

EFA BOOK ON

Respiratory Allergies

RAISE AWARENESS, RELIEVE THE BURDEN

Edited by Erkka Valovirta



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Foreword

by Breda Flood, EFA President

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 allergic rhinitis and allergic asthma is often severely impaired as is their social life, their career and even their school performance [1, 2]. Despite the dimension of respiratory allergies and their huge economic-social burden, these conditions are often largely ignored by society as a whole. Millions of patients suffer from respiratory allergy and the prevalence is increasing. The data collected by the European Federation of Allergy and Airway Diseases Patients Association (EFA) shows that approximately 30% of the European population suffers from respiratory allergies, and recent studies show that between 10% and 20% of adolescents aged 13 and 14 suffer from severe allergic rhinitis [3].

EFA has a 20-year history of advocacy and campaigning to give voice to the patients and to increase awareness about the personal and social impact of allergies. In 2009, EFA decided to go global and invited patients' organizations and supporters of allergy patients to build a Global Allergy and Asthma Patient Platform (GAAPP) whose first activity was to present the "Declaration of Buenos Aires" during the World Allergy (WAO) conference in December 2009. EFA is also an active partner of the Global Alliance against Chronic Respiratory Diseases (GARD) and contributes to the World Health Organization's global effort to prevent and control chronic respiratory diseases.

EFA identified low public awareness of allergies as serious chronic diseases as a major issue. Given the increase and alarming burden of allergies, the level of ignorance about allergies in the global community is hard to believe. EFA believes that the time has come for allergy patients to increase awareness about allergies across Europe and to establish allergies as serious chronic diseases.

Europe has certainly seen some improvements regarding respiratory diseases, particularly in the realm of air quality. For example, the EU currently invests €16 million a year in a "help campaign" ([http:// help.eu.com](http://help.eu.com)) to raise awareness about the importance of tobacco control and to promote smoke-free environments. This is just one area, where increased awareness is needed.

In fact, while allergy does not enjoy the same level of attention as cancer or cardiovascular diseases, it is certainly the most pervasive disorder globally. Allergic conditions pose a major public health problem, as documented by the WHO and other leading bodies. Allergies respect no national borders and are spreading inexorably throughout Europe. This major health concern should be addressed at European level. Following the adoption of the Lisbon Treaty, it is envisaged that the European Parliament and the Council may adopt incentive measures to "protect and improve human health and in particular to **combat the major cross-border health scourges**, measures concerning monitoring, early warning of and **combating serious cross-border threats**". The clear nature and scope of these incentive measures are not defined in the Treaty, but obviously increased action is envisioned at EU level.

In this scenario, this book is part of the EFA campaign to raise awareness about respiratory allergies and, ultimately, to reduce the burden of these conditions. The book should be viewed as a tool with which to identify the main issues experienced by patients with respiratory allergies in different countries, and also to learn about positive experiences, for example the Finnish Asthma and Allergy Programmes, which have been successfully implemented by national governments.

Finally, EFA wishes to thank all the patients' associations that took part in the project (from Austria, Belgium, Bulgaria, the Czech Republic, Denmark, Germany, Greece, Finland, France, Ireland, Italy, Lithuania, The Netherlands, Norway, Poland, Sweden, Switzerland and the UK) for their remarkable contribution to this book. Thanks to their work, we now have a map of respiratory allergies in Europe. We appreciate the support of the professional healthcare organizations: Allergic Allergic Rhinitis and its Impact on Asthma (ARIA), the European Academy of Allergy and Clinical Immunology (EAACI), the European Respiratory Society (ERS), the Global Allergy and Asthma European Network (GA²LEN), the International Primary Care Respiratory Group (IPCRG) and the World Health Organization's Global Alliance for Respiratory Diseases (WHO GARD). We also wish to thank our partners ALK-Abelló and Stallergenes that supported the EFA Allergy Project with an unrestricted educational grant.

Foreword

by Joanna Bottema, Astmafonds, The Netherlands

The patient's voice: Raise awareness, improve the patient's quality of life

Even in a small country like The Netherlands (total population approximately 16 million) more than half a million people suffer from asthma and severe respiratory allergies. I'm one of these patients. You would think that there was a lot of consideration for such a large group of patients. Nothing could be further from the truth! Most people with respiratory allergies have very little support in either their social or work environment.

Respiratory allergies, namely asthma and allergic rhinitis, severely affects your wellbeing and your social life. Things would improve a lot if society were to change its view about the quality of air both indoors and outdoors.

There are some positive developments. Lately, there is more concern about air pollution caused by traffic and industry. Awareness of the importance of a healthy indoor environment (classrooms, offices, etc) is increasing, and smoking is now prohibited in public buildings in most European countries.

On the other hand, some trends are worrying me. Fragrances are increasingly being used in places frequented by the public, for instance in department stores, and in the rest rooms of hotels, restaurants and some companies. Another aspect of this trend is the habit of making the fragrance of detergents long-lasting – a disaster if you have asthma and someone near you is using such products! This pungent odour (and the additives) makes it hard for people with (allergic) asthma to remain in the vicinity. They are forced to leave or in the best case to take more medication to be able to stay. Moreover, sadly the current government in The Netherlands has rescinded the law and now allows smoking in small bars. The Ministry of Health is listening to the tobacco industry lobby.

To improve the quality of life of allergic and asthmatic people, it is important that society becomes more aware of the high prevalence of allergic rhinitis and allergic asthma in both children and adults and of the consequences this has. Hopefully, greater awareness will induce politicians to make appropriate laws and take appropriate measures for the proper treatment and management of these conditions. The first aim is to achieve a better quality of life for patients, and a greater participation in work and social life. A positive side-effect will most likely be a reduction in healthcare costs.

Supporting Statements

by EFA Partner Healthcare Organizations

The **European Academy of Allergy and Clinical Immunology – EAACI** is the largest medical association in the world in the field of allergy, asthma and immunology. EAACI co-operates with EFA in initiatives to improve the conditions of patients with asthma and allergies. Cases in point are working to ensure that patients in Europe have equal access to allergen immunotherapy, and drawing attention to the need for allergologists throughout European countries and not just in main centres. The EFA Book on Respiratory Allergies is a valid tool with which to raise awareness of respiratory diseases among all stakeholders.

Pascal Demoly
EAACI Vice-President for Education & Specialty

Moises Calderon
EAACI Chair for Immunotherapy Interest Group

The **ARIA (Allergic Rhinitis and its Impact on Asthma)** initiative aims to disseminate, educate and implement the evidence-based management of allergic rhinitis in conjunction with asthma worldwide. ARIA works for and with the patients, and strongly supports the EFA respiratory allergy awareness project. This European patient-centered initiative is launched at the right time due to the prevalence and burden of allergy, and it strengthens two breakthrough worldwide initiatives: the 2011 priority in allergy and asthma in children of the European Presidency from Poland and the “Political Declaration on the Prevention and Control of Non-communicable Diseases (which includes chronic respiratory diseases)” adopted by the High Level meeting of the United Nations General Assembly on 20 September 2011. As always, ARIA is pleased to partner with the patients and wishes EFA good luck for the four-year project aiming to increase awareness of respiratory allergy as a serious disease.

Jean Bousquet, MD, PhD
Chairman of ARIA, WHO GARD and the WHO Collaborating Center on Asthma and Rhinitis

We must be prepared for the challenge of the rise in allergies, which has increased markedly in the EU population to 20% for allergy and 8% for asthma, and which will create substantial socio-economic costs and new healthcare challenges, mainly in children. Asthma continues to represent a major burden for affected children and their families, a challenge to public health organizations and healthcare providers. Millions of children worldwide are affected by asthma, which is a major cause of childhood disability. Asthma may limit a child's ability to play, learn and sleep. Prevention of chronic diseases starts early in life, healthy lifestyles need to be included in the school curricula and we must promote the concept of exposure standards for allergens and respiratory irritants as a major primary prevention initiative.

Professor Francesco Blasi
President Elect, European Respiratory Society

GA²LEN is a pan-European network of excellence founded by the EU in FP6 which is now self-sustainable but running in low gear. It has established Europe-wide platforms and tools offering optimal conditions for improving research and clinical care in allergy. EFA is one of the founding partners of GA²LEN and the current proposal of GA²LEN to set up a pan-European sentinel network for an early alert system detecting new trends in allergy will directly support EFA efforts for the best possible protection for the allergic citizen.

Professor Torsten Zuberbier
GA²LEN, Secretary General

The **International Primary Care Respiratory Group (IPCRG)** is committed to raising the standards of care in community settings for people with respiratory diseases. Recognizing that care needs to be a partnership between professionals and patients, the IPCRG collaborates at an organizational level with EFA to achieve optimum patient outcomes. Raising awareness of allergy as a major contributor to respiratory problems encountered in the community is an important part of that commitment.

Dr Dermot Ryan
General Practitioner, Loughborough, UK and Allergy Lead, IPCRG. On behalf of IPCRG

Introduction

by Erkkä Valovirta, MD, PhD, Professor, EFA Medical Advisor

Allergic rhinoconjunctivitis and allergic asthma are the first leading cause of loss of productivity worldwide followed by cardiovascular disease. Respiratory allergies are increasing worldwide, particularly in children. Today, 113 million citizens in Europe suffer from allergic rhinitis and 68 million from allergic asthma. Forty-three percent of patients with these conditions have sleep disturbances and 39% have difficulty in falling asleep. Obviously, this has a negative impact on work/study and daily life activities, and hence on the patient's quality of life as a whole. Despite this dismal scenario, respiratory allergies are underdiagnosed. Surprisingly, in fact, it is estimated that approximately **45%** of patients have never received a diagnosis.

Allergic rhinoconjunctivitis and asthma should be considered a continuum of a single disease ("one airway, one disease"). Epidemiological studies have consistently shown that allergic rhinitis and asthma often co-exist in the same patient. Moreover, allergic rhinitis is a risk factor for asthma. The **one airway, one disease** premise marked a change in the diagnosis and therapeutic management of respiratory allergies by inducing an integrated and unified approach to patients affected by allergic rhinitis and asthma.

Despite the severe impact on patients and on society as a whole, respiratory allergies are neglected and under-recognized both by national healthcare authorities and by people that interact with these patients. In fact, people around them just do not understand how impairing this condition can be – they tend to think that it is "only allergy".

In 2011 the World Allergy Organization (WAO) published the WAO White Book on Allergies that contains data on allergies worldwide. The data leave no doubt that allergy is a major global public health issue, and the WAO issued "high level" recommendations towards an integrated approach to the diagnosis and management of allergic diseases.

The **EFA Book on Respiratory Allergies** is the first step of EFA's more comprehensive campaign to raise awareness about the burden of respiratory allergies in Europe. The text was developed from the replies to a questionnaire sent to patients' associations belonging to EFA. We received replies from 18 European countries. Questions varied from the epidemiology of respiratory allergies, to the quality of treatment and how patients live their condition.

The results revealed a series of issues that need to be addressed:

- Allergic rhinitis, in particular severe allergic rhinitis, is not recognized as a disease.
- Inequalities in the management of respiratory diseases exist among countries and among regions, therefore access to treatment varies greatly throughout Europe, in particular for what concerns access to medical treatment.
- Also within the same country, patients' access to treatment may differ from region to region or between urban and rural areas.
- There is a lack of specialists (allergologists or allergy trained physicians) able to identify and to treat the more severe cases. Moreover, there is a lack of coordination among the different medical specialists (paediatricians, pulmonologists, ENT doctors, dermatologists) that usually "see" patients with allergies.
- There is a need for greater coordination in the diagnosis and management of respiratory allergies.
- There is a need for greater awareness of the importance of safe indoor and outdoor air quality for patients.
- There is a need for national programmes that ensure equal access to an early diagnosis and care especially of patients with moderate to severe symptoms. Patients' associations and pharmacists should be partners in these national programmes. People with mild symptoms should be encouraged to seek information and advice from patients' associations and pharmacists.
- There is a need to ensure that national guidelines on diagnosis and treatment of respiratory allergies are implemented. The most effective way to ensure implementation of national guidelines is through multidisciplinary educational meetings for healthcare professionals.
- In Europe, we are seeing some progress. Cases in point are initiatives to improve indoor and outdoor air quality and campaigns illustrating the dangers of smoking. In addition, in some countries, for instance, Finland, national programmes on asthma and allergies are being implemented. Thus far, these programmes have been successful both in reducing costs and in improving the treatment of patients, thanks also to coordination among patients' associations, healthcare professionals and scientific societies, and the involvement of national healthcare authorities.

Overall, there is a need for a European and national approach to respiratory allergies. It should also take into consideration local situations, and involve EU and national policy makers, healthcare professionals as well as all stakeholders, including patients' associations. This new coordinated approach, which stems also from a deeper understanding of the patient's conditions and of the social costs of respiratory allergies, will result in an improved quality of life and will relieve the burden that respiratory allergies, in particular severe conditions, places on patients, their families and on society as a whole.

To achieve this aim, it is essential to promote and strengthen alliances between patients and healthcare professionals. That's why, on behalf of EFA, I wish to thank ARIA, EAACI, ERS, GA2LEN, IPCRG and WHO GARD for endorsing the **EFA Book on Respiratory Allergies** as part of the initiatives to combat respiratory allergies.

I also wish to thank very warmly Daniela Finizio, Jean Ann Gilder and Giuliana Pensa from Scientific Communication srl (Naples) for their excellent work in coordinating the production of the book and to Felice Addeo from the University of Salerno for data analysis and data mining. And above all, my thanks go to the EFA patients' associations for their invaluable contribution in providing the information and for their untiring efforts to improve conditions for patients suffering from allergic rhinitis and asthma.

Finally, a special thanks to ALK-Abelló and Stallergenes for supporting the EFA Allergy Initiative with an unrestricted educational grant.

EFA Book on Respiratory Allergies. Raise Awareness, Relieve the Burden

Executive Summary

“Putting patients at the heart of healthcare”

Allergic conditions have a significant impact on the quality of life of patients and their families. This burden can only be relieved by continuous education of healthcare professionals (HCPs), and by raising awareness about respiratory allergies among the general public. EFA believes that all stakeholders in the healthcare sector should have the same focus, namely, the patient. We work for patients with patients by listening to their needs and translating that understanding into real change that improves the lives of EU citizens living with allergic diseases and decreases the inequalities of care.

Background

Respiratory allergies are increasing worldwide. Around 20% of people in Europe suffer from allergic rhinitis (15%-20% of whom are affected by a severe form of the disease [1]), whereas asthma is estimated to affect 5%-12% of people in Europe [2]. These diseases are the first cause of loss of workdays [3] and may even impair school performance [4]. Despite the significant social and personal impact of the disease, respiratory allergies are neglected and underestimated, and the general public is unaware that they are real diseases.

Accumulating evidence has led to the “one airway, one disease” premise according to which the two conditions should be viewed as one disease. In fact, there is a strong relationship between the two conditions: rhinoconjunctivitis is a risk factor to develop asthma later in life, and often patients with asthma also suffer from allergic rhinitis. The progression of one manifestation of allergy to another over a period of time is known as the “allergic march”. In this context, an integrated and unified approach to allergic rhinitis and allergic asthma is strongly recommended.

As recognized by international clinical practice guidelines and programmes, **control should be the main goal of the management of patients with respiratory allergies**. Too often patients tend to adapt to their symptoms. The lack of appropriate control may cause exacerbations, which, in asthma, may even cause irreversible damage to the lungs (irreversible obstruction).

EFA Allergy Project

The EFA Book on Respiratory Allergies is part of a broader 4-year initiative launched by the European Federation of Allergy and Airways Diseases Patients Association (EFA) in August 2010 to raise awareness of respiratory allergies. The book is based on the results of a questionnaire circulated among EFA member associations in 2011. Eighteen countries replied to the questionnaire: Austria, Belgium, Bulgaria, the Czech Republic, Denmark, Finland, France, Germany, Greece, Ireland, Italy, Lithuania, The Netherlands, Norway, Poland, Sweden, Switzerland and the United Kingdom for a total of 414 million people. The aim of the questionnaire was to collect up-to-date information, in each country, about respiratory allergy in terms of epidemiology, costs and practices as regards the management and treatment of patients, as well as support services for patients and best practices.

The burden of respiratory allergies in European countries

The picture that emerges from all the countries surveyed is that the burden of respiratory allergies is not adequately recognized by governments, decision makers, healthcare workers and often the patients themselves. As one association points out: “Patients do not know that treatments and measures exist that may improve their condition and prevent exacerbations”. For example, in Ireland, the Helping Asthma in Real Patients (HARP) study, conducted in conjunction with the International Primary Care Respiratory Group (IPCRG), the Asthma Society of Ireland and the Irish College of General Practitioners, found that the asthma was uncontrolled in 60% of patients. And over 50% of respondents reported symptoms of mild rhinitis with a further 20% reporting symptoms of significant rhinitis. In addition, respondents with uncontrolled asthma were more likely to have significant rhinitis (25%), and more likely to have symptoms of rhinitis (12%) than respondents with controlled asthma (15% and 27% respectively) (HARP Interim Report 2008 from www.ipcrg.org).

Regarding **prevention**, there have been some improvements with respect to the prevention of environmental risk factors. Measures have been taken in all the countries surveyed to ban smoking in public places and to improve outdoor air quality through anti-air pollution legislation.

The situation is less encouraging in the case of **preventive treatments**. In fact, although allergen specific immunotherapy seems to be the only treatment able to modify the course of the respiratory allergy in selected patients, especially those with a non-controlled disease, and may reduce the risk of asthma in patients with allergic rhinoconjunctivitis, access to immunotherapy is difficult in most European countries. This is mainly due to different healthcare and reimbursement policies (allergen specific immunotherapy is reimbursed only in some countries, and not in all regions of a country, which is the case of Italy), but it is also due to low awareness of preventive treatment on the part of GPs that see patients with respiratory allergies.

In general, access to treatment and specialist care in Europe is hampered by the low number of allergologists and physicians specifically trained in allergy and by different reimbursement policies. In fact, while asthma is now better recognized and adequate reimbursement policies and management programmes are in place, this is not the case of allergic rhinitis. In most countries, no matter how severe their condition, patients suffering from allergic rhinitis do not have access to specific reimbursement policies or management programmes.

There is an increasing need for more allergy specialists and for local and regional allergy diagnostic and treatment centres in order to facilitate timely referrals for patients with complex allergic diseases. Patients should have access to affordable and cost-effective therapy, and to novel therapies. Allergy diagnostic and treatment centres also play a crucial role in the education of medical students, allergy and asthma nurses and medical doctors.

In this context, national programmes, such as the Finnish Asthma Programme (1994-2004) and the Finnish Allergy Programme (2008-2018), which involve all stakeholders, have been effective in improving the management of patients suffering from these conditions and in reducing the costs and the impact of respiratory allergies on society as a whole. In fact, the more severe the symptoms of asthma, the greater the costs. Therefore, **prevention and good control of the disease can considerably reduce costs** [5, 6].

It also emerges from the EFA questionnaire that **allergies are a neglected disease**. Too often patients and even GPs underestimate the symptoms and the risk of exacerbation. Respiratory allergies are underdiagnosed and this prevents access to appropriate therapies and management. In many countries, in particular in France, Italy and Lithuania, patients do not have easy access to clear information about allergies, severity and appropriate control measures. In other countries, information exists but greater coordination of the information is needed.

Patients' associations play an important role in the management of respiratory allergies by providing support and information and by promoting effective education about preventive measures and a healthy lifestyle. The patients' associations that replied to the questionnaire are all active in implementing best practices to improve the quality of life of patients also in coordination with professional healthcare associations.

