

1. PROFESSIONAL RESPONSIBILITY

Core Principle

We are responsible for adding value to the FMF & AID Global Association and contributing to the ethical success of this non-profit organization. We are advocates for the FMF & AID Global Association by engaging in activities that enhance its credibility and value.

Intent

- To build respect, credibility and strategic importance for the employees/volunteers within our organization, the patients community, and the communities in which we work.
- To assist the FMF & AID Global Association, we serve in achieving its objectives and goals.
- To inform and educate current and future practitioners, the organizations we serve, and the general public about principles and practices that help the employees, volunteers and patients.
- To positively influence workplace and recruitment practices.
- To encourage professional decision-making and responsibility.
- To encourage social responsibility.

Guidelines

1. Adhere to the highest standards of ethical and professional behaviour.
2. Measure the effectiveness of our projects in contributing to or achieving organizational goals.
3. Comply with the law.
4. Work consistent with the values of a non-profit organization.
5. Strive to achieve the highest levels of service, performance and social responsibility.
6. Advocate for the appropriate use and appreciation of human beings as employees.
7. Advocate openly and within the established forums for debate in order to influence decision-making and results.

2. PROFESSIONAL DEVELOPMENT

Core Principle

As a non-profit organization, we must strive to meet the highest standards of competence and commit to strengthen our competencies on a continuous basis.

Intent

- To expand our knowledge of our field of interest to further our understanding of how our organizations function.
- To advance our understanding of how organizations work.

Guidelines

1. Pursue formal academic opportunities.
2. Commit to continuous learning, skills development and application of new knowledge related to both human resource management and the organization we serve.
3. Contribute to the body of knowledge, the evolution of the non-profit organization and the growth of individuals through teaching, research and dissemination of knowledge.

4. Pursue certification where available, or comparable measures of competencies and knowledge.

3. ETHICAL LEADERSHIP

Core Principle

FMF & AID Global Association employees/volunteers are expected to exhibit individual leadership as a role model for maintaining the highest standards of ethical conduct.

Intent

- To set the standard and be an example for others.
- To earn individual respect and increase our credibility with those we serve.

Guidelines

1. Be ethical; act ethically in every professional interaction.
2. Question pending individual and group actions when necessary to ensure that decisions are ethical and are implemented in an ethical manner.
3. Seek expert guidance if ever in doubt about the ethical propriety of a situation.
4. Through teaching and mentoring, champion the development of others as ethical leaders in the non-profit organization.
5. For relations with the pharmaceutical industry, see section 7 Code of Practice on Relationships with the Pharmaceutical Industry

4. FAIRNESS AND JUSTICE

Core Principle

As employees/volunteers, we are ethically responsible for promoting and fostering fairness and justice for all employees and their organizations.

Intent

To create and sustain an environment that encourages all individuals and the organization to reach their fullest potential in a positive and productive manner.

Guidelines

1. Respect the uniqueness and intrinsic worth of every individual.
2. Treat people with dignity, respect and compassion to foster a trusting work environment free of harassment, intimidation, and unlawful discrimination.
3. Ensure that everyone has the opportunity to develop their skills and new competencies.
4. Assure an environment of inclusiveness and a commitment to diversity in the organization we serve.
5. Develop, administer and advocate policies and procedures that foster fair, consistent and equitable treatment for all.
6. Regardless of personal interests, support decisions made by our organization that are both ethical and legal.
7. Act in a responsible manner and practice sound management in the countries in which the associations we serve operate.

5. CONFLICTS OF INTEREST

Core Principle

As employees/volunteers, we must maintain a high level of trust with our stakeholders. We must protect the interests of our stakeholders as well as our professional integrity and should not engage in activities that create actual, apparent, or potential conflicts of interest.

Intent

To avoid activities that are in conflict or may appear to be in conflict with any of the provisions of this Code of Ethical and Professional Standards or with one's responsibilities and duties as a member of the not-for-profit profession and/or as an employee of any organization.

Guidelines

1. Adhere to and advocate the use of published policies on conflicts of interest within our organization.
2. Refrain from using your position for personal, material or financial gain or the appearance of such.
3. Refrain from giving or seeking preferential treatment in the human resources processes.
4. Prioritize your obligations to identify conflicts of interest or the appearance thereof; when conflicts arise, disclose them to relevant stakeholders.

6. USE OF INFORMATION

Core Principle

FMF & AID Global Association employees/volunteers consider and protect the rights of individuals, especially in the acquisition and dissemination of information while ensuring truthful communications and facilitating informed decision-making.

