

Annex 'A' to Collected Act No. 3779

STATUTE

Article 1

A foundation named '**FONDAZIONE TELETHON ETS**' is hereby established, with headquarters in **Rome**.

The foundation has secondary offices in **Milan** and **Pozzuoli** (Naples). The address of the head office and secondary offices derive from the single national register of the third sector, pursuant to Article 48, paragraph 1 of Legislative Decree 117/2017. A change of address in the same municipality does not constitute a modification of the statute.

The foundation is obliged to use, in its name, deeds and correspondence, as well as in any distinctive sign or communication addressed to the public, the term 'entity of the third sector' or the acronym 'ETS'.

Article 2

The foundation is a non-profit-making organization and exclusively pursues civic, solidarity and socially useful purposes through activities with the following aims

- the scientific research of particular social interest referred to in Article 5(h) of Legislative Decree No. 117 of 3 July 2017;
- the disbursement of money, goods or services in support of patients and their families involved in scientific research projects, and/or medical assistance aimed at the provision of the foundation's innovative therapies or activities of general interest within the meaning of Article 5(u) of Legislative Decree No. 117 of 3 July 2017;
- the organization and management of cultural, artistic or recreational activities of social interest, including editorial tasks, as well as the promotion and dissemination of a culture and practice of voluntary work and undertakings of general interest, as referred to in point (i) of Article 5 of Legislative Decree No. 117 of 3 July 2017, which are necessary for the achievement of the purpose set out in these articles of association.

The purpose of the foundation is:

- a. To promote, support and implement, on the basis of the opinion of the appropriate medical and scientific commission, medical and scientific research activities aimed at the treatment of neuromuscular diseases and genetic diseases, including those of an oncological nature;

b. To disseminate knowledge to the public about the social issues surrounding genetic diseases, as well as the scientific research activities conducted and the results achieved;

c. To promote and support technological research aimed at developing aids that promote the autonomy of patients suffering from neuromuscular and genetic diseases.

The foundation may carry out all activities in the general interest, in Italy and abroad, that are necessary for the achievement of the purpose set forth in this article, as well as others, provided that these are secondary and instrumental to the aforesaid ones of general interest, in accordance with the criteria and limits set forth in Ministerial Decree No. 107 of 19 May 2021.

These undertakings will be better identified by the board of directors based on the contents of the aforementioned ministerial decree.

The necessary activities also include fundraising ones under Article 7 of Legislative Decree No. 117 of 3 July 2017.

In particular, by way of example, the foundation may:

- Promote fundraising, through donations, subscriptions, bequests or by any other means, including in connection with celebrations, anniversaries or awareness-raising campaigns;
- Promote fundraising in an organized and continuous manner, including by means of solicitation to the public or through the sale or provision of goods or services of modest value, using its own resources and those of third parties, including volunteers and employees, in compliance with the principles of truthfulness, transparency and fairness in relations with supporters and the public, in accordance with guidelines to be adopted by decree of the Minister of Labour and Social Policies pursuant to Article 7 of Legislative Decree No. 117 of 3 July 2017;
- Conduct research activities through universities, other entities and other foundations. In this case, relations between the foundation and the latter 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 for carrying out the research activities, and the forms of funding 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;

- Subsidize, support, create or participate in the establishment of any association, institution, foundation or body, including corporate ones, with similar purposes;

- Publish texts, documents, periodicals or scientific journals and use communication channels with the aim of disseminating and deepening research activities into scientific and social issues related to genetic diseases, as well as offering a range of useful services for users, including comprehensive answers on drugs, research, innovative treatments, hospitals of excellence and other related topics;

- Provide training for students and refresher courses for school teaching staff at all levels, especially through organizing courses, seminars and conferences and producing informational, educational and teaching material;

- Develop collaborations with public health institutions and pharmaceutical companies, according to the competencies and responsibilities of each, to translate the results of funded research into treatments and drugs that can be used by patients, despite the rarity of the diseases;

- Acquire, own, manage and lease both movable and immovable property, if necessary, in order to support the temporary residential needs of patients and their families involved in scientific research projects and/or medical assistance aimed at the provision of the foundation's innovative therapies;

- Enter into contracts, understandings and agreements with institutions, bodies, associations, organizations and commercial companies.

Article 3

The foundation's assets consist of:

a) the donated assets as stated in the deed of association;

b) contributions or donations received from the state, the European Union or other public or private entities, including non-profit organizations, to increase the foundation's assets;

c) funds collected from legal (public or private) or natural persons, including by public subscriptions duly authorized by law and which are intended to increase the assets;

d) movable and immovable property which comes to the foundation by way of inheritance, legacy or donation or any other title and which is allocated to the assets;

e) the sums withdrawn from income, referred to in Article 4 below, that the board of directors, by means of its own reasoned resolutions, decides to allocate to increase the foundation's assets.

