



## Food Allergy Patients Want to Know What They are Eating

An estimated 4% of adults and 8% of children in the European Union suffer from food allergy, for which there is no cure. The only thing that an affected person can do is to stop eating the food that causes the symptoms, which in some cases can be life threatening. The recent case of a young Swedish girl who died after eating chocolate containing nuts (which were not included on the label) is not rare. EFA welcomes the European Union initiative to amend the EU *Labelling of ingredients present in food-stuffs* Directive (2000/13/CE).

This is an enormous step forward, and means that allergic consumers will be better able to avoid allergenic foodstuffs in their own countries and when travelling in other EU countries. The main improvements to the Directive are:

- The ingredients and substances recognised as causing hypersensitivity are listed in the Directive and must be clearly labelled without exception, and the list will be updated as new scientific data become available.
- Strict limits have been set about ingredients that are a minor part of the finished product and about exceptions to compound ingredient labelling.

However, the Directive makes no reference to precautionary labelling, which concerns the risk of the presence of trace amounts of food substances, and we call upon the European Union to draft regulations for precautionary labelling!

### Pitfalls of current EU regulations on food labelling

Not all the ingredients of foodstuffs must be mentioned on the food label ('25% rule') and some ingredients are included under a category (vegetable fat, lecithin, aroma etc.). Therefore, people with food allergy are worried they might eat 'hidden' allergens that can provoke a severe, even life-threatening reaction. Many of them have stopped buying processed food, but others who are less well informed are not aware of the risk. They eat food they believe to be safe and wonder why they still have chronic symptoms like atopic dermatitis or asthma. The quality of life of both groups of people is reduced.

Some major food manufacturers have a policy of 'precautionary labelling' the main allergens, by mentioning the 'risk' of the presence of allergens in the case, for example, of accidental contamination during food processing. However, this practice is not mandatory.

Food allergic consumers in Europe have long waited for better regulations in food labelling. EFA appeals to the European Union to address the concerns of food allergy patients and their families. Join us in the fight to ensure appropriate information, a better quality of life and even to save lives

*Elisabeth Bell  
Erkka Valovirta  
Susanna Palkonen*

## Dear Friends,

After five years of outstanding and creative work on EFAnews, EFAnet and EFA publications in general, Mariadelaide Franchi has stepped-down as EFA Editor. The EFA Board rightly thought that not just one, but three people would be required to meet the high standards set by Lally. Therefore, the new team consists of an EFA Editor, and two Assistant Editors: Susanna Palkonen (Executive Officer) and Marta Almanza Lista (Board Member). It will be very difficult to follow in Lally's footsteps, but we will do our best to ensure that the EFA newsletter will continue to be a valid tool in the fight for patients' rights. This issue of EFAnews is our first effort. I hope you like it. It focuses on the EU Food Labelling Directive, which will have an enormous impact on food-intolerant people, consumers in general, and food producers in Europe and beyond.

*Elisabeth Bell, EFA Editor*

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## Attitudes to low allergen food produced using genetic modification



### Benefits and disadvantages of low allergen food

The benefits of low allergen food were being able to eat all food with no worries, no symptoms and no need to check labels; having more variety, more fruit and more vitamins in the diet; and having better health generally.

Respondents said that a high price would discourage them from buying low allergen food, and quality, particularly taste, was also important. Critically, respondents wanted to be sure that the food was safe.

### Labelling of low allergen food

Almost 90% of respondents wanted low allergen food to be clearly labelled, and many said they would trust the label only if it was checked (and approved) by an independent, expert, national or international organisation. They also wanted the food to be EU or WHO approved, regular checks of the validity of low allergy claims, and well controlled testing of the food.

*Further information about this study can be obtained from Dr. Susan Miles, Institute of Food Research, Norwich, UK.*

E-mail: [susan.miles@bbsrc.ac.uk](mailto:susan.miles@bbsrc.ac.uk)

The future of genetically modified (GM) foods will be determined by consumer acceptance, making it important to examine public attitudes towards GM food. Recent research indicates that public perception of GM food in Europe is generally negative. While the reduction or elimination of the allergenicity of particular food products may be seen as a benefit, food allergic individuals are concerned that genetic modification may accidentally lead to new food allergies.

One aim of the EU-funded SAFE project is to investigate attitudes towards low allergen foods produced using genetic modification in food allergic individuals (see <http://www.akh-wien.ac.at/safe/>).

As a first step, a small study was conducted to identify important issues about low allergen food.

### Attitudes towards low allergen food and genetic modification

An interviewer-assisted questionnaire was given by clinicians to 20 food

allergic individuals in each of Austria, Spain and The Netherlands. The respondents' age ranged from 17 to 79 years, with 23 men and 37 women taking part; most were allergic to more than one food, usually apple. Almost all respondents dealt with their allergy by avoiding the offending food; some also avoided other products containing this food and checked food labels. Two-thirds claimed that their food allergy did not affect their lifestyle. Others found their lifestyle was affected by not being able to eat the food in question and to difficulties when eating out.

Over 80% would like low allergen foods to be produced. Almost all respondents said they would buy low allergen food produced by conventional plant breeding, and three-quarters would buy low allergen food produced by genetic modification; only half of the Austrian sample would buy GM low allergen food. Two-thirds would prefer low allergen food to be produced using conventional plant breeding.

## InformAll

This massive EU project under Framework 6 is being set up to address the unexplained increase in food allergy, both real and perceived. It will also attempt to formulate strategies to frustrate the increase and to set out guidelines for the prevention and avoidance of the problems with which we in EFA are so familiar.

'Whilst we do not know why this is happening, it is becoming clear that certain actions need to be taken to ensure that we can anticipate and manage the problem effectively'. The results will affect many – from the 11-26 million EU citizens who already suffer from some form of food allergy, to the food providers and manufacturers. 'Given its public health, social and economic consequences, now and in the future, preventing allergic reactions to foods is a major challenge that must be met'.