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Call to Action: Raise Awareness, Relieve the Burden

Respiratory allergies in Europe are increasing and affect around 20%–30% of the European population. Allergies are a real and serious disease, they place a considerable burden on European societies, and on patients and their families. The European Federation of Allergy and Airways Diseases Patients Associations (EFA) calls upon the European Union (EU) and Member States to take the necessary steps to develop a strategic, comprehensive and integrated approach to respiratory diseases with a focus on respiratory allergies that brings all initiatives and actions under one umbrella, and supports the launch and implementation of national programmes on respiratory allergies.

EFA calls upon European policy makers to coordinate actions to:

1. Increase the political recognition of respiratory allergies as a real and serious disease
2. Promote national programmes on respiratory allergies
3. Prioritize the management and control of respiratory allergies
4. Promote training in allergy for healthcare professionals to improve accurate and early diagnosis
5. Align healthcare and reimbursement policies, to support appropriate disease management
6. Improve indoor air quality

1. Increase the political recognition and awareness of respiratory allergies as a real and serious disease

Respiratory allergies in Europe affect around 20%–30% of the European population. Nevertheless, allergies, and in particular respiratory allergies such as allergic rhinitis (e.g. hay fever), are not considered real and serious diseases, and, as a result, they remain frequently underdiagnosed and undertreated despite the heavy burden they place on patients, their families and society as a whole.

We call upon the European Union and Member States to recognize respiratory allergies as a serious disease and a real public health problem and to adopt a comprehensive and integrated approach to address these problems in order to improve the quality of life of patients, and decrease the social and economic burden of the disease.

2. Promote national programmes on respiratory allergies

Awareness of respiratory allergies remains relatively low in Europe. Many healthcare professionals and patients consider respiratory allergies, particularly allergic rhinitis, a trivial condition. Patients do not understand what inflammation in allergy means and are often unaware of the implications accompanying the progression of allergies. National programmes on respiratory allergies that involve healthcare authorities, healthcare professionals, patient organizations and all relevant stakeholders are essential in achieving better awareness and control of these conditions.

We call on the EU and Member States to implement large scale public health campaigns to increase awareness of allergies including respiratory allergies amongst the general public, general practitioners, and patients to prevent the exacerbation of the conditions and reduce the burden on society. These measures should aim at targeting the inequalities among EU citizens thus achieving equal access to treatment, preventive treatments, reimbursement and information and education programmes in particular for patients with moderate/severe conditions.

3. Prioritize the management and control of respiratory allergies

Respiratory allergy is a complex condition that can have a severe impact on daily life. It can result in work and school day losses and in a reduction of productivity; loss of confidence and sometimes depression. Effective management of respiratory allergies is crucial in keeping control of the condition to avoid exacerbation; and ultimately to improve the quality of life of the patients. Too often patients tend to adapt to and to live with their symptoms. The lack of appropriate control may cause exacerbations that, in asthma, may even cause irreversible damage to the lungs (irreversible obstruction).

We call upon the EU to adopt measures to establish European guidance on the appropriate management and control of respiratory allergies based on a multidisciplinary approach in order to avoid exacerbations.

4. Promote training in allergy for healthcare professionals to improve accurate and early diagnosis

In most European countries there is a lack of allergologists and physicians with specific training in allergy. Allergology is not recognized as a specialization in many European countries. Respiratory allergies are often dealt with in primary care. This means that patients often receive a late diagnosis and not always the appropriate treatment in line with the most recent international evidence-based guidelines. Nurses and pharmacists also play an important role, particularly in promoting early diagnosis, in monitoring and managing patients with a mild condition and in recognizing the onset of more severe symptoms thereby preventing exacerbations.

We call on the EU and Member States to ensure that allergology is included in the training of medical students and that dedicated training for physicians is available in all European countries. Dedicated training in allergies should also be provided to nurses and pharmacists.

5. Align healthcare and reimbursement policies, to support appropriate disease management

Allergen specific immunotherapy seems to be the only treatment able to treat and modify the course of the respiratory allergy in selected patients today, and may reduce the risk of asthma in patients with allergic rhinoconjunctivitis. However, access to and reimbursement of allergen specific immunotherapy is difficult in most European countries.

We call on the EU and Member States to improve access to preventive and/or disease modifying treatments.

6. Improve indoor air quality

European Union governments and the EU pay less attention to indoor air quality than to outdoor air quality. Poor indoor air quality and cigarette smoke are risk factors for respiratory allergies. Exposure to a poor indoor environment (e.g. air pollution in dwellings) has been linked to asthma and allergy symptoms, lung cancer and other respiratory and cardiovascular diseases, and is a real health problem. In addition, poor air quality can trigger exacerbations and worsen the patient's conditions. Patients have the right to breathe freely, and should have access to safe environments, in particular indoors, such as schools, public buildings, hotels, etc.

We call on the EU and Member States to ensure good indoor air quality, including measures to abolish smoking in both the work place and public places across Europe and a joint framework on healthy air indoors.

We call on the EU and Member States to develop EU guidelines for a healthier indoor environment including in schools and dwellings.

1. Basic Facts

What is allergy?

The term allergy is used to describe an overreaction to substances in the environment that are harmless for most people, but induce an immune response that causes a variety of symptoms in predisposed people.

Types of allergy and symptoms

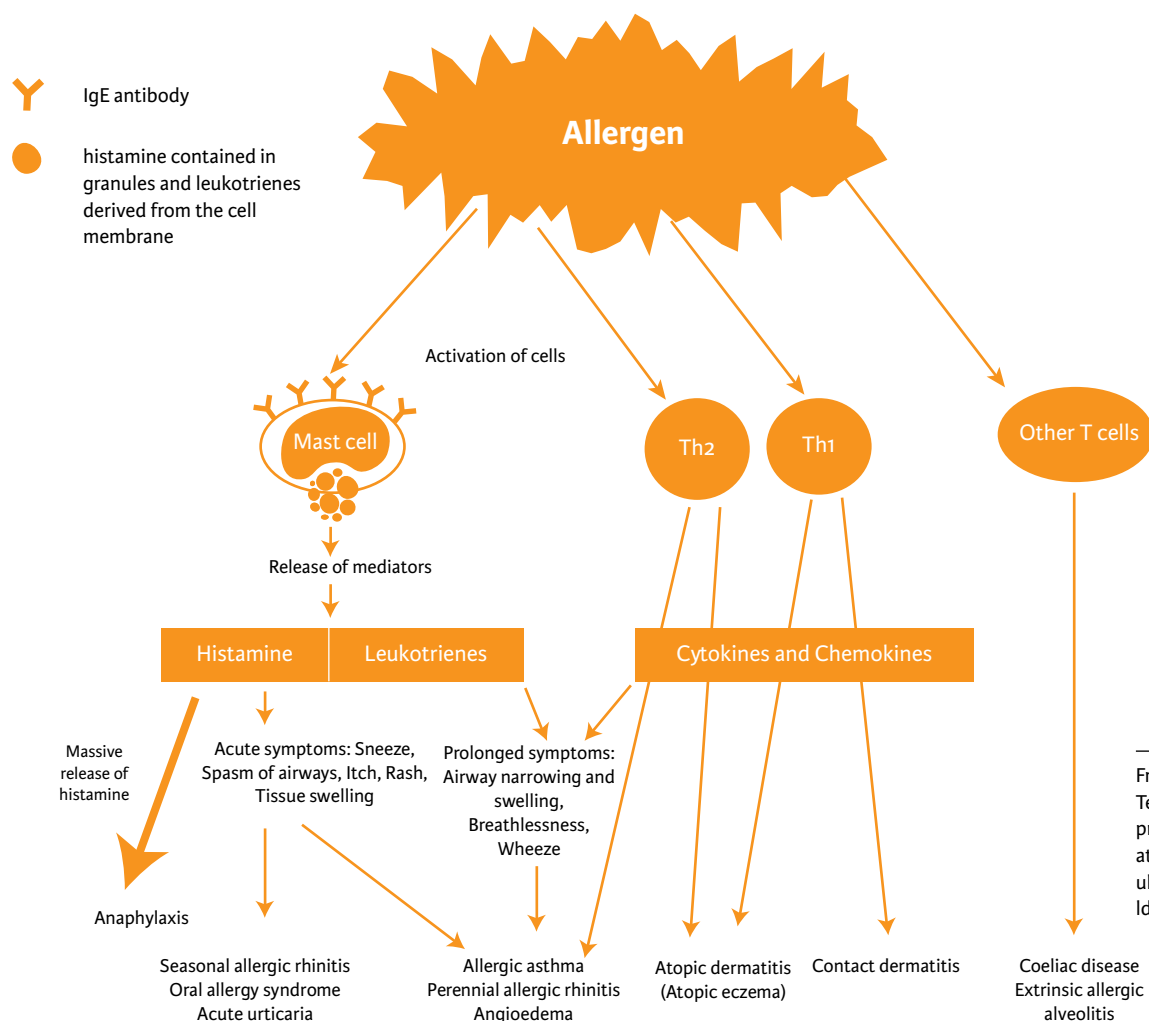
- **Respiratory allergies:** allergic rhinoconjunctivitis and allergic asthma, which cause wheezing, coughing, shortness of breath, sneezing, runny nose and sinus problems, and also red, watery and itching eyes.
- **Skin allergy (dermatitis):** atopic dermatitis (eczema) and contact dermatitis, which mainly cause skin rash.
- **Other allergies:** food allergies and insect venom, which cause different types of reactions that in some cases may be life-threatening (anaphylaxis).

Any substance that causes your body's immune system to overreact and produce antibodies against it is called an allergen. The most common sources of allergens are:

- house dust mites
- pollens
- pets
- fungal or mould spores
- food (particularly milk, eggs, wheat, soya, seafood, fruit and nuts)
- wasp and bees stings
- some medicines
- latex
- household chemicals (irritants such as detergents and fragrances)

Modified from NHS www.nhs.uk/conditions/Allergies

The mechanism of the allergic reaction



How do you get allergies?

An allergic sensitization develops when the body's immune system reacts to an allergen as though it is harmful, like it would for an infection. It produces a type of antibody, a protein that fights off viruses and infections, called immunoglobulin E (IgE) to fight off the allergen.

When the body comes into contact with the allergen again, IgE antibodies are released, causing inflammatory mediators to be produced. Together, these cause the allergy symptoms.

One of the most important mediators involved in an allergic reaction is histamine, which causes:

- tightening of your smooth muscles, including those in the walls of your airways
- more mucus to be produced in your airways, causing coughing, local itching and burning

Who is at risk?

Some people are more likely to develop IgE antibodies to allergens because it runs in their family. If this is the case, you are said to be atopic, or to have atopy. People who are atopic are more likely to develop allergies because their body produces more IgE antibodies than normal.

Environmental factors also play a part in the development of allergic disorders. The exact role of the environment is unknown, but studies have shown that a number of factors seem to increase the chance of a child developing atopy, such as:

- growing up in a house with smokers
- using antibiotics unnecessarily
- a certain level of exposure to dust mites*
- a certain level of exposure to pets*

* However, the introduction of high or low exposure may result in the development of tolerance to house dust mite and pet allergens among children.

Boys are more likely to develop atopy than girls, as are babies who have a low birth weight. The reasons for this are unclear.

Source: NHS Choices, UK www.nhs.uk/Conditions/Allergies/Pages/Causes.aspx Last reviewed: 23/03/2010

Respiratory allergies: A global problem

Allergies are increasing dramatically worldwide. Approximately 10%–30% of the world's adult population and up to 40% of children are affected by some form of allergy. **Respiratory allergies are the most common allergies in Europe and worldwide. Allergic rhinitis (with or without conjunctivitis)** affects 5%–50% of the population worldwide among which 15% to 20% suffer from a severe form of the disease [4], and its prevalence is increasing [5, 6]. It is estimated that allergic asthma affects 5%–12% of people in Europe [7].



Respiratory allergies in a nut-shell

	Definition	Symptoms
Allergic rhinitis	A common and distressing inflammatory condition affecting the upper airways and the membranes of the nose and eyes, caused by an allergic reaction to an allergen. Conjunctivitis often accompanies this condition. In this case, it is known as allergic rhinoconjunctivitis. This condition is often associated with asthma.	Blocked or running nose, sneezing, itching and watering eyes and inflamed eyelids. Symptoms may be seasonal (hay fever) or year-round.
Allergic asthma	A form of asthma caused by exposure of the bronchial mucosa to an inhaled airborne allergen. Asthma is a commonly occurring and potentially life-threatening illness where the respiratory airways become inflamed and swollen. This inflammation also causes an increase in airway responsiveness to a variety of stimuli.	Shortness of breath, tight chest, cough or bronchospasm, wheezing. These symptoms are usually associated with widespread but variable airflow limitation that is at least partly reversible with medication.



“One airway, one disease”

A large body of evidence points to a link between allergic rhinitis and asthma. **Epidemiological studies have consistently shown that these conditions often co-exist in the same patient.** It appears that **at least 60% of patients with asthma suffer from rhinoconjunctivitis**, whereas between 20%–30% of patients with allergic rhinitis also have asthma [8, 9]. Moreover, patients with non-allergic asthma commonly present with rhinitis [5]. Allergic rhinitis is the most important risk factor for asthma and typically precedes asthma, thus contributing to unsatisfactory asthma control. The presence and type of asthma is influenced by sensitization, and by the duration and severity of allergic rhinitis [10]. Furthermore, non-specific bronchial hyperreactivity is more common in patients with rhinitis than in the general population. Indeed, up to 50% of patients with allergic rhinitis have increased bronchial hyperresponsiveness [5]. These findings, in addition to the fact that the same kind of pathophysiological changes occur after allergen challenge in the upper and lower airways, support the “one airway, one disease” premise [11].

The **one airway, one disease** premise marked a change in the approach to the diagnosis and therapeutic management of respiratory allergies. Instead of being viewed separately, an integrated and unified approach to allergic rhinoconjunctivitis and allergic asthma is now strongly recommended [12].

The prevalence of allergies in Europe

It is not an easy task to compare prevalence data from different European countries. In fact, there is no clear common definition of the disease for prevalence purposes. In most cases, if official data are available, the definition of allergy doesn't always include all allergic reactions. Moreover, in some countries, statistics may report only severe cases of hospitalization, and exclude mild/moderate allergies, or patients who only use over-the-counter medicines. Similarly, differences in prevalence may also depend on the degree of awareness about allergic diseases.

In general, the prevalence of allergic diseases is increasing throughout Europe and is no longer restricted to specific seasons or environments.

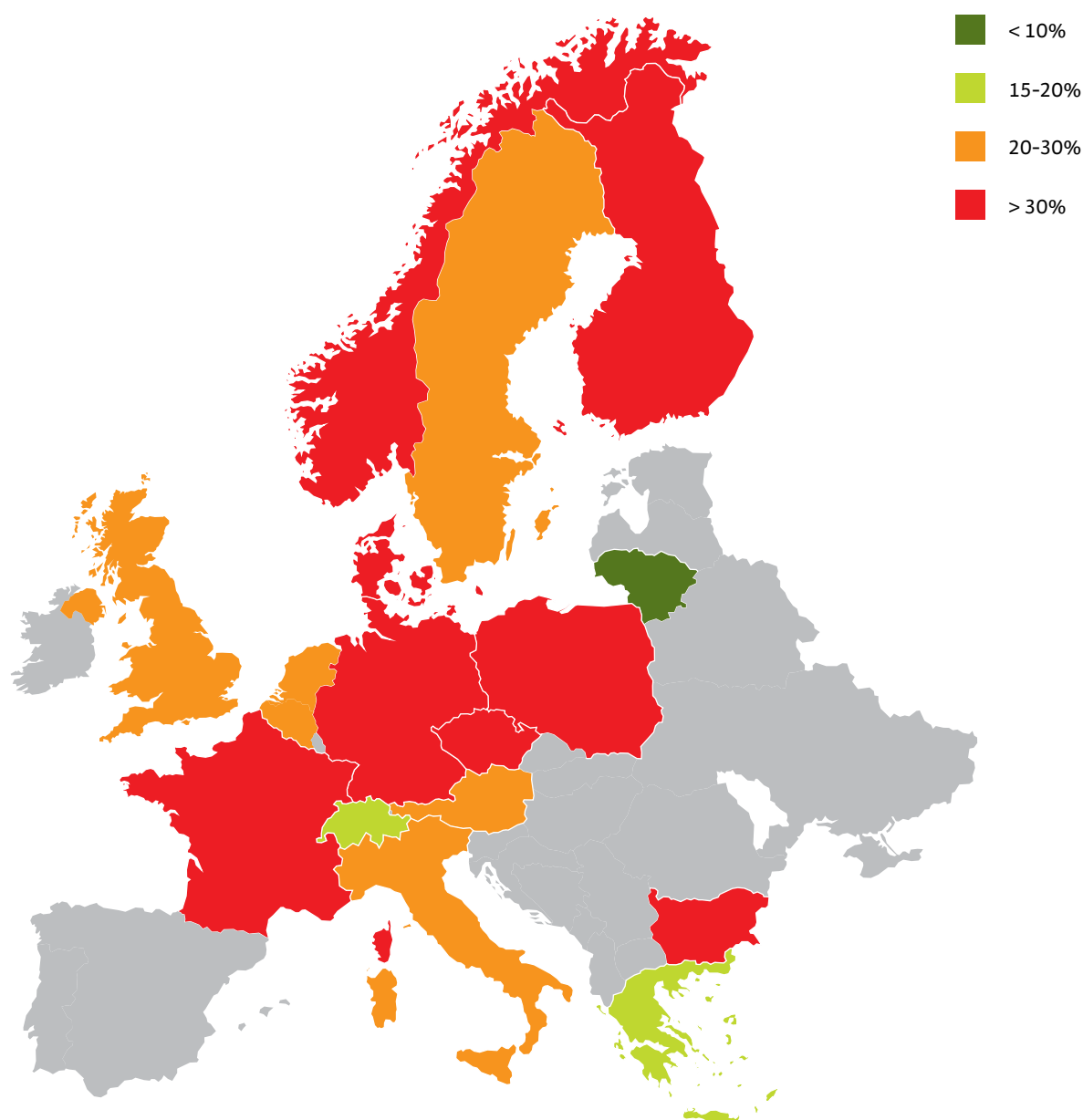
Atopy is the genetic predisposition to develop IgE-mediated sensitivity to common aeroallergens and is the strongest identifiable factor predisposing to the development of asthma, especially in children.

From the WAO White Book on Allergy

Asthma is a chronic inflammatory disorder of the airways in which many cells play a role, in particular mast cells, eosinophils and T lymphocytes. Allergic asthma is the basic term for asthma mediated by immunological mechanisms. When there is evidence of IgE-mediated mechanisms the term IgE-mediated asthma is recommended. IgE antibodies can initiate both an immediate and a late asthmatic reaction. However, as in other allergic disorders, T-cell-associated reactions seem to be of importance in the late and delayed reactions.

From the GINA Guidelines

The prevalence of allergies (not only respiratory allergies) in the countries surveyed



Austria: Statistik Austria (Chronic Diseases 2006/2007).

Bulgaria: Allergy and Asthma Suppl, 2000 and Official Reports of President of Society, 2006, 2007-2010.

Czech Republic: Kratenova J., National Institute of Public Health.

Denmark: The Public Health Report Denmark by The National Institute of Public Health 2007.

Finland: Haahtela & Hannuksela in: Allergia, Duodecim 2007.

France: Demoly P et al. Rev Fr Allergol 2011; 51:64-72.

Germany: German Society of Allergy and Clinical Immunology 2006.

Greece: Greek Society of Allergy and Clinical Immunology 2006.

Italy: Italian Society of Allergy and Clinical Immunology 2010. However, according to the Italian Ministry of Health (Relazione sullo stato sanitario del Paese 2007-8) the prevalence of allergy in Italy is 10.7%.

Lithuania: Data on patients >15 years old. Statistics Lithuania 2005 <http://www.stat.gov.lt/en/>.

