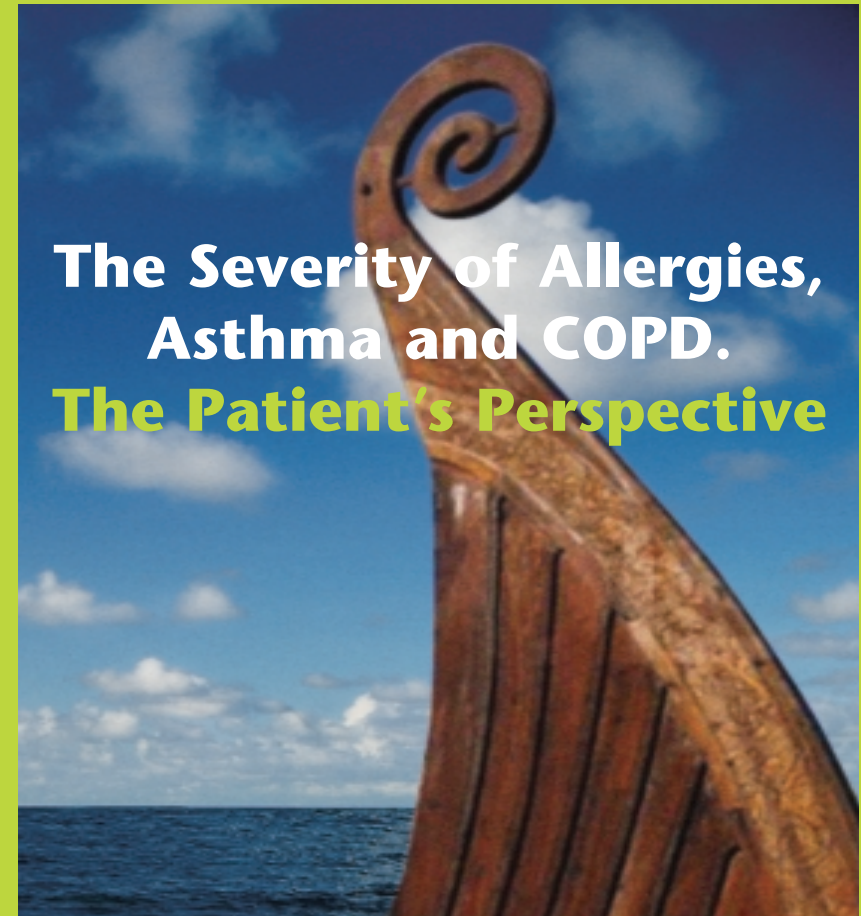




ABSTRACTS



**The Severity of Allergies,
Asthma and COPD.
The Patient's Perspective**

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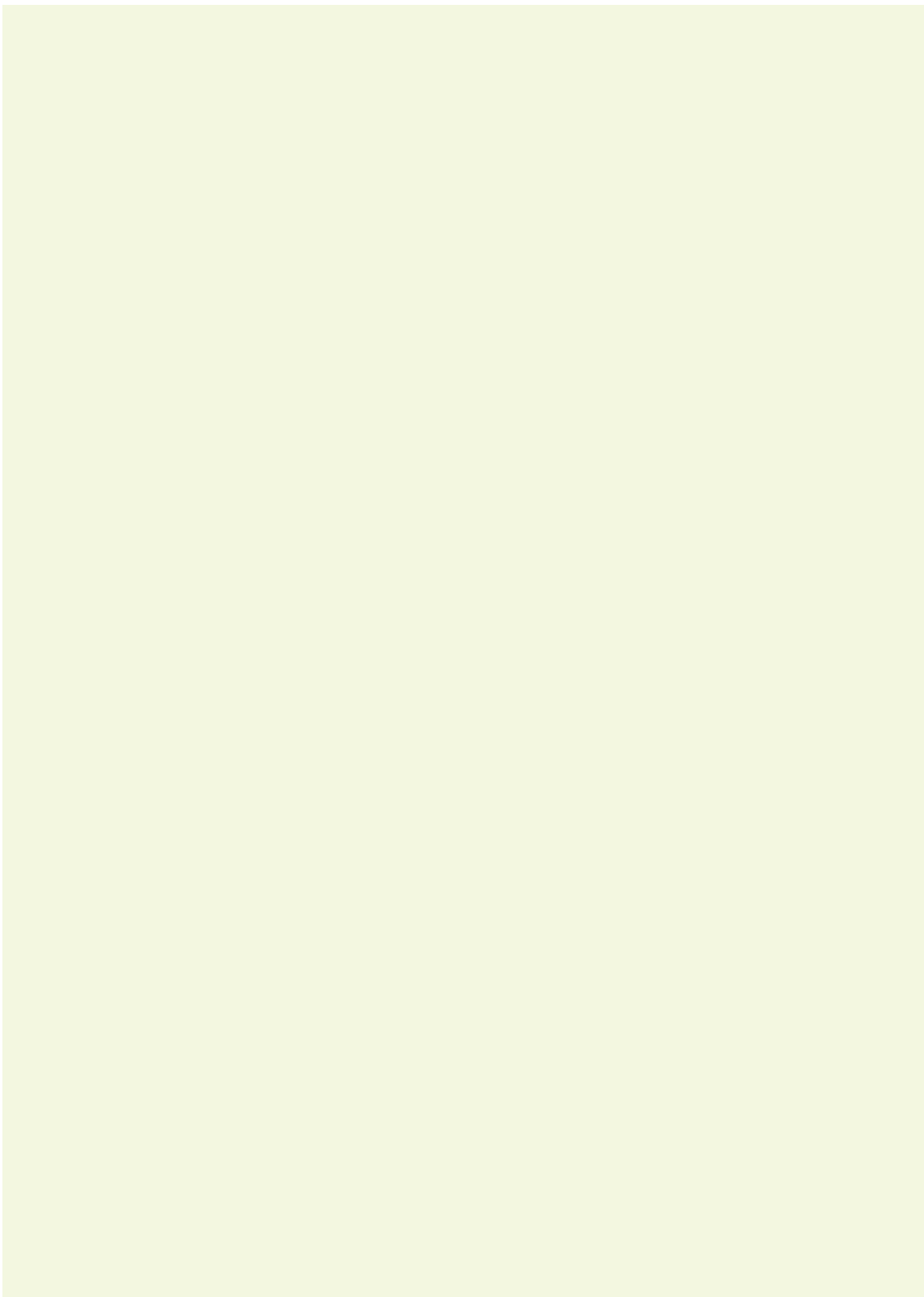


