



# The Allergic Patient in Europe

## Joint EFA-EAACI Symposium

**16 June 2004**

**Amsterdam, The Netherlands**



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**A B S T R A C T   B O O K**



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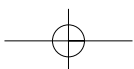
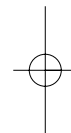
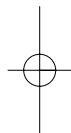
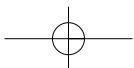
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**A B S T R A C T B O O K**



## Introduction

Allergic diseases are an important public health problem in Europe and their prevalence is increasing. Currently, 80 million people in Europe are affected. All too often the focus is on the medical control of allergy, which is undoubtedly the cornerstone of management, whereas environmental and quality of life measures are largely ignored. However, these measures are part of management of allergies. Areas for concern for the patient are therefore safe travelling, healthy housing and safe food.

EFA is a Federation of 42 associations of allergy and airways diseases patients in 23 European countries that works to improve the quality of life of these patients and their families. EFA strives for an environment that does not cause or trigger allergy, and for correct information and awareness about allergy triggers. It aims at empowering patients to take control of their disease and ensuring they can live all aspects of daily life just as healthy individuals do. To achieve this, medical, regulatory, educational and awareness-raising measures and solidarity are all needed.

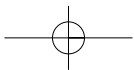
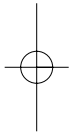
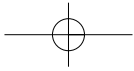
One of EFA's strategies is to educate health professionals on the patient's concerns, aspirations and about practical measures to help patients achieve a good health-related quality of life. To this aim, EFA organizes symposia in the main medical meetings in Europe in partnership with scientific societies. This booklet is a result of a symposium held at the EAACI Congress in Amsterdam 2004 and focuses on the allergic patient's right to be able to live a normal daily life and travel without barriers.



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## Travelling Patients. Problems and Solutions

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People with allergy and airways diseases tend to avoid going on holiday or travelling because they are afraid of exacerbating their condition, of encountering unexpected triggers, and of not having easy access to their doctor in case of an emergency. More than 50% of allergy patients have difficulty in staying outside because of their allergy (source: Allergy – Living & Learning survey). Unexpectedly, according to the Paediatric Asthma Pan European Survey, not all parents of asthmatic children consider taking asthma medications on a trip, 30% of the interviewees do not take their child's medication with them when leaving the house, for example for a journey.

One of the aims of patients' associations is to give people advice to help them enjoy travel and holidays just as much as their peers do. Below are recommendations in this sense, however the basic rule is that patients should ask their doctors what to avoid and what kind of limits they may incur when travelling or on vacation. Patients must strictly comply with their doctor's indications and follow a few simple rules in order to avoid unpleasant surprises. It is noteworthy that many patients tend to be less vigilant when away from their homes.

### Where to go on holiday

Choosing a holiday destination is always complicated because of various factors: the season, and the amount of time available, the different preferences of family members, availability of a second house, etc. Difficulties are compounded when a person in the family, especially if it is a child, is allergic or asthmatic. There are no specific rules. In general, people with allergy and asthma choose their holiday destinations according to the positive or negative experiences of previous vacations. A mild and dry climate is good for everyone.

**amsterdam 2004****General recommendations:**

- ✓ People allergic to dust mites may improve their condition by holidaying in the mountains (1500/1800 m), as dust mites do not survive these altitudes.
- ✓ People affected by pollen-related disorders should avoid travelling in high risk areas or during pollination seasons. They should know when the plants they are allergic to flower and check pollen counts (pollen calendars, newspapers, teletext, internet, etc).
- ✓ Asthmatic people, if their asthma is well-controlled, have no particular restrictions as to holiday destination. The doctor may indicate some limits in cases of severe asthma.
- ✓ Seaside holidays are particularly recommended for children with eczema (they should always carefully comply with their doctor's instructions).

**What to do when going on holiday in your own country**

1. Obtain the contact details of a doctor that could help in case of symptom exacerbation. Obtain the telephone number of the hospital nearest to where you will be staying.
2. Pack the following documents: (a) national health service card and other relevant health papers; (b) brief description of the patient's clinical history written by the family doctor; (c) a list of food- or drug-related adverse reactions or allergies.
3. Pack your written therapeutic plan, containing: (a) list of the prescribed treatments and indications on when and how drugs must be taken; (b) what to do: on a daily basis (in case of need), if symptoms worsen and during emergencies.
4. Pack your medicines (bring an extra supply for emergencies), and prescriptions (if required by the national health system).
5. In case of asthma prepare: (a) peak flow meter; (b) spacer (if recommended by the doctor); (c) nebulizer (if recommended by the doctor)
6. Pack a diary to note symptoms or other reactions in order to inform the doctor upon return home.

