

# The European Federation of Allergy and Airways Diseases Patients' Associations

**INFORM**

**PREVENT**

**CARE**

**INVOLVE**

# Who is EFA?

**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. EFA is a European alliance of 35 allergy, asthma and chronic obstructive pulmonary disease (COPD) patients' associations representing 30% of European citizens currently living with these diseases.

EFA is member of various organisations, including European Patients' Forum (EPF), Health and Environment Alliance (HEAL), European Network for Tobacco Control & Smoking Prevention (ENSP), Global Allergy and Asthma Patient's Platform (GAAP) or WHO Global Alliance Against Respiratory Diseases (GARD), and partners with healthcare professionals and other health non-profit organisations.

EFA operates with funding from membership fees, public EU funding, private unrestricted core-funding and project funding from corporate sources.



# EFA's vision and mission

Our vision is that European patients with allergy, asthma and chronic obstructive pulmonary disease (COPD) live uncompromised lives, have the right and access to the best quality care and 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 by:

1. Advocating at EU and regional levels for the needs of people with allergy, asthma and COPD
2. Enabling a powerful European network of patients' organisations
3. Valuing all members equally
4. Sharing knowledge and implementing best practices
5. Creating patient driven projects
6. Cooperating with health care professionals, scientists and other stakeholders/NGOs



# EFA Membership

Founded in 1991 in Stockholm, Sweden, EFA currently has over 30 members in 23 European countries

EFA holds an Annual General Meeting, regular Board Meetings, working groups, events and trainings throughout the year. These meetings are a basis for ensuring the fulfillment of member expectations in EFA's advocacy and own projects, their participation in EFA's EU projects and the dialogue between members to present best practices and experiences.

EFA membership provides a louder voice for national members when approaching local policymakers, enables their representation in EU policies and offers a springboard for networking with other patients associations in Europe.

## EFA's core values



# EFA's disease areas

Allergy, asthma and chronic obstructive pulmonary disease (COPD), EFA's disease areas, are among the most common chronic diseases in Europe.

**Allergy** knows no boundaries and affects people of all age groups. It is estimated that 1 in every 2 Europeans will suffer from an allergy by 2015. Allergy is the response of the body's immune system to generally harmless substances such as pollens, foods or house dust mites. Whilst for most people these pose no problem, in allergic individuals their immune system identifies them as a "threat" and produces an inappropriate response, including life-threatening anaphylaxis.

"Allergy is far more than huffing and sneezing for a couple of weeks during the pollen season. The quality of life of patients suffering from allergy is often severely impaired as is their social life, their career and even their school performance."  
(Breda Flood, EFA President from Ireland)

"Try putting a straw in your mouth and breathe through it – that's what asthma is like."  
(Patient from Sweden)

**Asthma** is the most common chronic disease in childhood. In Europe, almost 30 million of children and adults under 45 years old have asthma, with six million of them having severe symptoms. Approximately, one third of the population will develop asthma at some time, mostly before the age of 20. Asthma causes inflammation of the airways which results in breathlessness and wheezing. The severity and frequency of these symptoms vary from person to person.

## Chronic obstructive pulmonary disease (COPD)

is a progressive disease that affects 4 to 10% of all adults in Europe and, according to the World Health Organisation, will become the third leading cause of death by 2030. However, COPD is greatly unknown which puts early diagnosis, key for successful management of COPD, at risk. COPD causes inflammation in the lungs, damages lung tissue and narrows the airways. Breathing becomes progressively worse.

"It's frustrating – you don't look sick: I can get up and put make-up on, but I can't walk 10 yards without being out of breath. I'm not an old woman – no one expects you to be the way you are." (Patient from Ireland)

# EFA's work

As a European patient-led advocacy and action organisation, EFA strives to involve patients with asthma, allergy and COPD in European decisions that influence their health. Through our members, we advocate and try to ensure that the right of people with asthma, allergy and COPD to best quality of care and to live uncompromised lives is guaranteed by EU decision-makers.

## How?

- ◆ EFA fosters dialogue, exchange and collaboration among its network of national patients' associations to help people with allergy, asthma and COPD understand, be informed about and continuously take part in the EU legislative process through news, briefings, educational tools, position papers, responses to consultations or advocacy materials.
- ◆ EFA represents patients with allergy, asthma and COPD at high-level fora, such as the European Medicines Agency Patients' and Consumers' Working Party.
- ◆ EFA regularly organises high level events providing opportunities for stakeholders to come together with a patient-centered agenda on issues under discussion, raising awareness and giving visibility to topics that are crucial for people with allergy, asthma and COPD.
- ◆ EFA develops and promotes long term partnership with health professionals and scientists, industry and third sector organisations active in health, consumption and environment matters to ensure a holistic approach to policy changes affecting patients' health.

