

# 20

## The patient's voice in allergy prevention

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### Introduction

Allergy and asthma prevention have always been a priority for patients and patients' associations. They consider prevention as very important as it is a way to decrease the burden of the disease or even prevent symptoms from occurring. For patients and patients' associations prevention is also an essential part of disease control.

The range of possible preventive actions is very wide and the target groups vary greatly. They range from a single patient with his/her specific disease-related problems, to the society as a whole needing a more generalized approach to prevention. The institutions involved are as diverse, from patients' associations through health organizations and scientific societies to governmental bodies.

One can imagine that many questions arise:

1. What can be prevented in asthma and allergy?
2. Who has to do what in asthma and allergy prevention?
3. How do we translate scientific evidence into realistic prevention programmes?
4. How should EFA, the European Federation of Allergy and Airways Diseases Patients' Associations, cooperate in this field? (EFA and EAACI 2000)

Over the last three decades allergic disease and asthma have become increasingly prevalent throughout Europe, and the trend continues upwards. The increase has been noted for both children and adults across all social classes. The most pressing problem for public-health policy as well as for scientific reasons is to identify which of the changes or combination of changes that have occurred in Western society during the last thirty years can explain the rising trends.

### Short history of allergy patients' organizations

Allergy patients' organizations have been active in Europe since the end of the 19th century. Some developed from former tuberculosis associations, but most were established in response to a need to inform and support patients with allergy and asthma. Today, there are many asthma and allergy patients' associations throughout Europe. Some are national, with regional branches, local branches, and both local and regional branches. In other countries, several organizations exist side by side, sharing similar interests but with no common national association/federation. In several

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European countries, the national organization's secretariat is mainly staffed by professionals from different sectors, such as health education, information, environment and law. The local associations are run by volunteers who often have personal experience in dealing with allergic diseases (UCB 1999).

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

The European Federation of Allergy and Airways Diseases Patients' Associations (EFA) was founded in 1991 ([www.efanet.org](http://www.efanet.org)); it represents 39 national associations in 22 European countries. EFA is an alliance formed between organizations regarding allergic asthma and chronic obstructive lung diseases (COPD), whose aim is to represent the views and needs of allergy, asthma and COPD patients and their carers throughout Europe. EFA represents its members in the European Union and in European organizations.

EFA's mission is to improve the quality of life of people with allergies, asthma and COPD and of their carers. EFA's vision is a European community that shares the responsibilities for substantially reducing the frequency and severity of allergies, asthma and COPD, and recognizes the social, environmental, economic and health implications.

EFA represents over 100 million persons in Europe. In everyday life and in practice, there are huge possibilities and ways to promote better health for people with allergies, asthma and COPD. Patients' associations work on many levels locally, nationally and internationally, but their goal is always to improve the quality of life of an individual patient – to achieve the best possible quality of life for him/her despite the disease. The other goal is prevention and the protection of the future generations from these diseases (EFA 2001).

### **The patients' view of prevention**

These are all requirements for society and the medical profession to help individual allergic patients. The relevant question for allergy prevention is to develop and provide information to the society on how to avoid becoming allergic and/or to decrease the severity of allergic symptoms. Genetics is important in the development of allergic disease, but this cannot be altered. Lifestyle factors are also important but they can be adapted. This holds true for smoking behaviour, level of physical exercise, food and eating patterns, coping with chronic stress, etc. I think some of these parameters can be discussed by looking at consumer behaviour; others are more accessible and relevant in the discussion on prevention.

The EFA Declaration of Asthma and Allergy Prevention was published in 1999 (EFA 1999). EFA is concerned about the consequences of the increase in prevalence and recognizes that prevention is very important.

There is a need for:

- Information and education
- Full access to up-to-date diagnostic, therapeutic and training facilities
- Information of prenatal and mother-and-child clinics about prevention of allergy
- Allergy-adapted environments at schools and day-care centres
- Laws on tobacco-smoke-free public environments
- Tobacco-smoke-free homes for children
- European and national building regulations for healthy buildings

- Reduced outdoor air pollution
- More research.

What about patients own responsibilities: allergy management with respect to life style, food choice, exercise levels, holiday choices, etc.? These allow patients to control their own quality-of-life aspects while suffering from an allergy.

## **What are patients' organizations for?**

### **To promote better health for asthma and allergy sufferers**

To improve patients' knowledge of how to cope with their disease, educational programmes are being organized in many countries. There are many different ways how activities can be arranged at local and national level. Gathering patients and/or their carers together in informative training and educational meetings to learn and to exchange knowledge is an important objective. The realization that they are not alone but are fighting the disease alongside others has a major stimulating effect. People with severe allergic disease can often find themselves isolated and resigned to suffer their symptoms. It is therefore important to establish contact with them, so that they understand that their condition can be improved with appropriate medication and/or allergen avoidance and that facilities such as allergy schools are available where teams explain allergic diseases backed by patient information. Disseminating information about a disease is not something that can be improvised: training courses are essential for all educators in allergic disease.