If travelling abroad, you should also:

7. Ask for a European Health Card for EU countries, which is set to replace all current paper forms (E111 etc) used for medical treatment during temporary stays abroad.



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8. Write the active agent next to the name of each of the drugs used because medicines may not have the same name, composition or packaging in all countries.
9. If the patient's language is not English, all the relevant documents prepared by your doctor (especially those referring to emergencies) should be translated into English.

**What means of travel should be used**

Travelling by car is not a problem, except for people allergic to pollens who could suffer when driving through risk areas. The cars of cat owners could contain high levels of cat allergen, which could affect people allergic to cats.

Travelling by train could be a concern for those affected by dust mite allergy. Parents of allergic children should take an appropriate sheet or an anti-mites mattress cover to reduce risks.

The same relates when travelling by ferry or plane. The transmission of respiratory infections, well-known triggers for asthma and other respiratory diseases, is most likely to occur indoor, namely in trains or planes. In addition, pets may be allowed on public transport: therefore, it is not always possible to avoid contact with an animal.

**Choosing a hotel**

The hotel must guarantee for a healthy indoor environment for its guests and staff. Recommendations required to adapt an environment to the needs of allergic and asthmatic people are suitable for everyone. The main measures for a healthy indoor environment are:

- ✓ avoidance of environmental tobacco smoke;
- ✓ avoidance of moisture/moulds;
- ✓ avoidance of allergen sources;
- ✓ adequate cleaning and maintenance, practical shaping of the interior to facilitate cleaning and maintenance;
- ✓ good maintenance of heating and ventilation to ensure a satisfactory temperature and ventilation;
- ✓ appropriate training for hotel staff, catering staff and other staff who are responsible for management maintenance and cleaning.

### Renting a holiday apartment

This is a very important step. The apartment should be checked before making a final decision. Among the questions that should be considered are: is there a strange smell when entering the apartment? is it insufficiently ventilated? are there any damp patches? what is the general state of hygiene? is there any dust? are there any animals? Do cats and/or dogs normally live in the apartment? are there any allergenic plants? what does the floor look like? Are there any carpets, heavy curtains, cushioned sofas, piles of books and various objects? what type of cooker is there? Is it gas or electric? are there windows in the bathroom and kitchen? Are they equipped with electrical ventilation?

In conclusion, with a little planning and forethought people affected by asthma or other respiratory conditions, or allergy can enjoy their holidays whether at home or abroad.

## THADE

# Indoor Air Health Effects and Evidenced-based Recommendations

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### The THADE project

The THADE project (Towards Healthy Air in Dwellings in Europe) has been promoted by the European Federation of Asthma and Airways Diseases Patients' Associations (EFA) with the support of the European Commission. The aims of the project were to:

- ✓ Produce maps of pollutants in European dwellings.
- ✓ Review the data and evidence-based information related to exposure and to the health effects of air pollution in dwellings particularly as regards allergies, asthma and other respiratory diseases.
- ✓ Review cost-effective measures and technology to improve air quality in dwellings.
- ✓ Review legislation and guidelines on air pollution and air quality in dwellings.
- ✓ Recommend an integrated strategy that defines appropriate indoor air quality policies for implementation in Europe, and identify appropriate technology.

It was endorsed by the major scientific societies involved in the field of indoor air quality and related health effects. Sixteen associations affiliated to the EFA network took part in the project. Experts examined the various aspects of health determinants related to indoor air quality in dwellings and the actions to prevent the adverse effects.

### Health effects related to indoor air quality

The right to breath healthy air in dwellings was recognised as a fundamental right by the World Health Organisation in 2000 consequent

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to scientific evidence of the health risks related to poor air quality.