For some aspects, *InformAll* will co-ordinate existing nationally funded research but in other areas a significant additional RTD effort is required. Co-operation across the EU is vital. 'Support for the development of effective food allergy diagnostics and therapeutic options will hasten their realisation and delivery to the European public'.

The main aim of the project will be to develop holistic strategies for managing the apparently increasing prevalence of food allergies across the European Union.

### Norwich UK meeting 13-15 February 2003

This was the first meeting of *InformAll*, and after a background session at which EFA spoke on the patient aspect, it was geared to Risk Communication Issues in Food Allergy.

The main aims were to:

- define the most important issues regarding effective communication and food allergies;
- understand barriers to developing effective communication about food allergy;
- identify potential cross-cultural and intra-individual differences in communication needs, taking due account of the diversity in the European population regarding food allergenicity.

The report will eventually be published via the project website.

*Erkka Valovirta is EFA's representative on InformAll – Elisabeth Bell represented him at the Norwich meeting as he was engaged elsewhere.*

Shape the  
Future of Life



## WORLD HEALTH DAY 7<sup>TH</sup> APRIL 2003: HEALTHY ENVIRONMENTS FOR CHILDREN

The theme of this year's World Health Day is *Healthy Environments for Children*.

According to the WHO, every child should grow up in a healthy home, school and community and the future development of our children, and of their world, depends on their enjoying good health now. Allergy, asthma and indoor environment, and environmental tobacco smoke (ETS), are considered one of the major issues by the WHO for children's health.

Thousands of events across the world highlighted the importance of safeguarding the health of the millions of children who die each year from diseases, infections and acci-

dents related to their environments. For example, in Hungary, EFA Hungarian member association representative Dr. Kristof Nékam spoke in a special event at Parliament on allergy in Hungary and possible solutions to tackle it.

EFA's 8<sup>th</sup> Conference in June 2003 contributes to this theme with specific focus on improving indoor air in dwellings in Europe. Children as well as adults spend most of their time indoors. Therefore, the quality of indoor air is a significant factor in children's health, especially those with respiratory allergies, asthma and other hypersensitivities.

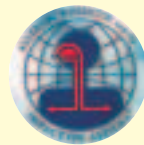
For more information (press release, events, facts etc.) visit:

[www.efanet.org](http://www.efanet.org), which provides link to World Health Day resources.

### Booklet on Children's Health and the Environment

EPHA, European Public Health Alliance, of which EFA is a member, published a booklet *Children's Health in Europe: Tackling environmental threats* on World Health Day. Allergy and asthma and respiratory health are among the major issues in this booklet. The booklet is targeted for authorities around the world and especially in Europe. EFA, as well as the European Respiratory Society (ERS) and the European Academy of Allergology and Clinical Immunology (EAACI) have given their input to the booklet, and EFA's Indoor Air Pollution in Schools EC project from 1999 is mentioned as an example of non-governmental organisation (NGO) activities in the field. The booklet can be downloaded and ordered from <http://www.ephaproject.org>

### ARIA



The WHO-supported ARIA guidelines, directed particularly at pharmacists on managing allergic rhinitis and its impact on asthma have been released. The guidelines aim to increase collaboration between pharmacists, physicians and other healthcare professionals, reduce the burden of allergic rhinitis and its co-morbidities, aid in identifying undiagnosed or uncontrolled asthma and improve cost-effectiveness in the management of allergic rhinitis.

The guidelines can be downloaded from: <http://www.whiar.com/>



### The World No Tobacco Day-2003 'Tobacco-free films tobacco free fashion Action!'

'If a tobacco product seems macho or feminine, sophisticated or rugged, sexy or sporty – it is because of the marketing around it' WHO.

This year's *World No Tobacco Day* (31 May) focuses on the role of the fashion and film world in fostering the worldwide tobacco epidemic and urges them to stop being used as vehicles of death and disease. The worlds of film and fashion cannot be accused of causing cancer. But they do not have to promote a product that does. EFA supports the World No Tobacco Day and many ENCPA, as well as EFA members, have activities during this day.

In November 2002, WHO was joined by medical associations and the Smoke Free Films project at the University of California in San Francisco in its call to the entertainment and fashion industries to ensure that their social responsibility is commensurate with their global influence. Hollywood and Bollywood (the Indian film industry) were invited to join the worldwide movement to rid films of their tobacco-promoting role.

More information and World No Tobacco Day poster, brochure and leaflet: <http://www5.who.int/tobacco/page.cfm?sid=86>

### Background of World Health Day 2003

In September 2002 WHO launched a campaign on Children's Environment and Health, and World Health Day was the start of this campaign. The theme will continue until the WHO Fourth Ministerial Conference on Environment and Health, entitled *The future for our children* (Budapest, Hungary, 23-28 June 2004).

By focusing on children as a target group, the WHO hopes to promote more effective measures to improve health and environment worldwide. The major output of the Conference will be the Children's Environment and Health Action Plan.



On World Asthma Day (6 May 2003) the Global Initiative for Asthma (GINA) will release the preliminary findings of

the *Burden of Asthma Report*. This will highlight the global dimension of asthma and will call upon people with asthma and those who provide asthma care to act to reduce the burden of asthma.

GINA has developed Five Positive Steps that people with asthma and their carers can take to reduce the burden of asthma:

1. Ask your doctor to prepare a written personal asthma management plan.
2. Take medications prescribed by your doctor.
3. Be aware of the factors that make your asthma worse.
4. Learn to recognise when your symptoms are getting worse.
5. Know what to do in an asthma attack.

Many EFA associations have activities during World Asthma Day: for example, Aniksi, the Greek association has organised a Fair in Athens, where the EFA Asthma Manifesto will also be displayed.

