

Code of Ethics

FONDAZIONE





What should be done to realise social responsibility?

If social responsibility is just a moral, a legal matter, there will be no social responsibility where there is little personal morality, or an ineffective law.

Only if we add the ethical dimension, based on sharing rules and values, can a true social responsibility be realised.

However, ethics cannot be formulated (L. Wittgenstein, Tractatus logico-philosophicus).

Therefore, the code is intended as a useful guide to inspire and direct the conduct of the organisation at all levels, orienting the road to follow.

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1. Introduction

1.1 SCOPE OF THE CODE

This code expresses the commitments made by directors, employees and collaborators of Telethon while conducting their work activities.

Compliance with the code is essential to ensure the proper functioning, reliability and reputation of the organisation, with the scope of reasonably preventing illicit conduct and avoid any involvement of Telethon in any criminal conduct.

The existence of a non-profit organisation is not justified by the mere goodness of its scopes. Conduct ethics must be an indispensable value for Telethon and honesty, moral integrity, transparency, reliability and a sense of responsibility must represent be the distinctive principles of all the activities carried out by the organisation.

The code defines the guidelines for the conduct of Telethon in the organisation's internal relations and its relations with the external world.

1.2 RECIPIENTS AND DISSEMINATION

The recipients of the Code of Ethics are the directors, all the employees and collaborators working, permanently or temporarily, on behalf of Telethon (hereinafter referred to as "recipients"). The Code will also be brought to knowledge of those third parties with stable or temporary relationships with the institution or that receive assignments from it.

The Recipients are required to act and conduct themselves in line with what is indicated in the Code, and to report to the Supervisory Body and/or to their head all violations of it as soon as they become aware of them.

Telethon will make available a copy of the Code of Ethics to all recipients and ensure the greatest possible diffusion within it.

1.3 VALIDITY AND APPLICATION

The Code of Ethics was approved by the Board of Directors at the meeting held on 9th February 2012 and it is binding for the conduct of all its recipients and third parties with a stable or temporary relationship with the Foundation or that receive assignments from it.

2. General principles

2.1 MISSION

We wish to bring scientific research forward towards the treatment of muscular dystrophy and other genetic diseases.

Since 1990, the year Telethon was set up, our task is to support the Italian scientific research of excellence for the study and treatment of genetic diseases, with the scope of developing effective therapies against these serious diseases. At the base of the pursuit of our mission are the following conditions that inspire all our activities:

- give priority to those diseases that, because rare, are neglected by great public and industrial investments;
- give funds to excellent research projects and to the best researchers in Italy;
- to involve Italians in the fight against genetic diseases;
- to let those who help us know how we spend the money we collect.

2.2 VISION

Making the results of excellent research selected and sustained over time available as therapies

Finding the cure is no longer a reaching point but it becomes a new starting point. We must make every effort to ensure that successful therapies, developed through research we fund, are available to all and do not stop at clinical trial grounds. For this reason, in the future, while we continue to support excellent research, we will work hard to develop collaborations with public health institutions and pharmaceutical industries, according to the skills and responsibilities of each one, to translate research results into treatments and drugs that can be used by all patients in the world.

2.3 VALUES

Ethics

Working with the priority scope of improving the quality of the life of those who benefit and will benefit from the Telethon research with respect to all the individuals involved in our work.

Transparency

Making the information accessible to all the people involved - in a clear and correct way - to evaluate our work.

Continuous improvement

Always questioning how to do our job at best, openly discussing with others, starting from successful cases to grow day by day.

Merit

Promote rigorous and competitive methods and selection criteria with the scope of rewarding and valorising talent and competence.

2.4 THE TELETHON SYSTEM

Telethon has set up a system based on the relationship between patients, civil society and the world of research. The goal is to ensure the balance between these realities, for patients to feel that they are guaranteed by the pursuit for quality, for donors to know precisely how their money is invested and the researchers feel supported and appreciated for the excellence of their skills and for the quality of their commitment

Telethon is based on the association of three major stakeholders, patients and their families, society, the research world. To develop this relationship and maintain the balance of this system, Telethon has established clear rules shared by everyone: the autonomy of each of these subjects with respect to the others and transparency.

Autonomy

- in the financing system, which ensures the right distance between those asking, deciding and giving;
- in operational strategies, where choices, objectives and positions should not be conditioned by political or commercial pressure;
- in respecting the rules of science that impose quality, rigour, patience and constant international comparison, avoiding the promises of miraculous and immediate solutions.