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The Severity of Allergies, Asthma and COPD. The Patient's Perspective







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Allergic Rhinitis and its Impact on Asthma (ARIA). Therapeutic implications

Oslo 2004



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Allergic rhinitis represents a global health problem. It is a common disease worldwide affecting at least 10 to 25% of the population, and its prevalence is increasing. Although allergic rhinitis is not usually a severe disease, it alters the social life of patients, and affects school performance and work productivity. Moreover, the costs incurred by rhinitis are substantial. Asthma and rhinitis are common co-morbidities suggesting the concept of 'one airway, one disease'.

Guidelines proposed within the past decade have been found to benefit patients with allergic rhinitis. ARIA (Allergic Rhinitis and its Impact on Asthma) is the latest guideline.

ARIA was developed as a state-of-the-art initiative for the specialist as well as for the general practitioner:

- to update their knowledge of allergic rhinitis
- to highlight the impact of allergic rhinitis on asthma
- to provide an evidence-based documented revision of diagnosis methods
- to provide an evidence-based revision of the treatments available
- to propose a stepwise approach to the management of the disease.

ARIA proposes a new subdivision of allergic rhinitis, i.e., patients presenting intermittent or persistent rhinitis. The severity of allergic rhinitis has been classified as 'mild' and 'moderate/severe' depending on the severity of symptoms and quality of life outcomes.

The management of allergic rhinitis includes allergen avoidance, medications (pharmacological treatment), immunotherapy and education. Surgery may be used as an adjunctive intervention in a few highly selected patients. A stepwise-therapeutic approach has been proposed depending on the subdivision and severity of allergic rhinitis.

Patients with persistent allergic rhinitis should be evaluated for asthma by



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history, chest examination and, if possible and when necessary, the assessment of airflow obstruction before and after bronchodilator. Patients with asthma should be appropriately evaluated (history and physical examination) for rhinitis. Ideally, a combined strategy should be used to treat upper and lower airway diseases in terms of efficacy and safety.

Some drugs are effective for both rhinitis and asthma (e.g., glucocorticosteroids), whereas others are only effective in the treatment of rhinitis or asthma (e.g., α - and β -adrenergic agonists, respectively). Moreover, some drugs are more effective in rhinitis than in asthma (e.g., H1-antihistamines). Finally, optimal management of rhinitis may partly improve coexisting asthma. Intra-nasal glucocorticosteroids were found moderately to improve asthma in some, but not all, studies. Less is known about the beneficial effects of inhaled (intra-bronchial) glucocorticosteroids on nasal disease. Drugs administered orally can influence both nasal and bronchial symptoms. Oral leukotriene receptor antagonists (eventually combined with H1-antihistamines) are effective on nasal, bronchial and conjunctival symptoms and are of great interest for the global treatment of patients.

Food Allergy

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In prospective studies in children the cumulated prevalence of food allergy has been shown to be around 7-8% in children less than 3 years of age with a decreasing prevalence during later childhood and early adulthood with a prevalence around 1.5-2%. In infancy and early childhood food allergy is the most common form of allergy. Most of the infants will develop food allergy in the same order as that in which the foods have been introduced into their diet thus reflecting the eating habits of a population. There is evidence that food allergy may be caused by one or more immune mechanisms, most often immediate IgE-mediated reactions (type I allergy). However, recent evidence indicates that non-IgE mediated reactions, type III-immune complexes, and mainly type IV-cell-mediated reactions may play a major role in delayed reactions. The skin and respiratory tract are most often affected by IgE-mediated reactions whereas gastrointestinal reactions are mostly caused by non-IgE-mediated reactions. The diagnosis of food allergy is based on a careful history, physical examination and controlled elimination/challenge procedures; in older children and adults preferably double-blind placebo-controlled food challenges. Once correctly diagnosed strict avoidance of the offending food is the only effective treatment. Due to a high recovery rate for most food allergies, except peanut, tree nuts, fish and sea foods, rechallenges are recommended at intervals of 6-12 months before 3 years of age and at intervals of 1-2 years after 3 years of age. For primary prevention breastfeeding should be encouraged in all infants for 4-6 months and likewise exposure to tobacco smoke should be avoided during pregnancy as well as during early childhood.

In high risk infants a documented extensively hydrolysed formula is recommended if exclusively breastfeeding is not possible for the first 4 months of life. There is no evidence for prenatal dietary intervention during pregnancy. In homes of high risk infants, current evidence supports measures to reduce the level of indoor allergens, e.g. pets and house dust mites. In infants with food allergy such preventive measures should be emphasized because of high risk of later development of inhalant allergy.