The Netherlands: Netherland Society of Allergy.

Norway: Hattevig G. et al. *Pediatr Allergy Immunol* 1993; 4:182-186.

Poland: Polish Society of Allergology 2010.

Sweden: The Swedish National Institute of Public Health 2010.

Switzerland: Society of Allergy and Immunology 2010.

UK: British Society for Allergy and Clinical Immunology 2010.

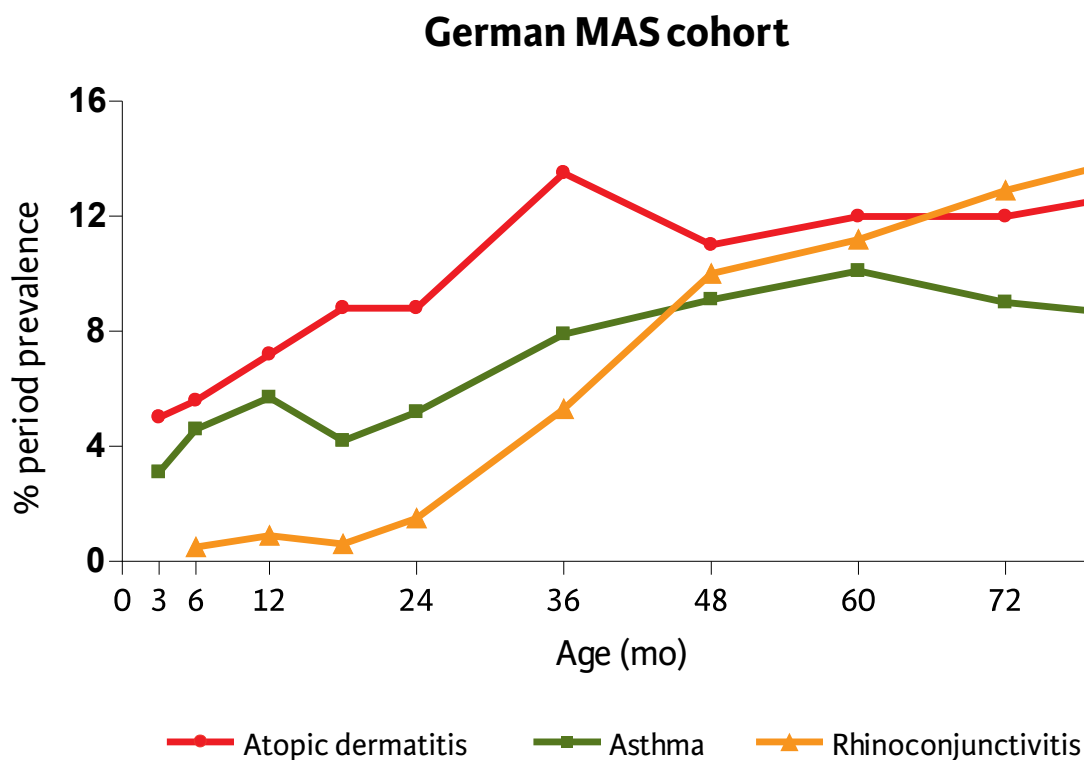
Respiratory allergies in children – a special issue

Asthma is the most common chronic disease in childhood and the leading cause of childhood morbidity from chronic disease as measured by school absences, emergency department visits and hospitalizations. Allergen-specific sensitization is one of the most important risk factors for the development of asthma in children [13]. In Europe, 10% to 20% of adolescents aged 13 and 14 suffer from severe allergic rhinitis [3].

In addition, children with one form of allergy are more likely to develop other forms of allergy. For instance, at a very young age they may have food allergies, and as this improves they develop respiratory allergies. The progression of one manifestation of allergy to another over a period of time is known as the “allergic march” [14]. Therefore, early diagnosis and adequate control of allergic rhinitis is crucial to halt the progression of the disease to asthma [5].



Development of allergic symptoms – Allergic march



Wahn & Mutius. J Allergy Clin Immunol 2001;107:567-74

2. Respiratory Allergies: Epidemiology



The WAO White Book on Allergy, published in 2011 by the World Allergy Organization [15], confirms that the prevalence of allergic rhinoconjunctivitis and allergic asthma is increasing worldwide. Allergic rhinoconjunctivitis is the most common non-infectious rhinitis. It affects approximately 400 million people worldwide [15]. Asthma is one of the most common chronic diseases, with an estimated 300 million individuals affected worldwide and its prevalence is increasing, especially among children [16].

Many studies have been performed to understand the epidemiology of respiratory allergies (allergic rhinoconjunctivitis and allergic asthma) in different countries. For example, the International Study of Asthma and Allergies in Childhood (ISAAC), which involves 306 centres in 105 countries, was established in 1991 to investigate asthma, rhinoconjunctivitis and eczema in children due to considerable concern that these conditions were increasing worldwide [17].

Based on the information provided by the EFA patients' associations and data collected from official sources, we have been able to draw a picture of the epidemiology of allergic rhinitis and allergic asthma in Europe. As suggested by the International Primary Care Respiratory Group (IPCRG) in the introduction to the WAO White Book, differences in prevalence among countries could be due to underreporting or to a lack of awareness of these diseases in deference to more important socio-economic medical problems.

Prevalence of allergic rhinitis

In a study of over 9000 people in Europe, Bauchau et al. [18] found that the prevalence of subjects with clinically confirmable allergic rhinitis ranged from 17% in Italy to 29% in Belgium, and the overall prevalence was 23%. But, surprisingly, 45% of these subjects had not been previously diagnosed by a physician. These statistics confirm the high prevalence of allergic rhinitis in Western Europe and demonstrates that this condition is frequently undiagnosed.

The data from the countries surveyed confirm the prevalence reported in the study by Bauchau et al. (Table 1).

The severity of allergic rhinitis symptoms is not considered in official statistics. The symptoms of allergic rhinitis are distressing and negatively impact on the patient's quality of life. Since allergic rhinitis is such a "neglected" condition, many patients who would benefit from treatment fail to receive it.

"One in three Britons suffers from an allergy, and it's got worse in the last 10 years."

British Allergy Foundation

Respiratory allergies – The inflammatory component

It is now well recognized that allergic inflammation is a component of respiratory allergies. During attacks of asthma, the bronchial tubes become acutely inflamed, whereas in the case of rhinitis the mucous lining of the nose becomes inflamed.

Table 1. The prevalence of allergic rhinitis in the countries surveyed

Country	Prevalence	Reference
Austria*	16.4%	European Community Respiratory Health Survey
Belgium	28.5%	Bauchau et al. Eur Respir J. 2004; 24:758-64
Bulgaria	20%	Allergy and Asthma Suppl, 2000 and Official Reports of President of Society, 2006, 2007-2010
Czech Republic	18%	Kratenova J. National Institute of Public Health
Denmark	18%	National Institute for Public Health, www.si-folkesundhed.dk
Finland	30%	Haahtela & Hannuksela in: Allergia, Duodecim 2007
France	24.5%	Bauchau V et al. Eur Respir J 2004; 24:758-64
Germany	13%-24%	“Weißbuch, Allergie in Deutschland”; Verlag Urban & Vogel, Auflage 2010
Greece	10%	Allergy Unit, University Hospital Attikon, Athens, www.allergyattikon.gr
Ireland	10%	Asthma Society of Ireland
Italy	16.9%	Bauchau et al. Eur Respir J 2004; 24:758-64
Lithuania	19%	Database of the Health Information Centre of the Institute of Hygiene of the Ministry of Health of Lithuanian Republic, www.lsic.lt/stbprg
Norway	10-25%	Norwegian Health Informatics, www.nhi.no
Poland	22.5%	ECAP (Epidemiology of Allergic Disorders in Poland) study
Sweden	20%	The Swedish National Institute of Public Health
Switzerland	13.5%	Wüthrich et al. Int Arch Allergy Immunol 1995; 106:149-56
The Netherlands	about 30%†	Nationaal Kompas Volksgezondheid
UK	20%	Scadding GK et al. Clin Exp Allergy 2008; 38:19-42

* Vienna Region

† All nasal allergies; data from 1996 and 2002.

Physicians need to be more aware of allergic rhinitis to ensure that all patients who need it receive an early diagnosis and appropriate treatment also based on follow-up when symptoms are moderate to severe.

Prevalence of asthma

In most of the countries surveyed there are no national statistics for allergic asthma alone, therefore we report data for all types of asthma (Table 2). Nevertheless, it must be noted that an allergy is the cause of asthma in about 80% of cases. Furthermore, according to the WAO, about 50% of asthmatics older than 30 years of age are concomitantly allergic. Younger asthmatics have an even higher incidence of allergies [19].

Studies from Europe and USA indicate that **one-third of school age children with asthma may be undiagnosed** [15]. Asthma is frequently undiagnosed also in adults and particularly in the elderly. This means that asthma is often undertreated and this may result in exacerbation and poor quality of life. Undertreatment may also increase the economic and social burden of the disease in terms of direct costs, and school and work day losses.

In most patients with a diagnosis, asthma may not be controlled. **This is partly because physicians often fail to appreciate the severity of their patient's asthma, and partly because patients do not take their prescribed controller medication** [15]. In addition,

“60-80% of allergic asthma cases in adults are caused by respiratory allergy”
Denmark

follow-up visits are not planned in advance; and often patients seek medical advice only when they have an acute asthma exacerbation. This worrying information illustrates the need for increased awareness and education about asthma among physicians (particularly general practitioners [GPs] and family paediatricians), patients and their families, as well as policy makers.

In Ireland, the HARP (Helping Asthma in Real Patients) study, conducted in conjunction with the IPCRG, the Asthma Society of Ireland and the Irish College of General Practitioners, found that the asthma was uncontrolled in 60% of patients. And over 50% of respondents reported symptoms of mild rhinitis with a further 20% reporting symptoms of significant rhinitis. In addition, respondents with uncontrolled asthma

Table 2. The prevalence of asthma in the countries surveyed*

Country	Prevalence	Reference
Austria	4.3%	Statistik Austria (2006/2007)
Belgium	8%	Astma en Allergiopel
Bulgaria	9%	Allergy and Asthma Suppl, 2000 and Official Reports of President of Society, 2006, 2007-2010
Czech Republic	8%	Kratenova J. National Institute of Public Health
Denmark	6.4%	Danish Institute of National Statistics
Finland	Adults 8-10% Children 5%	Finnish Allergy Programme 2008 -2018
France	6.7%	IRDES Question d'économie de la Santé - n. 138 Dec 2008
Greece	6-7%, Children up to 20%	
Ireland	11%	Elaborated from ISAAC and Central Statistics Office
Italy	6%	LIBRA-ARIA Project
Lithuania	1.3%	Database of the Health Information Centre of the Institute of Hygiene of the Ministry of Health of the Lithuanian Republic
Norway	Adults 9% Children 10%	Long term trends in asthma in Oslo, Norway: survey methods, symptoms and diagnosis, Jan Brøgger, Doctoral dissertation 2004 Nja F et al. Airway infections in infancy and the presence of allergy and asthma in school age children. Arch Dis Child. 2003 Jul;88(7):566-9
Poland	6%	PMSEAD study. J Investig Allergol Clin Immunol 2007;17(6):367-374
Sweden	10%	The Swedish National Institute of Public Health – 2010
Switzerland	2.3%	Global Initiative for Asthma (GINA) 2004
The Netherlands	Men: 6.5 per thousand, women: 7.9 per thousand 3.2%	Smit HA, Boezen HM, Poos MJJC. Hoe vaak komt astma voor en hoeveel mensen sterven eraan? In: Volksgezondheid Toekomst Verkenning, Nationaal Kompas Volksgezondheid. Bilthoven: Rijksinstituut voor Volksgezondheid en Milieu; 2006
UK	8.6%†	Asthma UK

*All asthma, not only allergic asthma.

† People receiving treatment for asthma.

were more likely to have significant rhinitis (25%), and more likely to have symptoms of rhinitis (12%) than respondents with controlled asthma (15% and 27% respectively) (HARP Interim report 2008 from www.iprg.org). In France, according to the Haute Autorité de Santé, in 2004 more than 80% of asthmatic patients had only partly controlled or uncontrolled asthma.

Apart from Ireland and France, in the countries surveyed we found no specific statistics about the severity of asthma as defined by the latest GINA recommendations [20].

Prevalence of respiratory allergy in children

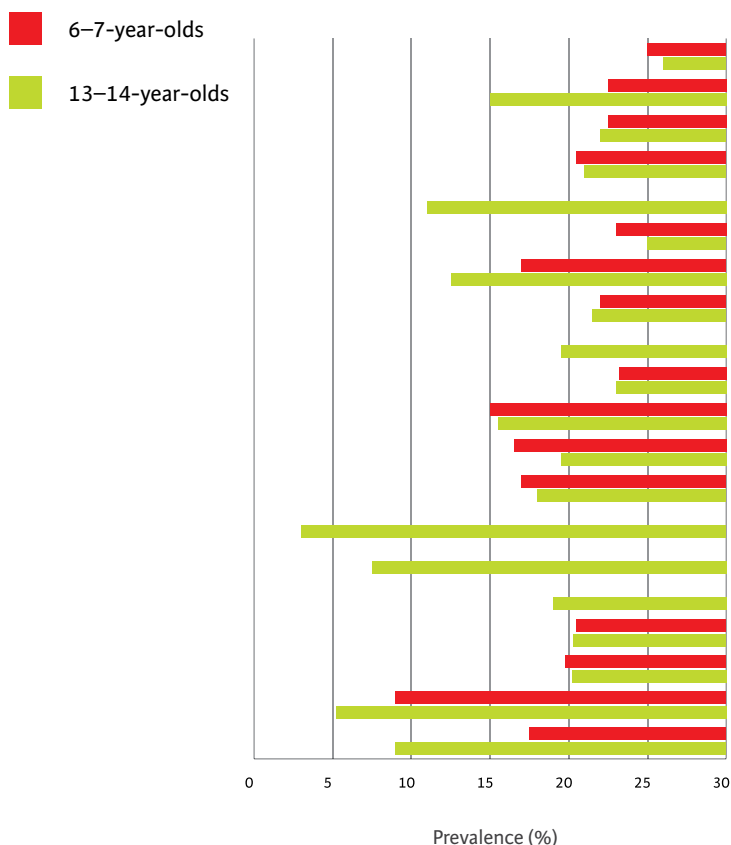
ISAAC Phase Three (1999–2004), which collected data from centres in 21 European countries, found that the prevalence of asthma and rhinoconjunctivitis is increasing in European children. It showed that the prev-

alence of asthma in children across Europe varies from 5% in Albania to over 20% in Ireland and the United Kingdom, whereas the prevalence of allergic rhinoconjunctivitis was highest in Malta and Poland (see Figure) [21].

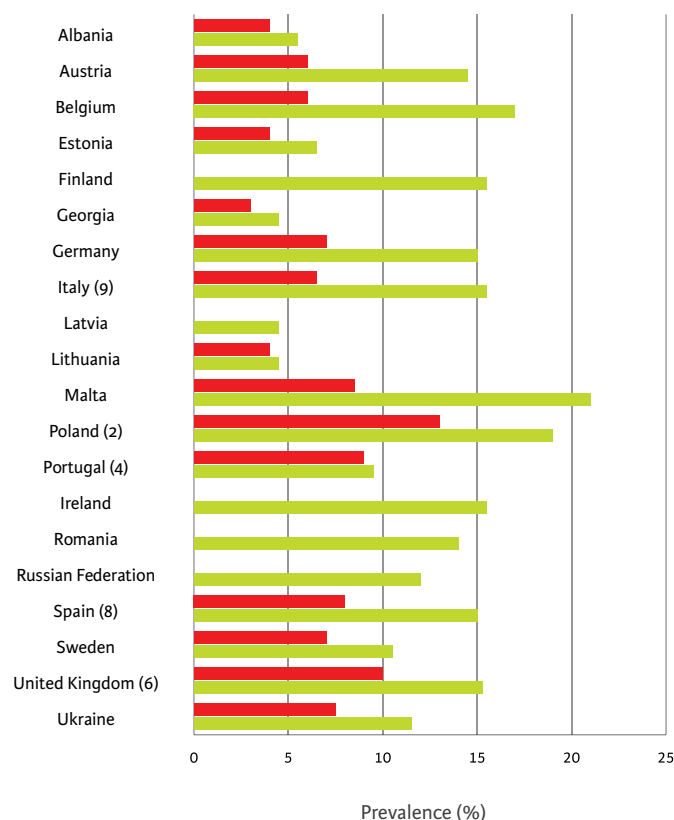
The ISAAC study also found an increasing trend in the prevalence of asthma and allergies particularly in urban areas, where children were found to have more allergic reactions to outdoor and indoor allergens [22]. In addition, the incidence of allergic symptoms in children was associated to allergens in indoor environments with poor air quality [23]. Children who are more frequently exposed to poor indoor air may be at greater risk of being affected by outdoor allergens [21].

Asthma is often uncontrolled because it is underdiagnosed and undertreated.

Prevalence of asthma symptoms in children aged 6–7 years and 13–14 years, ISAAC Phase Three, 1999–2004



Prevalence of allergic rhinoconjunctivitis symptoms in children aged 6–7 years and 13–14 years, ISAAC Phase Three, 1999–2004



Note. As the data were collected from specific centres only, prevalence figures are not country-representative. When data were collected from more than one centre, the number of centres is given in brackets. [21]

3. The cost of respiratory allergies for patients and for society



Direct costs are the costs directly attributable to the disease, for example hospitalization, emergency room visits, doctor's visits, homecare and medicine. Indirect costs are costs not directly attributable to the disease, for example working days lost and disability. We know that one in every four working patients took time off work due to allergic rhinitis [24]. Very few national statistics are available about the cost of respiratory allergies, particularly of allergic rhinitis, in the countries surveyed. What does emerge from the replies to the EFA survey and a search of the literature is that costs vary greatly from country to country; which may be also due to different reimbursement policies.

In all the countries surveyed, direct costs for respiratory allergy reach millions of euros (Table 3). According to statistics published in 2000, in Germany, direct costs for allergic rhinitis were €220M per year of which €179M for medication and €41M for doctor and hospital visits (Statistisches Bundesamt 2000). In Finland, the total direct costs for asthma (including loss of productivity) at the beginning of the Finnish Asthma Programme in 1993 were €218M and increased to €230M at the end of the programme in 2005. The increase was very small even though the share of asthmatics increased from 100 (index in 1993) to 140 (index in 2003). Moreover, the cost per patient per year decreased from € 1611 in 1993 to € 1031 in 2003, which is a decrease of 36%. Based on this encouraging experience, Finland launched the 2008-2018 Allergy Programme.

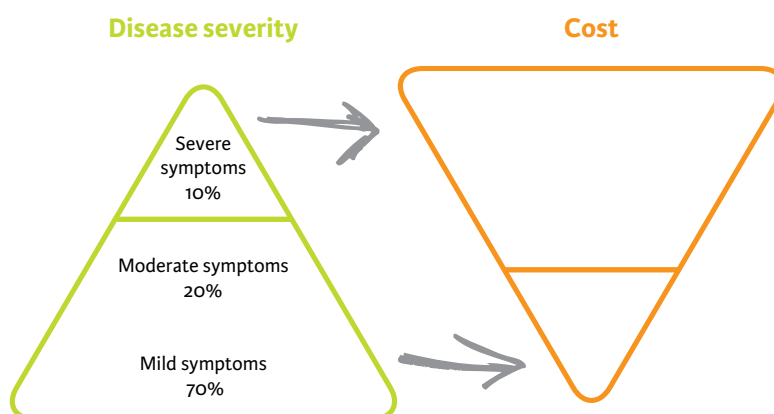
Despite the paucity of data, there is evidence that the more severe the symptoms of asthma, for instance, the greater the costs (Figure). Therefore, prevention and

good control of the disease can considerably reduce costs [25].

