

Manifesto

of the European Allergy Patient



European Federation of
Allergy and Airways Diseases
Patients Associations

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There are a lot of misconceptions on the nature, impact and seriousness of allergic diseases and their care and prevention. For this reason, EFA has drawn up this Manifesto of the European Allergy Patient.

The EFA Allergy Manifesto is a political declaration comprising a six-point strategy to counteract the growing prevalence of allergic disease, both in Europe and globally, and by doing so, improve the health conditions and quality of life of allergic patients and their families.

By endorsing and promoting the EFA Allergy Manifesto, European institutions and national governments, the scientific community, healthcare professionals and the industry ensure that allergic conditions are taken into consideration in the various aspects of daily life. They also give a clear message that they are ready to stand behind Europeans living with the burden of allergic diseases and give them hope for a better quality of life.



1. Change the cultural attitudes of society

Culture, legislation and healthcare systems vary among European countries, thus the level of knowledge of European citizens about the impact of allergy on individuals and society differs from country to country.

Allergy is intrinsic to daily life and it is vital that people's behaviour does not infringe upon the right of allergic patients to lead a normal life, within an acceptable social and health environment.

The introduction of this principle into European culture requires a considerable change in attitudes, as well as political commitment, time and financial resources.

Improving awareness about the social and environmental barriers faced by allergic people, such as allergens, air quality, smoking etc., must be a priority.

Progress made, in the form of smoking bans, allergic programmes in schools etc., should make other regions implement the same effective measures.

2. Adapt healthcare systems and resources

Healthcare systems must address the problem of the high prevalence of allergy.

They should provide sufficient financing and support to ensure that patients throughout Europe have equal access to diagnosis, treatment, continuity of care and social assistance. The general public must also be educated about allergic diseases and their prevention.

Legislation must be updated to integrate the allergy dimension into the national and regional context and to support measures to improve healthcare and assistance.

3. Understand the nature of allergy

People often believe they have an allergy without having obtained a medical diagnosis. This often leads to self-management without evidence, based on hearsay.

Additionally, lack of information could mean that allergic patients have low expectations and may be unaware that their allergy can be controlled. Both of these negative impacts on the quality of life of allergic patients can easily be avoided.

Hence, there is an urgent need to inform the public about the nature of allergy and the importance of obtaining a correct/precise diagnosis to allow for appropriate treatment, to prevent worsening of the disease and reactions that might prove fatal.

Campaigns must be organised at European, national and local levels to promote awareness among Europeans of all ages and socio-economic levels, of the dimension and impact of the disease and to increase the active participation of individuals, authorities, healthcare professionals, decision policy makers, etc. to reduce risk factors and improve the allergic patient's quality of life.



4. Establish programmes to train, educate, empower and rehabilitate

Training, education, empowerment and rehabilitation programmes must be based on the latest scientific information from the World Health Organisation (WHO), the European Union (EU) and other relevant organisations and institutions operating in this area.

Additionally, international guidelines and position papers should be implemented nationally and locally to ensure their application at all levels of healthcare.

An educational programme should be designed for each type of allergy with particular attention to environmental factors, especially at home, in day-care centres, schools and workplaces, in order to create a healthy and safe environment.

5. Establish research programmes

Improving measures to prevent allergy must be matched with research on the epidemiology, genetics, pathophysiology and pharmacology, as well as the social and psychological burden of allergic diseases and related environmental issues.

Socio-economic indicators should be investigated and monitored by a European scientific and economic network.

Research must focus on how best to reduce known risk factors, to minimise the symptoms, incidence and severity of exacerbations and acute attacks.

6. Establish an allergy-friendly environment for all

Allergy is triggered and worsened and even caused by many factors in our indoor and outdoor environment. Common allergy triggers are: allergens, mould, smoke, dust, smells and chemicals from many different sources. These could all be reduced or even abolished by establishing programmes and legislation on European, national and local levels to reduce indoor and outdoor air pollution, banning hazardous chemicals and improved consumer information and labelling.

In order to ensure the impact and sustainability of these actions, EFA urgently draws attention to the need for European, national and local programmes on allergy prevention and care.

EFA six point strategy to counteract allergy

- 1. Change the cultural attitudes of the society**
- 2. Adapt healthcare systems and resources**
- 3. Understand the nature of allergy**
- 4. Establish programmes to train, educate, empower**
- 5. Establish research programmes**
- 6. Establish an allergy friendly environment for all**

Why a European Allergy Patient Manifesto?

Allergy is a growing health problem that greatly impacts the day-to-day life of patients, as well as their families, school, professional and social life.

According to the World Health Organisation, allergy, defined as “immunologically mediated hypersensitivity”, is increasing and it is estimated that over 20% of the world’s population suffers from IgE-mediated allergic diseases, such as allergic asthma, allergic rhinitis, allergic conjunctivitis, atopic eczema, urticaria, angioedema, venom allergy and anaphylaxis. Allergy affects all age groups, from infancy to childhood, from adolescence to adulthood up to the elderly.