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The Global Initiative for Asthma (GINA) Programme

Oslo 2004



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In 1989 the Global Initiative for Asthma (GINA) programme was initiated with the National Heart, Lung, and Blood Institute, NIH and the World Health Organization in an effort to raise awareness among public health and government officials, health care workers and the general public, that asthma was on the increase. The GINA Guidelines were launched in 1995, revised in 2002 and is now the most references asthma guidelines worldwide. The GINA science committee provides yearly guideline updates available on the GINA web site. The GINA Internet Gateway has become the recognized source for prestigious and authorized information about asthma care on the internet with more than 10,000 visitors each day. GINA supervises the World Asthma Day (WAD, May 4) in cooperation with government health groups and medical academies worldwide to keep the awareness of asthma and commitment to improving asthma care at a high level. With the availability of the new updated GINA guidelines, a major effort will be made to bring the messages of improved asthma care to the level of the primary care physician and patient. This work is conducted by the Dissemination and Implementation Committee.

On World Asthma Day, 4 May, 2004, the *Global Burden of Asthma* report was presented. This report supply data on the burden and severity of asthma in 20 different regions worldwide. The report summary states the following:

1. Asthma is one of the most common chronic diseases in the world (300 million people suffer from asthma).
2. The international patterns of asthma prevalence are not explained by the current knowledge of the causation of asthma.
3. Asthma has become more common in both children and adults around the world in recent decades.
4. The rate of asthma increases as communities adopt western lifestyles and become urbanised.
5. In many areas of the world persons with asthma do not have access to basic asthma medications or medical care.



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6. The number of disability-adjusted life years (DALYs) lost due to asthma worldwide has been estimated to be currently about 15 million per year, which is similar to that for diabetes.
7. The burden of asthma in many countries is of sufficient magnitude to warrant its recognition as a priority disorder in government health strategies.
8. It is estimated that asthma accounts for about 1 in every 250 deaths worldwide. Many of which are preventable.
9. The economic cost of asthma is considerable both in terms of direct medical costs and indirect medical costs.
10. The future priority is to ensure that cost-effective management approaches which have been proven to reduce morbidity and mortality are available to as many persons as possible with asthma worldwide.

More detailed data from the *Global Burden of Asthma* report will be presented, ending with a special focus on Scandinavian challenges.

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The ERS White Book

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The fact that respiratory diseases are the leading cause of deaths worldwide is not widely known among the public. In addition, a further increase in the number of deaths from lung disease is predicted between now and 2020, in particular from chronic obstructive pulmonary disease (COPD), lung cancer and tuberculosis. In 2020, of 68 million deaths worldwide, 11.9 million will be caused by lung diseases (4.7 by COPD, 2.5 by pneumonia, 2.4 by tuberculosis, and 2.3 by lung cancer). Globally, in terms of mortality, incidence, prevalence and costs, respiratory diseases rank second (after cardiovascular diseases). Two major lung diseases (lung cancer and COPD) are generally, but not exclusively, caused by cigarette smoking. However, it is important to stress that lung diseases are not just related to smoking. There is a wide variety of other causes, ranging from genetic influences to nutritional, environmental and poverty-related factors. In addition, the human respiratory tract is vulnerable to many infectious agents, as shown by the recent epidemic of severe acute respiratory syndrome (SARS).

The total financial burden of lung disease in Europe amounts to nearly € 102 billion, a figure comparable to the annual gross domestic product of the Republic of Ireland. COPD accounts for almost one half of this figure, followed by asthma, pneumonia, lung cancer and tuberculosis.

The factors costing the most are lost workdays, accounting for € 48.3 billion (47.4%), and inpatient care € 17.8 billion (17.5%). Outpatient care contributes a further € 9.1 billion (8.9%) and prescription drugs add € 6.7 billion (6.6%). The majority of drug costs are due to the treatment of chronic diseases, asthma and COPD (approximately 95%).

Asthma

It is estimated that the frequency of asthma in western Europe has doubled in the last 10 years. In the UK, it is estimated that 1 in every 7 children aged 2-15 years and 1 in every 25 adults have asthma symptoms requiring treatment. In the UK, asthma has been shown to affect 12% of males and 10% of females aged 5-14 years. In Switzerland, 25 years ago the frequency of asthma was 2%, whereas currently it is 8%. The total annual costs of asthma care in Europe amount to approximately € 17.7 billion.



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COPD

The frequency of clinically relevant COPD varies in European countries from 4-10% of the adult population. Approximately 200,000-300,000 people die each year in Europe because of COPD. Data provided by WHO in 1997 showed that COPD was the cause of death in 4.1% of men and 2.4% of women in Europe. Among respiratory diseases, COPD is the leading cause of lost workdays in the EU: approximately 41,300 lost workdays per 100,000 population are due to COPD every year. In Europe, productivity losses due to COPD amount to a total of € 28.5 billion annually. By 2020, COPD is likely to account for over 6 million deaths worldwide every year, making it the third leading cause of death.

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Severe Asthma – UK Survey

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Background

In the UK asthma is widespread, serious and controllable. 2.6 million people with asthma report severe asthma symptoms which are avoidable for all but 0.5 million. It is estimated that 1,250 of the 1,400 deaths from asthma each year are preventable. Despite this, asthma continues to be seen by many as a relatively uncommon with mild but unavoidable symptoms. Asthma UK seeks to correct the widespread misunderstandings about asthma and to enable more effective public and personal responses.

Objectives

To explore and explain the lived experience of people with severe asthma so that practitioners, people with asthma and the general public are aware of the potential yet avoidable consequences of asthma.

Method

A series of personal testimonials were gathered, four semi-structured group interviews were conducted and interviews with a sample of 500 people with doctor-diagnosed asthma reporting either disturbed sleep on a weekly basis, attacks of wheeze monthly or one or more speech limiting attacks ever in the last year.

Main Results

Half the people in our survey reported more than one attack per week (49%). 1 in 6 report weekly attacks so severe that they cannot speak (15%). 1 in 5 experience their asthma as life threatening (19%). Severe asthma causes isolation, especially in those over 45 (44% reported missing out when friends or family go to restaurants or pubs where smoking is allowed). Few people expect their asthma to improve significantly over the next 5 years and more people expect to need emergency services for their asthma in the future than do now. One participant reported 'I didn't know asthma could be so serious until my daughter died in my arms'.