Unfortunately, this right and the adverse effects of indoor air pollution are largely ignored. Millions of Europeans spend more than 90% of their time indoors. Exposure to pollutants in indoor air may cause or aggravate illnesses, increase mortality, and have a major economic and social impact.

The main health determinants in dwellings are: environmental tobacco smoke, dust mites, pet allergens, mould, pollen, nitrogen oxide, formaldehyde, volatile organic compounds (VOCs), indoor-generated particulate matter, radon and carbon monoxide. These determinants can affect the respiratory system in various ways, in particular they can cause or exacerbate asthma and acute or chronic respiratory diseases.

They can also cause a decline in respiratory functions and sensitisation to common aeroallergens. Some pollutants, like radon, environmental tobacco smoke (ETS) and VOCs pose a significant cancer risk. People with allergy, asthma or chronic obstructive pulmonary disease (COPD), children and the elderly are particularly susceptible to indoor air pollutants.

**Recommendations to prevent the adverse effects of poor air quality in dwellings**

Methods and actions to prevent the adverse effects of poor air quality have been identified. The actions can be classified into five main categories:

- ✓ Improve ventilation
- ✓ Improve cleaning methods and housing hygiene
- ✓ Avoid wall-to-wall carpeting
- ✓ Moisture control to prevent accumulation of mould
- ✓ Control the sources of pollution, e.g., tobacco smoke and emissions from building and consumer products.

## **INFORMALL: Communicating about food allergies and information for consumers, regulators and industry**

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In the absence of effective treatment for food allergy, people with food allergy must live a life where they completely avoid the food(s) they are allergic to, especially since a tiny amount of the offending food can trigger severe, even life-threatening, reactions. Such a life style makes the provision of good quality, credible information on food allergies an imperative.

In response to this, the InformAll project is developing communication strategies for food allergy appropriate to allergic consumers, industry and regulators. This is being achieved by (1) determining the communication issues inherent in the food allergy arena; (2) developing communication recommendations and strategies to address those issues and the needs of the various stakeholders; (3) implementing these recommendations regarding allergen information communication through the development of a Food Allergy Information Platform (FAIP) which will comprise web-based information databases and a web-site jumpstation. Lastly, the project aims to bring together the researchers and outputs of Research and Training Development projects funded under the V Framework Programme in a cluster, networking it with nationally funded research. The work is being undertaken by a multidisciplinary team of researchers from Europe and the USA which includes social scientists, immunologists, biochemists, clinicians, food scientists and patient groups.

The approach taken to understand what the communication issues are regarding food allergy has been to (1) define the most important issues

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regarding effective communication and food allergies; (2) understand barriers to developing effective communication about food allergy; (3) identify potential cross-cultural and intra-individual differences (e.g. between adults versus children, or between different stakeholder groups) in communication needs; and (4) assess the efficacy of existing food allergy communication.

The results of a stakeholder analysis with researchers, health professionals, the food industry and regulators showed that there is a core of information about food allergies required by all these different groups. There are, however, some differences. For example, the industrial and retail sector required more information about clear guidelines for labelling practices, whereas patient groups and health professionals required more information about symptomology, treatment and prophylaxis. It was concluded that information that meets the specific needs of end-users and other interested stakeholders is not widely available and that health professionals (including nurses and dieticians) are an important route for delivering information about managing and living with food allergies. In response to this need future work will focus on developing an effective communication strategy which meets the needs of key stakeholders and end-users. Using the generic principles for preparing information, including its format and means of delivery, a web-based Food Allergy Information Platform is being assembled which comprises a webportal with credible food allergy information websites and a searchable database with information on allergenic food materials, together with a series of 'perspectives' based on the outputs of the EU-funded research in the InformAll project cluster, including control of allergen risks, allergen structure, the food matrix and processing, and the molecular basis of food allergenicity.

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## EFA Allergy Manifesto

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Allergy is a growing health problem that greatly impacts on the day-to-day life of patients, and on their families, school, professional and social life. Allergic diseases are a continuum from atopic eczema and allergic rhinitis to asthma; in certain cases food allergy is also a risk factor for the development of asthma. This 'allergy march' is a challenge for healthcare systems because there is a need for continuous control of patients with these diseases and also of those at risk of developing them.

