AISM and FISM CODE OF ETHICS

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INTRODUCTION

Associazione Italiana Sclerosi Multipla and Fondazione Italiana Sclerosi Multipla are non-profit organisations (Onlus) which form a single structure, as also recognised by the legislation governing the sector, engaged in fighting multiple sclerosis on all fronts. The Association, in over 40 years of activity, and the Foundation, in over 10, moving from the principles and values laid out in their respective Charters and Articles of Association, have progressively issued and updated rules, directives, policies, programmatic guidelines; they have drawn up best practices and work methodologies; and have matured styles, reference systems, distinctive elements, which today are part not only of the assets of the non-profit organisation universe, but also of all the group of individuals that interact and work with AISM-FISM on a daily basis.

AISM and FISM, moving from their history, and true to the mission undertaken, have decided to adopt this **Code of ethics**, which encompasses the principles, values, and commitments that characterise them as a whole, with the aim of:

Making explicit their guiding values, and in doing so, make then permanent and strengthen them;

• Preserving the ethical dimension and the association culture, fostering awareness also among people who come into contact with AISM-FISM for the first time;

• Anchoring the systems for the prevention of damaging behaviours for AISM and FISM and/or for individuals, and risk management systems, to general and universally acknowledged principles, and assure the certainty, and uniform and widespread application, of the rules of conduct and behaviour, from the general level to the actions of each individual;

• Offering a guarantee to all stakeholders of the commitment, seriousness, transparency, independence, and ability to act of AISM and FISM, applying logics of efficiency and economy to the sound and firm core of solidarity and volunteer work;

• Enhancing the ability to "establish a connection" with individuals affected by multiple sclerosis and their relatives.

This **Code** is constantly evolving and updated, so as to guarantee its full adherence to real-life and to the tangible expressions of the activities of AISM and FISM, and of Individuals, according to same methodology based on internal discussion, debate, and sharing, used for its adoption.

PRINCIPLES AND FIELD OF APPLICATION

The actions of AISM and FISM are guided, from the national to the local level, from the decisions of their internal bodies to the conduct of each individual, whatever his or her relation with AISM-FISM, and regardless of the interlocutor at that specific time represents a stakeholder, whatever the field of activity, by the following fundamental principles:

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a. Respect of the laws, rules, regulations, measures, relevant disciplines for all the fields and types of activity in which AISM-FISM are active; respect of the AISM-FISM Articles of Association, of the AISM Regulation, and of all the policies, guidelines, and directives adopted by AISM-FISM in their various fields of activity;

b. Respect of the dignity and centrality of the Individual; promotion and support of the independence, abilities, participation and social inclusion of the Individual affected by multiple sclerosis, supporting the fullest expression of individual personality, both within the Association-Foundation and in civil society, safeguarding privacy and the protection of the private sphere;

c. Rejection and active fight against any form of discrimination based on biomedical, anthropological, cultural, economic, and religious criteria, genre, sexual preferences, political views, individual or social conditions with particular reference to the condition of Individuals with disabilities and their relatives, to patients, operators, and in general to stakeholders;

d. Permanent and active attention and listening to the needs and expectations of Individuals affected by multiple sclerosis and their relatives, volunteers, partners, supporters, and, for their respective their level of involvement, of other stakeholders;

e. Commitment to act, and to address the resources of AISM-FISM, exclusively in pursuit of the institutional ends; effectiveness and efficiency of activities and actions, guaranteeing careful and cautious use of resources to pursue objectives, devoting appropriate attention to the organisational dimension as a condition to maximise results;

f. Seriousness in taking on and respecting commitments, and in communicating the results effectively achieved, fostering communication and the sharing of experiences with other Organisations active in similar fields, assuring clear, timely, exhaustive, accessible, accurate information on the activity of AISM-FISM and on the topics of interest;

g. Autonomy and independence of AISM-FISM from influences and conditioning exercised, or in any case deriving from, institutions, bodies, parties, trade unions, interest groups, organisations, public and/or private entities of any nature;

h. Fostering and tangible expression of a culture, of styles, processes, internal dynamics, founded on equality, active participation, on the centrality of the citizen, involvement and sharing, on bottom-up models of representation that guarantee real democracy based on conditions of impartiality, fairness, parity of access;