Conclusions

People with asthma commonly report severe but avoidable asthma symptoms, which include the fear of death. Poor public understanding of the potential seriousness of asthma contributes to excess morbidity and mortality.



Prevention of Allergy and Allergic Asthma. The PAA document by WHO and WAO

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Asthma is estimated by the World Health Organization (WHO) to affect about 150 million people worldwide, placing an enormous strain on health resources in many countries, and is a major cause of hospitalisations for chronic diseases in children in the western world.

Information may be thus derived from areas where a rapid increase in disease has occurred, to form the basis for prevention strategies in areas where the prevalence of these diseases is still low. Where current expert opinion is still divided, where future research is required, or studies have provided negative results, the available information may prevent the implementation of unnecessary, restrictive, and costly avoidance strategies.

Prevention of Allergy and Allergic Asthma is an outcome of the joint meeting between the World Health Organization and the World Allergy Organization-IAACI (WAO) held in Geneva on 8-9 January 2002. This document is focused of IgE-mediated allergic diseases and it deals with Primary, Secondary and Tertiary prevention as well as on education. The role of heredity, early environmental and immunological factors, predictive early diagnosis, preventive measures, education and costs are taken into consideration.

The recommendations indicated in the position paper are based on the literature available up to 2001. Longitudinal studies on the development of allergy and on the impact of intervention in early childhood have provided new data and new concepts but have been published later. Prevention of allergy and allergic asthma is a fast-moving field; the document will need to be updated soon to incorporate more recent information.



EFA Allergy Manifesto

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

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

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

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

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

Because of the extent of the problem, allergy should be a part of the European national political agenda. The *EFA Allergy Manifesto* urges European and national institutions, healthcare professionals and policy decision makers to work together



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to create the conditions for early diagnosis, correct treatment and control of allergic diseases as well as for the application of preventive measures including the elimination of social and environmental barriers.

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

The key goals are to:

1. Change attitudes in society
2. Adapt healthcare systems and resources
3. Understand the nature of allergy
4. Establish programmes for training, education, empowerment and rehabilitation
5. Establish research programmes

Conclusions

The rights of allergy patients, now and in the future, must be equal to the rights of patients with other chronic conditions:

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

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

EFA Asthma Manifesto

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The *EFA Manifesto* was written in 2002 by Erkkka Valovirta, the then President of EFA and Mariadelaide Franchi who was Editor and EFA's European Project Co-ordinator. The combined knowledge of the clinical expert and the political background has produced a manifesto that every one of the EFA member countries can accept.

1. Patients' Rights

'The rights of those people with asthma should equate to basic human rights.' These rights include equal access to diagnosis, treatment, information and education. Diagnosis is often incomplete with little access for those whose asthma is allergy related. It is now acknowledged that around 80% of childhood asthma is allergy related and many areas have limited facilities for good allergy monitoring. Physicians, doctors and nurses should ensure that their diagnoses and treatments are relevant to every patient's needs.

'The rights of patients to breathe clean and healthy air should be upheld at all times.' We have a long way to go to achieve this right. The campaign for safe indoor air has been one of EFA's main aspirations over the past years, with two major European funded projects completed.

2. Patient Aspirations and Expectations

Current asthma guidelines are geared to enable patients to achieve a life style with a minimum of symptoms and little or no limitation of activities. This is not always appreciated by either patients or healthcare professionals. Good adequate education should be made available for all healthcare professionals so that they can comprehensively interview and educate the asthma patients in their care

3. Patient Education and Re-education

The outstanding feature of asthma is its variability, both in the short term and throughout the lifetime of an individual. Patients without adequate educative access to their healthcare professional may cease to take their preventive medication for a variety of reasons including, forgetfulness, non-compliance or fear of permanent 'drug dependency'. For these reasons, a continuing lifetime education programme is necessary. Re-education programmes can also be implemented in clinics, surgeries and patient groups with patient friendly information.



4. Patient/Professional Dialogue

'Surveys indicate that ongoing, regular discussions between patients and their healthcare professionals are far from commonplace.' It is essential that the 'hands on' healthcare professional is aware of the patient's lifestyle and has an insight into the patient's continuing needs. Other information sources such as telephone and dedicated internet sites should be implemented.

5. Asthma Control

Many patients who have a good tailored treatment regime would like to know about new asthma treatments and these should be included in the comprehensive action plans.

6. Asthma Prevention

'Prevention can decrease the burden of asthma and even forestall the onset of symptoms.' All asthma patients should be aware of the benefits of a safe environment, both indoor and outdoor. This should be combined with lobbying, by all concerned, of the decision makers for action on pollution and chemicals. Patients and healthcare professionals alike need much more education in these areas.

7. Commitment to Research

'Improvements in asthma management must be matched with a commitment to ongoing research into the epidemiology, pathology and pharmacology of the disease, as well as related environmental issues by healthcare professionals, leading researchers, international, national and local government bodies, policy makers, third party organisations e.g. patient groups and pharmaceutical companies. By advancing our understanding of asthma and its treatment, we can reduce hospitalisations and deaths from this common disease and, through improved control, enhance the everyday lives of asthma patients worldwide.'

European COPD Manifesto

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GOLD (Global Initiative for Obstructive Lung Disease) considers COPD a major public health problem and believes that COPD fails to receive adequate attention from the healthcare community and government officials. In fact, some estimates suggest that up to 600 million people worldwide may currently suffer from COPD.

In Europe, on average, 5% of the population (an estimated 19 million people) have COPD. It is currently the fifth leading cause of death and is predicted to rise. According to WHO figures, the disease is the fastest growing cause of death in the world's advanced economies and is projected to rank third by 2020. In this respect, COPD is predicted to grow faster than all other lung diseases, including asthma and lung cancer. Yet, surprisingly given these statistics, it is estimated that as many as 75% of people with COPD in Europe are undiagnosed and therefore experiencing untreated symptoms.