Institutions and public opinion are often unaware of the impact of these diseases on individuals and on society as a whole. Allergy is often underestimated, underdiagnosed and undertreated, despite its high prevalence and its effect on the quality of life of affected people, their families and caregivers. It is a chronic condition that accompanies the patient throughout life. Reactions vary from mild to severe and even fatal. The social and economic burden is very high for families and for social security and healthcare systems.

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/atopic dermatitis, urticaria, angioedema, venom allergies and anaphylaxis. Allergy affects all age groups, from infancy to childhood, from adolescence to adulthood up to the elderly.

Scientific societies have produced international guidelines and position papers concerning the diagnosis, treatment and management of these common conditions. However, there is a need for more research in the different fields of allergy. Moreover, important new results are often slow in reaching healthcare professionals. Patients should be helped to understand their condition, to comply with their doctor's prescriptions

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and recommendations to improve their disease control and hence their quality of life.

Allergy knows no boundaries. Hence we call for a global strategy for European and national programmes and actions aimed at translating into daily life the scientific data that will help counteract the increase of allergy in Europe.

The EFA Allergy Manifesto urges European and national institutions, healthcare professionals and policy decision makers to work together to create the conditions for 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, so that people with allergy can live as normal a life as possible.

The EFA Allergy Manifesto is a political declaration by which EFA defines a global strategy to counteract the growing prevalence of allergy, with the aim of improving the health conditions and quality of life of patients and their families. The key goals are:

**1. Change in cultural attitudes in society**

Culture, legislation and healthcare systems vary among European countries, so that the level of knowledge of European citizens about the impact of allergy on individuals and society differs from country to country. Allergy is part of our daily lives and everyone must ensure that their behaviour does not infringe the right of allergy patients to conduct a normal life, i.e. to have an appropriate social and health environment.

The introduction of this principle into our cultures in Europe requires major changes in attitudes, political engagement, time and financial resources. The priority is to enhance knowledge about the social and environmental barriers faced by allergic people as a step to eliminating the barriers. Progresses made in some countries should encourage other regions to implement low-cost effective measures.

**2. Healthcare systems and resources**

Healthcare systems should address the problem of the high prevalence of allergy. They should provide finances and support to ensure equal access to diagnosis, treatment, continuity of care and social assistance as well



as education and prevention for patients in all parts of Europe. Legislation must be updated to integrate the allergy dimension in the national and regional context.

### **3. Understand the nature of allergy**

Frequently, people believe they have allergy without having a medical diagnosis. This leads to self-management largely practised based on hearsay and not evidence. On the other hand, allergy patients have low expectations because they are unaware that their allergy can be controlled. This negatively affects the person's quality of life.

There is an urgent need to inform the public about the nature of allergy and of the methods available to obtain a correct/precise diagnosis, which is a prerequisite to prevent worsening of the disease and reactions that can even be fatal. Campaigns should be organized at European, national and local level to make citizens aware of the dimension and the impact of the disease and to increase the role of all parties (individuals, authorities, healthcare professionals, decisions policy makers, etc.) in reducing risk factors and improving the patient's quality of life.

### **4. Establish programmes for training, education, empowerment and rehabilitation**

Training, education, empowerment and rehabilitation programmes must be based on the latest scientific information from WHO, WAO–World Allergy Organisation and the European Union. International guidelines and position papers should be circulated internationally, nationally and locally to ensure their application at all levels of healthcare. An educational programme should be designed for each kind of allergy.

Particular attention should be paid to environmental factors, especially at home, in schools and working places, in order to create the conditions for a healthy and safe environment.

### **5. Establish research programmes**

Improvements in allergy preventive measures must be matched by research on the epidemiology, genetics, pathophysiology and pharmacology as well as the social and psychological burden and

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

### Conclusions

Allergy patients, now and in the future, must have the same rights as patients with other chronic conditions:

- ✓ The right to receive an early and accurate diagnosis
- ✓ The right to receive optimum standards of care and treatment
- ✓ The right to receive correct and precise information
- ✓ The right to continuous social and health assistance
- ✓ The right to research and investments to improve healthcare standards

By endorsing and promoting the EFA Allergy Manifesto, European institutions and national governments, the scientific world, healthcare professionals and industry ensure that a real cultural change will take place whereby allergic conditions will be taken into consideration in the different situations encountered in everyday life throughout Europe.