### **To raise awareness of asthma and allergy**

Proper and adequate information on allergic disease must be disseminated using all possibilities in the media. The internet is becoming more and more important. Common issues are living with the disease and the needs for better and early diagnosis and treatment, or preferably control of the disease. It is important that people at large are informed about asthma and allergic diseases and about the consequences for health and quality of life. Awareness days at local, national and international level are important; EFA has proclaimed an annual asthma and allergy awareness day, which is organized nationally and locally all over Europe.

### **To promote the interests of asthma and allergy sufferers**

Patients' organizations work on behalf of allergy sufferers, with representations to governments urging the promotion and protection of the interests of allergy patients. EFA's role is lobbying in the European Commission and European Parliament as well as participating in European organizations representing the views and perspectives of allergic patients. Health and social-affairs authorities are also important target groups for the attention of lay organizations.

The patients' organizations in Europe have several aims to fulfil; these include healthy buildings and a healthy indoor climate, improved design of school buildings, improved food labelling, enhanced recognition of asthma both as a social and a chronic disease, and recognition of the benefits of healthy work practices, for example, protection against the allergenic effects of latex and rubber products.

### **To promote research**

There is a great need for research about prevention of allergy and asthma. EFA is an active participant in many EU-funded scientific projects and EFA has also

performed two projects itself: “Indoor Air in Schools” and the THADE Project, “Towards Healthy Air in Dwellings in Europe”. A close collaboration between patients’ organizations and scientists already exists. This collaboration exists not only internationally, but also nationally and locally. Many of the patients’ organizations in Europe fund scientific research. They support scientific positions and give grants for specific projects (Borres et al. 2002). They can also initiate their own research projects. Allergy research must be encouraged and expanded! One of the objectives of the patients’ organizations is to draw attention to this and to campaign for greater funding of allergy and asthma research programmes. EFA has been invited to give comments on the “Prevention of Allergy and Allergic Asthma” document published by the World Health Organization (WHO), in cooperation with WAO, the World Allergy Organization (WHO 2003). EFA was also invited to give comments and endorsement to the ARIA Project, “Allergic Rhinitis and Its Impact on Asthma”, by WHO (Allergic rhinitis and its impact on asthma 2001).

### **To further patients’ self-management and well-being**

The patients’ organizations initiated the recent move towards the patient taking a role in self-management and him or her being considered an informed decision-maker. As an active partner with responsibility for his or her own health and recovery, the patient ultimately makes own decisions and choices. The better a patient is informed and involved in treatment choices, the greater the chance that he or she will be compliant with the physician’s advice. This is especially important with the preventive measurements: what information is given to the public at large and what information to the so-called high-risk families without inducing any frustrations with ineffective procedures? All information must be based on evidence-based medicine.

Patients’ satisfaction with their physician and health services affects health outcomes. It is directly related to the physician’s efforts to deal with the patient’s need for information, support and advice.

Improvement of patients’ well-being also depends on the skills of professionals. Partnership with health-care professionals is therefore one of the important goals of patients’ associations as well as EFA.

### **Key action points**

1. To promote better health for allergy and asthma sufferers via informative meetings, actions, training and education.
2. To enhance communication between the allergic consumers and other stakeholders.
3. To raise awareness of allergies and asthma via the media.
4. To promote the interests of allergy and asthma sufferers.
5. To lobby and cooperate with governmental institutions and the European Commission as well as the European Parliament.
6. To promote research and cooperation with scientific organizations and society.
7. To further patients’ self-management and well-being.
8. To work in partnership with health-care professionals.

### **References**

Allergic rhinitis and its impact on asthma, 2001. *Journal of Allergy and Clinical Immunology*, 108 (5), S147-334.

- Borres, M.P., Abrahamsson, G., Andersson, B., et al., 2002. Asthma and allergies at school: a Swedish national position paper. *Allergy*, 57 (5), 454-457.
- EFA, 1999. *European declaration on asthma and allergy prevention*. EFA.
- EFA, 2001. *Asthma and allergy prevention: first priority for patients: in remembrance of Kerstin Hejdenberg, EFA president 1996-2000, 7-9 June 2001, Stockholm, Sweden: abstracts*. EFA.
- EFA and EAACI, 2000. *Patients' views and values: joint EFA and EAACI round table, Lisbon, Portugal, 4 July 2000: abstracts*. EFA.
- UCB, 1999. *European allergy white paper. Update*. UCB Institute of Allergy, Brussels.
- WHO, 2003. *Prevention of allergy and allergic asthma: based on the WHO/WAO meeting in Geneva 8-9 January 2002*. WHO, Geneva.