A survey of published data conducted in 2004 showed that the costs of childhood asthma also vary widely across the European Union. In fact, the direct and indirect costs of childhood asthma in Ireland amounts to an average of €613 per child each year versus €269 in the UK, €300 in France, €429 in Finland and €559 in The Netherlands (see Figure on page 25).

For children with respiratory allergies, in addition to direct and indirect costs, one must consider the cost of work day losses, as well as the loss of productivity due to a poor night's sleep for parents of children with allergic rhinoconjunctivitis. No specific study has been done in the countries surveyed to calculate this yet.

“Respiratory allergy causes a loss of 7,000,000 working days every year.”
France



The allergy pyramid. Most allergy symptoms are mild and intermittent, but due to the high prevalence of allergy, severe symptoms are also common and account for most of the costs. From: The Finnish Asthma Programme [25].

Table 3. Yearly direct costs for allergic rhinitis and asthma in the countries surveyed

Country	Moderate/severe allergic rhinitis	Allergic asthma
Austria ¹	—	Between €220M and €450M in 2004 ²
Belgium	—	€2,441 per patient (1996) ³
Denmark ⁴	Direct and indirect: DKK 16,000 per patient	Estimated direct and indirect costs DKK 1.9 billion (2000)
Finland ⁵	€118M	€230M (2005) €626 euro per patient
France	—	€1.5 billion €1,122 per patient ⁶
Germany	€220M ⁷	—
Ireland	—	€ 265 per patient - estimate from 2007 ⁸
Italy	€1,000 per patient ⁹	€1,400 per patient ¹⁰
Poland	—	PLN 3,988 per patient
Sweden ¹¹	—	SEK 4,931 per patient ¹²
The Netherlands	—	€300 per patient ¹³
UK	—	£889M (£171 per patient) ¹⁴

1. Costs of visits in Austria: GP (per office visit): €16.74; allergy specialist (per office visit): €7.73; accident & emergency (per visit): €270.00.

2. iPAC: An initiative to fight the burden of allergies in children. <http://onlinelibrary.wiley.com/doi/10.1111/j.1399-3038.2008.00762.x/full>

3. <http://www.educationsante.be/es/article.php?id=125>

4. Folkesundhedsrapporten 2007. http://www.si-folkesundhed.dk/upload/kap_10_astma_og_allergi.pdf

5. GARD/Finnish Allergy Programme. <http://www.who.int/gard/countries/Allergy%202008-2018%20Program.pdf>

6. Godard P et al. Costs of asthma are correlated with severity: a 1-yr prospective study. <http://erj.ersjournals.com/content/19/1/61.full>

7. Statistisches Bundesamt 2000.

8. Asthma Society of Ireland. <http://asthmasociety.ie/news-events/the-cost-of-asthma/>

9. Federasma website. www.federasma.org

10. Federasma website. www.federasma.org. Another study calculated the cost of asthma per patient per year in Italy to be €1226 (Dal Negro et al. 2007).

11. The total cost for respiratory allergies and asthma has been estimated to be SEK 7–10 trillion (Prof. Sven Erik Dahlen, Karolinska Institutet)

12. Jansson et al. 2007 The economic consequences of asthma among adults in Sweden.

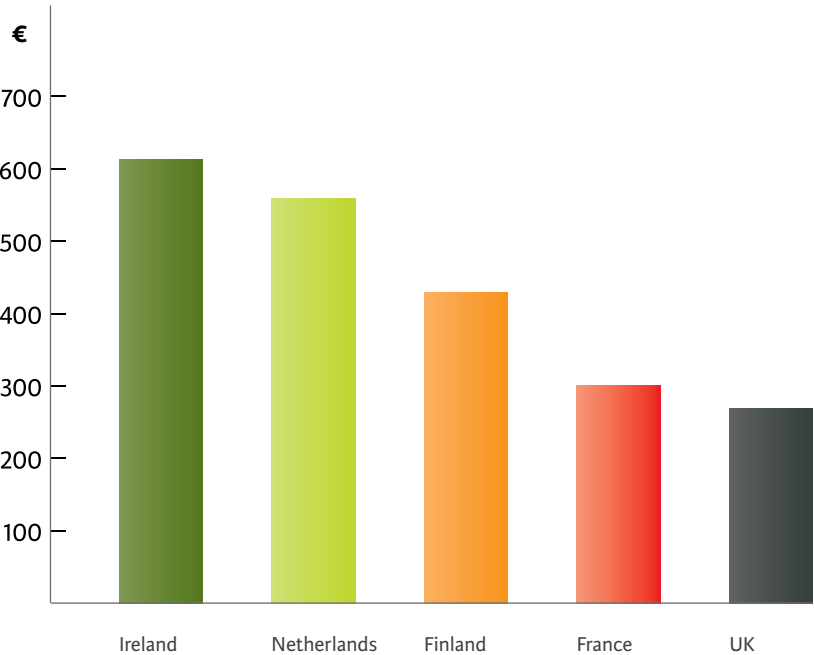
13. National Public Health Compass. <http://www.nationaalkompas.nl/gezondheid-en-ziekte/ziekten-en-aandoeningen/ademhalingswegen/astma/welke-zorg-gebruiken-patienten-en-kosten/>

14. Asthma UK document “Where do we stand?”, 2004. <http://www.asthma.org.uk/document.rm?id=18>

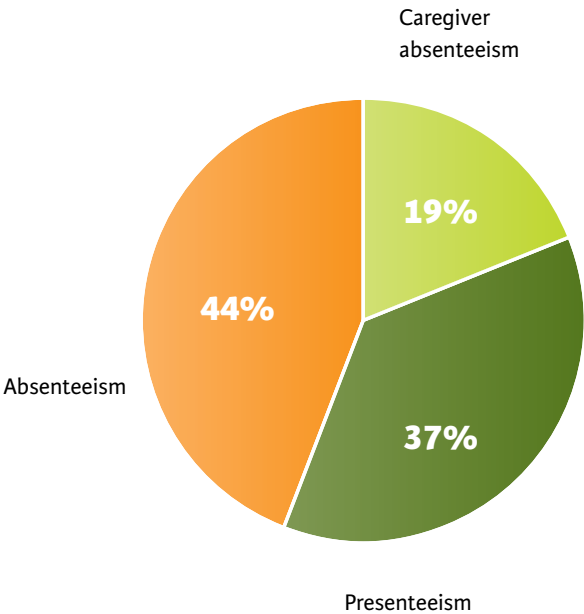
A recent study of Swedish patients suffering from allergic rhinitis estimated that the mean productivity loss was 5.1 days or €653 per worker per year, resulting in a total productivity loss of €2.7 billion a year [26]. Of the total costs, absenteeism (44%) was the dominant factor, followed by presenteeism (37%) and caregiver absenteeism (19%) (see Figure below). The study calculated the cost of rhinitis in Sweden at €2.7 billion a year in terms of lost productivity. A reduction in lost productivity of 1 day per individual per year would potentially save €528M.

It is even more difficult to calculate indirect costs for patients with allergic rhinitis since, as demonstrated by the Burden of Allergic Rhinitis in Europe study [27], fewer than 45% of these patients seek medical advice. In contrast, most use self-medication over-the-counter antihistamine therapy. In all countries surveyed, allergic patients make large use of over-the-counter therapies but percentages are unknown. In Germany it is calculated that approximately 10-15 million patients take symptomatic treatment (but only about 700,000 receive specific immunotherapy).

Yearly direct and indirect costs of childhood asthma per child



Factors of productivity loss for patients with allergic rhinitis



Source: Hellegren et al. 2010 [26].

Severe allergic rhinitis negatively impacts school performance

A case-control study of 1834 students (15-17 years) sitting for national examinations in 2004 in the UK [2] found that between 38% and 43% of students reported symptoms of seasonal allergic rhinitis on any one of the examination days.

Students who dropped a grade in any of three core subjects (mathematics, English, and science) were more likely to:

- have allergic rhinitis symptoms
- have taken any allergic rhinitis medication
- have taken sedating antihistamines on any examination day

In a French study [28] of 1002 students (18-29 years) who recently passed the baccalauréat:

- 22% had allergic rhinitis and 30% of them reported severe allergic rhinitis
- 20% of students reported underperforming at school
- 40% of students with allergic rhinitis were disturbed in their school-work
- 50% of students reported sleep disturbances and missed classes

“My son doesn’t sleep well because of his rhinitis, so he gets sleepy during the day. Although he is still young, I’m beginning to worry about his school work”

A mother from Italy

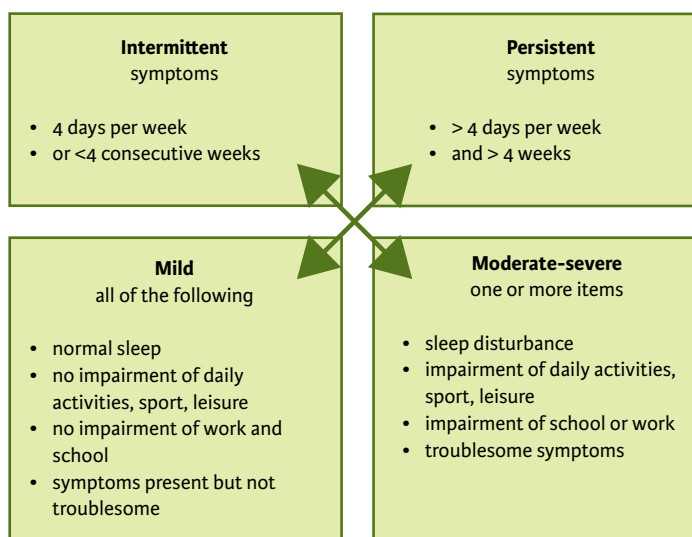


4. Respiratory allergies: Definitions



Allergic rhinitis: the ARIA classification

Traditionally, allergic rhinitis was divided into seasonal and perennial, however some allergens are present throughout the year (e.g., *Parietaria* in Mediterranean countries, pets and house dust mites). To address this issue, the Allergic Rhinitis and its Impact on Asthma (ARIA) guidelines, the first evidence-based guidelines on allergic rhinitis, proposed a new classification, namely “intermittent rhinitis” and “persistent rhinitis”, which is subdivided in mild and moderate-severe disease based on the severity of symptoms and quality of life outcomes [6]. This classification is useful for the implementation of treatment [15]. However, there are no widely agreed measures of allergic rhinitis control/treatment objectives, as there are for asthma.



Source: ARIA Guidelines [12]

The Allergic March (from allergic rhinitis to asthma)

The “allergic march”, which refers to the natural history of atopic diseases, is characterized by a typical sequence of sensitization and manifestation of symptoms that appear during a certain age period, persist over years or decades, and may show a tendency for spontaneous remission with age. Although wide individual variations may be observed, atopic diseases tend to be related to the first decades of life, and obviously require a juvenile immune system.

In general, no clinical symptoms are detectable at birth, and although the production of IgE antibodies is possible from the 11th week of gestation, no specific sensitization to food or inhalant allergens as measured by elevated serum IgE antibodies can be detected with standard methods.

During the first months of life, the first IgE responses to food proteins develop particularly those to hen’s egg and cow’s milk.

Even in completely breast-fed infants, high amounts of specific serum IgE antibodies to hen’s egg may be detected. It has been proposed that exposure to hen’s egg proteins occurs via the mother’s milk, but this needs further clarification. Sensitization to environmental allergens from indoor and outdoor sources requires more time and is generally observed between the first and tenth birthdays. The annual incidence of early sensitization depends on the amount of exposure.

Wahn U. What drives the allergic march? *Allergy* 2000;55;7:591-599

Asthma: the GINA classification

Formerly, asthma patients were classified according to their clinical severity into four levels: intermittent, mild persistent, moderate persistent and severe persistent. A major change came about in 2004 when the Global Initiative for Asthma (GINA) recommended that patients be classified based on their degree of clinical control rather than severity (Table 4). The new classification changed the approach to the asthma patient and reflected the recognition that control of clinical manifestations and of future risks are the main goals of asthma management.

Asthma control in children under the age of 5 years

Because of the peculiarities of asthma in children under the age of 5 years, GINA issued specific guidelines for

these young patients [13]. Asthma control in childhood will help to prevent exacerbations and severe damage of the lungs later in life. Scarce control (increased day-time cough, daytime wheeze etc.) is a strong predictor of exacerbation in children with asthma under the age of 5 [29]. Appropriate control in children will also reduce the need of medication thus preventing possible side effects and a “future risk” of harm due to excessive medications.

Classification of asthma based on control in children under the age of 5 years posed a problem because clinical control is assessed from reports of caregivers who may overlook less evident, albeit important, symptoms and signs. Consequently, the GINA experts developed a classification for this age group (Table 5).

Table 4. Clinical characteristics of controlled, partly controlled, and uncontrolled asthma

A. Assessment of current clinical control (preferably over 4 weeks)

Characteristic	Controlled (All of the following)	Partly Controlled (Any measure present)	Uncontrolled
Daytime symptoms	None (twice or less/week)	More than twice/ week	Three or more features of partly controlled asthma*†
Limitation of activities	None	Any	
Nocturnal symptoms/awakening	None	Any	
Need for reliever/ rescue treatment	None (twice or less/week)	More than twice/ week	
Lung function (PEF or FEV1)‡	Normal	<80% predicted or personal best (if known)	

B. Assessment of future risk (risk of exacerbations, instability, rapid decline in lung function, side-effects)

Features that are associated with increased risk of adverse events in the future include:
Poor clinical control, frequent exacerbations in the past year*, ever admission to critical care for asthma, low FEV1, exposure to cigarette smoke, high dose medications

*Any exacerbations should prompt review of maintenance treatment to ensure that it is adequate.

†By definition, an exacerbation in any week makes that an uncontrolled asthma week.

‡Without administration of a bronchodilator, lung function is challenging in children 5 years and younger.

Source: GINA Pocket Guide for Asthma Management and Prevention. Available from www.ginasthma.org

Table 5. Levels of asthma control in children 5 years and younger*

Characteristic	Controlled (All of the following)	Partly Controlled (Any measure present in any week)	Uncontrolled (3 or more of features of partly controlled asthma in any week)
Daytime symptoms: wheezing, cough, difficult breathing	None (less than twice/week, typically for short periods in the order of minutes and rapidly relieved by use of a rapid-acting bronchodilator)	More than twice/week (typically for short periods in the order of minutes and rapidly relieved by use of a rapid-acting bronchodilator)	More than twice/week (typically last minutes or hours or recur, but partially or fully relieved with rapid-acting bronchodilator)
Limitation of activities	None (child is fully active, plays and runs without limitation or symptoms)	Any (may cough, wheeze or have difficulty breathing during exercise, vigorous play, or laughing)	Any (may cough, wheeze or have difficulty breathing during exercise, vigorous play, or laughing)
Nocturnal symptoms/awakening	None (including no nocturnal coughing during sleep)	Any (typically coughs during sleep or wakes with cough, wheezing and/or difficult breathing)	Any (typically coughs during sleep or wakes with cough, wheezing and/or difficult breathing)
Need for reliever/rescue treatment	≤ 2 days/week	> 2 days/week	> 2 days/week

*Any exacerbation should prompt review of maintenance treatment to ensure that it is adequate. Although patients with current clinical control are less likely to experience exacerbations, they are still at risk during viral upper respiratory tract infections and may still have one or more exacerbations per year.

Source: GINA [13]

Success stories



Italy: “In the Piemonte region and in Tuscany, there is a well organized network of public allergological centres, and other regions are working in the same direction.”



France: “A specific protocol is implemented in schools for each asthmatic child to ensure that everyone caring for the child is aware of his/her asthma symptoms, and to help promote a better understanding of the child’s needs and medical requirements. This protocol should result in better management of symptoms and in dealing with emergency situations if they arise. It should also allow for effective communication between schools, the parents, child carers and medical professionals who should help both the asthmatic child and everyone involved in his/her care. This protocol exists also for children affected by food allergy but it is more difficult to implement. Concerning adults: once a disease has been recognized as an occupational disorder, costs related to the disease are reimbursed 100% by national health insurance, and compensation for eventual loss of salary can be applied for (under certain conditions).”



Czech Republic: “The establishment of 9 centres for difficult-to-treat asthma has lowered the morbidity and mortality in the last two decades; there have been no deaths in children up to 15 years old in the last few years.”

5. Respiratory allergies in Europe: Diagnosis and management



Who diagnoses respiratory allergies?

Patients should receive an accurate and early diagnosis made by a physician, preferably specifically trained in allergic diseases, to ensure appropriate and effective management and control of respiratory allergies and to avoid exacerbations. The diagnosis of respiratory allergies is based on clinical history, physical examination and specific questions. Skin prick tests and blood tests to measure specific IgE are useful to confirm allergic sensitization of the patient. They lead to the diagnosis and reveal which allergens are the most important causes of the symptoms so that appropriate treatment can be administered and patients can avoid exposure depending on symptom severity. These tests may not be necessary in cases of mild respiratory allergies that are kept under control.

In the countries surveyed, a number of specialists are involved in the diagnosis of respiratory allergies, with some differences between allergic rhinitis and allergic asthma, and between adults and children (see Figures).

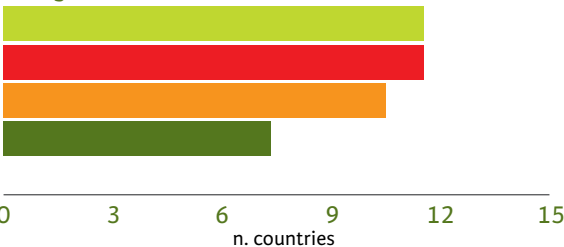
In adult patients, allergic asthma is often diagnosed by pulmonologists (13 replies). Primary care physicians are involved in the diagnosis of both allergic rhinitis and allergic asthma (11 replies respectively). ENT specialists diagnose allergic rhinitis in 11 countries. In children, respiratory allergies are diagnosed by the paediatrician in 12 countries.

Interestingly, allergologists diagnose allergic asthma and allergic rhinitis in adult patients in 9 and 10 countries respectively, and in 9 and 8 countries respectively

Allergic asthma



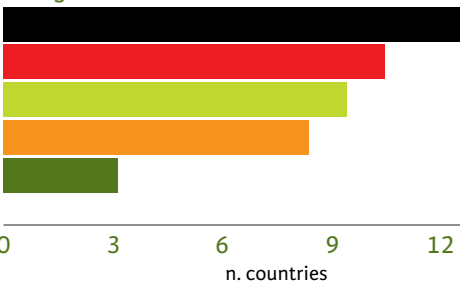
Allergic rhinitis



Allergic asthma



Allergic rhinitis



Who usually diagnoses respiratory allergy in adults in the countries surveyed?

- Pulmonologists
- Primary care physicians
- Allergologists
- ENTs

Who usually diagnoses respiratory allergy in children in the countries surveyed?

- Paediatricians
- Pulmonologists
- Primary care physicians
- Allergologists
- ENTs

in children. As shown in the Figures, it appears that allergologists are less involved than other specialists in the diagnosis of respiratory allergies. This may depend on the fact that in almost half the countries surveyed allergology is not recognized as a specialization, or that there are too few allergologists. Indeed, there are only two allergologists in the whole of Ireland, and allergology is not a specialty in Austria, Belgium, Denmark, France or Norway.

These replies are consistent with previous findings that in many countries patients with allergic rhinitis are often seen in primary care [30]. These findings also show the need for greater coordination among different specialists to ensure that patients receive an early diagnosis and appropriate care.