## THADE - Towards Healthy Air in Dwellings in Europe

During the meeting of the scientific committee and project partners of EFA's EU-funded THADE project in Rome on 25 October 2002, the project consultants, P. Carrer, G. Viegi, A. van Bronswijk, O. Seppänen, E. Rameckers and D. Kotzias presented



Rome, 25 October 2002. Edith Rameckers presenting her report and Lally Franchi in the chair.

their interim reports. Importantly, the list of pollutants that will be considered in the project was discussed at length among the experts. This meeting was important to fine-tune the working schedule and to lay the basis of the 'Contents' of the final report and recommendations that will be sent to the European Commission.

The consultants of the project subsequently met in Luxembourg on 13 March to prepare the final stages of the project and to finalise the contents of the Final Report. In describing what the European Commission expects from this report, Marc Seguinot, EC officer responsible for the project, stressed that the Commission expects specific and clear recommendations

and guidelines regarding good air quality in dwellings.

The new EU Public Health Programme recognises the importance of indoor air and its health effects, and it appears that there is the political intention to bring this issue to regulatory level.

A recurrent theme of all the meetings held within the THADE project is that national and international bodies active in this area will exploit the national and international experiences that are described within the project, and the recommendations to produce comprehensive national plans on indoor air quality in dwellings. It is in this area that the EFA member associations can be of particular help.



## AIRNET: PATIENTS' VIEWS

First AIRNET Conference London, 11-12 December 2002

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

*The first of three annual AIRNET conferences brought together key investigators and nationally funded research projects on air pollution and health, the EU, WHO, EEA and UNECE representatives, policy makers, stakeholders, consumer organisations, and environmental non-governmental organisations. Edith Rameckers attended the conference on behalf of EFA; below is an excerpt from her presentation.*

### Why are EFA target groups important?

Asthma prevalence in children in Europe is as much as 15%; COPD prevalence in Europe is between 2% and 10%. Asthma affects 150 million people worldwide. Respiratory diseases are second in Europe in disease incidence, prevalence and costs. They are the first cause of death worldwide and the second cause in Europe.

Total hospital costs due to respiratory diseases in EU countries is €17.8 billion/year, of which asthma and COPD account for 19% each. Workdays lost due to respiratory diseases in EU countries are 66,155 per 100,000

inhabitants, of which 62% is due to COPD and 21% to asthma. The cost of lung disease in Europe is €100 billion annually, which is almost the Gross Domestic Product of the Republic of Ireland. And regarding allergy, one out of four children is allergic. These are large numbers indeed! And they are on the rise all over Europe!

### EFA's aims in AIRNET

EFA hopes that with an open discussion based on facts and on the right to know, the network will review scientific data on pollution related to triggering allergy and airway diseases, in order to define an integrated strategy to avoid or reduce exposure, especially for sensitive persons, and to define policies for implementation in Europe.

Communication about these issues, and specifically for vulnerable groups like children, the elderly and people with pre-existing diseases, should continue, with the co-operation of all stakeholders, also after the AIRNET project. Skills are needed to deliver the right message to the right person.

### Issues raised by patients

- What is the effect of the single pollutants and what is the effect of the total pollutant load of 'normal' air, i.e. the air that people breathe.

- Both the short-term and the long-term effect are important.
- What is the effect in the different age groups; we expect the effect of air pollution to be greater in children and the elderly.
- What is the effect in fragile persons with a pre-existing disease (lung diseases, allergy, heart diseases, etc).
- Extra mortality risk.
- Extra morbidity: from discomfort to hospitalisation; chronically ill persons live with the disease and its discomforts.

'Acceptable risk' should be defined for potentially more vulnerable groups. AIRNET should contain European pollution maps so that combined outcomes can be easily understood. Risk profiles for age groups should also be 'illustrated', and diseases should be linked with pollutants. Last but not least, advice and measures to lower personal and damaging exposure should be included. Many questions cannot yet be answered, but let's use the best knowledge available today to ensure that breathing is an activity as healthy as possible. EFA's standpoint is: implement today's knowledge and continue with good research to provide updates for tomorrow.

*E.M.A.L. Rameckers*

## A new voice to represent the interests of patients in Europe

On 31 January 2003, 12 pan-European patients' organisations came together in Brussels to create a common platform, the European Patients' Forum. We are proud that EFA is amongst those 12 founding members. The European Patients' Forum should be seen as a response to calls by the European Commission and other EU institutions to have one pan-European patient body to address and be consulted on issues concerning the interests of patients in the European healthcare debate.

The main objectives of the Forum are:

- To facilitate an open and inclusive Patients' Forum enabling all pan-European patients' groups to exchange information and points of view in the area of EU Health Policy and all other EU initiatives of interest or concern to patients.
- To share health experiences and examples of good practice in order to strengthen the role and voice of European patients' organisations.
- To offer the views of patients, as external stakeholder in the European healthcare debate, by means of a broad, truly representative and independent patient group resource.
- To provide a forum for patients' organisations to develop common positions on European health policy issues and to lobby on behalf of those organisations, giving them a central position in the provision of healthcare in Europe.
- To become the natural first point of reference for the European Commission and other European institutions when seeking the opinions of patients and/or when seeking to consult patient groups.
- To co-operate in the formation and execution of joint projects aimed at improving health outcomes and the quality of life of European patients.

The European Patients' Forum is open to other European patients' organisations that fulfil the following criteria:

- *Legitimacy:* EPF member organisations should have statutes registered in one of the member states of the European Union. If the applicant organisation is not registered in an EU Member State, additional information needs to be provided demonstrating EU focus and activities.
- *Representation:* EPF member organisations should have members of their own in more than half of the member states of the European Union.
- *Democracy:* EPF member organisations should have governing bodies that are elected by their members, who shall be patients, their carers, or their elected representatives.
- *Accountability and Consultation:* Statements and opinions of EPF member organisations should reflect the views and opinions of their memberships and consultation procedures with those memberships should be put in place.
- *Transparency:* European patients' organisations should disclose their sources of funding and generally make available their audited financial accounts.