Fundamental to the mission of EFA is raising awareness of COPD among the public-at-large and institutions, with the aim of recognising the social dimension and the economic impact of this disease that is greatly under-estimated and under treated.

The first political action that EFA has taken is the dissemination of the *European COPD Patient Manifesto* which makes a call for better rights for patients. The Manifesto was adopted in Rome on October 9, 2002 and launched during the first World COPD Day (20 November 2002).

The *Manifesto* will safeguard patients through priority actions regarding early and correct diagnosis and the application of treatment corresponding to the most recent scientific evidence.

The *Manifesto* is a strategy of interventions that concern each of the crucial aspects involved in improving the quality of health of COPD patients.

EFA has developed and agreed the following seven key objectives:

1. Diagnosis and management of COPD
2. Reduction of risk factors
3. Programmes for training, education, empowerment and rehabilitation
4. Safeguard COPD Patient Rights
5. Build patient unity
6. Financial and social support
7. Commitment to research



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This strategy requires political interventions, including new legislation at European national level to ensure access to diagnosis, treatment, education, prevention and research as well as environmental control measures to improve air quality rights of COPD patients.

Access to pharmaceutical treatment recommended by the International guidelines based on scientific evidence is the guarantee for the improvement of health conditions and quality of life of patients and therefore to reduce the total costs of this disease.

There is a need for awareness campaigns on the meaning of this disease, its symptoms, risk factors and progressive nature. There is also the need for well-structured educational programmes for patients and members of their family to improve the COPD management, reduce the number and severity of exacerbations which are the cause of worsening of the condition and reduction of life expectation.

EFA calls upon institutions and scientific societies to help to translate research advances into daily life through specific programmes on the above objectives.

We believe that increased awareness is the first step in ensuring the COPD patients are diagnosed earlier and receive appropriate treatment sooner.

European Patient's Forum

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The European Patient's Forum was founded on 31 January 2003 to address and be consulted on issues concerning the interests of patients in the European health-care debate. The group was officially launched in Brussels on 23 March 2004. It also addresses the fact that, in this debate, non-patient groups and consumer organisations are currently expressing views supposedly on behalf of European patients in general but without prior consultation with patients. The European Patient's Forum criteria for membership include the requirement that each member organisation be patient-driven and have a democratic structure. The Forum believes that such groups can best represent the interests of patients with serious long-term conditions and can best secure the rights of such patients. There is no other group to whom the quality of health care is of more central importance than those with long-term serious – often chronic – illness. The Forum itself aims to be as transparent, democratic and inclusive as possible.

Patient organisations are increasingly advocacy organisations, campaigning for best practice care to be available to all and populated by people with close experience of a specific condition. As such, they are looking for a seat at the table – an input into policy making and the evaluation of implemented policies.

The European Patient's Forum has represented the point of view of the patient at various meetings and conferences and is endeavouring to secure the funding required to enable it to work at a really effective level. The Forum welcomes all pan-European patients' groups – both disease-specific as well as umbrella groups – working for patients and/or carers of people unable to represent themselves.

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Continuous Medical Education

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We have to consider the reason why CME is such an important tool in the medical profession, and why it has a tremendous impact on patients.

We have to analyze what makes a good doctor and why we encounter poor physician performances related to Patients dissatisfaction. This is why we encounter an ever rising number of claims and complaints that makes us inquire on how to maintain a good level of performance among doctors.

We believe that CME is the answer through an objective feedback on performance, with an involvement of several key players such as Government, Professional Bodies, Scientific Societies, Insurance Companies, Medical Associations, and also Patients Associations.

CME is still a growing structure throughout Europe, that becomes stronger and more harmonized year after year, with reciprocity status enforced in many countries, as well as between Europe and the USA, and a harmonized system of CME is inevitable in the next few years.

The governing body of European Medical Specialists is represented by UEMS, and its affiliate EACCME, European Accreditation Council for CME, a clearing house that harmonizes and validates credit systems and ratings in Europe.

CME is mandatory in few countries (Italy, Austria, Ireland, Netherlands, Norway, Switzerland, UK, Croatia, Slovenia, Romania, Check Republic), while it remains voluntary in most others, and is not in place as yet in Portugal, France and Greece.

The European Academy of Allergology and Clinical Immunology (EAACI) has been working on CME development since 1996 and through the publication of guidelines has been implementing their CME activity in its international and national events. A CME Committee rates events and proposes them to the EACCME for validation, standing among the first 4 Specialties in CME accreditation.

From the patients' point of view, there has been an interesting appraisal questionnaire developed by Federasma, Italy, and the University of Genova Allergology & Respiratory Diseases Dept., analysing 228 asthma outpatients. The first 3 priorities were Doctors updating of Medical Knowledge, Attention to Patients' Quality of Life and Communication with Patients. A new survey is going to be designed with the help of EFA.

Towards Healthy Air in Dwellings in Europe – THADE

Oslo 2004



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In November 2001, the European Commission has approved funding for the EFA project 'Towards Healthy Air in Dwellings in Europe' (THADE), within the framework of the programme devoted to pollution-related diseases. The project was undertaken in the wake of the 'Air Pollution in Schools', which highlighted the extent of poor air quality in schools and produced recommendations to rectify the situation.

The aims of the THADE project are to evaluate the magnitude of poor air quality in dwellings, to determine the legislation in Europe and elsewhere governing air quality in dwellings, and to recommend measures to counteract the problem.

Specifically, the aims were to:

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

The same team that worked on the EU project 'Indoor Air Quality in Schools' (2000-2002) worked on THADE, so that the experience gained and the contacts made were put to good use. The major scientific societies devoted to this area (EAACI, ERS, GINA Group, REHVA and ISAIQ) appointed representatives to sit on the Project Scientific Committee. Sixteen EFA member associations officially pledged their collaboration in the project, and others that were unable to meet the deadline for the project application, were also involved.