Transparency

- on the goals we want to achieve and that we are pursuing;
- on the projects we select, firstly rewarding the scientific merit and research potential;
- on the rigorous evaluation by an independent commission made up of experts from all over the world, in the science forefront;
- on the destination of the resources that are available to us, publishing figures and updated data with a careful and precise report.

3. Rules of conduct

3.1 CONDUCT CRITERIA IN THE RELATIONSHIPS WITH THE STAFF

3.1.1 STAFF MANAGEMENT AND DEVELOPMENT

To manage and valorise its resources, Telethon draws inspiration from a continuous improvement, a motivation based on a strong mission sharing and the common goal of achieving statutory objectives.

The relevant office selects, hires and manages the staff based on the criteria of competence, merit and equity described in the "Human Resources Development" procedure (P3) subject to ISO 9001: 2000 Quality Certification. Telethon devotes SPECIAL attention to selection, performance evaluation and training.

Staff selection is one of the main tools for organisational development.

The staff's office is committed to avoiding forms of favouritism, nepotism, or patronage in the selection and recruitment phases (for example, avoiding that the selector is not related to the candidate). In particular, Telethon undertakes to avoid recruiting staff members that have a kinship or affinity with:

- the Telethon Board of Directors; the control bodies, the senior management and its first line managers;
- the Telethon suppliers (in particular those that provide public goods or services as well as controllers such as the Non-profit Organisations' Agency, the Revenue Agency);
- the top figures employed in public administrations (also the so-called "semi-state bodies", public shareholdings and so on) that are among the donors or those offering services for the collection of the Telethon funds.

The selection process is based on a correct identification of positions and roles that allows:

- clarifying the hierarchy and delegation relations in the organisation;
- indicating the tasks and responsibilities of each role;
- weighing the importance of each competence of the role (and not of the person);
- defining the frameworks.

This tool produces a real overall improvement of the organisation's effectiveness and therefore is the indispensable premise for the introduction of a performance evaluation system.

The performance evaluation is characterised as a tool for the development of people, as well as for performance analysis and performance. With this tool Telethon has 4 macro-scopes:

- evaluate the efficiency and effectiveness of the actions of individuals with respect to the organisation's expectations;
- focus the quantitative and qualitative results of each role;
- identify the strengths and areas of improvement of people in order to direct their best placement;
- identify the training needs for each person to improve the performance as well as the evaluation of the effectiveness of the courses that have already been carried out.

The staff's professional adjustment is a fundamental requirement for Telethon. For this scope, a training plan and a method to detect its effectiveness is drawn up every year.

3.1.2 SAFETY AND HEALTH

Telethon wants to ensure a suitable working environment with respect to the needs of its employees and collaborators and guarantee that the mentioned premises are used in safe conditions with regards to their hygiene and cleaning and maintenance, the furnishings and systems, including extraordinary adjustments and maintenance.

Compliance with the requirements of regulation 81/2008 concerning safety and health in the workplace, is ensured by Telethon even by means of the formal designation of a Head of the Protection and Prevention Service, a Competent Physician and a Representative of Workers for Security.

To keep all workers updated on the risks they are exposed to, Telethon convenes thematic meetings on an annual basis.

Telethon also assigns to some of its employees - in implementation of Law 81/2008 - specific tasks that are analysed and updated (based on possible law changes) upon quarterly meetings agreed upon with the Head of the Prevention and Protection Service.

3.1.3 PRIVACY PROTECTION

Staff privacy is protected by adopting standards that specify which is the information that Telethon requires and the related methods of processing and storage. Any investigation on political ideas, preferences, personal tastes and, in general, the private life of collaborators is excluded.

As part of carrying out its activities, the staff that gains knowledge on sensitive data and confidential information undertakes to process them in compliance with applicable privacy laws.

3.1.4 STAFF DUTIES

The Staff must act loyally to comply with the obligations stipulated in the employment contract and with this code of ethics' provisions, ensuring the services requested; and is required to report any violation of the established rules of conduct to the Supervisory Body and/or to his/her superior; and is required to process their documents using a

clear, objective and exhaustive language, allowing any verification by colleagues, managers or external parties authorised to request it.

