



European Federation of Allergy and Airways  
Diseases Patients' Associations

## **Code of Ethics and Conduct**

*Draft*

Updated from [the original](#) from 2008

## Preface

In recent years, there has been a significant increase in the importance of, and the need for, greater transparency of governmental institutions and non-governmental organisations in order to ensure ethical impact on policies. At the same time, there has been an increased recognition of the need and the demand of patients' perspective and participation.

The European Federation of Allergy and Airways Diseases Patients' Associations (EFA) is an independent, non-profit organisation with its central office located in Brussels, Belgium. Founded in 1991 in Stockholm, Sweden, EFA is a growing European alliance of over 30 allergy, asthma and chronic obstructive pulmonary disease (COPD) patients' associations representing 30% of European citizens currently living with these diseases.

Our vision is for all people with allergy, asthma and COPD in Europe to live uncompromised lives, have the right and access to best quality care, participate in their care and have a safe environment. Our mission is to be the voice of allergy, asthma and COPD patients at European level and to be actively involved in the decisions impacting their health.

In doing that, EFA ensures that its conduct adheres to the highest standards of probity, due diligence, and transparency in its decisions and operations, and that it is the representative, democratic and accountable voice for people with allergy, asthma and COPD at the European level. EFA has the responsibility to be honest, accountable and ethical, to give out accurate information and not to manipulate situations for the benefit of the Board and its staff. It has a duty to go beyond the boundaries of race, religion, ethnicity, culture, politics, disease and disability. EFA has the obligation to respect each person's rights and does not align itself with, or stand in opposition to, any particular political or health organisation, nor will it become controlled by a governmental or corporate body.

**EFA Code of Ethics and Conduct** is a set of fundamental principles and standards that guide the actions and management of the organisation as above. These standards are based on the following selected references:

- [Belgian Law 10 May 2007 against discrimination](#);
- [Treaties on the European Union](#) (articles 2 and 3) and [on the Functioning of the European Union](#) (articles 10, 18, 19 and 157);
- [Charter of Fundamental Rights of the European Union](#) (article 21);
- [European Union Code of Conduct in Annex 3 of the 2014 Interinstitutional Agreement on the Transparency Register](#);
- [Revised framework for interaction between the European Medicines Agency and patients and consumers and their organisations](#);
- [European Patients' Forum \(EPF\) Code of Conduct](#);
- [European Federation of Pharmaceutical Industries and Associations \(EFPIA\) Code of Practice on Relationships between the Pharmaceutical Industry and Patient Organisations](#);
- [World Association of Non-governmental Organisations Codes of Ethics](#);
- [International Alliance of Patients' Organisations \(IAPO\) Consensus Framework for Ethical Collaboration between Patients' Organisations, Healthcare Professionals and the Pharmaceutical Industry](#).

## Central Values and Guiding Principles

EFA is a non-profit, non-governmental, independent, self-governing and voluntary organisation, its governance and actions are guided by the following **central values**:

**Patient Perspective**

**Involvement**

**Sharing Knowledge and Experience**

**Partnership and Cooperation**

**Visibility and Presence**

**Health Equity in Europe**

EFA operates under fundamental principles of ethics and code of conduct.

### **Non-discrimination**

EFA combats all discrimination, and especially that on the grounds of illness, and address health inequalities from patients' perspective. EFA respects the rights and the integrity of all patients with asthma, allergy, including eczema, and COPD, of their families and carers.

### **Patient-centred**

EFA respects the individual right to full participation in society, the right of the individuals to make decisions affecting their health, and the right for patients' participation. EFA ensures equal participation of its members and supports special needs of patients with allergy, asthma and COPD. EFA events are inclusive, smoke-free and fragrance-free and take into consideration dietary needs of participants.

### **Cooperation beyond boundaries**

EFA is willing to work beyond the boundaries of politics, religion, culture, race and ethnicity, and maintains ethical, cooperative relationships with other similar organisations and partners that share common values and objectives for improving health in Europe.

EFA recognises that the organisation, the Board and the staff activities and conduct on EFA business impact on the perceptions of other organisations, and that they are corporately responsible for ensuring the public's trust at all times.

### **Transparency and accountability**

EFA strives for openness and honesty, both internally and externally. EFA provides clear and transparent information on governance structures, activities, listing of officers, sponsors, members and partners. EFA conducts all its activities in relation to the European institutions in true transparency. To this end, since 2012, EFA is registered in the EU Transparency Register (Identification Number: 28473847513-94). EFA produces financial statements for public scrutiny and has its financial records reviewed periodically by a qualified, independent, outside examiner who can certify that the organisation is operating legally and according to generally accepted accounting practices within European and national laws.