An enormous amount of data were collected, evaluated and collated. Based on the information available a series of actions were recommended to ensure healthy air in people's homes.



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These fall into five main categories:

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

The measures recommended to implement these actions are:

- Avoidance of smoking indoors
- Labelling systems to control emissions from building and consumer products
- Better building codes and guidelines for ventilation and moisture control, and
- Education and information campaigns.

We expect THADE will be a fundamental step forward to improving the living conditions not only for patients affected by respiratory disorders and their families, but for everyone.

The condensed report of THADE is now being printed (together with a CD-rom). The full report of each expert consultant will be available on the EFA website: www.efanet.org

Asthma Peer Support

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The concept of peer support has its beginnings in 1935 with the establishment of alcoholic anonymous. Self-help is founded upon the principle that people who share a disability have something to offer each other that cannot be provided by professionals. There is not a generally accepted definition of peer support. There are as many definitions of peer support, as there are peer support programs. There is one common element that is agreed and that is that peer support is offered by people with disabilities to people with disabilities.

Asthma is one of the major causes for emergency room visits, hospital admissions and school or occupational absenteeism. Patients seem to know little of their problem, how to manage it or even how to prevent attacks. Physicians usually lack sufficient time to inform patients and families, that changes might inevitably take place in their lives. Patients, having to deal with new aspects are usually discouraged. Discouragement usually prevents proper therapy.

Asthma peer support should provide patients as well as their families with practical information on altering everyday habits in order to prevent attacks and also offer psychological support. The main challenge and aim for an asthma peer support group is to help each other regain self-confidence and pursue a better quality of life.

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GA²LEN Global Allergy and Asthma European Network

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I. Introduction

Allergic diseases and asthma pose an important and increasing problem for populations and health care systems around the world, especially in Europe. European research groups have been at the forefront of investigations into the causes and management of these conditions. Nevertheless, there still exists across Europe a lack of permanent structures to support this type of work and relatively poor links between the different disciplines. The Sixth Framework Programme (6th FP) focuses on Community activities in the field of research, technological development (RTD) for the period 2002 to 2006. GA²LEN is a European Network of Excellence (NoE), selected for funding in the 6th FP, to address allergy and asthma in their totality.

II. GA²LEN (Global Allergy and Asthma European Network: Network of Excellence)

GA²LEN is a consortium of leading European research teams committed to work with each other and to establish a European Research Area of excellence in the field of allergy and asthma.

The acronym GA²LEN was chosen to commemorate the last great physician of Antiquity, Galenos (129-201), who first described the relationship between the nose and the lungs.

Currently, the partners of GA²LEN are 25 leading European institutions and 2 organisations, the European Academy of Allergology and Clinical Immunology (EAACI) and the patients' organisation European Federation of Allergy and Airways Diseases Associations (EFA).

At Ghent University, we have the honour to coordinate this challenging project.

III. GA²LEN in figures

Sixteen countries and 259 senior researchers are involved in the GA²LEN project. On the other hand, 289 young researchers will participate to the different scientific programs. A EU funding of € 14.4 million for a period of 5 years is foreseen.



IV. Structure

GA²LEN consists of an assembly composed of all partners, an executive committee, a management office and an advisory board. All partners are involved in the different research programs or task forces.

V. Objectives

The main objective of the GA²LEN NoE is to establish an internationally competitive network of European centres of excellence in order to strengthen European research, to tackle the fragmentation of European research, to spread excellence and knowledge, to integrate European research centers in a durable way, to address allergy and asthma in their totality and, at long term, to decrease the burden of allergy and asthma in all regions of Europe.

VI. Tools and methods

The activities of the GA²LEN NoE will be subdivided into 26 Workpackages which consist of four types of activities: integration and coordination of the scientific activities, jointly program of scientific activities and spreading excellence.

VII. GA²LEN provisions for

- Scientists
- Junior researchers
- Healthcare professionals
- Patients, public and policy makers

To reduce the socio-economic burden of allergy and asthma, patients and their families should be better informed about these diseases. There is also a need for more prevention, precaution and identification of the risks for human health taking into account particularly vulnerable groups such as children.

The public awareness about allergy and asthma should be improved towards a public 'right to know' about the impact of the environment on diseases such as allergy and asthma.

For patients and successful disease management, it is fundamental that new scientific evidence, relevant for each target group is disseminated in a language they can understand and in a model they can use friendly. A large amount of information is available nowadays, especially through the internet, but the quality of the information is sometimes questionable.



EFA and its members at national levels are specialised in adapting and harmonizing evidence-based information for all patients in all regions of Europe. EFA will therefore play a critical role in the project in preparing information materials targeted for patients and their dissemination towards the patients. A link between the EFA and GA²LEN websites will increase the interactions.

VII. Conclusions and Perspectives

GA²LEN will strengthen, inside and beyond the network, excellence in allergy and asthma research by consolidating past achievements into a formal and enduring structure and extending the achievements to other areas.

Allergy Early Diagnosis Campaign

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One child in four is allergic today. And tomorrow?

Allergic disease is one of the major causes of morbidity in the westernized world and its prevalence is increasing steadily. In EU countries, allergic disease is the most common chronic illness in childhood, affecting more than one child in four in some countries. In 2001 the European Academy of Allergy and Clinical Immunology (EAACI) launched a three-year awareness campaign to fight this epidemic. The target was the general public, policy makers and health authorities. And the message was 'One child in four is allergic today. And tomorrow? How can we stop this epidemic?'

The aim was to raise awareness about allergy as public health problem to:

- obtain more investment in allergy research at European level
- meet the demands of the growing allergic population: more and better education.