Allergic diseases should be considered as part of a continuum from atopic eczema and allergic rhinitis to asthma. In certain cases food allergy is a risk factor for the development of asthma. This continuum or ‘allergy march’ is a challenge for healthcare systems, particularly because there is a need for continuous control of children affected by these diseases and of children at high risk of developing them.

Although scientific societies have produced international guidelines and position papers regarding the diagnosis, treatment and management of allergic conditions, there is a great need for increased research into the different fields of allergy. Important new results often reach healthcare professionals late. Patients often need assistance in understanding their condition, as well as encouragement to comply with their doctor’s prescriptions and recommendations to see how these will improve control of their disease and hence their quality of life.

Institutions and the public are generally unaware or misinformed of the impact that allergic diseases have on individuals and on society as a whole. Allergy is a chronic disease that is highly prevalent but too often underestimated, underdiagnosed and undertreated. Reactions vary from mild to severe and even fatal. Allergic diseases can accompany a patient throughout their life, affecting not only their quality of life of allergic patients, but also those of their families and caregivers. The social and economic burden is very high for families and for social security and healthcare systems.

EFA and its members call for European action to counteract and prevent the increase of allergy across Europe and improve the quality of life of allergy patients through evidence-based programmes, legislation and national awareness campaigns. Because of the extent of the problem, allergy should be a part of the European and national political agenda.

The EFA Allergy Manifesto urges European and national institutions, healthcare professionals and policy decision makers to work together to ensure early diagnosis, correct treatment and control of allergic diseases as well as for the application of preventive measures including the elimination of social and environmental barriers that impact the quality of life of allergic patients. Allergy knows no boundaries and all European citizens should be empowered and encouraged to participate actively in this process.



The nature of allergic diseases

Allergy is a chronic disease, meaning that it may reoccur over a long period of time and the WHO report Preventing Chronic Disease – A Vital Investment, emphasises that chronic diseases are a very pressing and urgent threat; Allergy is the “major cause of death among adults in almost all countries and the toll is projected to increase by a further 17% in the next 10 years”.

What is “allergy”?

Allergy is a hypersensitivity reaction initiated by immunological mechanisms and it can be antibody or cell-mediated.

For instance, genetically predisposed people have an abnormal reaction to certain stimuli, which are usually harmless. When they come into contact with these stimuli their body reacts aggressively, as if the stimulus was potentially damaging, producing in many cases immunoglobulin (IgE) antibodies, and activating immune cells, such as eosinophils or mast cells. This usually occurs after repeated exposure.

The initial process, by which an individual becomes sensitive, is called “allergic sensitisation”. The offending substances are called “allergens”.

Clinical allergy symptoms are a consequence of the release of damaging substances from the activated cells. People who are constitutionally predisposed to produce IgE antibodies and have allergy symptoms are termed “atopic”. The type of allergic reaction depends on the individual’s immunological makeup and the organ affected by allergy, i.e., the “target organ”. So, allergic people may have allergic rhinitis and asthma (target organ: upper and lower airways), conjunctivitis (target organ: the eye), eczema, urticaria and angioedema (target organ: the skin), and food allergy (target organ: all of the above, plus in some cases the gastrointestinal tract).

Even if allergic symptoms appear in these target organs, allergy is a systemic disease in which the whole defence system of the body is involved, although symptoms may appear in only one target organ. These manifestations can appear singly or in various combinations in the same patient and at any time during life. If the whole body suddenly responds to the allergen, there will be an acute, generalised allergic reaction, which is called an “anaphylactic” reaction. Anaphylactic reactions may result in the drop of blood pressure, in which case the patient would suffer from “an anaphylactic shock”. Anaphylactic shocks can be very severe and may even be fatal.

In addition to allergens, irritants frequently cause symptoms in allergic individuals. However, some non-allergic people can also have hypersensitivity to irritants and substances. This is called intolerance and the symptoms are perceived by many patients as allergy. A correct diagnosis is needed to apply the adequate treatment and control.



The allergy march

Food allergy to (e.g. cow's milk proteins and hen's egg), atopic eczema and allergic rhinitis are important risk factors for the development of asthma. The early recognition and treatment of these conditions is beneficial both for the affected individual and for society, because early treatment will probably mean a decrease in disease severity and even in the prevalence of people who progress to respiratory allergy.

National and local healthcare systems should ensure continuous control of patients at risk of developing respiratory allergy.

Diagnosis and treatment

The GINA (Global Initiative for Asthma) and ARIA (Allergic Rhinitis and Its Impact on Asthma) documents are the key references for matters concerning an early diagnosis and appropriate treatment, because they are based on the most recent evidence and are regularly updated.