Intent

To build trust among all organization constituents by maximizing the open exchange of information, while eliminating anxieties about inappropriate and/or inaccurate acquisition and sharing of information.

Guidelines

1. Acquire and disseminate information through ethical and responsible means.
2. Ensure only appropriate information is used in decisions affecting the employment relationship.
3. Investigate the accuracy and source of information before allowing it to be used in employment related decisions.
4. Maintain current and accurate HR information.
5. Safeguard restricted or confidential information.
6. Take appropriate steps to ensure the accuracy and completeness of all communicated information about HR policies and practices.
7. Take appropriate steps to ensure the accuracy and completeness of all communicated information used in HR-related training.

7. Code of Practice on Relationships with the Pharmaceutical Industry

The purpose of this code is to ensure ethical, accountable and transparent collaboration between the FMF & AID Global Association, its members and the pharmaceutical industry. The FMF & AID Global Association also suggests to its members and affiliated associations to use this code. The code draws upon the existing *EFPIA (European Federation of Pharmaceutical Industries and Associations) Code of Practice on Relationships between the Pharmaceutical Industry and Patient Organisationsⁱ*, the *World Health Organisation's Guidelines on Interaction with Commercial Enterprises to Achieve Health Outcomes, eB107/20ⁱⁱ* and the *Interaction PVO Standards (pertaining to Pharmaceuticals and Medical Resourcesⁱⁱⁱ*.

The FMF & AID Global Association, its members and pharmaceutical companies share an inspiration in ensuring that their individual integrity is maintained when collaborating. Hence, all types of collaboration between the parties are not only to apply to any given rules and guidelines, but also to 'good corporate governance, including this document that defines agreed best practice for collaboration between the parties.

In developing relationships with pharmaceutical companies to further the mission of the FMF & AID Global Association, consideration should be given as to whether the proposed relationship might involve a real or perceived conflict of interest and the FMF & AID Global Association members' reputation must be ensured.

The FMF & AID Global Association commits itself to adhering to the provisions of this code in all its dealings with the pharmaceutical industry. It also encourages its affiliated associations to commit to adhering to the provisions of this code when dealing with the pharmaceutical industry. The FMF & AID Global Association expects pharmaceutical companies to adhere to the provisions of this code in all its dealings with the FMF & AID Global Association or affiliated associations.

Principles of the Code

- The FMF & AID Global Association shall not promote or show favour to a particular prescription-only or non-prescription medicine
- The pharmaceutical industry shall not request the promotion of a particular prescription-only or non-prescription medication
- All partnerships between the FMF & AID Global Association and the pharmaceutical industry shall be based on mutual respect, with views and decisions of each partner having equal value
- The objectives and scope of any partnership shall be transparent. Financial and nonfinancial support provided by the pharmaceutical industry shall always be clearly acknowledged
- The FMF & AID Global Association welcomes broad funding from multiple sources

Code of Practice

1. Funding Relationships

- 1.1 The FMF & AID Global Association welcomes unrestricted grants from industry and will always report these as part of its usual accounting and transparency policy, including in annual reports and on the website. Such donations will not be accepted as an inducement to influence of change its positions on issues, plans or priorities.

- 1.2 Acknowledgement will be attributed to the funding person or organisation, but not to a specific product or project
- 1.3 The FMF & AID Global Association will disclose the percentage of overall income that each funder (individual person, government organisation, industry, etc..) represents
- 1.4 Funds will not be sought or accepted from pharmaceutical companies that have a direct commercial interest in the outcome of the project toward which they would be contributing.
- 1.5 Wherever possible, the FMF & AID Global Association will seek to have funding from more than one company
- 1.6 Private donations to individual officers or members of the FMF & AID Global Association, whether paid staff or volunteers, are not acceptable.
- 1.7 When the FMF & AID Global Association accepts a donation in support of any specific activity, it retains control of the content at all times. Any ensuing publication will be the property of the FMF & AID Global Association and findings may not be used or quoted by the funder without explicit permission. No information in relation to the project should ever be used to promote the use of any specific product or business of the funder.
- 1.8 The FMF & AID Global Association welcomes invitations to industry events, providing reasonable travel and subsistence costs can be covered and, where appropriate, an honorarium to the FMF & AID Global Association to compensate for time invested by staff or elected representatives.
- 1.9 Other situations where industry may propose honoraria to the FMF & AID Global Association or a member organisation's volunteers or staff include:
 - 1.9.1 Reviewing industry materials, leaflets, protocols, etc.
 - 1.9.2 Consultancy on industry policy, advisory committees etc.
Payments made to officers or members arising from any such activities should be directed to the FMF & AID Global Association rather than to the individual participant or officer of the FMF & AID Global Association personally. This is in line with current practice for health care professionals.
- 1.10 The FMF & AID Global Association may accept funds, sponsorship or assistance in kind for its own specific events. Funding should ideally and, where possible, come from more than one source.