The European Patients' Forum is currently working on registration in Luxemburg, setting up a working plan and getting funds. The website is under construction and can be found at [www.europeanpatientsforum.org](http://www.europeanpatientsforum.org).

The email address is [info@europeanpatientsforum.org](mailto:info@europeanpatientsforum.org)

*Bernd Arents*  
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[bwm.arents@chello.nl](mailto:bwm.arents@chello.nl)



### Abstracts of the 9<sup>th</sup> International Conference on Indoor Air Quality and Climate 'Indoor Air'

held June - July 2002, in Monterey, California are available online at: <http://www.indoorair2002.org/abstracts.htm>



## 8<sup>th</sup> EFA Conference Allergy and Airways Diseases

Towards a New European Programme for Healthy Indoor Air

**Exciting Working Programme! Outstanding Social Events!**

**A MEETING YOU MUST NOT MISS!**

**A SELECTION OF TOPICS**

Living with COPD

COPD and asthma: similarities and differences

The role of ENCPA in improving COPD management

Living with COPD: an interactive session

Indoor air pollution and health effects

Risk factors and environmental tobacco smoke

International approach to indoor air pollution prevention

Technology to improve indoor air quality in dwellings

The INDEX Project - Indoor Exposure Limits for pollutants

Ventilation procedures for better indoor air quality

Network of European patients' associations

Guidelines and standards on indoor air quality in dwellings

Future Community Strategies for Health and Environment  
How can optimal control for patients with airway diseases be achieved?

Self-treatment from the patient's perspective

What should patients expect in terms of control and education

New approaches to treat respiratory disease

Self-treatment from the patient's perspective

- If you are going to attend just one meeting this year, make it the 8<sup>th</sup> EFA Conference that will take place in the attractive city of Lisbon.
- Prominent personalities will speak on various aspects of Healthy Indoor Air
- EFA member associations are encouraged to suggest topics for Working Group Sessions, and to present posters illustrating their activities. Don't miss this opportunity of communicating with your colleagues from all over Europe!

The registration fee has been kept low to encourage all those interested to attend. The accompanying person fee is particularly low.

**Participants Package** (3 nights accommodation in a single room, Conference documentation, scientific events, Opening Ceremony and Welcome Reception, Conference Dinner, Farewell Dinner, 2 lunches and coffee breaks) is Euro 360 before April 30, and Euro 390 after.

**Accompanying Persons** (3 nights accommodation sharing a room, Opening Ceremony and Welcome Reception, Conference Dinner, Farewell Dinner, 2 lunches and coffee breaks) is Euro 120.

**The complete scientific and social programme and registration form are on [www.efanet.org](http://www.efanet.org)**

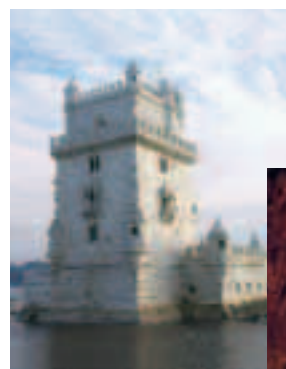
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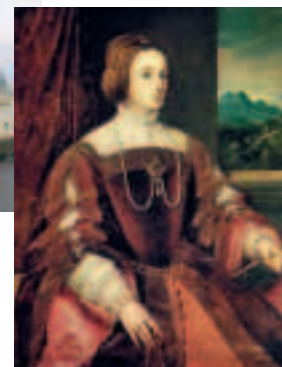
*Monastery*



*Lisbon*



*Belém Tower*



*Isabella of Portugal*



## EFA has been allocated a Main Symposium at the EAACI Paris Congress 2003

Over the years the EFA has gradually taken a more prominent part in the annual EAACI Congress. This year, the allocation of a main symposium to EFA by the main European scientific society in Allergy and Clinical Immunology is a recognition of EFA's role in this field.

For more details about EAACI 2003, check [www.congrex.com/eaaci2003](http://www.congrex.com/eaaci2003)

The aim of the symposium is to address, together with doctors, the problems and possibilities of patient/doctor communication and the role of the new forms of media and variable information flow in allergy and asthma, which patients face today, in the management of these diseases.

### Sunday 8 June 15.30/17.15 - Joint EFA/EAACI Workshop New Language and Medias in Allergy and Asthma and the Patient

#### Opening

Erkka Valovirta, EFA President

#### Media and Quality of Information

Esmé Newton-Dunn, UK

*A communications expert specialized in medical PR who has worked with several health-related non-governmental organisations.*

#### Ethics in Allergy

Kristof Nékam, EAACI, Hungary  
*Medical Doctor, Chair of the EAACI Ethics Committee and delegate of the EFA member association in Hungary.*

#### Understanding Medical Language and the Patient - Role of the Patients' Associations

Bernd Arents, European Patient Forum, The Netherlands  
*Represents EFA at the European Patients' Forum, delegate of EFA member association in The Netherlands.*

#### Internet and Patient-Doctor Relationship

Nikos Papadopoulos, Greece  
*Medical Doctor, member of the EAACI Executive Committee and delegate of EFA member association in Greece.*

**During EAACI 2003, EFA will take part in the launching of the European Campaign on *Early Diagnosis in Children*. Two symposia, held on 8 June, will be devoted to this event.**