3.1.5 CORRECTNESS IN CASE OF CONFLICTS OF INTEREST

A conflict of interest arises when a subject, that covers a dual role, to achieve the goals of one must - in certain cases - sacrifice those of the other.

The conflict of interests is more evident - in a common experience - when one of the two spheres of interests is merely private and afferent to the business and personal interests (however legitimate), while the other is contingent to the scope of the institution or common interest of the company.

Employment relationships and individual conduct, at all corporate levels of the company, must be based on principles of honesty, correctness, transparency, confidentiality, impartiality, diligence, loyalty and mutual respect. The recipients engage to refrain from activities, even occasional ones, that may cause conflicts with the interests of Telethon or that could interfere with the ability to make decisions that are consistent with the company objectives.

Telethon requires the most rigorous compliance with the discipline that regulates the conflict of interests, as required by laws and regulations.

In particular, all recipients:

- do not accept or put pressure on, make recommendations or reports that could prejudice or bring undue advantages to themselves, Telethon or third parties;
- refuse and do not make promises and/or undue offers of money or other benefits, unless these are of low value and not related to requests of any kind;
- do not use information received while performing their functions to obtain benefits directly or indirectly and avoid any improper and unauthorised use;
- refrain from engaging in conducts that may benefit competing entities;
- carry out their work acting in a correct and linear way, in compliance with the provisions of the Organisational Model 231 adopted by Telethon;

- inform the Supervisory Body or their supervisor on any situations in which they may be holders of interests in conflict with those of Telethon and in any other case in which there are important reasons for an unfair advantage.

3.1.6 FUND RAISER CODE OF CONDUCT (FR)

All the staff of Telethon engaged in fund-raising activities are inspired by the conduct standards illustrated below.

In particular:

- guarantees, in relation to its work, maximum transparency and fairness towards the donor, favouring and implementing the adoption of these principles within the organisation;
- engages to efficiently coordinate the contribution of the various subjects (donors, volunteers, collaborators) that contribute, according to their various capacities, to the collection of funds, so that no solidarity resource is wasted;
- respects the privacy of donors and the confidentiality of the information collected in fulfilment of their professional obligations.

In relation to these obligations, the Telethon Fund-Raisers abide by the following principles:

1. Right of information for the donor

- on the mission and scopes pursued by Telethon;
- on the operative structure of Telethon, on its governing bodies, on the identity and role of the entities collaborating with the institution and with which they come into contact;
- on the scopes, timing and implementation methods of the individual initiatives to be supported;
- on how to use the resources that are donated and on the results that are obtained through Telethon annual reports (economic-financial and social);
- on the tax implications for the donations.

2. Impartiality, respect and non-discrimination of the donor

- refraining from receiving donations that, due to political, cultural, ideological and commercial features of the donor, undermine the independence element of Telethon and condition the pursuit of the mission;
- refraining from any arbitrary discrimination between donors based on sex, race, ideology and religious belief;
- respecting the free will of donors, avoiding to inducing them to donate by means of excessive pressures, solicitations or misleading and untruthful advertising tools;

3. Protection of personal data and recognition of the donation

- the communication of information regarding donations must take place in compliance with the principles of confidentiality established by the current law; in particular the personal data of the donors is only used according to the scopes of Telethon, excluding any unauthorised and even free transfer to other persons, structures or organisations;
- respect of anonymity is recognised, when requested;
- the resources collected through donations are to be finalised in an effective, efficient and fair manner for the scope for which the donation is made;

- any proposal of a potential alteration of the original conditions of the donation are to be explicitly communicated to the donor;
- the donative action must be acknowledged and gratified by the FRs.

Furthermore, in the context of the conflict of interest, the FRs refuse and do not make promises and/or undue offers of money, other benefits or undue benefits (unless these are of modest value and unrelated to requests of any kind) concerning in particular relations with institutions and the PA.

3.2 CONDUCT CRITERIA IN THE RELATIONSHIPS WITH THE OTHER STAKEHOLDERS

3.2.1 GENERAL APPROACH WITH THE STAKEHOLDERS

The main interlocutor of Telethon is the community: only the utility produced towards the community legitimises the existence of a non-profit organisation.