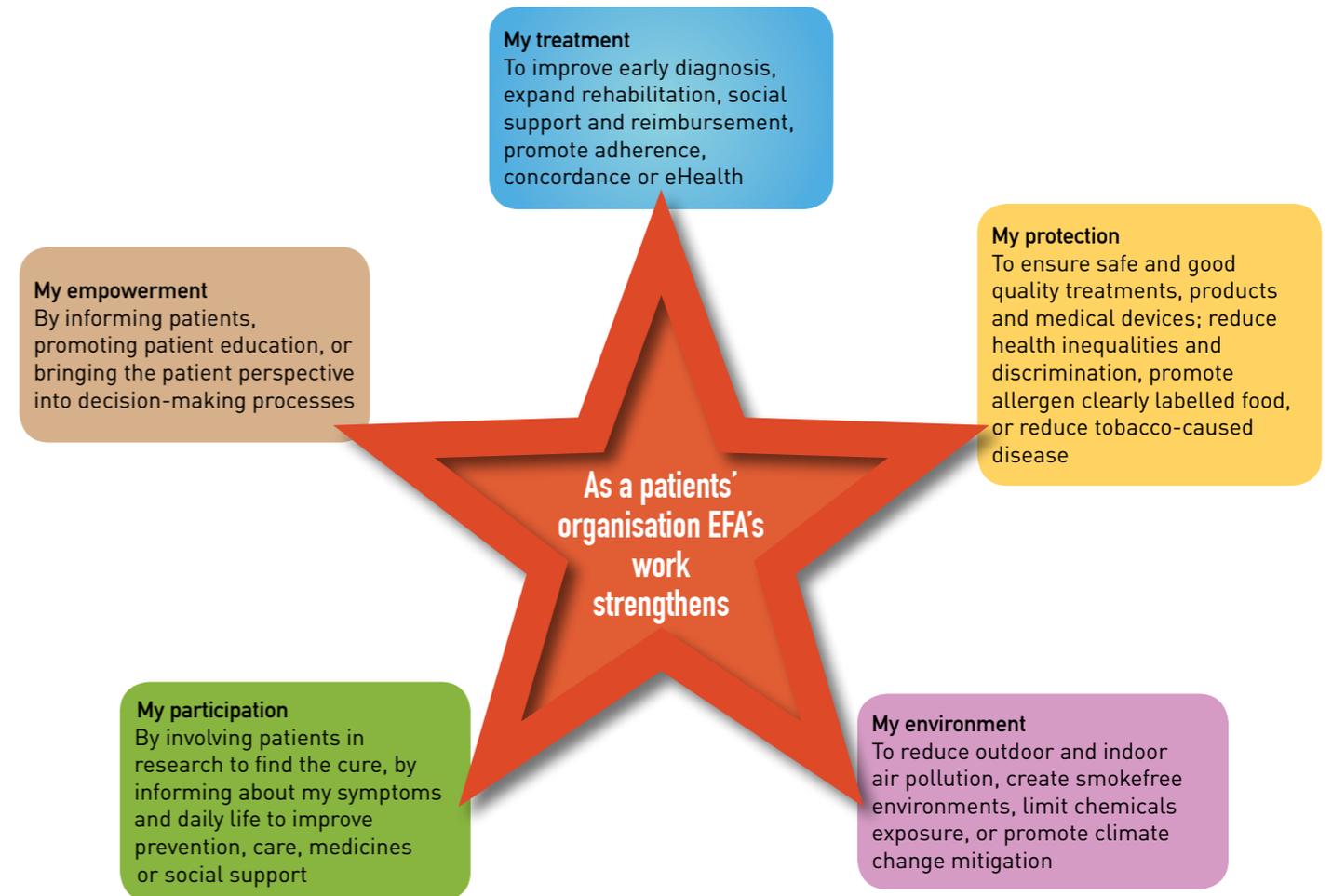
Ahead of the European Parliament elections in 2014, EFA launched a Manifesto to place the concerns from European patients with allergy, asthma and COPD in Europe in the new political agenda.



## What?

EFA's advocacy aims at both preventing the onset of asthma, allergy and COPD, acting on health determinants (such as improving air quality, tackling tobacco and exposure to second-hand smoke, reducing the use of hazardous chemicals) and at improving the quality of life of those patients already affected by these diseases (by promoting equal access to good care for everyone and safe environments, reducing health inequalities within and between Member States and fostering patient-centred research in our disease areas).

Throughout the year, EFA hosts training activities which are designed to assist members in understanding the functioning of the European Union and European Medicines Agency (EMA). EFA's Meet & Greet the EU Institutions Training provides opportunities for EFA members to meet policymakers and learn about how the EU institutions function. EFA's EMA Training Workshop empowers members to become involved as patient representatives at the EMA.