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 socially useful purposes.

Article 4

For the fulfilment of its tasks, the foundation provides:

a) income from the assets referred to in Article 3;

b) sums received by the foundation from other bodies or private individuals interested in its purposes;

c) sums collected through fundraising under Article 7 of Legislative Decree No. 117 of 3 July 2017;

d) sums - arising from the sale of parts of its assets - which are allocated, by reasoned resolution of the board of directors, for use other than to increase its assets;

e) any sums received by the foundation as a result of entrepreneurial or commercial activities, the proceeds of which will be allocated to the pursuit of the foundation's statutory activities for the exclusive pursuit of civic, solidarity and socially useful purposes.

In order to carry out its activities, the foundation disposes of income received for any reason whatsoever, in addition to operating surpluses and any profits and proceeds of its assets as well as any other that, for any reason whatsoever, becomes part of its assets, expressly forbidding the distribution, even indirectly, of operating profits and surpluses, funds and reserves however denominated to founders, employees and collaborators, directors and other members of the corporate bodies.

Article 5

The organs of the foundation are:

- the president of the foundation;
- the vice-president;
- the board of directors;
- the secretary general, if appointed;
- the medical-scientific commission;
- the controlling body.

Each office is free of charge, except for the remuneration of the controlling and supervisory bodies and the tokens for participation in the meetings of the medical-scientific commission, and without prejudice to the reimbursement of any

out-of-pocket expenses incurred in the performance of the office or by specific resolution of the board of directors. This is also without prejudice to the right of the board of directors to deliberate the allocation of remuneration to individual board members for specific tasks.

Article 6

The board of directors includes between seven and 15 members, according to the number to be decided by the board itself, which, in this regard, will decide with the presence and favourable vote of at least two thirds of its members. The members of the board of directors hold office for three financial years or for a different period established at the time of their appointment, which expires on the date of the shareholders' meeting called to approve the financial statements for the last financial year of their office, and may be re-elected. In any case, the outgoing directors retain the powers of administration until the date of appointment of the new board of directors.

The number of members may be increased up to 15, through co-optation by the board of directors, which, in this regard, shall decide with the presence and favourable vote of at least two thirds of its members.

Should the number of members of the board of directors fall below seven, the board may be convened by the president or, in his stead, by the secretary general, if appointed, or by the eldest director, for integration.

The term of office of the new members shall coincide with that of the members already in office, so that the entire administrative body will be renewed at the same time.

If, due to resignation or any other cause, the number of members of the board of directors is reduced to fewer than five, the entire board of directors shall be deemed to have lapsed and the president or, in his stead, the secretary general, if appointed, or the eldest director, shall immediately convene the board itself, for the appointment of the new administrative body. Until the acceptance of the office by the new administrative body, the lapsed board will only have the power to perform ordinary administrative actions.

If the co-opted person does not accept the office in writing within 15 days of being informed by the president of the foundation, he shall be deemed to have refused it.

Should the maximum number of board member positions be filled, it must be ensured that at least one of them, in addition to the vice-chairman, is chosen from among persons who have held positions in non-profit organizations that, by statute, are dedicated to issues related to genetic diseases. The board of directors has all the powers necessary for the ordinary and extraordinary administration of the foundation.

In particular, the board of directors may:

- prepare programmes and guidelines for the management of the foundation;

- if it deems it appropriate, invite to its meetings, through the chairman, experts (both internal and external to the medical-scientific commission) of the highest standing in the field of biomedicine, who may provide non-binding guidance opinions for the board of directors; representatives of the organizational and administrative offices in order to receive clarifications and information on management activities, or external consultants that it deems useful for the work of the board of directors. The presence of such persons is conditional on their acceptance by two thirds of the board of directors;
- deliberate on the acceptance of donations, gifts and legacies;
- deliberate on contributions, subsidies and collaboration to be given to the initiatives of other bodies, which correspond to the foundation's aims;
- enter into agreements on the use of contributions;
- verify the use of the contributions granted;
- ratify acts of extraordinary administration to be carried out by its president or a person delegated by him in cases of unavoidable necessity and urgency;
- determine the guidelines and signature powers for the management of current accounts and banking operations;
- delegate all or part of its powers and functions, including those of an exclusively advisory nature, to one or more of its members, even severally, with the exception of the powers indicated below;
- appoint directors and attorneys for the performance of certain acts or categories of actions, determining their duration and powers;
- identify, on the basis of the contents of Ministry of Labour and Social Policies Decree No. 107 of 19 May 2021, the activities other than those of general interest that can be carried out by the foundation.

In the aforementioned cases, the managing directors, directors and attorneys have the power to represent the foundation within the limits of the powers conferred on them.