The management of respiratory allergies

Respiratory allergies can have a severe impact on daily life. Almost 70% of allergic rhinitis patients feel that their condition limits their way of life. The symptoms are distressing and adversely affect quality of life [24]; they also result in work and school day losses [1, 24]. It is noteworthy that allergic rhinitis has been associated with learning difficulties in children and a poor examination performance in teenagers [2]. A study showed that UK students with a history of allergic rhinitis who had symptoms > 2 (on a 10-point Likert scale) on any examination day were more than twice as likely to drop a grade [2]. Due to the resulting irritability, tiredness, inattention, lack of concentration, sleep disturbances and daytime sleepiness, allergic rhinitis could reduce short-term memory in children compared with non-allergic children. It is also accepted that allergic rhinitis in children, and its complications, can lead to emotional disorders (shame, loss of self-esteem), family problems (parent anxiety, overprotection, hostility), and even to an increased risk of depressive disorders [31].

In almost half the countries surveyed allergology is not recognized as a specialization

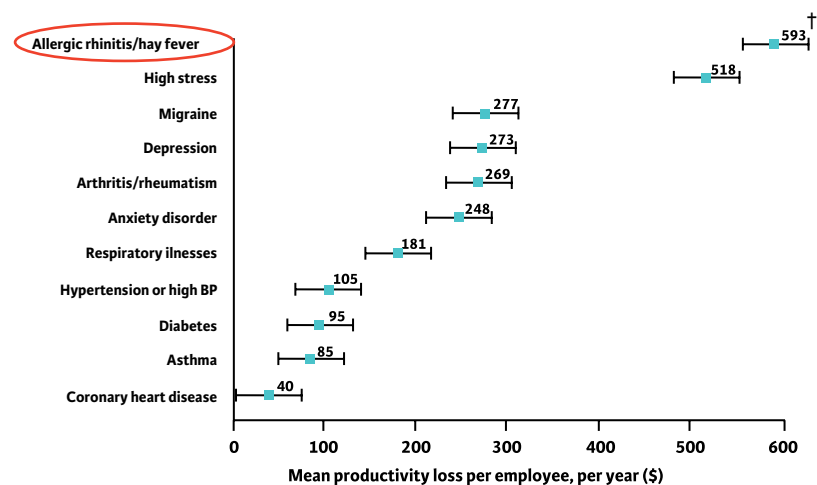
Effective management of respiratory allergies is required to improve the patient's quality of life, avoid more severe conditions and, in the case of allergic rhinitis, possibly prevent the condition from turning into asthma. We know that only 45% of allergic rhinitis patients seek medical advice or treatment for their condition [27].

A variety of measures and interventions are available to keep allergic rhinitis and allergic asthma under control: educational measures, appropriate monitoring, medication and measures to ensure a healthy environment. Guided self-management helps patients recognize the start of exacerbation of their lung, nose and eye symptoms, so that they can immediately act according to their individual written treatment plan. Ideally, the patients and their caregivers, GP or family paediatrician, a specialist and respiratory and rehabilitation nurses, where they exist, as well as dieticians and psychologists should be included in the strategy to control respiratory allergies.

From the replies of patients' associations to the EFA Questionnaire on Respiratory Allergies it emerges that patients are often not fully aware of the importance of the management of respiratory allergies. The reason is often that patients and caregivers do not understand what inflammation in allergy means and are often unaware of the implications accompanying the progression of allergies. The Lithuanian Council of Asthma Clubs stresses that, despite evidence of the social and economic burden of these conditions, **they are not considered a serious disease by the public**. Patients, especially those with less severe allergies, tend to adapt to their condition and they are not aware that their symptoms can be alleviated. The Association Asthme & Allergie (France) points out that patients are often not aware of the existence of therapeutic, educational and support services that can improve their condition. It appears that there is a general lack of knowledge in the countries surveyed about the severe consequences of poor management of respiratory allergies. In addition, the EFA survey shows that the importance of team work in the management of respiratory allergies is not fully recognized.

The key to effective management of patients with respiratory allergies is team work and coordination among the professionals taking care of the patient. This is well illustrated by the Finnish Asthma Programme (1994-2004) that aimed to reduce the burden of asthma on individuals and society [25]. The programme focused on specific training for primary care doctors and appropriate communication flows within a network of specialists, pharmacies and patients' organizations of asthma and allergies. This 10-year project resulted in better use of specialist services, shorter periods of specialist care and a more rational system (based on structured referrals) that allowed specialists to take

Comparison of the burden of allergic rhinitis to other diseases



†P<0.05 for allergic rhinitis/hay fever vs other conditions.

Lamb et al. Curr Med Res Opin. 2006;22:1203.

care of people suffering from more severe asthma. Importantly, regular check-up visits in primary care also increased. Given the successful results of the Finnish Asthma Programme, a programme specific for allergies has been established in Finland that runs from 2008 to 2018.

The role of general practitioners, primary care doctors and family paediatricians in the diagnosis and management of respiratory allergies

In the countries surveyed, GPs, primary care doctors and family paediatricians are the first healthcare professionals to see patients with respiratory allergies. They make the first diagnosis, follow-up patients with mild/moderate conditions and patients whose allergies are under control. In nearly all the countries surveyed (12/18) patients must consult their GP before seeing a specialist in the public health care system. Therefore, efforts should be made to spread awareness of early diagnosis and management guidelines among these first-line professionals. Moreover, their training should focus on recognizing the disease and on the management of exacerbations, and they should learn when to refer the patient to the specialist, and which specialist to refer to. The basic training should start in medical school for doctors and in nursing school for nurses.

GPs should also be aware that allergic rhinitis is a risk factor for asthma, and asthma should be routinely investigated in patients with allergic rhinitis. Spirometry should be part of the evaluation of asthma in patients with this disorder [32].

The role of specialist care in the diagnosis and management of respiratory allergies

A variety of specialists are involved in the diagnosis and management of respiratory allergies: allergologists, pulmonologists, ENT specialists and paediatricians, both in public and private healthcare. In Europe, patients with severe conditions are usually under specialist care.

In the countries surveyed, ENT doctors diagnose most of the moderate to severe forms of allergic rhinitis, and in some cases they also diagnose other allergies, and may treat severe cases and complications. In some countries, for example in Denmark and Norway, they are also involved in follow-up. In all countries, pulmonologists see patients with severe asthma and treat severe symptoms. In some cases, pulmonologists tend to deal with asthma in general rather than respiratory allergies. In fact, too often, they do not offer specific diagnostic tests for allergies or provide immunotherapy. Interestingly, pulmonologists in Lithuania give their patients an individual written treatment plan, and in-

form them about treatment options, preventive measures etc. This is also the case in Finland.

Patients in 50% of the countries surveyed have difficulty in seeing an allergy specialist. As shown in the Figure on page 34, in some countries allergologists do not exist or are too few (for example, allergology is not a specialty in Norway, Denmark or in many other EU countries), while in other countries they practice only in major cities (Lithuania and Italy). There are indications that allergology may soon be established as a specialty in Norway. In France, patients are rarely referred to a specialist by their GP due to the lack of allergologists. On the positive side, in most countries there are pulmonologists trained in allergic diseases.

Despite the high prevalence and complexity of allergic diseases, allergies are not sufficiently addressed in medical schools, during post-graduate medical training, or during nurses' training. Many countries do not recognize allergology as a specialty or sub-specialty [15]. As a consequence, many patients receive less than optimal care. The World Health Organization recently recognized that specific training in allergic diseases is required to respond effectively to patients' needs, and stressed the importance of promoting the recognition of allergology as a medical specialty [33, 34].

The role of other healthcare professionals: allergy and asthma nurses and pharmacists

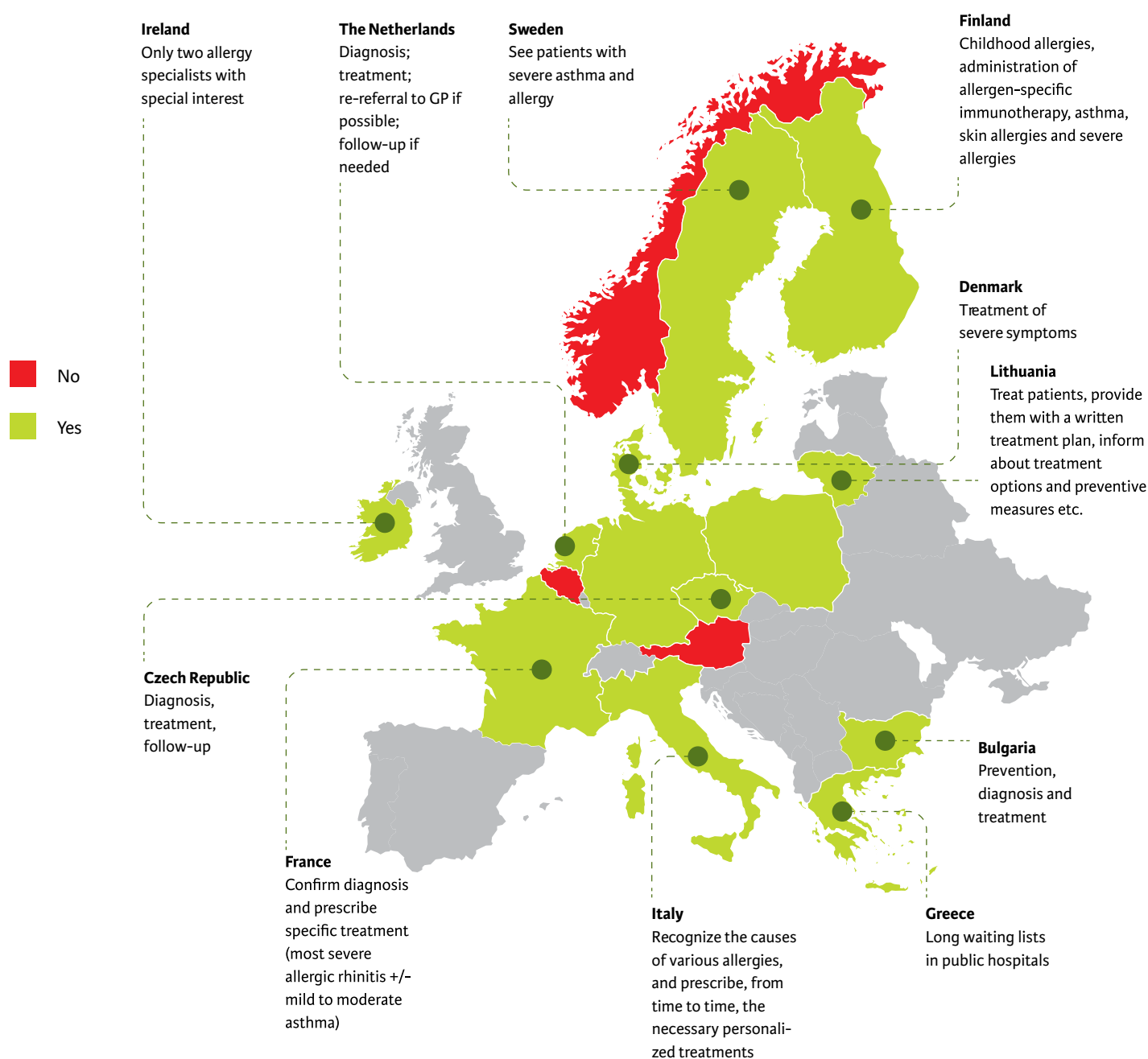
Allergy is a disease that should be monitored also when it is under control. Patient education regarding appropriate lifestyles and the use of devices should be part of the management strategy. Allergy and asthma nurses, where they exist, may play a key role in the management of respiratory allergies. In many coun-

“Only those living in larger cities have good access to treatment” Norway

International scientific societies and other associations specifically involved in the treatment of allergies and respiratory allergies

ARIA Allergic Rhinitis and its Impact on Asthma www.whiar.org
EAACI European Academy of Allergy and Clinical Immunology www.eaaci.net
EAACI ENT Section www.eaaci.net/sections-a-igs/ent-section
EAACI Pediatric Section www.eaaci.net/sections-a-igs/pediatrics-section
ERS European Respiratory Society www.ersnet.org
European Rhinologic Society www.europeanrhinologicsociety.org
Ga²len Global Allergy and Asthma European Network www.ga2len.net
GARD Global Alliance Against Respiratory Diseases
www.who.int/respiratory/gard/en
GINA Global Initiative for Asthma www.ginasthma.org
IPCRG International Primary Care Respiratory Group www.theipcr.org
WAO World Allergy Organization www.worldallergy.org

Presence of allergologists in the countries surveyed and their role



An accurate and early diagnosis of respiratory allergy is the first step to keep the condition under control.

tries, they are already involved in patient education and in monitoring the disease through, for example, validated questionnaires. However, the role of allergy and asthma nurses is not fully recognized and in most cases they are employed only in large allergy/respiratory centres. Training in respiratory allergies should be implemented for nurses in order to optimize the delivery of care to patients.

In the countries surveyed, pharmacists play an important role in supporting patients with respiratory allergies, particularly mild allergic rhinitis. Patients consult pharmacists mainly for advice about over-the-counter medicines and how to use therapeutic devices. For example, in Austria, most patients with mild/moderate allergy turn to a pharmacist for advice. This highlights the need to include pharmacists in the alliance against respiratory allergies. They should be given

specific information and updates on the most recent evidence-based guidelines, and training on symptom recognition. They should also learn how to motivate customers at risk for allergy to see a physician for a proper diagnosis. This is in line with the recommendations for pharmacists issued by ARIA [35] according to which pharmacists can play a role in:

- Recognizing allergic rhinitis and differentiating allergy from other causes including infection;
- Assessing the severity of allergic rhinitis;
- Managing patients under control and identifying patients for referral to physician.

The role of patients' associations in the diagnosis and management of respiratory allergies

Patients' associations can play a major role in the diagnosis and management of respiratory allergies in various ways. One important way is by organizing educational programmes. Gathering patients and/or their carers together in informative training and educational meetings to learn how to cope with their disease and to exchange knowledge is an important objective of patients' associations. The associations can also have an effect on the diagnosis and management of respiratory diseases by producing and disseminating reliable information specifically targeted to patients in layman's terms for easy comprehension and efficient communication.

Importantly, patients' associations initiated the recent move towards the patient taking a role in individualized guided self-management and he or she being considered as an informed decision-maker. The better a patient is informed and involved in treatment choices, the higher the probability that he or she will be compliant with the physician's advice. Partnership with healthcare professionals is one of the important goals of patients' associations and of EFA. In fact, patient 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 the patient's well-being also depends on the skills of professionals [36].

National programmes on respiratory allergies

Integrated national programmes, such as those launched in Finland [25, 37] and in the Czech Repub-

lic ([www.ginasthma.org/Czech Initiative For Asthma](http://www.ginasthma.org/Czech%20Initiative%20For%20Asthma)), have proven to be effective in terms of an improved quality of life for patients and reduced costs despite the increase of allergy in the population.

National programmes should:

- Involve different specializations as well as primary care physicians and paediatricians
- Involve allergy/asthma/respiratory/rehabilitation nurses, dieticians and psychologists
- Involve patients' associations and pharmacists' organizations
- Be based on the most recent evidence-based international guidelines
- Plan specific interventions for paediatric and adult patients
- Plan educational interventions
- Include healthy environment measures
- Be fully endorsed by the national health system (Ministry of Health)

Respiratory allergy programmes have been implemented in all the countries surveyed, however in some countries, programmes are limited to asthma (Ireland and Lithuania).

Allergy units: A multidisciplinary cost-effective approach

There is an increasing need for more allergy specialists and for local and regional allergy diagnostic and treatment centres in order to facilitate timely referrals for patients with complex allergic diseases. Patients should have access to affordable, cost-effective and novel therapies. These centres play a crucial role in the education of medical students, allergy and asthma nurses and medical doctors. They may also provide information and training for allergy and asthma patients, their families and caregivers. Allergy units would not constitute an additional burden, but can be established by reorganizing existing resources.

Allergy is a complex disease. In order to deliver effective treatment to patients and reduce the burden of allergies in general and of respiratory allergies in particular, there is a need for a multidisciplinary approach to control this condition and to reduce its burden.

It is possible to reduce the morbidity of allergy and its impact on individuals as well as on society

The Finnish Allergy Programme



The Finnish Allergy Programme (2008–2018) was based upon the very successful Finnish Asthma Programme (1994–2004) [25].

The aim of the Allergy Programme [37] is to educate and train physicians, pharmacists and nurses in each Finnish municipal healthcare centre about asthma and allergy care, prevention and diagnosis and management.

The overall aim is to reduce the burden of allergy. The six main goals are:

- To prevent the development of allergy symptoms: prevalence of asthma, allergic rhinitis and atopic eczema is decreased by 20%.
- To increase tolerance against allergens: number of subjects on elimination diets caused by food allergy is decreased by 50%.
- To improve allergy diagnostics: all patients are tested in quality certified allergy testing centres.
- To reduce work-related allergies: allergic diseases defined as occupational are decreased by 50%.
- To allocate resources to manage and prevent exacerbations of severe allergies: “Allergy Control Cards” are in use throughout Finland, and emergency visits caused by asthma are decreased by 40%.
- To decrease costs due to allergic diseases: predefined costs are reduced by 20%.

The programme involves the Ministry of Social Affairs and Health, the National Public Health Institute, the Social Insurance Institution, the Finnish Institute of Occupational Health, the Association of Finnish Pharmacies, specialist associations, the Finnish Lung Health Association (FILHA), and the patient organization, the Allergy and Asthma Federation, the Pulmonary Association (Hengityслиitto) and the Skin Association (Iholiitto).

All stakeholders are actively working and promoting implementation of the programme. The main tools are education of the healthcare professionals during their normal working hours (hence without any additional cost), information and awareness to the patients, families, lay public, politicians and authorities. Individual guided self-management with a written action plan for the patients is the practical tool.

The following Global Alliance Against Respiratory Diseases (GARD) partners co-operate in the programme: GA²LEN (European Allergy Network), the Global Initiative for Asthma (GINA), and the Allergic Rhinitis and its Impact on Asthma (ARIA) project.

6. Indoor environment and health



The quality of a given indoor environment is affected by ambient air quality, building materials and ventilation, consumer products, including furnishings and electrical appliances, cleaning and household products, occupants' behaviour, including smoking, and building maintenance (for example, energy-saving measures). Exposure to particulate matter, chemicals and combustion products, and to dampness, moulds and other biological agents has been linked to asthma and allergy symptoms, lung cancer, and other respiratory and cardiovascular diseases.

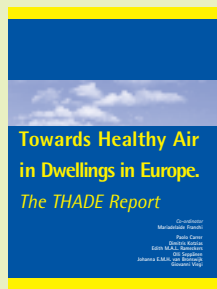
An analysis of the benefits of measures designed to improve indoor air quality showed that the greatest health benefits come from smoking restrictions. Building and ventilation policies that control indoor exposure to particulate matter, allergens, ozone, radon and noise from outdoors result in high long-term benefits. Better building management, prevention of moisture accumulation and mould growth, and prevention of exposure to exhausts from indoor combustion result in substantial medium- to long-term benefits. Substantial short- to medium-term benefits result from harmonized testing and labelling of indoor materials and consumer products.

Estimated years of life lost in reference year 2005 attributable to long-term PM_{2.5} exposure



From: ETC/ACC Technical Paper 2009/1. http://air-climate.eionet.europa.eu/docs/ETCACC_TP_2009_1_European_PM2.5_HIA.pdf.

EFA actions and recommendations for healthy indoor air quality



THADE – Towards Healthy Indoor Air in Dwellings in Europe

*Project coordinator: Mariadelaide Franchi
Supported by a EU grant under the Public Health
Programme 2002-2004*

Objectives

- 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 technologies to improve air quality in dwellings.
- Review legislation and guidelines on air pollution and air quality in dwellings.
- Produce maps of pollutants in dwellings (available on CD-ROM).
- Recommend an integrated strategy that defines appropriate indoor air quality policies for implementation in Europe, and identify appropriate technology.