#### EAACI Paediatric Session

Chairs: Ph. Eigenman, Switzerland & Per Grinsted, Denmark

#### Early sensitisation and development of allergic diseases

F. Rancé, France

#### Genetic and environmental factors as determinants for the atopic march

U. Wahn, Germany

#### Risk factors and predictors for developments and persistence of allergic diseases

M. Wickman, Sweden

#### Allergy testing in children.

#### Indications and methods

A. Host, Denmark

#### Prevention and early treatment of allergic diseases

A. Muraro, Italy

#### Early Diagnosis in Europe

Chair: U. Wahn, EAACI

#### Allergy testing in children: Why, who, when and how?

Host, President of EAACI Paediatric Section

#### WHO/EURO activities in the area of allergy and environment in childhood

L. Nemer, WHO Europe

#### Early diagnosis, a patient's right

E. Valovirta, EFA

#### EAACI Campaign 'Early Diagnosis in Children'

U. Wahn, EAACI

#### INTERNATIONAL HIGHLIGHTS

##### 22nd EAACI Congress

June 7-11, 2003, Paris, France  
Information: Congrex Sweden  
Tel. +46 8 4596600; Fax +46 8 6633815  
[www.eaaci.org](http://www.eaaci.org)

##### 8th EFA Conference

**Allergy and Airway Diseases: Towards a New European Programme for Healthy Indoor Air**

June 26-29, 2003, Lisbon, Portugal  
EFAOffice@skynet.be, [www.efanet.org](http://www.efanet.org)

##### Interasma 2003

##### XVII World Asthma Congress

July 5-8, 2003, Saint-Petersburg, Russia  
Information: Congress Secretariat  
Tel. +7 095 4299620; Fax +7 095 3365000  
acicis@ibch.ru, <http://www.isir.ru>

##### European Respiratory Society

September 27-October 1, 2003  
Vienna, Austria  
[www.ersnet.org](http://www.ersnet.org)

##### Healthy Buildings 2003

July 13-17, 2003, Singapore  
Due to the Severe Acute Respiratory Syndrome (SARS), the Congress has been **postponed to 7th to 12th December 2003**.  
Information: Conference Secretariat  
Tel. (65) 62955 790; Fax (65) 62955 792  
secretariat@hb2003.org

##### Forum on Respiratory Allergy A 21st Century Approach

November 6-8, 2003, Montecarlo  
Information: Publications  
Tel. +377 97973555; Fax +377 97973550  
allergy2003@publiccreations.com  
[www.aim-internationalgroup.com](http://www.aim-internationalgroup.com)

##### 23rd EAACI Congress

June 12-16, 2004, Amsterdam, The Netherlands  
Information: Congrex Sweden AB  
eaaci2004@congrex.se  
[www.congrex.com/eaaci2004](http://www.congrex.com/eaaci2004)

##### 12th World Conference on Tobacco or Health Global Action for a Tobacco-Free Future

3-8 August 2003, Helsinki, Finland  
[www.wctoh2003.org](http://www.wctoh2003.org)

##### WHO 4th Ministerial Conference on Environment and Health

**The Future for Our Children**  
June 23-28, 2004, Budapest, Hungary  
[www.euro.int/budapest2004](http://www.euro.int/budapest2004)

##### Critical Operations: Supporting the Healing Environment through IAQ Performance Standards

Tampa, Florida, March 15-17th, 2004  
Information: Steve Hammerling  
TEL. 404-636-8400 x1158; Fax 678-539-2158  
IAQ2004@ashrae.org  
[www.ashrae.org](http://www.ashrae.org)

## EFA welcomes the new EU Action Programme for a Healthier Europe



The new EU Public Health Programme (2003-2008) was published on 15 March 2003, and is open also to applicant countries. The EU Commission, Directorate General for Health and Consumer Protection presented the programme and highlighted priorities for the year 2003.

The general objectives of the Programme are to:

1. Improve information and knowledge for the development of public health.
2. Enhance the capability of responding rapidly and in a co-ordinated fashion to health threats.
3. Promote health and prevent disease through addressing health determinants across all policies and activities.

A total of Euro 312M has been allocated to this Programme, of which Euro 50.912M for 2003.

### Four priority areas for 2003

The priority for 2003 concerns cross cutting themes – themes that are part of and addressed in all other themes. These include health impact assessment, health in the EU applicant countries, tackling inequalities in health, co-operation between Member States on the implications of patient

mobility for health services, promoting best practice and effectiveness in health and ageing. Another priority is health information, specifically developing, co-ordinating and operating the health information and monitoring system in the EU, mechanisms for reporting and analysis of health issues and producing public health reports, improving access to and transfer of data at EU level and other publishing platforms.

In other words: the development of a systematic health information and surveillance system for the EU. The third priority for 2003 concerns health threats: surveillance, early warning and response, health security and preparedness, safety of blood, tissues and organs, antimicrobial resistance, supporting the networking of laboratories, capacity building and rare diseases.

The fourth priority is important health determinants (factors influencing/contributing to health): obesity, tobacco, environment, alcohol, drugs, mental health, sexual health, training, health promotion in particular settings and injuries.

### What does all this mean for the patient?

Compared with the previous Public Health Programme, which addressed health issues in a disease-oriented fashion, the new Programme looks at health in relation to policies. For example, tackling health determi-

nants like environment- and tobacco-related issues should lead not only to better prevention, but also to improved quality of life for allergy, asthma and COPD patients. The Programme is also concerned with safeguarding health services, and the mobility of patients in Europe.

Although public health is addressed more comprehensively than before, to quote EPHA, European Public Health Alliance General Secretary, Ms Tamsin Rose: 'let's be realistic, although the Public Health Programme is a welcome step forward, the amount of funds distributed is 17 cents/EU citizen, when cows in the EU receive 20 euros subsidiaries/head and in the new EU Research Programme approximately 80 euros/EU citizen is distributed'.