The following matters fall within the exclusive competence of the board of directors and cannot be delegated under any circumstances: the amendment of the articles of association and/or memorandum of association, dissolution of the foundation, appointment of members and indication of the guidelines for the functioning of the medical-scientific commission, and approval of the budget and final accounts, as well as the social balance sheet.

It must be convened at least twice a year (the first time to approve the financial statements and the balance sheet, and the second time to approve the budget) and, in addition, whenever the president deems it appropriate, or it is requested by at least one third of its members.

For resolutions of 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, when this statute does not require qualified majorities; in the event of a tie, the president's vote shall prevail. For acts of extraordinary administration, the resolution is valid if taken by a two-thirds majority of the members of the board of directors. Resolutions of extraordinary administration include those relating to the appointment of the president, the medical-scientific commission or members of the board of directors; amendments to the articles of association and/or memorandum of association; the devolution of assets; and the dissolution of the foundation if its purpose becomes impossible or of little use or if the assets become insufficient or, in general, when the causes of extinction envisaged by Article 27 of the Italian Civil Code occur.

Meetings of the board of directors may also be held by teleconference and videoconference.

In this case, the president, or in his absence, the vice-president, must verify the presence of the quorum for the valid constitution of the meeting, identifying, personally and with certainty, all the participants connected by teleconference or videoconference, and ensure that the audiovisual instruments allow them, in real time and continuously, to follow the discussion and intervene in the discussion of the topics.

Meetings of the board of directors may also be held outside the municipality where the foundation's registered office is located, but must in any case take place with the simultaneous presence in the same location as the president, or in his absence, the vice-president, and the secretary in charge of taking minutes.

The board of directors shall be convened by the chairman by means of a notice containing the date, time and place of the meeting and the list of items to be discussed, to be sent by any means suitable to ensure proof of receipt, with at least eight days' notice and, in the event of urgency, the board of directors shall be convened, in the same manner, with at least 24 hours' notice.

Article 7

The president of the foundation is appointed by a two-thirds majority of the members of the board of directors, holds office for three financial years, or for a different term that may be established upon appointment, and may be reappointed. 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 governing body and its president shall be renewed at the same time.

If the person appointed as chairman is not already a member of the board of directors, he/she must first be co-opted to the board of directors.

The president of the foundation is also chairman of the board of directors.

The president has all powers pertaining to ordinary administration. Within the scope of all the powers vested in him, the president may appoint attorneys and determine their powers and delegate to persons within his organizational and administrative departments.

The president is the legal representative of the foundation both vis-à-vis third parties and in court.

The president:

- convenes and chairs the board of directors, proposing the matters to be discussed at the respective meetings;
- oversees the smooth administrative running of the foundation;
- ensures the execution of the resolutions of the board of directors with the help of the secretary general, if appointed, or of special attorneys;
- in cases of urgency and necessity, adopts acts of extraordinary administration within the competence of the board of directors, subject to ratification by the latter at its next meeting.

The president's signature certifies the existence of urgency and necessity for the adoption of the act of extraordinary administration in place of the board of directors.

The vice-chairman is appointed by a majority of the members of the board of directors from among its members, serves for three financial years, or for such other term as may be determined at the time of appointment, and may be reappointed.

In any case, the term of office of the vice-chairman shall coincide with that of the members of the board of directors already in office.

The vice-president has the task of deputizing for the president in all cases of the latter's temporary unavailability and absence.

The signature of the vice-president attests the impediment (unavailability and absence) of the president.

The president and vice-president are domiciled for office at the foundation's headquarters.

Article 8

The board of directors may, if it is deemed necessary for a better management of the foundation, appoint from among its members a secretary general, with a resolution adopted by an absolute majority of the members in office, whose task is to ensure the execution and fulfilment of the resolutions of the board of directors.

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

The secretary general, within the guidelines of the board of directors, has all the powers pertaining to ordinary administration and supervises all the

activities of the foundation's administrative and organizational structures. Should the secretary general leave office, a successor will be appointed by the board of directors, which must decide with an absolute majority of the members in office.

Article 9

The foundation avails itself of the medical-scientific commission for all matters concerning the opinions referred to in Article 2 of these articles of association.

The members of the medical-scientific commission, including the president and vice-president, are appointed by the board of directors. The term of office of the members of the medical-scientific commission is four years. The president and vice-president are appointed by the board of directors from among the current members of the commission. The term of office of the chairman and vice-chairman is two years. In the event of an appointment at the end of the term of office, the term of office of the chairman and vice-chairman on the medical-scientific commission may be extended for a maximum of two years.

The medical-scientific commission is made up of Italian and/or foreign experts in the biomedical field and has the task of assessing the research projects submitted by the foundation in order to formulate opinions on their validity and innovativeness in the field of diseases of genetic origin.