Actions: Allergy as a priority research in EC FP6 (ITRE Committee etc.), Green Week, advertising in newspapers, journals, TV, radio, information session, congresses etc.

Allergy care starts with early diagnosis

In June 2003 EAACI launched a new two-year campaign devoted to early diagnosis – in synergy with EFA – to make doctors and families more aware of the importance of an early diagnosis.

Too many children with allergic diseases are diagnosed too late. To better prevent and treat infants and children, it is crucial to detect if they are allergic, and to what, at a very early stage. Thus, the unnecessary suffering from allergy symptoms can be minimised and best possible health related quality of life ensured. Allergy testing is indicated for an early identification of infants at increased risk for later development of allergic diseases and for a specific allergy treatment. A test is required when suspected allergic symptoms persist or appear episodically with rather severe symptoms.

Allergy testing provides significant information to the families and the doctors about the child's atopic constitution.



Abstracts

Target: Specialists, general practitioners (GPs), European organisations, health authorities, non-governmental organisations (NGOs), paramedical organisations, patients, public-at-large.

Message: *'Allergy Care starts with Early Diagnosis', '1 child in 4 is allergic. Identify who'*

- To identify who is at risk
- To better prevent allergy
- To better treat allergic infants

Scientific Basis: EAACI Paediatric Section Statement: *'Allergy Testing in Children: Why, Who, When and How ?'* (Allergy June 2003).

Material:

- Statement *'Allergy Testing in Children : Why, Who, When and How?'*
- GP's leaflet
- Patients leaflets

Translated into: English - French - Dutch - German - Swedish – Danish - Italian – Spanish- Portuguese

Actions

EAACI

Special events with symposium involving EAACI Paediatric Section Speakers, together with EU and WHO strategies on allergy childhood are organized within the frame of annual EAACI congresses. National and local activities are organized, like symposium and information sessions involving both paediatric allergy societies and GP/Paediatric societies. Education sessions are also organized in some countries, with case discussions and local guidelines.

New educational material is in preparation: pharmacist leaflet and GP/Paediatrician brochure. Insertion of allergy press articles in health journals, daily newspapers and internet – TV/Radio broadcasts on allergy topic.

EFA

EFA role in the Campaign is to disseminate the message on early diagnosis to patients via EFA member associations, and to collaborate in dissemination to gen-



eral practitioners and other health care professionals. Associations in Sweden and the Netherlands are already taking part in the campaign and in Belgium a national campaign has been launched successfully.



AIRNET: A Thematic Network on Air Pollution and Health

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AIRNET is based on the need to develop an EU-wide framework for air pollution and health research to strengthen the science-policy interface and integrate information from individual projects.

The objective of AIRNET is to create a widely supported basis for public health policy related to improving air quality in Europe and regulatory needs to achieve this goal.

The project started in January 2002 and will end in January 2005. The expected achievements include a generalised framework to interpret findings from studies on air pollution and health in a policy-relevant way. This will be achieved by linking data from exposure assessment, epidemiology and toxicology to risk and health impact assessment and subsequently policy issues like standard setting, source control etc. The main result will be a transparent link between research data on the one hand and policy implications on the other hand. The interpretation of exposure, epidemiology and toxicology findings, as well as the risk and health impact assessment and the science-policy interface, are developed in Working Groups.

EFA is one of the AIRNET partners: the partnership consists of one co-ordinator, eight contractors (among which EFA) and 14 members. The contractors represent the scientific community as well as the stakeholders; they will lead most of the work done in the Working Groups. This position has given EFA the possibility to really influence the ongoing process, especially in the Science-Policy Interface Working Group.

The presentation of AIRNET will focus on the effort to establish an effective communication plan between scientists and non-scientists like policy makers, patients' advocates, the medical world and other stakeholders like industries.

The final report of AIRNET will be presented in the 3rd AIRNET Conference in Prague (CZ), 21-24 October 2004. Some of the preliminary outcomes will be presented at the EFA Conference.

For more information: <http://airnet.iras.uu.nl>

PINCHE, Policy Interpretation Network for Children's Health and Environment

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The Pinche Network, funded by the European Union, started in January 2003 and will exist for three years.

The network is designed to provide decision-makers, environmental health professionals and other stakeholders with information relevant for policy development, to help making decisions about issues in the area of children's health and the environment. To reach this, studies related to children's health and environment will be analysed and interpreted and the results will be used to make recommendations for policies.

The themes of the network are: Children and Air Pollution, Children and Environmental Carcinogens, Children and Noise, Children and Neurobehavioural and Development Toxicants.

EFA is one of the stakeholders in the PINCHE project for the theme children and air pollution.

At the moment the project is half way and recently concluded the data collection. At the INCHES/PINCHE congress in London, April 2004, the stakeholders were invited to discuss the results.

Air pollution will cover outdoor and indoor air pollution; the latter mainly as biological agents and environmental tobacco smoke. EFA's role in PINCHE will be discussed.



SAFE Plant Food Allergies

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Apples (*Malus domestica*) and other soft fruits are a healthy and enjoyable part of our diet. However, a number of people can develop allergies to fresh fruits and vegetables, often as a consequence of allergies to pollen. Approximately 4% of the population can develop allergies to pollen from trees like birch, alder and hazel. More than half of those tend to have allergic reactions when eating plant foods such as apples, celery, nuts and spices. In countries like Scandinavian countries, with large area of birch forests, birch pollen and consequently apple allergies are more common. However, this is less of a problem in countries with only sparse or no birch woods, such as the UK or the southern European countries.

The symptoms of the pollen-fruits allergy syndrome are generally mild; in many cases people only experience itching or tingling and swelling around the mouth. However, there are groups of allergic individuals that suffer from severe allergies to fruits, including life threatening anaphylactic reactions. These are especially well documented towards fruits such as peach in Southern European countries.