*Susanna Palkonen*

### More information

Public Health Programme:  
Official Journal of EU

[http://europa.eu.int/eur-lex/en/oj/2003/c\\_06220030315en.html](http://europa.eu.int/eur-lex/en/oj/2003/c_06220030315en.html)

The first call of proposals for the Programme, deadline 16<sup>th</sup> May 2003:  
[http://europa.eu.int/eur-lex/en/oj/2003/c\\_04920030301en.html](http://europa.eu.int/eur-lex/en/oj/2003/c_04920030301en.html)

Materials and presentations of the Info Day:

[http://europa.eu.int/comm/health/ph\\_programme/howtoapply/info\\_day\\_en.htm](http://europa.eu.int/comm/health/ph_programme/howtoapply/info_day_en.htm)

## HISTORIC AGREEMENT ON THE WORLD'S FIRST GLOBAL FRAMEWORK CONVENTION ON TOBACCO CONTROL (FCTC)

The sixth and final round of negotiations for a Framework Convention on Tobacco Control (FCTC) closed on 1 March. The negotiations are expected to produce a final text that will be presented to the May 2003 World Health Assembly. The Convention is part of a global strategy to reduce tobacco-related deaths and disease around the world. The final text will represent a groundbreaking moment in global public health history, with the goal of stemming the current rise in death and disease caused by tobacco. Last year 4.9 million people died due to tobacco use. Without a co-ordinated international intervention, the number of deaths is projected to rise to 10 million per year by 2020. In the European Union alone, 500,000 deaths occur every year due to tobacco related diseases.

This global health treaty – the first ever created under the auspices of the World Health Organisation (WHO) – includes international rules on tobacco taxation, smoking prevention and treatment, illicit trade, advertising and promotion, and product regulation.

For more details about the FCTC see: <http://www.who.int/gb/fctc/>

## The European Community Respiratory Health Survey II (ECRHS II)



The proportion of the population with asthma and allergy has increased substantially over the past 50 years in many countries. The reasons for the increase are unknown.

Many people with asthma develop their disease in childhood but some develop it for the first time in adulthood. Adults are exposed to a range of lifestyle and environmental factors that have been suggested to cause asthma and allergies, however the causes of the development of asthma in adults are largely unknown.

The European Community Respiratory Health Survey I (ECRHS I) was set up in 1990. The aim was to assess the proportion of people with asthma and allergies in different countries and assess the extent of variation in the prevalence of the disease. For the first time researchers in different countries used the same standardised methods to conduct this work. Over 140,000 young adults from 24 countries (mostly European), representative of their local communities were surveyed. Some of those taking part in the survey underwent more intensive investigation, includ-

ing a clinical examination where more detailed information on lifestyle and risk factors for asthma was collected via a questionnaire, blood samples for measurement of specific E-immunoglobulins (IgE) to house dust mite, cat, grass and *Cladosporium* (mould) and total IgE were taken and lung function and bronchial reactivity tests were carried out.

Large geographical differences were found in the prevalence of asthma (see map). Similar large variations were observed for allergy and bronchial reactivity. This variation indicates that environmental factors are important. Variation in the treatment of asthma across Europe was observed and, at the time of data collection, many asthmatics were inappropriately treated. Over 100 papers using ECRHS I data have been published.

Many researchers who took part in ECRHS I are now involved in a study to re-contact the people who took part in the detailed examination to find out what has happened to them. The researchers were interested in finding out if any of the people have developed symptoms suggestive of asthma, which asthmatics have less troublesome disease now and which have gone on to develop more severe symptoms.

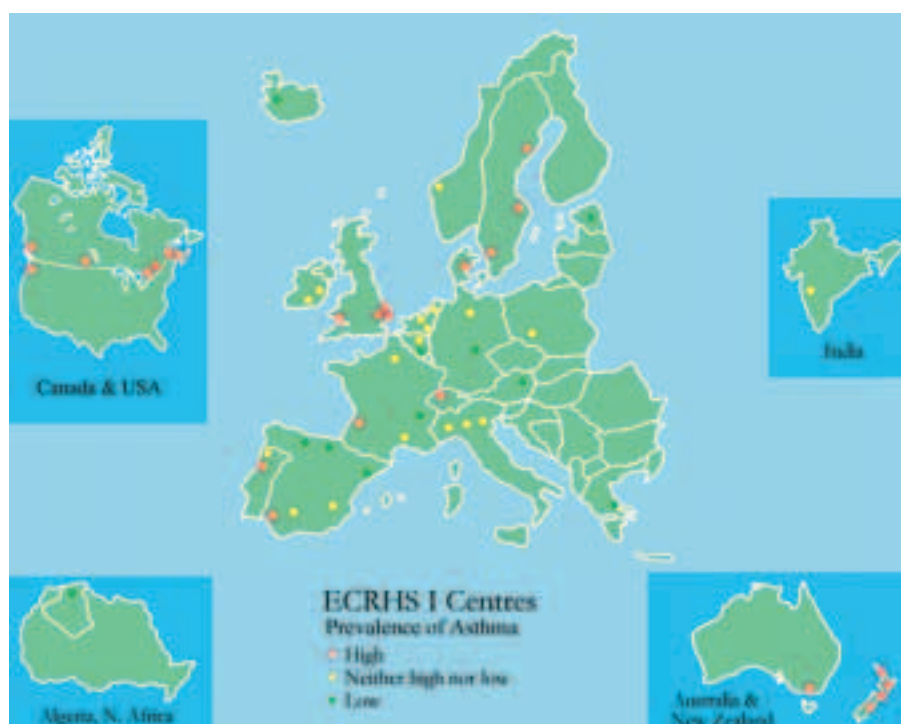
ECRHS II began in March 2000 and is funded by the EU as part of their Quality of Life Programme. The main aims of ECRHS II are to:

- Identify the lifestyle and environmental factors that may cause asthma in adults and factors associated with a poor prognosis in asthma.
- Identify sub-groups most at risk (for example, are women more susceptible than men?).
- Collect and store blood samples suitable for future DNA analysis to examine the genetic basis for asthma and allergy

All data for ECRHS II have now been collected and the database includes information on respiratory health on over 13,000 people with and without asthma. Information on environmental exposures (including occupational exposures and information on their homes), quality of life and treatment for asthma has also been collected from many of these people. Blood samples to assess allergy have been taken and some of these people have had their home visited and a sample taken from their bed mattress to assess for levels of house dust mite allergen. Pollution monitoring in each geographical area was conducted to examine the amount of particulates in the air.