Evaluations may be conducted by all or some of the members of the medical-scientific committee, depending on the number of proposals to be considered and/or the areas of expertise. Depending on the type of proposal to be assessed, the medical-scientific committee may be supported by ad hoc recruited external experts. For particular funding initiatives, the foundation may make use of additional technical commissions.

The opinions expressed by the medical-scientific commission are binding only for the definition of the ranking of funding priorities, and the board of directors will proceed to allocate funds on the basis of these views. The president or the secretary general, if appointed, may allocate funds and activate research projects, subject to subsequent ratification by the board of directors, provided this is done in accordance with the guidelines issued by the board of directors.

Article 10

The financial year shall open on 1 January and close on 31 December of each year. The budget, the balance sheet and the social budget shall refer to these periods. The balance sheet and the social balance sheet, prepared by the administrative offices, shall be examined by the controlling body, referred to in Article 11 below, and by the external auditor or auditing company, referred to in Article 12 in order to obtain their respective and expected reports and certificates. No later than six months after the end of the financial year, the

president, the secretary general, if appointed, a delegated director or the administrative and financial director shall submit to the board of directors the final balance sheet and the financial statements, together with the reports and certificates of the controlling body and the external auditor or the auditing company.

Where the law does not provide for it, the board of directors, having heard the opinion of the controlling body and the external auditor or the auditing company, shall indicate which accounting records are to be adopted in order to guarantee an orderly and transparent management of the foundation's economic and financial activities. For public fundraising, pursuant to Article 87, paragraph 6 of Legislative Decree No. 117 of 3 July 2017, a specific statement of income and expenditure for each of the celebrations, anniversaries or awareness campaigns will be prepared and included in the final budget.

Article 11

The controlling body consists of three regular members and two alternates, pursuant to Article 2397 of the Civil Code. The regular and alternate members of the controlling body are appointed by the board of directors by a two-thirds majority vote.

Article 2399 of the Italian Civil Code applies to the members of the controlling body and they must be chosen from the categories of persons referred to in the aforementioned Article 2397.

The controlling body supervises and verifies during the financial year, at least on a quarterly basis, the management of the foundation. In particular, the controlling body monitors compliance with the law and the statute, respect for the principles of proper administration and, specifically, the adequacy of the administrative and accounting organizational structure adopted by the foundation and its actual functioning, in addition to examining the final balance sheet prepared by the administrative offices in order to prepare the relative report. The controlling body also performs tasks to monitor compliance with the civic, solidarity and socially useful purposes, with particular regard to the provisions of Articles 5, 6, 7 and 8 of Legislative Decree No. 117 of 3 July 2017, and certifies that the social report has been drawn up in accordance with the guidelines set out in Article 14 of the same decree.

The controlling body also monitors compliance with the principles of proper administration, with reference to the provisions of Legislative Decree No. 231 of 8 June 2001, in compliance with the competences of the specific supervisory body where established. The controlling body remains in office for three financial years, expires with the approval of the financial statements for the third financial year of office and may be re-elected for a further two terms. The members of the controlling body attend the meetings of the board of directors. Members of the controlling body who do not attend two consecutive

meetings of the board of directors 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 an external auditor or an auditing company, who is chosen from among those entered in the register of statutory auditors set up at the Ministry of Justice and appointed by the board of directors.

In particular, the auditor or the auditing company:

- verifies during the financial year, at least quarterly, the regularity of the company accounts and the correct recording in the accounting records of the management events, as well as the commitments undertaken and their financial coverage;
- verifies whether the financial statements correspond to the entries in the books and records and whether they are in accordance with the rules governing them;
- expresses an opinion on the annual accounts in a report.

The Auditor or Auditing Company is appointed for three financial years and ceases to hold office upon approval of the financial statements for the third financial year of office and may be re-elected for a further two terms.

Article 13

The foundation is established with no time limitation.

The foundation resolves to wind up, with the majorities provided for in Article 6 of the statute, if its purpose becomes impossible or of little use or if its assets become insufficient and in general when the causes of extinction provided for in Article 27 of the Civil Code occur.

In the event of its extinction or dissolution, the foundation's residual assets shall be devolved, subject to the positive opinion of the office pursuant to Article 45, paragraph 1 of Legislative Decree No. 117 of 3 July 2017, and unless otherwise required by law, to other third-sector entities in accordance with the provisions of the board of directors. Should the foundation be liquidated for any reason, the board of directors shall appoint three liquidators who may be chosen from among the members of the board of directors.

Article 14

For all matters not provided for in these articles of association, reference is made to the provisions of Legislative Decree No. 117 of 3 July 2017 and the provisions of the Civil Code, as well as the applicable laws on the subject.

Article 15

The foundation has been recognized by decree of the Ministry of Universities and Scientific and Technological Research.