It is possible to identify more specific groups within the community based on the relationship they have towards Telethon:

- the contributors, namely all those who participate in the "fight against genetic diseases" by offering an economic or logistical support. This category includes donors, fund-raising partners and volunteers - supporters;
- those operating within the Telethon structure guaranteeing professionalism and mission sharing: the administrators, managers, employees and collaborators working within the structure;
- the beneficiaries, namely the main recipients of the utility produced. The direct beneficiaries of Telethon are those suffering from muscular dystrophy and other genetic diseases, their families and, secondly, the associations for the disease and the entire community (including future generations). Added to these are the funded researchers that are considered as indirect beneficiaries because they are entrusted with the funds collected by Telethon to "bring research forward towards the cure".

To each of the interlocutors contributing to the creation of value and social quality - Telethon distributes its Mission Report, or an extract, every year so that all those involved can develop their overall opinion on the effectiveness and efficiency of the management.

It also communicates the research activities' results through Telethon Notizie (house-organ), the website, the audio-video media.

Telethon considers this involvement as a fundamental requirement for transparency and informational responsibility.

Furthermore, Telethon guarantees its own and others' integrity in the use and management of information in compliance with individual and corporate dignity. Personal or business data relating to donations, personal identity and other information are deemed as confidential, unless the people or organisations do not agree to their processing.

The institution ensures the adoption of security measures, even preventive measures, suitable to avoid situations of risk, compliance or alteration of the data and measures necessary to facilitate the involved party in exercising their rights.

3.2.2 RELATIONSHIPS WITH THE PATIENTS, RESEARCHERS AND DONORS

With the financing activity for scientific research, Telethon produces a service of social utility addressed to the "community". Telethon identifies three categories within the community that are strategically important for their activities: patients, researchers and donors.

The activity of funding scientific research on genetic diseases is, indeed, characterised by specific criteria of competence and merit in the allocation of resources that outline a real "moral contract" towards patients, researchers and donors. **With respect to the sick people**, Telethon is committed to funding the most promising research for the cure always abiding by the rules of science that impose quality, rigour, patience and a constant international comparison, avoiding promises for immediate miraculous solutions.

With respect to the researchers, Telethon is committed to meeting the requirements of maximum independence of judgement and maximum technical expertise for the evaluation activity. For this scope, Telethon, to rigorously evaluate the research projects makes avail of "...the binding opinion of the Scientific Medical Commission" and the "Peer review" system as described in the "Programming, Initial Evaluation and Selection, Activation, Monitoring and Final evaluation of research projects" procedure (P 6) subject to ISO 9001: 2000 Quality Certification.

With respect to the donors, Telethon is committed to satisfying their need for a scientific progress through a rigorous and efficient use of funds collected and through the selection of the most capable researchers and that offer greater guarantees of results.

Moreover, to develop the relationship with researchers, donors and patients, Telethon directs some activities to the development of tools and methods able to develop and allow a constructive dialogue that identifies and meets their expectations, making avail of evaluation questionnaires, individual interviews, focus groups, market surveys and institutional engagements to analyse and evaluate their satisfaction with respect to the overall rating of the social utility service (cure progress), to the visibility and transparency of the funds collected and, in general, to the procedures and communication tools dedicated to them.

3.2.3 RELATIONS WITH THE TELETHON FUNDS COLLECTION PARTNERS

Fund-raising partners have a key role in supporting Telethon's scientific research. These are foundations, institutions and voluntary associations that mobilise their structures or members for fund-raising operations aimed at their customers, employees, suppliers or stakeholders.

In particular, for each organisation collaborating in a fund-raising, Telethon asks to:

- Direct its activity in favour of Telethon, in compliance with Your mission, and in particular for the point stating: "We want the Italians to participate in the fight against genetic diseases" in the perspective of a continuous and long-lasting collaboration;
- Inform and make the donor aware of Telethon, promoting a real spirit of solidarity and acknowledges, within the correctness and transparency of this relationship, the principles around which to build and empower the sense of their commitment towards Telethon;
- Involve one's own staff so they actively participate in raising funds for Telethon. For this purpose, and compatibly with its internal organisation, it performs an informational and motivational role for its resources on the Telethon mission and on the fund-raising activity that is carried out;
- Communicating outside (also through the media) defining the themes of the collaboration with Telethon. The communication activity must be carried out in a clear, complete and transparent way; aimed exclusively at informing, raising awareness and involving the recipients in the topics of the collection, destination and use of the funds and is not inspired by sponsorship relationships or the mere exploitation of Telethon's reputation and image.