Currently, analysis of change in asthma and allergy symptom status is underway. For the first time, changes in the prevalence of asthma and other allergic conditions in groups of adults as they age will be described for various countries across Europe. This will improve our knowledge of the burden of asthma and allergy in adults in Europe. Risk factors for change in symptom status in the general population and poor outcome in asthmatics will be identified. The knowledge gained will contribute to the development of appropriate public health and clinical interventions to prevent asthma and limit the effect of the disease on individuals. In particular, the role of particulate pollution, occupational exposures, and indoor pollutants will be examined.

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www.ecrhs.org







## New EFA Members

**EFA is pleased to introduce five new member associations, from Bulgaria (2), France, Italy and the Netherlands. There are currently 22 European countries represented in EFA.**



### Association of Bulgarians with Bronchial Asthma - ABBA

The patient association ABBA was established in 2002. We have 450 individual and group members. The main aims are to represent the views and interests of people who have asthma and allergy and to ensure a continuing improvement in their quality of life. Among their activities are asthma schools and educational gatherings organised around Bulgaria. Currently ABBA is working to advance asthma patients' rights, as there are concerns in Bulgaria about the attention given to asthma by the government. In addition, a booklet on asthma is being compiled for patients. New information especially from the Internet is translated into Bulgarian and distributed to members on a regular basis. One of the biggest projects is helping poor families and kindergartens with asthma sufferers thanks to donations from local representative of GSK. ABBA also co-operates with their equivalent Bulgarian scientific society and the other associations for asthma patients.

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ASSOCIATION OF PATIENTS WITH BRONCHIAL ASTHMA

### Association of Patients with Bronchial Asthma - APBA

Established in Bulgaria in 2002, the Association of Patients with Bronchial Asthma has 47 members. Its objectives are prevention, supporting asthma patients and protecting and defending the patients interests connected with health on international and national level, namely, to preserve and promote the general interests of patients in relation to the state administration, institutions and other communities, when necessary. The association also co-operates with the other patient association in Bulgaria, ABBA.

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### AFPRAL (Association française pour la prévention des allergies)

AFPRAL – The French association for allergy prevention – was established in 1991. It has 562 members, 95.4% of whom are patients. The aim of AFPRAL is to promote research, information and prevention relating to allergic diseases. This is done by providing information to the public about recent knowledge, improving training and education of and information for medical and paramedical professionals, promoting scientific research, investigating and proposing measures on prevention, supporting patients and their families and co-operating with similar associations – especially in other countries of the European Community.

One example of this co-operation is active lobbying and networking on the renewal of the EU Food Labelling Directive particularly in co-operation with the Belgium association FPA (*Fondation pour la Prévention des Allergies*) and EFA. AFPRAL contributes to the quarterly journal *Oasis Allergies*, which is published together with FPA. *Oasis Allergies* is the only periodical in French, for patients and for the public, dealing with all the aspects and all the kinds of allergies. AFPRAL focuses its attention mainly on food allergies, food labelling and allergy at school.

In 2002-2003, we contributed, with other patient's associations, to a task force convened by the Food Industries National Association (ANIA), to set up a guide for deciphering lists of ingredients.

In December 1999, AFPRAL launched its internet site. Its key features are: up-to-date legislative information, food labelling issues, acceptance of allergic children in schools... and ease of consultation. It draws about 17,000 visitors a month. Occasionally, an e-mail Newsletter is circulated to over 1000 subscribers; the Newsletter also includes *Alerts*, sometimes sponsored by food industries. On 27 April 2001, AFPRAL opened six free forums (Allergy in General, Allergy at School, Food Allergy, Respiratory Allergy, Eczema, Allergy, Skin, Tips and

Recipes) on its website, which allows exchanges of ideas among patients.

AFPRAL has seven volunteer regional co-ordinators and one central Help-line, which functions only twice a week. Indeed, AFPRAL does not yet have any central office, nor any employed staff.

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 and Zoltan Zalay, Vice President  
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## Associazione Italiana Pazienti BPCO AIP-BPCO

AIP-BPCO, established in 2001, represents COPD patients and patients with other chronic respiratory diseases in Italy and has already been active in EFA in connection with ENCPA.

The President and founder of the association is Mariadelaide 'Lally' Franchi. The aims are to gather patients together and provide them with information, educational and cultural services and publications aimed at improving their health condition, increase awareness of the social impact of these diseases, promote information and prevention campaigns directed to the public on reducing the risks of developing COPD, promoting initiatives aimed at improving the quality of life of patients, promoting and supporting scientific research and raising funds for it and collaborating with other associations in Italy and abroad, that share the same goals. Among recent activities was raising awareness on COPD during the World COPD Day in November 2002 and promoting the EFA COPD Patient Manifesto, which was also translated into Italian. AIP-BPCO has 200 members, most of them patients.