As part of the effort to stem the rise in food allergies and to ensure that all consumers enjoy the benefits of a healthy diet and the pleasure of consuming fresh fruits, SAFE project is researching the mechanism underlying both mild and severe forms of fruits allergies, using apple as a model system. This will enable us to:

1. Identify pre-existing apple varieties with intrinsically low allergen levels
2. Provide breeders with guidelines to select new cultivars with low allergen levels
3. Recommend apple growing and post harvest storage conditions which minimise the content of allergens
4. Identify processing regimes used in the manufacture of fruit juices and other fruit products that are optimal for both product quality and reduced allergenicity
5. Compare general and allergic consumer attitudes to novel foods with a health benefit such as reduced allergenicity.

Information arising from this research will provide improved diagnosis of fruit and vegetable allergies by providing better defined fruit allergens, as opposed to the highly variable crude extracts currently employed. It will also contribute towards



a better understanding of the relationship between pollen and fruit allergies based on the identification of the relevant allergens and their presence in different plant varieties.

Information on allergen structure and properties will also underpin future efforts to develop therapeutic options for food allergies, a much needed alternative to dietary avoidance, the only currently available option. Information on allergenic protein families is also of interest for the allergic patient in his or her daily life management. Allergen detection assays once established and evaluated may assist regulatory authorities to determine threshold levels for allergens in foods. And finally, ensure that the most effective strategies are adopted by the market place to control the level of allergens in food.

SAFE is a European Union funded project; Quality of Life and Management of Living Resources; Key Action: 1. Food, Nutrition and Health; QLK1-CT-2000-01394. SAFE is coordinated by Dr. Karin Hoffmann-Sommergruber.

Website: www.akh-wien.ac.at./safe/



INFORMALL Communicating about Food Allergies

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Food allergy is an area of intense research interest. The European Union has commissioned a concerted action project to promote the provision of visible, credible food allergy information sources to a wide variety of stakeholders, including general consumers, the agro-food industry (including primary producers, manufacturers and retailers), allergic consumers, health professionals and regulators. The project brings together clinicians, food chemists, social scientists, allergy patient groups, food manufacturers and retailers across Europe, and from the USA.

Food allergies are thought to affect around 1-2% of European adults and between 5-7% of children. However, the perceived prevalence of food allergy amongst the general population is much higher, with around one in three individuals believing they suffer from some form of food allergy or intolerance.

The perception that food allergy is a common condition is heightened by the fact that food allergies, along with other types of allergy, appear to be on the increase. Food allergy, true or perceived, can have severe social implications, with allergic children being excluded from full participation in school life. It can impair an individual's ability to work. This ultimately translates into an economic loss for society. Adequate information provision is crucial if these problems are to be addressed. At present there is a bewildering amount of food allergy information available, with little insight into its credibility. This is exacerbated by the proliferation of web sites offering allergy information, much of which is of poor quality, anecdotal in nature and commonly linked to specific, alternative remedies.

This project will provide credible information sources, which address the concerns and needs of various stakeholder groups. These include consumers, allergic individuals, the agro-food industry, health professionals and regulators involved in safety assessments of allergenic risks posed by novel foods.

The topics of INFORMALL Project are:

1. Risk communication issues in food allergy
2. Recommendations for communicating food allergy information
3. Database on allergenic foods



4. Consumer friendly web gateways
5. Clustering of European food allergy research
6. Exploitation and dissemination of information

INFORMALL is funded under the 5th Framework programme of the European Union through the Quality of Life and Management of Living Resources Key Action, QLKI-CK-2002-02284.

INFORMALL is co-ordinated by Dr Clare Mills, UK.

Website: www.informall.eu.com



Methods for Analysis of Allergens - Standardization

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Materials and products can contain contact allergens and some respiratory allergens/irritants that affect the skin and respiratory tract. It is of great important to develop uniform standards for the analysis of known allergens in order to be able to control material and products with a view to avoiding diseases. Today, many people suffer from contact allergy and asthma. In Europe 15% of women have contact eczema from nickel.

An international committee, within the European Committee for Standardization (CEN/BT/WG 132), has produced a document on methods for analysis of allergens in products and materials, as a basis for future European standardization work. The aim was to examine the need to develop CEN Standards as analytical methods, applicable to known allergens in products and materials in occupational and private life.

Four working groups reviewed 69 known allergens including:

- Metals (nickel, chromium in leather, chromium I cement, cobalt)
- Plastics and rubber chemicals (isocyanates, acrylates, epoxy, anhydrides etc.)
- Preservatives and dyes (formaldehyde, 9 disperse dyes etc.)
- Perfumes and colophony (24 fragrance chemicals addressed by the Cosmetics Directive, rosin)

Experts from nine countries representing authorities, industry and science participated. Liaison partners were the European Society of Contact Dermatitis (ESCD), European Federation of Allergy and Airways Diseases Patients Association (EFA) and European Flavour and Fragrance Association (EFFA). Contacts with the European Commissions has of course also been of great important.

The final report from CEN/BT/WG 132 was approved in January 2003. The report includes a review of 69 allergens, and of the need for development of standardized analytical methods in support of European legislation to create a new CEN Technical Committee (CEN/TC 347 'Methods for analysis of allergens').



Professor Carola Lidén, M.D. at the Department of Occupational and Environmental Health Occupational and Environmental Dermatology, Sweden has been the Convenor of CEN/BT/WG 132.

Standardised analytical methods are often lacking for control of compliance with regulations. On behalf of CEN Technical Committee the Swedish Standards Institute (SIS) during year 2004 will start the urgent work 'Methods for analysis of allergens, CEN/TC 347'.

The Swedish Asthma and Allergy Association participated and sponsored the Swedish group at the Swedish Standards Institute – SIS. And of course EFA as a liaisons partner will participate too.