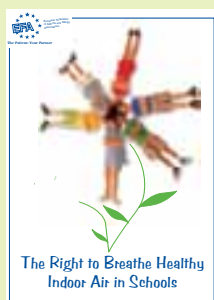
Results

The results of the THADE project confirm that air pollution in dwellings is a real health problem. It is a complex issue that must be approached at European and international level, and involves the medical profession, scientific societies, patients' organizations, lawmakers, architects and the building industry as a whole, ventilation experts, etc.

Conclusions and recommendations

- Indoor air quality (IAQ) is not taken in due consideration by either the public-at-large or policy decision makers.
- The public-at-large is unaware of the negative effects of poor IAQ.
- Air quality, mainly outdoor air quality, has received great attention in recent decades, whereas IAQ has been largely ignored.
- Health determinants of the indoor environment have been identified. The most relevant are: second-hand smoke, dust mites, mould, pollen, nitrogen oxide, formaldehyde, volatile organic compounds, suspended particulate matter, man made mineral fibres, cockroaches, allergens from pets, carbon monoxide and carbon dioxide.
- Reduction of indoor air pollution requires a combination of public health policies and protective measures taken by the individual.
- Indoor air pollution may cause or aggravate health effects.
- National and international bodies, together with all parties concerned, should draw-up comprehensive national/international plans to improve IAQ.
- Guidelines for a healthier indoor environment should be developed on European and national level with the help of professional societies.

The full THADE Report is available at www.efanet.org



EFA Indoor Air Pollution in Schools

*Project coordinator: Mariadelaide Franchi
EFA representative: Erkkka Valovirta
EU Commission grant 1999-2000*

The aim of the project was to compile an overview of literature data, and governmental and other initiatives relating to indoor air in schools, and to make recommendations for a healthy school environment.

From the research conducted, indoor air pollution in schools emerged as a threat to children, but a problem for which there are various solutions.

However, local initiatives cannot have a lasting impact. In fact, the general consensus arising from this study is that the complex issue of indoor air pollution in schools must be approached at a European and international level.

The key recommendations, made by a multidisciplinary panel of experts based on the data collected, were:

- Avoidance of environmental tobacco smoke.
- Avoidance of moisture/moulds in the building.
- Avoidance of allergen sources.
- Adequate cleaning and maintenance, practical shaping of the interior to facilitate cleaning and maintenance.
- Good control of the maintenance of heating and ventilation to ensure a satisfactory temperature and ventilation in the classroom.
- Adequate periodical monitoring of the indoor air quality parameters in schools.
- Appropriate training of students, teachers and school staff who are responsible for management, maintenance and cleaning.

The complete EFA Indoor Air Pollution in Schools report is available at www.efanet.org

7. Living with allergy in Europe: Access to information, care and services



In the attempt to understand what it's like living with allergy in Europe, the patients' associations were asked to give their views about:

- Access to information about the disease (including educational programmes for patients)
- Access to specialist care and treatment
- Access to support services

Access to information on respiratory allergies

In most countries, information for patients, their families and the public-at-large comes mainly from patients' associations or doctors' associations.

Another issue is the digital divide. In fact, the Associations from Lithuania and Italy observe that despite the wealth of information on the internet, often older patients and patients in rural areas do not have the possibility or knowledge to access information online. In addition, as pointed out by the Belgian and The Netherlands associations, patients may not distinguish between reliable and less reliable sources of information on the internet.

Some associations call for better coordination between organizations (patients, doctors and the government) to ensure effective delivery of information to patients as well as to the public-at-large (Belgium, France and The Netherlands). Moreover, national healthcare authorities should provide information for patients.

The availability of pollen calendars and the reporting of air pollution levels have improved over recent years.

In practically all the countries surveyed, information about pollen count and the air pollution level is available daily in the press and on the internet. In Italy and Lithuania, information in the media is limited to the peak pollen season.

Patients' empowerment and guided self-management measures

As stated in the WAO White Book [15], the most effective measure for the management for allergic disorders is to teach patients guided self-management skills.

“Information exists, but patients are not aware of it.”
France

Access to reliable information about allergies and appropriate environmental control measures



France
Italy
Lithuania



Austria
Belgium
Greece
Norway
The Netherlands



Czech Republic
Denmark
Finland
Germany
Sweden

“Allergy testing varies greatly with geography and the GP’s knowledge and competence.”
Norway

The EFA questionnaire revealed that patients’ empowerment and the use of guided self-management measures differ considerably between people and doctors involved in patients’ and professional associations and those who are not. This highlights the need to encourage patients to join associations also with a view to improving their condition.

In general, self-assessment tools are rarely used in the countries surveyed (Ireland, Lithuania, Norway, Belgium, Austria, France and The Netherlands). Self-assessment tools, such as peak flow meters, nasal peak flow meters, the asthma control test (ACT) and quality of life questionnaires enable the patient to recognize exacerbations and the need to refer to a specialist. Training patients to use self-assessment tools is time-consuming for busy GPs; consequently there is a need to train nurses to carry out this task or to establish guided peer-groups in patients’ organizations that can teach patients how to use these tools.

Access to specialized care and treatment

Consultation with a specialist for an appropriate diagnosis and management programme will result in better patient outcomes and a reduction in costs thanks to fewer misinterpretations of diagnostic tests that may lead to inappropriate treatment [15]. Unfortunately, almost half the patients’ associations surveyed find it difficult to access allergy specialists in their countries (e.g., in Denmark there are long waiting lists). This is due mainly to two factors: the lack of allergy specialists and because specialists are located mainly in large urban areas (see Figure on page 41). Obviously, this is a problem for patients living outside main centres.

“Not many people bother to travel to see a doctor for such a trivial thing as allergy”
Lithuania

Access to treatment and medications

Unfortunately, in many countries access to information about the treatment options available is considered “difficult” or “very difficult” (Belgium, Lithuania, Italy and Sweden). One problem is the paucity of information about treatment in plain, easy-to-understand language (Italy and Lithuania). Another is that doctors

often do not dedicate enough time to inform patients about treatment options.

There are some problems also in countries that judged access to information “normal” (Austria, Belgium, Denmark, France, Norway and The Netherlands). In The Netherlands there is a lot of information about treatment, especially as regards over-the-counter medicines, but it is not always from independent sources. Moreover, it is not always easy for non-experts to understand official information in, for instance, patients’ leaflets. Patients’ associations are often a primary source of information (Ireland, Norway and The Netherlands). In all the countries surveyed, patients’ associations are active in disseminating information to the public (see chapter 8).

Reimbursement policies

In severe respiratory allergies, as for all chronic diseases, reimbursement of treatment costs is crucial to ensure the patient’s compliance and adherence to their treatment plan. Compliance to treatment will result in control of the disease and prevent exacerbations, which in turn, will reduce the costs of hospitalization and of work or school days lost. If drugs are not reimbursed, patients tend to treat only acute symptoms [38]. In the countries surveyed, asthma treatments are reimbursed more often than treatments for allergic rhinitis. This is an example of the lack of awareness among policy makers and of the public-at-large about the impact of allergic rhinitis on health resources and its role as a risk factor for asthma [39].

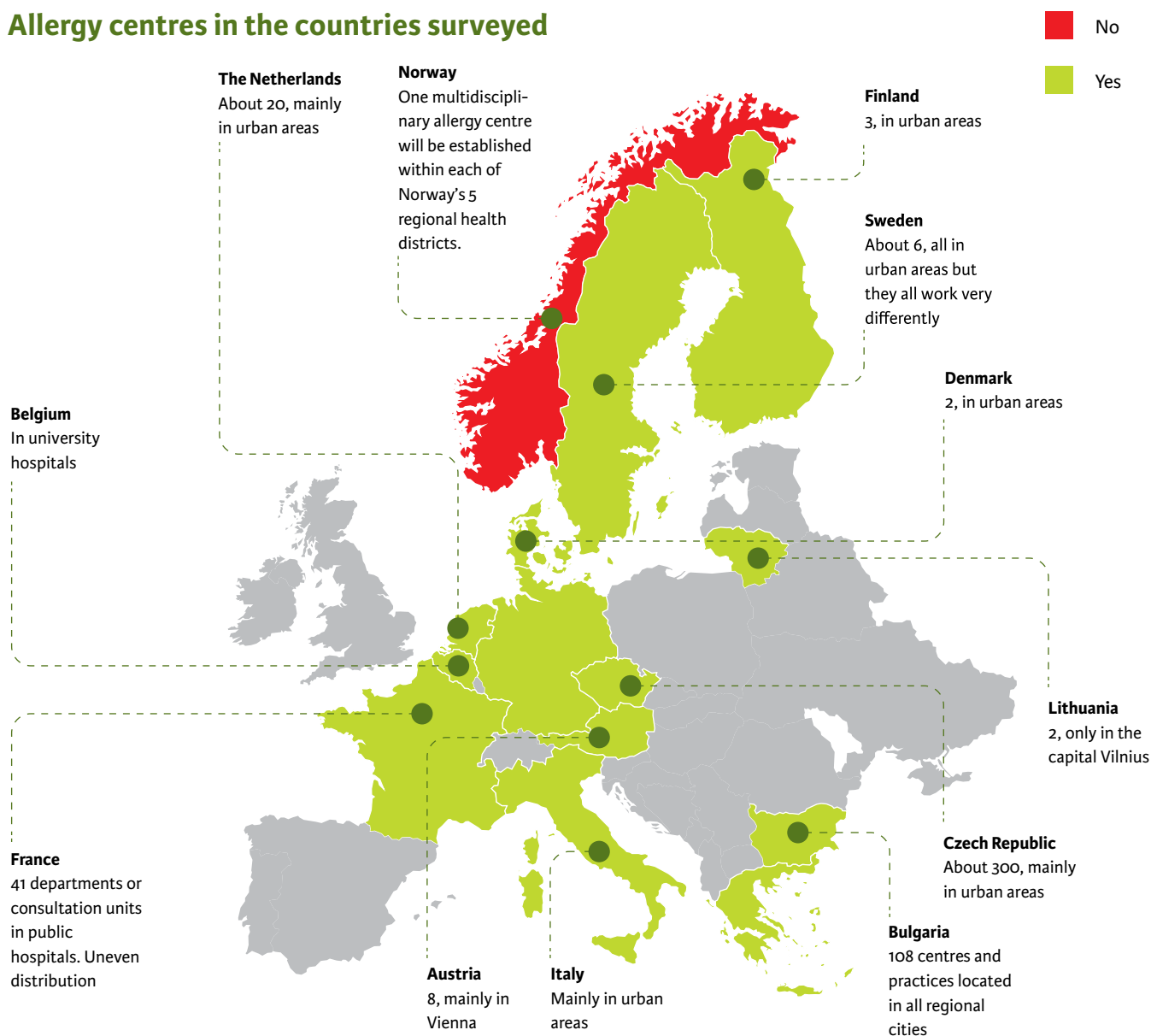
Over-the-counter medicines such as antihistamines are often used to treat acute allergic rhinoconjunctivitis, for example, during the pollen season. Antihistamines are widely used in all the countries that replied to the questionnaire, but the dimension of the phenomenon is unknown. There are no over-the-counter medicines for asthma.

The European Medicine Agency (EMA) has recognized allergen specific immunotherapy to be the only treatment to have disease modifying effect in allergic respiratory diseases. However, immunotherapy should be initiated at the early phase of the allergic disease in order to influence the natural course of the disease. In most countries, allergen immunotherapy, preferably initiated for patients with moderate to severe respiratory allergies not controlled by symptomatic treatments, is still not fully recognized and reimbursement policies vary greatly (see Figure on page 42). In fact, access to immunotherapy is judged “difficult” or “very difficult” in Belgium, Lithuania, Italy, Norway and Sweden and is very limited in Ireland. In some countries this therapy is not reimbursed, and it is available only in specialized centres (Belgium), which are mostly located in large cities.

Allergen specific immunotherapy for respiratory allergies

Allergen-specific immunotherapy, which consists in the administration of gradually increasing amounts of the most common allergens by the subcutaneous or sublingual route, is recognized to be effective and safe in the treatment of respiratory allergy. To-date, allergen-specific immunotherapy seems to be the only treatment that can modify the natural course of the disease. This may prevent the development of asthma in patients with allergic rhinitis and the onset of new sensitizations in mono-sensitized patients.

Allergy centres in the countries surveyed



In France, the reimbursement rate is evaluated according to the therapeutic benefit and takes into account several aspects: the disease severity, evaluation of the medication (benefits/risk balance, position in the therapeutic strategy, public health interest). Reimbursement rates vary as follows: 100% or 65% for serious or chronic diseases, and 30% or 15% for moderate or mild diseases. For reasons linked to economic policy or public health strategies, the evaluation of similar products may change at different times. Recently evaluated sublingual immunotherapy tablets are currently reimbursed at 15% despite their therapeutic value, versus 65% for sublingual drop preparations or subcutaneous injected allergen immunotherapy.

In Ireland, 65% of patients with respiratory allergies are not entitled to reimbursement. Furthermore, drug use is particularly expensive because the European transfer price in Ireland reaches as much as 300%. In Lithuania, asthma medications are reimbursed

100%. Allergic rhinoconjunctivitis medications are reimbursed 80% for children and not reimbursed for adults. In Italy, patients with asthma are entitled to reimbursement of medicines, but not patients with allergic rhinoconjunctivitis regardless of severity.

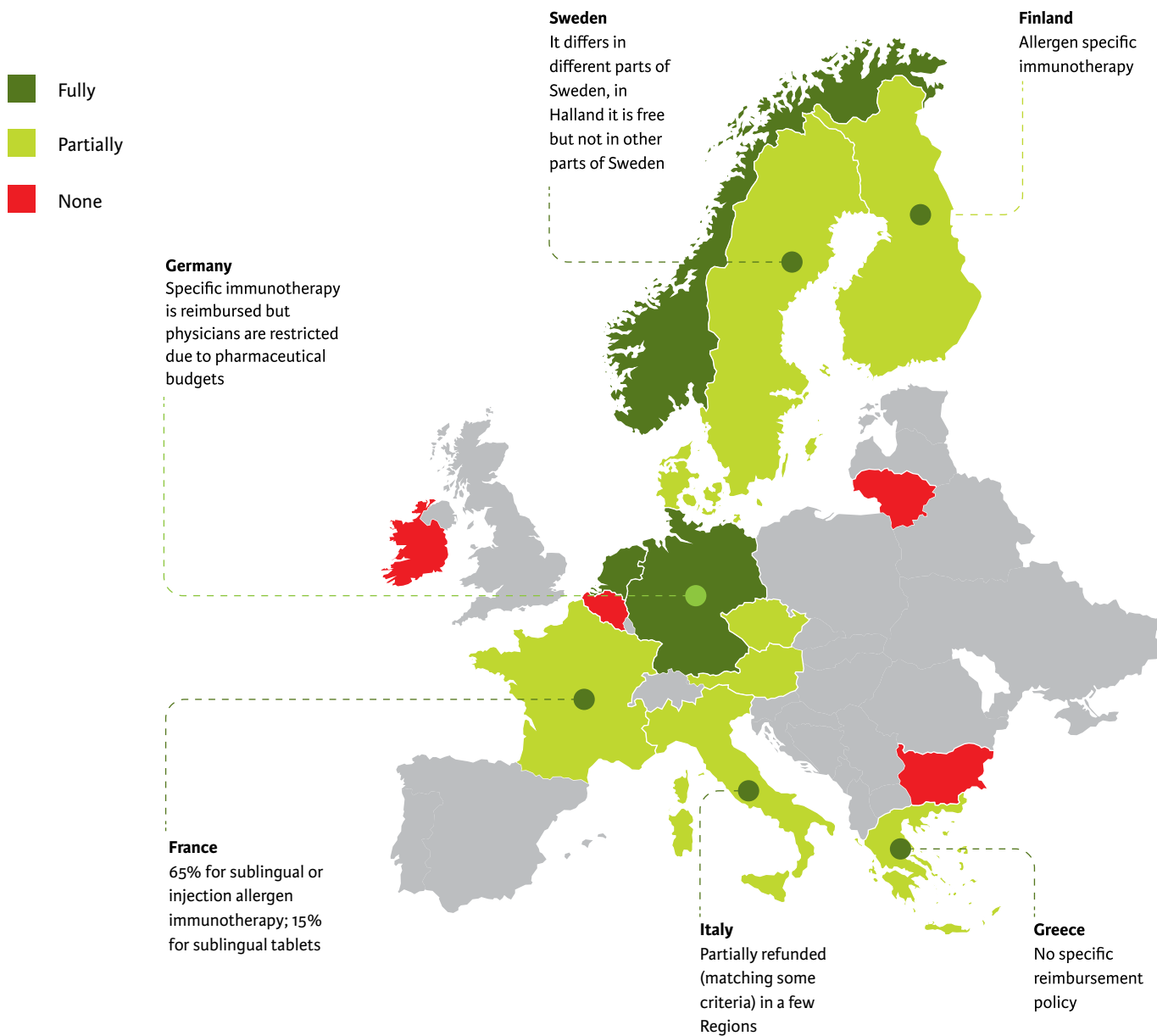
Support services for patients

Patients with severe chronic respiratory allergies often require continuous care and support to keep their disease under control, which, as stated in the WAO White Book [15], should be the main goal of the management of their condition. Support services include patient education programmes, patient support groups, help lines, and support for parents in the care of their allergic child.

Of the countries surveyed, only Finland provides support services for patients with severe chronic respiratory allergies. These are either delivered by the na-

“Patients with allergic rhinitis don’t even know that treatment could make them feel better”

Reimbursement policies for immunotherapy in the countries surveyed



tional healthcare system or are part of specific national programmes. In most other countries, support services are organized by patients' associations. For example, such services are provided by Federasma (Italy) thanks to good cooperation between patients and doctors' associations; the government is not involved. The Lithuanian patients' association runs short-term support programmes, but lacks the financial resources for long-term projects. Other activities run by patients' associations are: training programmes targeted to children, adults and linguistic minorities in Norway, class-style

programmes in Austria, and peer support groups in Ireland. Other support services are allergy-free hotels, holidays, spas etc. For further details on support services provided by patients' organizations, see chapter 8.

Support services for parents of children with respiratory allergies

Respiratory allergies may cause distress and loss of work days for the parents of children with severe asthma or allergic rhinoconjunctivitis. In the UK, 69% of parents or partners of parents of asthmatic children report having to take time off work because of their child's asthma, and 13% had lost their jobs [40]. Support services for parents may relieve the burden of the disease on family life. Table 6 shows the support services offered in some countries.

Patients in Europe should have equal access to the best available treatment based on scientific evidence and on national as well as international guidelines.

Table 6. Support to parents of children with severe respiratory allergies

Austria	Allowance for nursing care: 7 steps from €154.20 to €1,655.80 per month.
Belgium	Medication and care are partially refunded by the healthcare institution. Reimbursement is greater if the patient has a recognized invalidity.
Denmark	Government support. www.retsinformation.dk/Forms/R0710.aspx?id=130455
Finland	Finnish law on rehabilitation. Support to take care of the child at home. Support for children under 16 years old that have some kind of disability. Support for medical and discretionary rehabilitation, 100% refund for healthcare costs, 100% refund for medical costs, and partial nursing leave.
France	Patients with severe chronic asthma are 100% reimbursed by national social insurance. Patients on a very low income can benefit from free access to treatment and care.
Lithuania	Those who have been given disability status due to severe asthma get disability benefit and, in the case of a child, benefits for care are also paid to one of the parents looking after the child. Reference: Law on Social Integration of the Disabled, State Social Benefits Act.
Norway	There are various schemes for adults and children/parents. For example, paid leave in relation to the child's illness, funding for medication and treatment options. See also www.naaf.no/no/min-guide/ and The Norwegian Labour and Welfare Administration www.nav.no/English .
The Netherlands	Some healthcare insurance companies reimburse the membership dues of patients' organizations (depending on type of extra insurance). Drugs prescribed by MDs are reimbursed (both to patients and to MDs); but over-the-counter medication is not.