2. Nature and Execution of Collaboration between the FMF & AID Global Association and a pharmaceutical company

Any collaboration between the FMF & AID Global Association and a pharmaceutical company must be structured and delivered to ensure and consolidate the integrity, reputation and continued success of the involved parties, and on adding value to patients. Collaboration between the FMF & AID Global Association and a pharmaceutical company must comply with:

- a. Relevant national laws and regulations
- b. The pharmaceutical company's specific code of practice/internal guidelines

Collaborations should also have specific aims and meet the following basic criteria:

- i. The relationship should contribute to improving the health and quality of life of people living with AID and/or their carers
- ii. Terms of all relationships should be recorded as an exchange of clearly written letters or agreements indicating the contribution (financial or otherwise) and expectations that each of the parties brings to the relationship

3. Promotional Activities

- a. The FMF & AID Global Association will not take part in any promotional activities related to approved prescription medicines, as required by current EU legislation and respective industry codes of ethics. The FMF & AID Global Association will always be mindful of potential conflicts and unintended consequences and ensure it strictly adheres to its own independent, patient-centred agenda.
- b. Types of activities that could be considered promotional and therefore might cause a conflict of interest and/or be against the law, include the following:
 - i. Disseminating unbalanced, non-validated or partial information about a product/service which is produced, marketed or provided by a company, whether or not it funds the FMF & AID Global Association
 - ii. Being quoted in the company's corporate communications in favour of, or against a product/service
 - iii. Participating as a speaker/participant in a company event for the launch of a pharmaceutical product/service
 - iv. Participating in an ad hoc meeting sponsored by a single company to inform patients on their products
 - v. Agreeing that a company displays/disseminates the FMF & AID Global Association's own materials on the company's exhibition stand at any commercial or trade exhibition or scientific conference
 - vi. Appearing in promotional materials for a certain product/service of the company or to testify as a 'consumer' of that medicine.
- c. The FMF & AID Global Association will refrain from contributing to industry websites.
- d. The FMF & AID Global Association will refuse to be quoted in industry press releases that relate to a marketed product or a product under development

- e. If the FMF & AID Global Association feels the need to communicate to the media about a product/service, it will issue its own press release which is clearly independent of industry
- f. Commercial organisations wishing to publicly mention the FMF & AID Global Association's name should seek prior written authorisation from the latter.
- g. If a company quotes the FMF & AID Global Association's opinion or refers to its own communication materials without its written permission, the FMF & AID Global Association will object to the company by registered letter with a copy to the company's national industry association.

4. Disease Awareness Campaigns

a. Disease awareness campaigns by Industry

Disease awareness campaigns can be considered as an indirect form of advertising in some EU countries and therefore against the legislation. The FMF & AID Global Association will always ensure that such campaigns respond to a well characterised public health need, that is agreed and supported by the national and/or European public health authorities.

b. Disease awareness campaigns by the FMF & AID Global Association

If conducting its own disease awareness campaign, the FMF & AID Global Association will ensure that any information regarding a commercial product must be based on the Summary or Product Characteristics (SmPC) or another commercially independent and validated source. The FMF & AID Global Association will also observe the following conditions:

- i. Provide a clear statement of how the information was arrived at
- ii. Mention the validated source of information
- iii. Mention health professional/independent experts who have been consulted
- iv. Identify the Editorial Board who has control, responsibility and oversight
- v. Ensure there is a Transparency Policy in place, disclosing funders

This Code of Practice has been adopted by the FMF & AID Global Association and will govern its relationship as a separate body with commercial organisations in the field of autoinflammatory diseases. The FMF & AID Global Association will encourage its affiliated member associations to adhere to the provisions of the Code of Practice and express itself to be bound by its terms and express the expectation that commercial organisations will adhere to the principles herein contained in all its dealings with national patient and research organisations.

Date: January 2nd, 2017

References:

ⁱ EFPIA code of practice on relationships between the pharmaceutical industry and patient organisations (5/10/2007)

ⁱⁱ World Health Organisation (EB107/20, November 2000). Guidelines on interaction with commercial enterprises to achieve health outcomes

ⁱⁱⁱ Interaction PVO Standards (November 2009)