As recommended by these international guidelines, patients should receive a diagnosis of allergy based on tests of a proven efficacy (specific IgE in serum, prick test, etc.) including a lung function test. A clinical diagnosis is made based on the history of the patient and the clinical examination.


Allergy is a systemic disease and not an “organ disease”. The patient should be evaluated globally and preferably in a specialised asthma and allergy centre. The implementation of GINA and ARIA guidelines as well as other European Scientific Societies position papers through CME (Continuous Medical Education) could ensure optimal clinical practice based on solid scientific evidence.

Quality of life and the burden of the disease

Recent decades have seen an increase in efforts to understand the socio-economic burden of allergy in terms of the effect of health-related quality of life and healthcare costs.

Surveys show that allergy has a tremendous effect on the patient's professional, social and family life: almost 70% of the patients feel that their condition limits their way of life. Patients are restricted in their physical activity and in their social life. Patients are understandably anxious about the risk of severe reactions caused by food or by insect stings. A stuffy, blocked or runny nose and sneezing make them feel frustrated and irritable. Children with allergy may have learning difficulties, and adults may under-perform in their work.

It is vital that allergic patients and doctors are encouraged to discuss the effect of the disease on their daily quality of life. Patients should learn to participate actively in prevention and control measures. Healthcare professionals and others (family members, teach-



ers, friends and the public-at-large) should safeguard each allergic individual's quality of life.

Given the growth of allergy, there is a need to make the general public aware of the problems faced by people with allergy and educate them to prevent allergic diseases in general.

The importance of information, education and communication

There is evidence that empowered and educated patients can better manage their disease and prevent known risk factors. There is also evidence that correct information and education can reduce the cost of the disease by preventing exacerbations and the worsening of symptoms. Although education can increase the amount of money spent on drugs both by individuals, their families and the health security system, it also drastically reduces the number of emergencies, hospitalisations and of days lost from school and work, thereby resulting in an important reduction in allergy health costs overall.

Allergy patients must be informed correctly about their disease, its causes, treatment and the possibilities of prevention and environmental control. Patients should be empowered to participate actively in disease control and prevention procedures. Healthcare professionals must ensure that their patients understand the nature of their disease. Children involved in the “allergy march” must be controlled within the healthcare system on a regular basis. Patients should receive a detailed, written treatment plan that contains recommendations about daily treatment and indications on how to handle worsening and alarming symptoms, especially in case of patients at risk of anaphylaxis.

Partnership with doctors is the prerequisite of a good disease control. Healthcare professionals should have a clear understanding of the patient's perception of their condition, their attitudes and beliefs, and take into consideration their expectations and needs.

Barriers for the empowerment and education of patients seem to be lack of time, resources and the cost of the healthcare training. National and local health systems should recognize empowerment and education as essential parts of treatment and disease control.

Prevention

Prevention is one of the main objective of patients' organisations, scientific societies and institutions.

The aim of prevention is to prevent immunological sensitisation (primary prevention), the development of an allergic disease following sensitisation and development of atopic eczema, food allergy, upper airway respiratory allergy and allergic asthma (secondary prevention) and to treat the disease (tertiary prevention) according to the latest scientific evidence.



There are no reliable genetic and immunological markers to detect an at-risk child, which makes primary prevention of IgE sensitisation difficult. A prerequisite for secondary prevention is a correct and proper diagnosis of individuals who have developed IgE-sensitisation. Various international guidelines and consensus reports give guidance as how to treat and manage asthma and allergic diseases according to disease severity. European and national health programmes should include asthma and allergy in the active participation plans.

Patient's rights

Allergy patients of all ages should have a symptom-free life as far as possible and be able to live a normal life. Allergy should not prevent patients from sleeping, attending school, working, enjoying social and physical activities and eating out. That means that society should work hard towards removing the barriers that prevent allergy patients doing so; Patients have the right to breathe clean, healthy outdoor and indoor air, to live in a healthy environment, to be able to eat food safely in all circumstances and not risk adverse reactions because of some “unlisted” ingredient.

People need not die because of asthma, food allergy, venom allergy or other allergy reactions.

All stakeholders should address the problems of allergy patients, and their needs should be integrated in the normal daily life context (at schools, kindergarten, hospital, workplaces, restaurants, public transportation, etc.).

The basic rights of allergic patients include equal access to diagnosis, treatment corresponding to the most recent scientific evidence, information and education, and preventive measures. Patients affected by chronic allergy have the right to receive continuous monitoring and assistance from the social security and healthcare system.

Commitment to research

The rapid increase in allergic diseases indicate that the condition is not only due to genetic factors, but also to social and environmental factors.

Despite the abundance of research aimed at identifying the causes of the different allergic diseases, the question remains open. Not all risk factors have been identified. It is also essential to evaluate the weight of the social and environmental factors to identify the measures to prevent allergy. Additional resources are needed to study the natural history of allergic diseases in order to stop the “allergy march”.

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