i. Protection and fostering of health, well-being, quality of life not only as an individual asset, but as a key factor of progress and development for the Community at large;

j. Integrity and honesty in any circumstance of relevance for AISM-FISM; lack of undue personal interests, own or of others, in any activity lent internally to and/or on behalf of AISM-FISM, and towards the latter; prohibition to draw profit or benefits for oneself or others, whether of a private nature or tied to positions or situations of public relevance – or to operate towards this end – from the position, office, responsibility, role held in AISM-FISM;

k. Sense of responsibility in any activity undertaken within and/or on behalf of AISM in terms of the level of diligence, adequacy, skill, professional competence required by the type of role, position, office, assignment, relation held in AISM-FISM;

l. Solidarity among Individuals who are part of AISM-FISM, between AISM-FISM and the Individuals and bodies belonging to them, between AISM and FISM themselves;

m. Integrated work and approach geared to networking at internal level as well as with Institutions and other Organisations of the Third Sector, at the local, national, and supranational levels, based on criteria of loyal and open collaboration and respect of its autonomy and specificity;

n. Dynamicity and innovation interpreted as attention to ongoing improvement, to an evolution capable of preserving past paths, experiences, results, to the turnover of Individuals and activities while safeguarding the value of AISM-FISM's history and roots, to the widespread contribution made to the contexts and networks in which AISM-FISM operate;

o. Training as a permanent dimension of AISM-FISM; quality in processes, Individuals, activities, assuring transparency, traceability, documentation of actions; attention in the selection of partners, in the selection and management of suppliers, in the search for and sharing of best practices;

p. Monitoring, control and dynamic and permanent assessment of all processes and activities.

ENACTMENT TOOLS AND SYSTEM OF GUARANTEES

As well as programmatic, this **Code** is also regulatory in nature, to the extent to which it implies the commitment of AISM-FISM to guarantee the actual implementation, in the broadest and most systematic manner, of the principles it lays out.

Therefore, the **Code** requires and binds AISM-FISM to:

Review, in its light, systematically and with due timeliness, internal rules, policies, orientations, guidelines, processes, procedures, practices, methodologies, work styles, communication criteria and approaches, training, information, so as to make every moment in the life and expression of AISM-FISM a tangible opportunity to put in practice its values and ethical dimension;
Introduce appropriate systems and instruments to prevent and manage the risk of deviation in the conduct and behaviours of

individuals and/or bodies, to prevent access to offices, assignments, roles, positions, marred by the presence of undue interests and/or personal situations that are in contrast with the ends, interests, and ethical dimension of AISM-FISM, to prevent illicit behaviours, albeit held with the intention, malicious or not, to benefit and favour AISM-FISM;

• Build, maintain, develop, implement, systems to control and verify the effective level of conformity of the actions of AISM-FISM with the principles laid out in this Code, according to criteria of continuity, accuracy, pertinence, trustworthiness of the information gathered and processed, and of the relevant supporting information flows;

• Structure guarantee and protection systems and models, that provide for the attribution of supervisory and sanctioning powers

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to bodies that are truly autonomous, assuring adequate connection and coherence with the governance model adopted by AISM-FISM and the statutory mechanisms in place, so as to prevent, and in any case contain and reprimand, any detected instances and situations of deviation.

This Code, of general validity, will see the addition, as an integration to it – based on the same shared methodology – of derived ethics or values charters referred to single categories of stakeholders and/or fields of activity, or environments of operation. These charters will act as integrations and as an application of this **Code**, and in no case will they introduce exceptions or limitations to the principles represented in it.