What Can Allergen Immunotherapy Achieve

For Patients

Immunotherapy is effective in reducing symptoms of allergic rhinitis and/or asthma and improving the quality of life of allergy sufferers. It also results in reduced use of symptom relieving medications. Immunotherapy has long-lasting benefits, even after cessation of the treatment. In patients with allergy to insect venom, immunotherapy is able to prevent life-threatening reactions.

For Doctors

Allergy specialists benefit from a therapeutic intervention that not only reduces symptoms in their patients, but also gives strong hope that the underlying allergy will be cured and/or stopped in its progression. Especially in children in whom the prospect of one allergy following the other (the allergic march) is ever present, it also offers a way for putting a break to this process, stopping the progression to more serious forms such as asthma.

For Public Health

Immunotherapy is currently the only treatment that offers the possibility of reducing long-term costs and burden of allergies, changing the natural course of the disease. Several pharmacoeconomic studies have shown important benefits even from early time points, with a steady increase with time. It is conceivable that further research may lead to preventive vaccination for allergies, as is now the case of infectious diseases.

EAACI, *A European Declaration on Immunotherapy*, 2011 available from: www.eaaci.net



In the patient's own words

The replies to the questionnaire clearly show that European patients' associations feel the need to improve access to care, in particular access to specialist care for patients with severe respiratory allergies. The associations were asked about the number of allergy specialists in their country and about actions taken to ensure continuity of care for these patients. The main problems are a low number of allergy specialists and uneven geographic distribution of specialists and specialized centres. Most associations call for specific actions to ensure continuity of care.

Österreichische Lungenunion (Austria)

No allergologists in Austria. Small number of allergy centres. Five different types of doctors treat allergic patients (GPs, ENT specialists, dermatologists, paediatricians and pulmonologists). It is difficult for patients to know to whom they should go.

Astma-Allergi Danmark (Denmark)

Allergy is no longer a specialty. ENT specialists, pulmonologists, GPs etc. now see these patients.

Allergy- and Asthma Federation Finland

Lack of resources concerning specialized doctors. Patients must travel long distances.

Association Asthme & Allergies (France)

There are various problems, including late diagnosis (especially when patients are not referred to a specialist by their GP), difficult access to allergologists (due to the lack of these specialists) and poor adherence to treatments (particularly asthma treatments).

Asthma Society of Ireland

No established healthcare programmes: no allergy specialists or clinics, specific reimbursement or data collection.

FEDERASMA (Italy)

Economic support is provided for asthma patients only after a lengthy bureaucratic procedure and only under certain conditions.

Astma Fonds (The Netherlands)

Overall low number of physicians trained in allergic diseases.

Norwegian Asthma and Allergy Association

Currently there is no medical specialty in allergology. However, a process is in place to develop such a specialty. Norway lacks multidisciplinary medical centres for allergy treatment and diagnosis, but several stakeholders including professionals and NAAF, are working to establish regional centres across Norway. The establishment of such allergy centres has now been politically confirmed. Many people who work in community health services have limited knowledge about allergy, and there is a need for better transfer of knowledge from specialist health service to general practice.

Swedish Asthma and Allergy Association

The main problem is lack of allergologists. In ten years most of them will have retired.

8. Patients' associations – best practices

The analysis of the questionnaire clearly shows the need for better awareness on the part of the general public about allergies, their recognition and management. To this aim, the patients' associations participating in this project are implementing various strategies; below are only a few examples of their many activities.



AUSTRIA - Österreichische Lungenunion/Austrian Lung Union www.lungenunion.at

Österreichische Lungenunion is a patient organization working for everyone affected by allergy or lung disease. It helps people to understand and manage their condition by providing patient-centred information on paper, on the web, on the telephone and in a newly-built education centre.

Brochures

Title: "All About Allergies"

Target: Respiratory allergy patients

Title: "Does Rhinitis Lead to Asthma"

Target: Respiratory allergy patients

Various allergy informative folders (pollen, grass, mites, mould, specific immunotherapy, indoor allergies etc).

Target: Respiratory allergy patients

Title: "Help, My Child Coughs - Could it be Asthma?"

Target: Parents

Title: "Tips and Tricks for Asthma"

Target: Asthma patients

Title: "How to Learn to Live with Asthma"

Target: Allergy and asthma patients

Patient/parents' support groups

Allergy, asthma, COPD, lung cancer

Activity description: Lobbying, providing information and education, organizing awareness events

Helpline

Tel. 4313304286

Activity description: Advice, information on allergy, asthma, COPD

Target: Allergy and lung diseases

Education, information and awareness events

Conferences: Paediatric allergy and pneumology education for paediatricians (10 workshops for certificate)

Days dedicated to allergy: World Allergy Day, World Asthma Day

Days dedicated specifically to respiratory allergy: World Allergy Day, World Asthma Day, 1 large public event in spring in Vienna city hall.

Other initiatives: Allergy and Asthma Patient School.



BELGIUM - Astma- en Allergiekoepel vzw www.astma-en-allergiekoepel.be

Astma en-Allergiekoepel is a Dutch-speaking patients' association that strives to inform the general public and individuals about asthma, allergy and COPD. The association supports patients and helps them to adapt their life and activities so they can cope with their disease. It represents the voice of the patients in dealing with the authorities. The association also raises awareness about indoor and outdoor air pollution and food allergies. It keeps in touch with French speaking colleagues and works on projects with them. The association generally organizes a conference every two years, and distributes informative material at exhibitions and fairs.

Brochures

Several brochures

Content: Information about allergens

Helpline

Tel. 0800 84321

Target: General public seeking information

Activity: Supplying information and empowering the patient

Website

www.astma-en-allergiekoepel.be

Target: General public and the patient

Education, information and awareness events

Days dedicated to allergy: 1 day per year – a conference every two years

Days dedicated specifically to respiratory allergy: 1 day per year

Other initiatives: Camp for children with asthma and allergy.





BULGARIA - Association of Bulgarians with Bronchial Asthma *www.asthma-bg.com*

ABBA was established in 2002 consequent to an increasing crisis in healthcare, an unequal position of asthmatic patients versus other patients, lack of information about asthma for the general public, and the alarming fact that asthma is the most common chronic disease among children. ABBA works for an accurate diagnosis, treatment and prevention for patients. Its goal is to promote training and qualification of doctors in order to improve the control and treatment of respiratory diseases, namely asthma, chronic obstructive pulmonary disease (COPD) etc.



Brochures

Titles: "Bulletin of ABBA"

"Popular Asthma"

"Asthma Control Test"

"Asthma questionnaire"

"COPD questionnaire"

Target: Children with asthma and allergies and their parents; patients with asthma, allergies and COPD and their families

<http://asthma-bg.com/info.html>

<http://asthma-bg.com/info-popular.html>



Patient/parents' support groups

Target: Children with asthma and allergies and their parents; patients with asthma, allergies and COPD and their families

www.asthma-bg.com, asthma@mail.bg

Activity description: Asthma school

Helpline

Tel. +359 980 45 46

Target: Asthma, allergy and COPD

Activity description: Program for early prevention of respiratory diseases in kindergartens (2005-2011).

Website

www.asthma-bg.com

Target: Asthma, allergy and COPD patients

Education, information and awareness events

Conference: Annual Meeting of the European Federation of Asthma, Allergy and respiratory diseases (EFA) May 2007, Sofia.

Days dedicated specifically to respiratory allergy

National Day Children's Allergies

World Asthma Day

World Spirometry Day

World COPD Day

The Year of the Lung

Advocacy initiatives/activities

- Since 2009, ABBA has represented the rights of the patients at the National Health Insurance Fund.
- 2003 Goldfish campaign: All members of Parliament received a live goldfish and the head of the Parliamentary Healthcare Committee received a fish tank that could be emptied so leaving the fish without air.
- 2003 Easter card campaign: Easter is here, and so are we – Christ was reborn while our children are still waiting and cannot breathe freely.
- 2003 Men in Black campaign: A vigil in front of key institutions (Parliament, Ministry of Health etc.) with clearly written demands.
- ABBA founded the "Coalition for a Life Without Tobacco", which protects the interests of Bulgarian patients and supports the prohibition of smoking in public places.
- 2010 The Year of the Lung: 2,000 spirometries were performed in 7 cities.



CZECH REPUBLIC - Czech Initiative for Asthma

www.cipa.cz

ČIPA is an independent non-profit organization for the diagnosis, prevention and treatment of bronchial asthma in the Czech Republic. In 1995, it launched the Global Initiative for Asthma (GINA) under the auspices of the World Health Organization. The membership consists mostly of teachers, doctors and members of the Czech Pneumological and Tuberculosis Society and the Czech Society of Allergology and Clinical Immunology. ČIPA also operates a Pollen Information Service, and organizes expert meetings. The most important is the Asthma Annual Conference in May, which includes a seminar for doctors, a meeting with patients, and an information centre located in a large tent, where people can have their lung function measured. ČIPA has organized various international meetings in collaboration with EAACI and ERS.

Brochures

"Bronchial asthma in childhood"

Target: Parents of children with asthma

"Bronchial asthma in adulthood"

Target: Patients with asthma

"Allergic rhinitis: Questions and Answers"

Target: Patients with allergies

Website

www.pylovasluzba.cz

Aim: Education

Education, information and awareness events

Annual World Asthma Day

Asthma Annual Conference

Helpline

Tel/Fax: 224266229

e-mail: cipa@volny.cz (ČIPA Secretary)

www.cipa.cz/infolinka (questions and answers' line)



Astma-Allergi
Danmark

DENMARK - Astma-Allergi Danmark / Asthma-Allergy Denmark

www.astma-allergi.dk

Asthma and Allergy Denmark is a patients' association, operating for the Danish population affected by allergic diseases (about 1.8 million), especially asthma, pollen allergies and eczema. The organization keeps abreast of the latest research, participates in political committees, offers various courses, educational programs and activities, arranges family trainings, family days, eczema schools, open lectures, etc. It also offers free advice on asthma, allergies and eczema. Under the auspices of GINA, Astma-Allergi Danmark has participated in such events as the World Asthma Day.

Brochures

Several brochures

Target: Patient empowerment

Helpline

Tel. 4543434299

Target: Patient empowerment

Website

www.astma-allergi.dk

Target: patient empowerment

Mobile telephone pollen information

Education, information and awareness events

Information about food allergy for families

Asthma camps for young people, information about asthma for families, information about allergy for families, World Asthma Day – every year

Other initiatives: Family training, Family days, Eczema schools, Open lectures.



FINLAND - Allergy and Asthma Federation Finland www.allergia.fi

The Allergy and Asthma Federation is a non-profit public health organization. Its aim is to improve the quality of life of allergy and asthma patients by improving their daily life, supporting their care, and protecting their interests. The Allergy and Asthma Federation cares for allergy and asthma patients also at international level. It is a member of EFA, the Nordic Asthma and Allergy Organization and EAACI.



Patient/parents' support groups

Adaptation training, peer groups, first knowledge

Helpline

Allergy guidance, indoor air guidance

Websites

www.allergia.fi, hengitysliitto.fi, duodecim.fi and websites of medical companies.

Education, information and awareness events

Education (8 days in 2011), The National Allergy Programme, First Knowledge Days (food allergies, 2/2011)

Implementation of the Finnish Allergy Programme among patients, families and the public-at-large in collaboration with pulmonary patients' associations and skin patients' associations.

FRANCE - Association Asthme & Allergies www.asthme-allergies.org

The Allergy & Asthma Association is a non-profit organization, founded in 1991, whose main objectives are to inform and support patients with asthma, parents of children with asthma, as well as doctors and health professionals. The association uses several media to deliver information: free booklets, comic books, newspaper, websites, call centre for the general public and health professionals. It also participates in World Asthma Day and the Day of French Allergy. In December 2010, the Association was awarded the gold medal of the National Academy of Medicine. The Allergy & Asthma Association is a member of EFA, a founding member of the French Federation of Allergy and a member of the French Federation of Pneumology.



Brochures

43 brochures including "Asthma & Allergy News"
Target: Patients, families, caregivers, doctors

Patient/parents' support groups

Asthma schools

Individualized Home Project (IAP)

Activity description: Taking care of children with asthma and allergies and their parents in order to make them feel welcome in their communities.

Helpline

Asthme & Allergies Info Service

Target: Patients, families, caregivers, doctors

Activity description: Toll-free help line supported by the health authorities. Open 5 days/week from 9:00-13:00 and 14:00-18:00.

Websites

<http://etats-generaux.asthme-allergies.org>

www.allergiesrespiratoiresagir.org

www.asthmatiic.org

Target: Patients, families, caregivers, doctors.

The new website (asthmatiic.org) is a social network for severe asthmatic patients and families; its aim is to facilitate networking and sharing experience.

Education, information and awareness events

Conferences: Journées Francophones Asthme et Education (continuing education sessions for health professionals on patient's therapeutic education)

Days dedicated to allergy: Creation and organization of the annual French Allergy Day: www.allergiesrespiratoiresagir.org, World Asthma Day

Other initiatives: Organization of art competition. www.asthme-allergies.org/concours/index.php

Advocacy initiatives/activities

Creation of asthma schools in France (1992).

Writing and implementation of a "Charter".

Federation of the asthma schools network.

Supporting the inclusion of respiratory allergies as a National Health Priority.

Participation in the production and implementation of the asthmatic children school protocol.

Participation in writing guidelines etc.



GREECE – Aniksi www.allergyped.gr

“Aniksi” (Greek for Spring) is a non-profit organization with the aim of contributing to the fight against allergies and asthma, through information, education, social intervention and support of research. “Aniksi” organizes presentations, seminars, interactive sessions and other educational events for patients and parents of patients with asthma and allergic diseases. It also organizes presentations for the general public to provide scientifically sound and authoritative information on allergies and asthma. It facilitates care-taking procedures for allergic children with special needs. It intervenes in the public sector for the protection of people with allergies and asthma.

Brochure

Title: “Asthma (cause and management)”

Target: Children with asthma and their parents, and the general public

Education, information and awareness events

Conferences and presentations on various aspects of allergic diseases with information for the general public and guest speakers on specific areas (e.g., child psychology and asthma)

Asthma Day

Public days in major cities where allergologists see children and perform a quick allergy blood test.



IRELAND - The Asthma Society of Ireland www.asthmasociety.ie

The Asthma Society of Ireland is a charity dedicated to improve the health and wellbeing of the 470,000 people in Ireland affected by asthma. The organization actively engages with the general public, healthcare professionals, the government, party organizations and other stakeholders to keep high on the national agenda people living alone with asthma. The organization’s mission is to optimise asthma control through support, education, effecting change and research, using various media, such as helpline, booklets, school policies and several campaigns. The Asthma Society of Ireland is encouraged by the fundamental purpose of the Health Service Executive “enabling people to live healthier and more fulfilled lives”.

Brochures

“Take control of your Asthma & Allergy Rhinitis”, “Asthma and Allergy Friendly Gardens”, “Asthma and Allergy in Babies and Young Children”

Target: Patients and Parents of Children with Asthma and Allergy

Patient/parents’ support groups

Target: Asthma Society of Ireland

Helpline

Asthma helpline: 1850 45 54 64

Target: All patients

Education, information and awareness events

Conference: Healthcare Professional Education Days

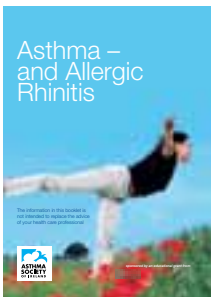
Days dedicated specifically to respiratory allergy: 6 regional asthma and allergy days for patients/year - regional distribution plus participation in 6 national events/year

Other initiatives:

By request, education/awareness in schools/pharmacies/social clubs/disadvantaged groups etc. throughout the year, “the asthma nurse” on the website, a person available to help who has a question about asthma.

Advocacy initiatives/activities

Development of a solution-based strategy for the Department of Health in 2009 for asthma. This has been adopted by the Health Service Executive, and is now incorporated into a National Asthma Society for implementation in 2011 over a 5-year period.





ITALY - FEDERASMA Onlus

www.federasma.org

FEDERASMA, founded in 1994, is a Federation of the main Italian asthma and allergies' associations. It supports the struggle of patients with asthma and allergies and its many local associations help to protect the interests of patients with allergies and asthma. FEDERASMA works closely with leading scientific pulmonary and allergy societies, and is supported by a highly qualified medical and scientific committee. The association keeps patients informed through newsletters, meetings and initiatives such as "the treasure hunt" in which children learn about the most common allergens and what allergic people should avoid.



Brochures

Titles: "Spirometria", "Conoscere l'asma", "Io aspiro", "Allergie e asma", "Liberati dalle barriere"

Target: Parents and children

www.federasma.org/pubblicazioni_federasma.html

Patient/parents' support groups

Target: Allergic and/or asthmatic patients/parents

Helpline

Tel. +39 800 12 32 13

Target: Everyone

Activity description: Two days a week, people can obtain general information about asthma and allergies

Website

www.federasma.org

Target: Everyone

Education, information and awareness events

Conferences: The most active associations affiliated to FEDERASMA organize about 15 events a year.

Days dedicated to allergy: About 15 days a year.

Days dedicated specifically to respiratory allergy: About 15 days a year.

Other initiatives: Collaboration with other associations in relation to cardiologic disease, obesity, smoking and cancer.

Initiatives carried out in piazzas, schools, sporting events, hospitals etc., on:

Learning to know all about smoking.

Asthma at school, the correct use of the instrument for asthma.

Allergic rhinitis, the drugs for asthma and allergic disease.

Immunotherapy for allergic children.

The cost of the management of asthma and allergy.

Allergy treasure hunt for children.



REPUBLIC OF LITHUANIA - Lithuanian Council of Asthma Clubs

www.astmainfo.lt

The Lithuanian Council of Asthma Clubs (LCAC), established in 2001, is an association of local clubs of asthma patients for a total of more than 2000 patients. The main goals are: educational and self-support programmes for asthma patients, increasing awareness of asthma and allergic diseases, awareness and control of patients' rights, building bridges between patients with chronic illnesses and the community, and international co-operation. The association participates in the World Asthma Day and the World COPD day, organizes conferences entitled "Asthma at school" for school nurses and teachers, and seminars and conferences for the leaders of patients' organizations.



Publications

Title: "EFA Manifesto of the European Allergy Patient" translated into Lithuanian

Web link: www.astmainfo.lt/index.php?al_manifestas

Title: GA²LEN brochure "Does Rhinitis Lead to Asthma?" translated into Lithuanian

Web link: www.astmainfo.lt/img/galenLi.pdf

Target: Mostly asthma patients, also some information about allergies.

Education, information and awareness events

Conferences: "Asthma at School" seminars for school teachers and nurses in 2003 and 2006

Days dedicated to allergy: World Asthma Day, World COPD day and dedicated conferences 2004-2009



THE NETHERLANDS - Astma Fonds

www.astmafonds.nl

The mission of the Astma Fonds Association can be translated as: healthy lungs for everyone! Among the association's goals, stemming from the current policy plan, are:

Actions that will motivate people with COPD to get sufficient exercise, Diminishing the occurrence of second-hand smoking and assistance with smoking cessation, Developing quality standards for healthcare from a patient's perspective, Giving people instruments for self-management.

Brochure

Title: Iespakket "ik heb't"

Target: Children at school

Patient/parents' support groups

Longpunt: All patients with chronic respiratory diseases

Activity description: Contact meetings between patients, relatives, healthcare providers and others
www.astmafonds.nl/ons-werk/longpunt

Helpline

Tel. 0900 227 25 96

Target: People who need advice about their (or their relative's) respiratory disease.

