Directors based on the proposals made by the director in charge, in compliance with the criteria set by the Board of Directors; the President and Vice President of the Committee are designated from among its members.

The Scientific Medical Committee has the task of assessing the research projects assigned by the Foundation, to formulate opinions on their validity and innovativeness in the field of diseases of genetic origin.

Evaluations may be carried out by all or some of the members of the Scientific Medical Committee depending on the number of

the research projects to be assessed and/or their areas of expertise, in compliance with the operating procedures set.

Based on the type of research project to be assessed, the Scientific Medical Committee may be supported by external experts (so-called "External Reviewers"), who are identified ad hoc by the director in charge and who make themselves available for this purpose.

In the case of specific funding initiatives, the Foundation may utilise ad hoc Experts Committees, set up by the director in charge, who will appoint its members.

The opinions expressed by the Scientific Medical Committee and by the ad hoc Expert Committees are binding only for the definition of the funding priorities based on the scientific merit and the Board of Directors shall assign the funds based on these opinions.

The President or the Vice President or the Secretary General, if appointed, or even two jointly acting Board members, can assign funds and activate research projects, subject to subsequent ratification by the Board of Directors.

Article 10

The financial year opens on the first of January and ends on the thirty-first of December of each year. The budget, the balance sheet and the social budget refer to these periods. The balance sheet and the social budget, prepared by the administrative offices or by other offices responsible, are reviewed each within the scope of their remit, by the Supervisory Body pursuant to Art. 11 below, and by the External Auditor or Audit Company, pursuant to Art. 12 below, to obtain their respective and necessary reports and certificates.

The President or the Secretary General, if appointed, or the administrative and financial Manager, or a mandated Board member or function mandated by the latter, shares and submits to the members of the Board of Directors, the Supervisory Body and the External Auditor or the Audit Company, the draft balance sheet and social budget, prepared as specified above, at least 30 days prior to the date set for the Board of Directors' approval. During the approval meeting, the draft balance sheet and social budget report are submitted together with the reports and certificates from the Supervisory Body and External Auditor or Audit Company, according to their remit. The approval process is completed within six months from the date of the financial year-end.

Where there are no provisions set by law, the Board of Directors, having heard the opinion of the Supervisory Body and the External Auditor or the Audit Company, shall specify which accounting records adopt to ensure an orderly and transparent management of the Foundation's economic-financial activities.

Regarding public fund raising, pursuant to Art. 87, paragraph 6 of Italian Legislative Decree No. 117 of 3 July 2017, a specific report of income and expenses for each of the celebrations, annual events, or public awareness campaigns, will be prepared and included in the balance sheet.

Article 11

The Supervisory Body comprises three standing members and two alternate members, pursuant to Art. 2397 of the Italian Civil Code. The standing and alternate members of the Supervisory Body are appointed by the Board of Directors by a two-thirds majority vote.

Art. 2399 of the Italian Civil Code applies to the members of the Supervisory Body, and they must be chosen from the categories of persons referred to in the aforementioned Art. 2397.

The Supervisory Body supervises and verifies the Foundation's management over the financial year, at least on a quarterly basis. Specifically, the Supervisory Body monitors the compliance with the Law and the Statute, the respect for the principles of proper administration, and, in particular, the adequacy of the administrative and accounting organizational structure adopted by the Foundation and its actual functioning, examines the balance sheet, according to its remit, prepared by the administrative offices in order to prepare the relative report.

The Supervisory Body also monitors compliance with the civic solidarity and social utility purposes, with due regard to the provisions under articles 5, 6, 7 and 8 of Italian Legislative Decree No. 117 of 3 July 2017 and certifies that the social budget has been prepared in accordance with the guidelines set out in Art. 14 of the same Decree.

The Supervisory Body likewise watches over the compliance with the principles of proper administration, also with reference to the provisions under Italian Legislative Decree No. 231 of 8 June 2001 in compliance with the competencies of the specific Supervisory Body, where established. The Supervisory Body remains in office for three financial years, expires with the approval of the balance sheet for the third financial year of office and may be reappointed for further two terms. The Members of the Supervisory Body attend the meetings of the Board of Directors. Members of the Supervisory Body who do not attend two consecutive Board of Directors' meetings during a financial year without a justified reason, shall forfeit their office.

Article 12

The task of ascertaining that the accounting records are properly kept is entrusted to the External Auditor or Audit Company, selected from those registered in the Auditors

Register held by the Ministry of Justice, and are appointed by the Board of Directors.

In particular, the Auditor or the Audit Company shall:

- verifies during the financial year, at least on a quarterly basis, that the Foundation's accounts are regularly kept and that management events have been properly accounted in the records, as well as the commitments undertaken and their financial coverage;
- verifies whether the balance sheet corresponds to the accounting records and inspections performed, and whether they are in accordance with the rules governing them;
- express an opinion on the balance sheet in a report.

The Auditor or Audit Company is appointed for 3 (three) financial years, ceases to hold office upon approval of the balance sheet for the third financial year of their term and may be reappointed for a further two terms.

Article 13

The Foundation is established with no time limitation.

The Foundation approves the dissolution with the majorities foreseen by Art. 6 of the Statute, should its purpose become impossible or of little relevance or if the assets should become insufficient, or generally, when the causes for dissolution foreseen in Art. 27 of the Italian Civil Code should occur.

In the event of termination or dissolution, the Foundation's residual assets shall be assigned to other Third Sector entities according to the provisions of the Board of Directors, subject to approval from the Office pursuant to Art. 45, paragraph 1 of Italian Legislative Decree No. 117 of 3 July 2017 and unless otherwise required by Law.

In the event of the Foundation's liquidation for any reason, the Board of Directors shall appoint three liquidators, who may be selected among members of the Board of Directors itself.

Article 14

For all matters not provided for in these Statute, reference is made to the provisions as per Legislative Decree No. 117 of 3 July 2017, the provisions of the Italian Civil Code and the applicable laws.

Article 15

The Foundation has been recognised in terms of the Decree issued by the Ministry of University, Scientific Research and Technology.