EFA is accountable for its actions and decisions not only to the patient community it represents, but also to the people it serves: members, partner organisations, staff and the public at large.

### **Independence and autonomy**

EFA governs itself autonomously, in line with the organisation's statutes and according to the governance structure.

EFA is an independent organisation, not controlled by any governmental or intergovernmental body, or by corporate interests. EFA does not align itself or stand in opposition to any particular governmental body, political party or corporate entity. In its relations with

pharmaceutical sponsors EFA applies the European Federation of Pharmaceutical Industries and Associations Code of Practice on Relationships between the Pharmaceutical Industry and Patient Organisations.

### **Truthfulness and legality**

EFA has proper financial and legal procedures and safeguards in place, it meets legal obligations. EFA does not engage in any unlawful activities, and is strongly opposed to corruption, bribery and other financial improprieties or illegalities.

EFA actively encourages its membership, partners and employees to confidentially bring evidence of any misconduct associated with the organisation to the Board. EFA will take prompt action if wrongdoing is discovered amongst its staff, Board, members, contractors, and partners.

### **Non-profit**

EFA is a non-profit organisation. Any surplus that is generated through its operations is solely utilised for the purpose of enabling the organisation to fulfil its mission and objectives. No part of its earnings is used for the benefit of Board members, member organisations, or employees, or any other private person. EFA, however, provides reasonable compensation for services provided to the organisation by non-volunteers, as appropriate, and information on any compensation can be disclosed at all times. EFA Board prevents the distribution of profits for the benefit of individuals.

### **Organised**

EFA is a registered legal entity and is recognised by any government within the EU. EFA statutes clearly define the mission, objectives, governance structure, membership rights and obligations, rules and procedures.

Democratically elected Board members determine the organisation's activities and monitor compliance with the mission. The Board exercises responsibility for appropriately securing adequate human and financial resources for the organisation, and is responsible for overseeing fiduciary and legal requirements.

### **Integrity of volunteers and staff members**

Board members serve in a voluntary capacity, and receive no remuneration although their travel, accommodation and out of pocket costs while on EFA business are covered by EFA. Volunteers are treated with respect and integrity.

EFA seeks suitably qualified staff members and offers them training and supervision, treat them fairly and with equity, providing them with opportunities for growth and development.

EFA employees and volunteers maintain the highest standards of professional conduct, use information and resources responsibly, and avoid conflicts of interest.

### **Ethical fundraising**

EFA only accepts funding for activities that are related to its mission and stated objectives excluding any resources provided by natural persons or legal entities that are in the service of or associated with the tobacco industry, its liaison groups or affiliated companies. EFA ensures that all forms of funding are open and transparent, guaranteeing accountability to its sponsors and partners. EFA has a Framework for Sustainable Corporate Partnership to ensure its integrity when receiving funding from corporate sources.

### **Inclusive mission**

EFA's mission, as approved by EFA's highest governing body, the General Meeting, is the frame of reference for all its activities and organisational planning. Each Board member fully understands and supports EFA mission and objectives. The mission is made publicly available and accessible to all Board members, staff, member organisations, sponsors, partners, beneficiaries, and the public in general.

EFA evaluates its mission every five years, to ensure its continued relevancy. Among the issues evaluated will be: whether the mission has been accomplished, either by EFA or another entity, whether it should be changed to reflect societal changes in health, and whether there is a desire for EFA to address new needs that require amendments to/or a new mission statement.

### **Coherent and consultative activities**

All activities are consistent with EFA mission. Objectives and work programmes ensure that EFA works efficiently and effectively toward achieving its mission. EFA regularly seeks feedback on its activities from stakeholders, members and from the beneficiaries of its activities.

EFA's activities are periodically examined to determine their relevance to its mission, their efficiency and effectiveness. Among the issues evaluated will be: whether the activities need to be revised in light of changes to the mission, the outcomes and impact of activities, including a cost-benefit analysis to ensure that the cost of work is directly related to its impact/outcome. Evaluations are open and honest and include input from stakeholders.

EFA carries out its activities with a high degree of professionalism with the central value of serving patients being paramount.

### **Related Publications and Selected References**

- EFA Statutes: <http://www.efanet.org/images/2012/06/EFA-Statutes-2003.pdf>
- EFA Internal Rules: <http://www.efanet.org/images/documents/EFAInternalRules.doc>
- EFA Mission and Objectives and Central Values: <http://www.efanet.org/who-we-are/mission-and-vision>
- EFA Framework for Sustainable Corporate Partnership: [http://www.efanet.org/images/documents/EFA\\_Sustainable\\_Corporate\\_Partnership\\_Framework\\_2016.pdf](http://www.efanet.org/images/documents/EFA_Sustainable_Corporate_Partnership_Framework_2016.pdf)