3.2.4 8 – RELATIONSHIPS WITH SUPPLIERS

Telethon, in consideration of its social scope and the economy constraints as a non-profit organisation, is engaged in the economic management of its fund-raising activities and of research support.

Relationships with suppliers are managed only by the Purchasing Department that obtains advantageous contractual conditions by centralising the purchases relative to the research projects financed by Telethon and the support activities.

The Purchasing department takes care of procurements according to the "Procurement" procedure (P5) - subject to ISO 9001: 2000 Quality Certification and guarantees transparency with respect to suppliers, ensures the selection of the most advantageous choices (request for estimates and expressions of interest), monitors the quality of the products that are supplied and avoids the occurrence of any conflict of interest.

In order to implement the procurement process at best, Telethon maintains and updates its Register of Qualified Suppliers. All supplier selection and evaluation activities are described in the "Qualification and Monitoring of Suppliers" procedure (P4) - subject to ISO 9001: 2008 Quality Certification.

Telethon appreciates, as offers in reply to the expressions of interest, free or absolutely favourable supplies necessary for the management and operation of its facilities, without prejudice to any commitment and responsibility of the supplier regarding the technical quality of the products or services provided and any other warranty obligation.

In respect of transparency and business ethics, Telethon considers, for the scope of assigning an expression of interest, contextual donations in cash or nature if these are made, during the tender procedure stage, as alternatives to discount percentages.

When the required services show a high degree of parcelling out of the suppliers, as in the case of external planning and post-production of the Television Marathon, Telethon undertakes to guarantee the control over the suppliers' actual technical references.

Lastly, Telethon undertakes to maintain maximum punctuality in the payments of the services provided by the suppliers.

Telethon, always within parental control, undertakes to avoid selecting suppliers that are related or have affinity with:

- the Telethon Board of Directors; the control bodies, the senior management and its first line managers;
- the top figures employed in public administrations (also the so-called "semi-state bodies", public shareholdings and so on).

3.2.5 RELATIONSHIPS WITH PUBLIC INSTITUTIONS

Relationships with Institutions and Public Administration offices are inspired by the principles of correctness, impartiality and independence and are reserved to the competent corporate offices.

In particular, the natural persons that, within the corporate sphere, have any type of relationships with the Public Administration, and external collaborators, partners and any other external entity must operate abiding by the indications included in the Organisational Model 231 adopted by Telethon.

The Code recipients are forbidden to take the following actions:

- examine or propose employment opportunities that could benefit Public Administration employees personally or provide usefulness to them in any way;
- offer, or provide, accept or encourage gifts and favours that are not based on transparency, correctness and loyalty;
- promise or offer money or utility of various kinds to Public Officials or Public Administration employees as a compensation for acts of their office to promote and favour the interests of the institution or their own, or obtain the execution of acts contrary to their office's duties;

- soliciting or obtaining confidential information that could compromise the integrity or reputation of both parties or that, in any case, violates an equal treatment and public evidence procedures set up by the PA.

In general, the statements made to the Institutions and to the Public Administration must include only truthful elements, they must be complete and based on valid documents to guarantee the correct evaluation by the Institution and by the Public Administration involved.

Relations with public institutions are also regulated by the parental control criteria provided for the Telethon staff and suppliers.

In case the PA intends supporting the funding of scientific research with its own liberal donation, Telethon engages to carry out a clear, complete and transparent activity of communication. This communication is aimed exclusively at informing and raising awareness for the recipients on issues concerning the fund-raising, destination and use and is not inspired by sponsorship relationships or the mere exploitation of one's reputation and image.

4. Staff communication and training

Specific communication activities are planned to promote the knowledge of the Code of Ethics and of the Organisational and Control Model by all internal and external stakeholders that are activated upon the initial issuing of the code and upon all subsequent revisions.

To facilitate a correct understanding of the Code of Ethics and of the Organisational and Control Model by the staff, the Human Resources department carries out a training plan aimed at promoting the knowledge of the ethical principles and rules of conduct.

The training interventions are differentiated according to the role and responsibilities; the newly-recruited employees follow a specific training program that illustrates in detail the contents of the code and of the organisational and control model they are requested to comply with.

All the staff receives a copy of this code of ethics. Like what takes place with the communication, the entire corporate population undergoes training again when important revisions of the code of ethics and of the regulatory system connected to it take place.