Education, information and awareness events

Conferences: Allergy symposium (2007)

Other initiative(s): Local meetings; regional meetings; annual day for volunteers and association members.

Advocacy initiatives/activities

Indoor pollution: Clean schools - better environment in schools. Some schools have been cleaned, and awareness among politicians and school directors is higher due to campaigns.

Outdoor pollution: 2010 campaign; helping with the EFA green book; political lobbying.

Tobacco law: Smoking restriction in public places; political lobbying.



ASTMA- OG
ALLERGIFORBUNDET

NORWAY - Norwegian Asthma and Allergy Association

www.naaf.no

NAAF is a national patient and interest organization for people with asthma and allergy counting approx. 16,000 members. It is divided into 14 regions and has 70 local associations across the country. The association owns the Norwegian Health Centre in Gran Canaria, Spain and Geilomo children's hospital in Norway. NAAF works to disseminate information of diagnosis, treatment, patient education and prevention of asthma, COPD and allergic diseases. It is actively working to reduce the burden of increasing diesel traffic on local air quality and to improve indoor environments in schools, public buildings etc.

Brochures

"Asthma Control", "Does my child have asthma?", "Pollen allergy", "Food allergy", "COPD", "Healthy Christmas for everyone", "Allergy safe birthday menu", "Jonas thermal mask", "A good working life in the hair salon", "A good working life in restaurants and in the food processing industry"

Other material:

Phrasebooks on food allergy for travellers

Various education materials on asthma

Target: Adults, children, parents, foreign language speakers, health workers

Weblink: www.naaf.no/opplaring

Hotline

Consultation by phone and email. Permanently staffed by nurses and highly qualified personnel on indoor/outdoor air.

Target: Entire population

Education, information and awareness events

By NAAF's national association:

Four different national tours to selected schools, cit-

ies etc. to increase: students' and teachers' knowledge of asthma, people's knowledge of asthma and COPD, people's awareness of respiratory health, students' awareness of pollen allergy.

Educational seminars on allergies (food allergies in particular), asthma, indoor and outdoor air quality for health personnel, teachers, industries, local and national authorities etc.

By NAAF's local associations: Such regional initiatives as cooking classes, parents' education sessions, family weekends, youth events etc.

Advocacy initiatives/activities

Working to:

- improve local air quality in cities and reduce traffic-related problems from diesel cars,
- improve indoor air quality in schools, childcare centres and public buildings
- meet the targets and goals set in the National strategy for prevention and treatment of asthma and allergic diseases (2008-2012) including creation of six regional multi-disciplinary allergy centres.

Other activities: advisory services for industries, e.g., building and food; product recommendation





POLAND - Polish Federation of Asthma, Allergy & COPD Patients' Association

www.astma-alergia-pochp.pl

The aim of the Polish patients' federation is to represent the interests of people with asthma, allergic diseases and COPD at national and local level throughout the country and in relation to other national and international organizations. Besides safeguarding the patient's rights, the association promotes and supports up-to-date treatment, coordinates activities in this area and helps to ensure that patients live an active social life. It is also engaged in various initiatives, events, conferences, symposia and trainings, such as the National Day of Spirometry where free spirometry is offered. The results of the various initiatives are publicized by involving the media and opinion leaders.

Education, information and awareness

events

National Day of Spirometry

Patron: Programme of medical environment



SWEDEN - The Swedish Asthma and Allergy Association

www.astmaoallergiforbundet.se

Asthma- och Allergiförbundet was formed in 1956 by local associations. Today we have 148 local associations and 21 county associations around the country. Here allergic sufferers and their families gather to support and help each other and influence society. The Association is a resource for the local associations. Asthma och Allergiförbundet works as a popular movement for allergic people. County and local associations are independent and have their own committees elected at their annual meetings. Work in the associations is voluntary. The association is working to: influence society to achieve better conditions of living for people with asthma and allergic illnesses; through education and information achieve a greater understanding of the problems of people with asthma and allergy; support the work of the county and local associations; support research in asthma and allergy.

Brochure:

"Hooray, an allergic guest! And Safer Food"

Training for restaurant staff and allergy certification for restaurants

Patient/parents' support groups:

www.astmaoallergiforbundet.se/Mailinglist.aspx?type=316

Education, information and awareness events

World Allergy Day

World Asthma Day

Other initiative(s):

Recommended products

The association has developed a system of product recommendations as a guide for consumers in search of allergy safe products. The recommended products are labelled with the association's name and logo. The products are free from allergens, perfume and irritating substances in such amounts, for which there are no known medical incidents reported.

Hooray, an allergic guest! And Safer Food Training for restaurant staff and allergy certification for restaurants

We want to make it easier for restaurants wishing to profile themselves as a safer alternative for people with food allergies, by developing rules for certification.

Checklist for allergy inspections – a tool for improving the indoor environment

We all need help in trying to prevent children contracting allergy and in alleviating the symptoms of those who have already been affected. There is now a tool available, in the form of a checklist, which will help in the work environment and in schools to bring about an environment that is as free of allergy as possible. This checklist is an aid for a quick and easy overview of where the risks are to be found and what must be put right.





SWITZERLAND - aha!

www.ahaswiss.ch

AHA is a charitable foundation, active in Switzerland as a centre of competence for the support of allergy and asthma patients. The main aim of the association is to make available, mainly free of charge, knowledge and skills about allergies and asthma in order to improve the patient's quality of life. The organization offers a helpline, booklets, advanced training courses, campaigns and various other initiatives. AHA has participated in the National Day of Allergies (in collaboration with the Swiss Society for Allergology and Immunology).

Premiere mit grossem Finale

Die erste Allergie-Welt und 7. Schweizer Allergie-Welt (AW) sind die ersten beiden regionalen Premieren, die in der Schweiz, an der rund 100 hochqualifizierten Allergologen und Kinderärzte teilnehmen und gemeinsam Allergien erklären, behandeln und helfen, sie zu vermeiden. Die Allergie-Welt wird am 10. Oktober 2011 in der Schweiz und am 11. Oktober 2011 in der Schweiz und am 12. Oktober 2011 in der Schweiz.



Brochure

Title: "aha!news"

Target: Members and people who want to learn more about their illness

Web link: http://www.ahaswiss.ch/index.cfm?parents_id=711

Patient/parents' support groups

"AHA!kinderlager", a campus guided by experts of education, gymnastics, medicine and nutrition to help children with allergies, asthma, eczema etc., to know and face their diseases.

Helpline

Tel. 031 359 90 50 (Monday to Friday)

Target: People who need advice regarding their (or their relative's) respiratory disease.

Education, information and awareness events

Days dedicated to allergy: National Day of Allergies, every year.

Other initiatives: An informative stand at the Bern Grand Prix where an expert team is available for advice, information and testing.



UK - Allergy UK (British Allergy Foundation)

www.allergyuk.org

Allergy UK is the operational name of the British Allergy Foundation, the leading national medical charity providing advice, information, and support to people with allergies, food intolerance and chemical sensitivity. The association is made up of a group of leading medical specialists determined to improve awareness, management and treatment of allergies. The main aims of the association are promoting wellbeing, empowering patients, improving research, educating corporate bodies in the need for products suitable for allergy, food intolerance and chemical sensitivity sufferers. Allergy UK uses several ways to reach people, such as helpline, newsletter, meetings and events, website etc. An important goal for the Foundation has been the endorsement of the Seal of Approval for products that have been tested scientifically and proven to reduce allergens.

Brochures:

Titles: "Focus", "Four Seasons"

Target: Members, people with asthma and allergic rhinitis who want to learn more about their illness

Web link:

http://www.allergyuk.org/news_focus.aspx

http://www.allergyuk.org/news_fourseasons.aspx

Helpline

Tel. 01322 619898

Consulting by phone and email. Several occupations and highly qualified personnel to answer questions.

Target: Entire population

Web

www.blossomcampaign.org

Dedicated to childhood allergies

Education, information and awareness events

Conferences: The Good Health Show

Days dedicated to allergy: National Allergy Week, Indoor Allergy Week, Food Allergy and Intolerance

Other activities: The Allergy Forum, endorsement of the Seal of Approval, Allergy Friendly Services, Indoor Allergy Week Survey.

Advocacy initiatives/activities

Fundraising events, such as the London Duathlon 2011, the British 10K Run, the London Triathlon 2011 etc.

Respiratory allergies in Europe

9. Needs and actions

Prevention

Need: To prevent exacerbation of asthma and allergic rhinitis.

Action: Implement written guided self-management action plans for all patients.

Need: Access to allergen specific immunotherapy for suitable patients should be increased. Immunotherapy seems to be the only treatment able to modify the course of the disease, and may reduce the risk of asthma in patients with allergic rhinoconjunctivitis.

Action: Implement appropriate measures and policies in order to ensure that patients who will benefit from allergen specific immunotherapy receive it.

Need: Patients affected by respiratory allergies have the right to a healthy environment (especially indoors).

Actions: (1) Promote and support no-tobacco initiatives and initiatives to reduce the chemicalization of society and to promote allergen-free indoor environments.

(2) Disseminate recommendations for healthy indoor air, e.g., *Health-Based Ventilation Guidelines for Europe* (www.healthvent.eu), and the EFA publications *Indoor Air Pollution in Schools* and *Towards Healthy Air in Dwellings in Europe* (www.efanet.org).

Healthcare systems and policies

Need: Reinforce the concept that allergic rhinitis and allergic asthma must be considered a continuum of a single disease ("one airway, one disease").

Actions: (1) Include this concept in the training of medical students and other healthcare professionals.

(2) Encourage healthcare authorities to recommend that first-line healthcare professionals and specialists take an integrated and unified approach to allergic rhinitis and allergic asthma in order to optimize treatment efficacy.

Need: Many patients with allergic rhinitis do not receive a diagnosis. This prevents them from receiving appropriate care and, in the long term, may result in exacerbations and negatively impact on their quality of life as well as on health costs.

Action: Increase awareness that allergic rhinitis is not merely troublesome but a real disease that, if not adequately treated in children, can lead to more severe respiratory problems later in life and to impairment in everyday life (e.g., poor performance at school).

Need: Control should be the main goal of the management of allergic rhinitis and allergic asthma.

Actions: (1) Reinforce this concept, particularly regarding allergic rhinitis, during the training of medical students and other healthcare professionals.

(2) Educate patients about disease control, and ensure they receive a guided self-management plan.

(3) Implement national programmes for the control of respiratory allergies that involve all stakeholders as well as national healthcare institutions.

Need: Patients should be treated according to the most recent evidence-based guidelines. In allergic rhinitis, immunotherapy should be considered if there is a family history of asthma or if the patient with allergic rhinitis also has lower airway symptoms.

Actions: (1) Educate and inform primary care professionals about guidelines and available treatments.

(2) Reduce barriers to access to treatment, in particular long waiting lists for immunotherapy.

Need: There is a need for more allergologists and other specialists specifically trained in allergic diseases.

Action: Advocate for the recognition of allergology as a specialty or sub-specialty throughout Europe.

Need: Pharmacists and nurses, preferably asthma and allergy nurses, can play a role in patients' education and in the management of their illness.

Action: Include these professional figures in national programmes devoted to respiratory allergies.

Need: Increase collaboration between patients' organizations and healthcare professionals.

Action: Promote education focusing on the benefits of a partnership between these two stakeholders.

Patients

Need: Patients with respiratory allergies should receive an early diagnosis.

Actions: (1) Encourage patients to consult a physician at the first signs of respiratory allergy.

(2) Make primary care professionals aware of the importance of patient empowerment in fighting the disease and the importance of addressing patients to specialists trained in allergic diseases, preferably to allergy specialists where available.

(3) Produce simple treatment and management guidelines for the general public.

Need: Patients should be treated according to the most recent evidence-based guidelines.

Action: Produce simple standard of care guidelines for the general public (also for reimbursement purposes).

Need: Patients tend to underestimate and "adjust" to their condition.

Action: Encourage patients to join associations to obtain reliable information, achieve a better understanding of their disease and how to effectively control it, and improve their condition.

Patients' organizations

Need: Healthcare professionals and patients' organizations should agree on common evidence-based management and education programmes for patients with respiratory allergies.

Action: Reinforce the partnership between these two stakeholders.

Need: Understand the need for healthy indoor air quality.

Actions: (1) Implement educational programmes to alert patients and the public-at-large to the risks associated with poor indoor air quality.

(2) Disseminate recommendations about healthy air in schools and in dwellings.

Need: Effective implementation of treatment and management guidelines.

Action: Ensure that patients' organizations are involved from the very beginning in guideline development.

Need: The public-at-large needs access to reliable information.

Action: Produce easy-to-understand publications and websites for the lay public.

Policy makers/Laws & legislation

- Need:** Reduce the impact of respiratory allergies on society and on the patient's quality of life.
- Action:** Launch national programmes of specifically targeted actions, and disseminate real-life guidance tools that are easy to use in daily life on the model of the Finnish Allergy programme. Such programmes should include objective indicators for prevalence, diagnosis, treatment and costs.
- Need:** Reduce inequalities in the treatment and management of patients with respiratory allergies between those living in urban versus rural areas, and among countries.
- Action:** Make healthcare authorities aware that appropriate treatment and management of respiratory allergies throughout their country will reduce healthcare costs.
- Need:** There is no accurate comparable assessment of direct and indirect costs of respiratory allergies in Europe.
- Action:** Form a coalition of national and European institutions as well as all stakeholders to determine what respiratory allergies cost patients, their families and society as a whole.
- Need:** Patients across Europe should have equal access to treatment.
- Action:** Reduce or abolish economic barriers so that all patients can access appropriate preventive measures and medications.
- Need:** More allergy specialists are required in Europe.
- Action:** Make allergy training a specialty or sub-specialty in all European countries.

Public-at-large

- Need:** Many patients and doctors tend to view allergic rhinitis as a trivial condition. They are not aware that it can adversely affect the patient's daily life and can progress to a more severe condition.
- Action:** National patients' associations, supported by EFA, must join forces with national medical societies to inform the public and policy makers about the importance and benefits for the patient and for society of early recognition and treatment of allergic rhinitis.
- Need:** Information from reliable sources.
- Action:** Promote the certification of websites.

Research

- Need:** Understand better the epidemiology of respiratory allergies in Europe.
- Action:** Promote national epidemiological studies of respiratory allergies based on severity and disease control in both children and adults.
- Need:** Understand how the increased prevalence of respiratory allergies and the tendency to progress from mild to severe conditions will affect national and European health authorities in coming years.
- Action:** Promote national and European studies to estimate the short-, mid- and long-term prevalence of allergic rhinitis and allergic asthma, and the burden this will place on healthcare resources.

10. Conclusions:

Understand the burden, relieve the burden

The aim of the EFA survey was to obtain an overall picture of the various aspects of respiratory diseases in Europe as seen by the patients themselves. A specifically designed e-questionnaire was sent to the 32 EFA member associations for a total of 21 countries. Replies were received from 18 countries, which were representative of Europe.

The survey is part of EFA's Allergy Project, which is a four-year plan designed to address low public awareness that allergy is a serious chronic disease. Within this framework, EFA identified **four main challenges**:

1. To raise awareness of respiratory allergies as serious chronic diseases which place a heavy burden on those affected and on society as a whole.

Many healthcare workers and patients consider respiratory allergies, particularly allergic rhinitis, a trivial condition – for which it is hardly worth going to the doctor! Nevertheless, timely treatment can improve the patient's quality of life and prevent progression to a more serious condition, which places a heavier burden on healthcare resources.

At national level, as recommended also by the WHO GARD, policy makers, physicians' associations and patients' organizations should implement comprehensive national programmes and set targets for relieving the burden of respiratory allergies.

A compelling example of how a coalition of stakeholders can focalize national attention on respiratory diseases is the Finnish National Allergy Programme that has proved effective in improving the patients' quality of life and in reducing the burden of the disease on society as a whole.

2. To increase the ability of patients and their caregivers and of healthcare professionals to identify early symptoms and thus to ensure an early diagnosis of allergic diseases.

This challenge is best tackled at medical school. The concept of respiratory allergy should be included in medical training. Pharmacists, who are often the first professionals to see the allergy patient, should be aware of current allergy management guidelines to be

able to advise their customers to see a doctor if necessary.

3. To establish European guidance on the appropriate management and control of allergic disease in order to avoid exacerbations of allergies.

Respiratory allergy is a complex condition that requires a multidisciplinary approach. Regional allergy units could be the answer. These units, staffed by different specialists and a trained dietician, respiratory nurses and psychologists, could provide specialist care for allergic diseases, manage the disease for people that cannot be dealt with in primary care, and provide education and training for medical students, doctors and nurses in primary and secondary care. Allergy units would not be an additional burden, but can be established by reorganizing existing resources.

4. To develop and promote simple educational services for primary care physicians, paediatricians and patients that can be made available in local languages and disseminated by EFA to support early diagnosis and appropriate treatment, including guided self-management tools for better disease control.

EFA recognizes the need to produce educational tools and information in local languages for professionals and in an easy-to-understand form for patients and the general public. EFA encourages translations of its publications.

These challenges can be effectively met only if there is close collaboration among all stakeholders: healthcare authorities, healthcare workers, pharmacists, patients' associations, patients and their families at local and national level, and with the help of the media.

The results of the EFA survey revealed a lack of official information about epidemiology, socioeconomic costs and the quality of care and treatment of respiratory allergies. This information is essential to achieve a real understanding of the dimension of these diseases and their impact. Therefore, all countries need to improve the statistics/indicators on prevalence, costs, access to care and quality of care.

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Methodology

Research goals

The main research goal of the EFA survey was to get an overview of how Europe is doing in the area of respiratory allergies (specifically allergic rhinitis and allergic asthma). EFA wanted to hear the voice of patients through their national associations in order to understand what needs to be done to improve awareness of the importance of prevention, an early diagnosis and management of respiratory allergies. The empirical research aims were to: 1) evaluate allergy and asthma in European countries from an epidemiological, medical and social point of view as seen from the patient's perspective; 2) learn about issues that are important for patients and for the activities of patients' associations and 3) illustrate the work done by patients' associations to enable them to share best practices.

Research design

The research goal was to collect national information about respiratory allergies directly from patients' associations. The main topics covered by the research were: **Basic facts:** information on respiratory allergies (mainly official data), i.e. epidemiology, disease definitions, prevalence and costs.

Access to care for patients with respiratory allergies: diagnosis, management of the disease, role of health-care professionals in the management and follow-up of patients and national programmes devoted to respiratory allergies.

Quality of care and involvement of the patients' associations: quality of care for patients with respiratory allergy, and the role and involvement of the associations in improving the quality of care.

Best practices: activities conducted by the associations.

Data collection

Research topics were operationally defined into the items of a semi-structured questionnaire, i.e. with a mix of open-ended and close-ended questions. Data were collected through an online questionnaire; this technique was chosen because: 1) it guarantees a global reach at a low cost; 2) respondents are free to complete the questionnaire in their own time; 3) online questionnaires are easy to complete and they assure fast and automatic data entering and data analysis.

For epidemiological information, as well as information on national programmes, guidelines and legislation, the patients' associations were invited to consult their scientific boards, Ministry of Health, relevant scientific societies and other authoritative sources such as their National Institute of Statistics.

Sampling

Invitations to take part in the survey were sent via mail to the EFA member associations. The associations of 18 countries returned the questionnaire: Austria, Belgium, Bulgaria, Czech Republic, Denmark, Finland, France, Germany, Greece, Ireland, Italy, Lithuania, The Netherlands, Norway, Poland, Sweden, Switzerland and the UK.

Data analysis

Data analysis relies mainly on univariate procedures (tables and graphs) based on the respondents' answers. Missing or incomplete information was collected from official sources and from the scientific literature.

This methodological note was prepared by Felice Addeo (University of Salerno) and Daniela Finizio (Scientific Communication srl).

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