REFERENCES

This **Code** integrates with the body of documents and references which regulate the life of AISM and FISM, and although not provided for here, should be read, interpreted, and applied in light of such documents and references for the pertinent criteria and fields, with particular reference to:

Main INTERNAL References	Fields and contexts of application
AISM Articles of Association	Listing of the institutional ends of AISM, the nature and character of the organisation, its guiding principles, the structure and role of its internal bodies.
AISM Regulation	Regulates the functioning of the Association at all its levels, with regards to both its bodies and individuals.
FISM Articles of Association	Listing of the institutional ends of FISM, the nature and character of the organisation, its guiding principles, the structure and role of its internal bodies.
AISM and FISM Governance Model	Defines the running and management systems and mechanisms of AISM and FISM, the connection among bodies, control of the organisational dimension, the central and integrated management of the group.
AISM National Governing Board Implementing Regulations	Listing of specific aspects of the functioning and operations of the organisation in terms of their interpretation and implementation, in respect of the AISM Articles of Association and Regulations.
FISM Board of Directors Implementing Regulations	Listing of specific aspects of the functioning and operations of the organisation in terms of their interpretation and implementation, in respect of the FISM Articles of Association.
Rules for access to AISM offices	Listing of the criteria and modalities of access to AISM and FISM offices by AISM appointment, outlining the tangible application of the guiding principles of the Association for each specific office.
AISM-FISM Policies and Guidelines	Provide AISM-FISM strategic guidance on issues of special sensitivity and interest for the bodies and the stakeholders.
Recommendations	Express orientations of strong morale suasion, albeit not of a binding nature.
AISM NGB and FISM BoD Directives and Resolutions	Measures regulating general or specific situations and aspects of the Organisation's life.
AISM and FISM Charters of Services	Listing of the characteristics of the services provide by the Organisation and the level of quality and commitment guaranteed, also in respect of any agreements with public bodies, and based on a transparent approach to the recipients of the services.

Main EXTERNAL References	Fields and contexts of application
MSIF International Federation of MS Associations Articles of Association	Regulate the presence and participation of the National Associations in the international network of MS Organisations, encouraging exchange opportunities and projects, and networking.
Guidelines for Relations with Pharmaceuticals Companies Adopted by MSIF	Criteria and guidelines for relations and collaborations with pharmaceutical companies involved with MSIF, and/or with individual member national organisations.
EMSP European MS Associations Platform Articles of Association	Regulate the presence and participation of the National Associations in the international network of MS Organisations, encouraging exchange opportunities and projects, and networking.

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FISH Federazione Italiana Superamento dell'Handicap Articles of Association	Rules for membership and participation in the Federation that brings together the main organisations engaged in overcoming handicaps.
FISH Code of Ethics	Contains principles, values, rules of conduct and behaviours that condition the life and the functioning of the Federation and of its individual members, with particular reference to the fields of disability and relations with the media on issues tied to disability, the fostering of a culture of recognition and affirmation of rights, to relations with reference public institutions, to relations with and among members and external entities.
Third Sector Forum Articles of Association	Rules for membership and participation in the Forum of non-profit organisations at the national level, definition of criteria for the connection of non-profit organisations within the network, and guidelines for relations between the Third Sector and reference institutions and entities.
CNESC Conferenza Nazionale Enti di Servizio Civile Articles of Association	Rules for membership and participation in CNESC of non-profit organisations in the realm of civil service, and criteria for the connection of civil service bodies and the competent institutions.
Civil Service Ethics Charter (adopted by UNSC, Ufficio Nazionale Servizio Civile)	Bind CS bodies and youths to the respect of the primary values of civil service, with particular reference to national defence, peace, and solidarity.
Charter of Volunteering Values (proposed by FIVOL)	Acknowledges and fosters volunteering as a direct and vital expression of the civil society, as an instance of citizen participation in the life of the community, as a factor of pluralism and democracy, a founding element of the culture of solidarity based on the principles of horizontal subsidiarity.
Charter of Representation in the Third Sector (promoted by CSVNET)	Regulates and guides the relations of Third Sector organisations among themselves and with the institutional world.

DIFFUSION AND AWARENESS

In order to ensure adequate and appropriate knowledge of this Code, by level of interest, AISM-FISM undertake to:

Diffuse it through the main institutional channels (website, association reviews, periodicals, other);
Ensure the availability and accessibility of the Code at the headquarters of bodies, both national and local;

• Provide for differentiated and pertinent forms of acknowledgement, sharing, underwriting of the Code depending on the level of participation and belonging of the different categories of individuals to AISM-FISM;

• Monitor the level of actual knowledge application of the principles and rules of conduct laid out in this Code and in the derived Charters.

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