# EFA's Project Programme

## EFA's projects: Evidence for policy-making

### Allergy Awareness Project

After identifying low public awareness of allergies as serious chronic diseases, EFA is committed to raise awareness on respiratory allergies, increase the ability to identify early symptoms and to provide early diagnosis. Through this project EFA has published the Book on Respiratory Allergy, a first comprehensive study by patients reporting on diagnosis, quality and accessibility of best practices of care and prevention of respiratory allergy across Europe. The book includes actions to support raising awareness for the respiratory allergy epidemic in Europe.

### COPD Project

EFA works to promote increasing cooperation between primary and secondary care for COPD patients in Europe and the availability of rehabilitation to those patients in need, including smoking cessation services.

To date, EFA has produced the EFA Book on COPD in Europe – Sharing and Caring and EFA Book on Minimum Standards of Care for COPD Patients in Europe, which highlights the common problems confronting COPD patients across Europe and accounts for different approaches taken to address these issues. The project also focuses on oxygen harmonisation, an issue for which EFA has published the Enabling Air Travel with oxygen in Europe – An EFA Handbook for Patients with Chronic Respiratory Diseases, which presents testimonies of patients requiring oxygen therapy who have experienced difficulties when they travel in Europe by airplane.

### Capacity Building Project

The EFA Capacity Building Project aims at placing EFA members in a better position to contribute to EFA project activities and to run projects themselves together with national stakeholders (e.g. national allergy programmes). Building on its experience organizing training events for members in previous years, EFA organises meetings in different EFA countries to ensure their sustainable capacity and growth to represent patients at national level.

## EFA's involvement in EU projects: Patient centered innovation

### U-BIOPRED (2009-2015)

U-BIOPRED (Unbiased BIOmarkers in PREdiction of respiratory disease outcomes) is a research project from the European Commission's Innovative Medicines Initiative to understand more about how severe asthma affects patients, involving scientists from universities, research institutes, the pharmaceutical industry and small companies. EFA participates in U-BIOPRED primarily through dissemination, ethics board and safety monitoring board activities. Another important role has also been to assist coordination of the project's Patient Input Platform, which serves to include patient perspective across work packages of the project.

### MeDALL (2010-2014)

Funded under the European Union's 7th Framework Programme (FP7), MeDALL (Mechanisms of the Development of ALLergy) aims at improving the health of European citizens by investigating the mechanisms causing allergy. Its results will help to improve the quality of life of people with allergy across Europe, permitting earlier diagnosis, targeting different allergy prevention strategies and the development of novel cost-effective treatments for allergic disorders. EFA's primary role in MeDALL is to assist with dissemination activities and provide patients' input for the creation of a customizable template with the aim of establishing national allergy programmes in Europe.

### EARIP (2013-2016)

EARIP (European Asthma Research & Innovation Partnership) aims to promote best practices for asthma through national asthma programmes in Europe, by identifying research gaps and establishing strong stakeholder networks for research and change within healthcare systems. In this project, EFA heads its own work package specifically addressing healthcare systems change through a literature review of published European national asthma programmes to outline how to develop better and more efficient health and care systems that put individual patients at the heart of asthma management/treatment, and achieve much improved outcomes.

### AIRPROM (2011-2016)

AIRPROM (Airways Disease Predicting Outcomes through Patient Specific Computational Modelling) aims to bridge the gaps in the clinical management of airways disease, by customising a lung model for patients that will enable to accurately predict human reaction to medications, in order to permit personalised treatments. EFA's main role is to assist with dissemination activities and provide input from the patient perspective on the exploitation strategy of the consortium as the project approaches its conclusion.

# EFA Patients' Daily Life

"Asthma feels like a huge weight upon my chest. It is a very scary feeling."

Asthma patient, Ireland

"Food labelling is a daily activity to keep our son alive, but when we go overseas things become a lot more difficult, I do wonder why there cannot be a pictorial or icon based system to get over the language barrier."

David, dad of a 10-year old boy with food allergy, United Kingdom

"People with asthma merit significant attention from health services. We live with the heartache of social, health and political isolation."

Jesús Baglietto, asthma patient, Spain

"In order to secure the participation of patients in the decision-making, funding for patients' organisations must be secured."

Ilkka Repo, patient leader, Finland

"COPD makes everyday social life and arranging journeys difficult for me, my family, and others."

COPD patient, France

"I felt that I only really had the choice between giving up smoking and giving up breathing."

Michael Wilken, COPD patient, Germany

[www.efanet.org](http://www.efanet.org)



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35 Rue du Congrès  
1000 Bruxelles, Belgium

Phone +32 (0)2 227 2712 • Fax +32 (0)2 218 3141  
[info@efanet.org](mailto:info@efanet.org)



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