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## Nederlands Anafylaxis Netwerk

The Netherlands Anaphylaxis Network (NAN), which is a new Dutch patient association, established in November 2002, aims at increasing the well-being of those at risk of anaphylaxis. We, individually and collectively support, inform, mediate for and educate patients, family, friends, healthcare professionals and all who will have to deal with food, insect poison, latex protein, food protein, medicine or other cause-induced anaphylaxis. NAN has 200 members. One of the NAN's goals is to be a guide and partner of industry in Allergen Management and Labelling. The network was founded by parents with a young daughter (10 years old) at risk of anaphylaxis due to peanut and tree-nuts and willing to share their experience and network with all in need of support. It is also affiliated with the Food Allergy and Anaphylaxis Alliance, a worldwide patient organisation. On June 14, the NAN will hold a symposium on the topics: 'Anaphylaxis! How to deal with the fear!' and 'Anaphylaxis, causes, symptoms, prevention and therapy'. The lectures will be followed by a forum of specialists who will answer questions and give general advice. It will also organise *Anaphylaxis Child-Awareness Training* for children aged from 10 to 14 years, on the topics: What is anaphylaxis; how do I tell my friends? (can my friend kiss me after having eaten peanuts?); how do I order food in a restaurant/school canteen; exchange experiences between companions in distress; make acquaintances, etc. The network will publish at least three times a year a newsletter and give (individual) support and guidance to patients, parents and institutions. We also have a website (mainly in Dutch, with some English, German and French) containing a variety of information about the causes of anaphylaxis. We are always seeking to expand our network, so if you want to co-operate and work together in the recognition of anaphylaxis as a social problem, please contact us!

Frans Timmermans: [info@anafylaxis.net](mailto:info@anafylaxis.net)  
 website: [www.anafylaxis.net](http://www.anafylaxis.net)

## International Coalition of COPD Patients Associations

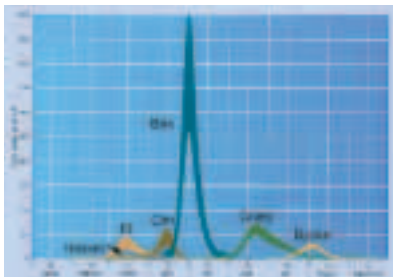
A new body for collaboration between COPD patient associations worldwide will take its first steps in the founding meeting during the American Thoracic Society (ATS) Meeting in Seattle, USA in May 2003.

This event of the GOLD Global Initiative of COPD is endorsed by ENCPA, the EFA Network of European COPD Patient Associations, that will be represented in the meeting by EFA President, Erkka Valovirta. Any organization representing and working for COPD patients, and interested in ICC, is advised to contact Dr. Lawrence Grouse: [lgrouse1@email.msn.com](mailto:lgrouse1@email.msn.com)

# News from EFA Member Associations

## Denmark

The Asthma and Allergy Association in Denmark has, in cooperation with the Danish Meteorological Institute, published a new pollen calendar showing the six most allergy-causing pollens in Denmark. This calendar is based on average data from the counting station in Copenhagen for the years 1984-2001. Our old calendar was based on counting results from the period 1977-1990. A comparison between the old and new calendars has revealed that the tree pollens alder (*Alnus*), hazel (*Corylus*) and birch (*Betula*) now start pollination 2-3 weeks earlier and the amount of pollen has increased.



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## Germany



### Networking food allergies

Every year the German allergy and asthma association (DAAB) deals with more than 2000 questions about allergies to food, neurodermitis and prevention. When the allergy is diagnosed by a doctor, the patient's problem is to put the recommendation of a low-allergen diet into practise. People suffering from a food allergy have difficult shopping and they do not know how to feed themselves in a balanced way. Deficiency symptoms are often the consequences. In order to offer appropriate consultation to people with food allergies in Germany and to ensure the quality of consultation, the DAAB founded the network for allergies, neurodermitis and prevention. The project relies on registered nutritionists who focus on helping people with food allergies or neurodermitis and who have undergone further vocational training. In Germany, nutritionists provide consultations for allergy patients in hospital and for outpatients. Independent, established nutrition specialists give therapeutic advice to patients suffering from diseases such as obesity, diabetes, gout or allergic reactions to food. Of course, a close co-operation with the doctor is essential. If the doctor prescribes a consultation, health insurance pays the costs of advice by a nutrition expert. With the help of our network people with food allergies can easily find a local consultant. The consultants are funded by donations and by membership fees. A newsletter is published four times a year with news about case-examples, practical tips, relevant literature and recipes. The DAAB organises two nationwide further educational courses for consultants and funds regional task forces.

Sonja Lämmel,  
infor@daab.de – www.daab.de

## Finland



### Know what you eat!

The Finnish Allergy and Asthma Federation has dedicated the year 2003 to food allergies. The campaign slogan is *Know what you eat!* and the main objective is to ease the everyday life of those suffering from food allergies and especially families with food allergic children. The other important aim is to increase the public's awareness and understanding of food allergies. Food allergies will be emphasised in all activities of the Federation: advice, rehabilitation and communication. For example, new 'Food allergies' and 'Food allergies and the child' guides have already been published, several education sessions will be organised focusing on food allergies and the allergy daycare centre Histamiini will serve as an example of organising diets in day care.

**Indoor Air 2002** - The national *Indoor Air 2002* information and education campaign is nearly completed. On 26 February a seminar on 'Indoor Air and Health' took place in Allergy House. It was aimed at medical journalists and it focused on health risks arising from poor indoor air, and challenges how to recognize and treat patients suffering from symptoms caused by poor indoor air. The aim of *Indoor Air 2002* is to increase the awareness of consumers and building trade professionals of the impact of indoor air on health. Over 100 indoor air information centres have been opened nationally. Associations, including the Allergy and Asthma Federation, research institutions, educational organisations and government and regional administrations have taken part in the campaign.



## Yugoslavia

The Yugoslavia Association for Asthma and COPD (JUDAH) has produced a series of publications for patients: a leaflet for asthma control, a translation of the GINA Asthma Patients' Pocket Guide and a translation of the GOLD COPD Patients' Pocket Guide.





