

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

ANNUAL REPORT 2007



European Federation of Allergy and Airways Diseases Patients' Associations

2007 Annual Report

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1 INTRODUCTION

FOREWORD

This report summarises the main activities, outcomes and progress towards the mission and objectives of the European Federation of Allergy and Airways Diseases Patients' Associations (EFA) 2008. The main areas include building capacity, extending funding sources, EU policy formulation & advocacy, membership development and partnerships, the major objectives arising from our business plan 2006-2008.

We are grateful for all the support and valuable input received by EFA members in various capacities during 2006. We would also like to thank our platinum sponsors: European Commission, GlaxoSmithKline and Novartis and silver sponsor MerckSharp&Dohme for their continuous support and trust.



Marianella Salapatas
Acting President

ABOUT EFA

EFA is a European network of patient organizations that was founded in 1991, prompted by the belief that an international organization formed by European patients associations that share the same aims would be a more effective way to serve the needs and safeguard the rights of patients and their carers.

EFA was created to combine the forces of national patient associations on asthma and allergy for results at European level and to improve the health and quality of life of people in Europe with those diseases. Serving the interests of allergy and airways patients at the national level is the primary responsibility of individual members and EFA supports member organisations by facilitating the sharing of knowledge and experiences.

Mission

EFA is a European community of patient organizations that share the responsibilities reducing the frequency and severity of allergies, asthma and COPD, minimizing their societal improving health related quality of life and ensuring full citizenship of people with these pursue equal health opportunities in the field of allergy and airways in Europe.

Objectives

To accomplish its mission, the EFA focuses on the following strategies:

1. Influencing European Union policy making in such a way that it will result in:
 - appropriate regulations for healthy (indoor and outdoor) air in Europe
 - appropriate regulations about the quality (including accessibility) of healthcare for people with allergies, asthma and COPD
 - appropriate regulations about societal participation of people with allergies, asthma and COPD
 - adequate funding of demand driven research on allergies, asthma and COPD
2. Supporting the realization of a European network of strong and professional national organizations of people with allergies, asthma and COPD, and a strong and professional EFA.
3. Empowering member organizations to reach a comparable level of serving the interests of patients by exchanging experiences on:
 - influencing national policymaking on public health, healthcare, societal participation and research in relation to allergies, asthma and COPD
 - products and services for people with allergies, asthma and COPD
 - increasing awareness

Central Values

- Patient perspective
- Involvement
- Sharing knowledge and experience
- Partnership and cooperation
- Visibility and presence

ORGANISATION

Board (until 30 May 2007)

President

Svein Erik Myrseth
LHL Norwegian Heart and Lung Association
Postboks 4375 Nydalen
0402 Oslo, Norway
Tel +47 22 799300
Fax +47 22 225037
Email: sem@lhl.no

Vice President

Marianella Salapatas
ANIKSI
75, E. Venizelou
15561 Holargos, Greece
Tel +30 210 6134254
Fax +30 210 6134254
Email: sophia@hol.gr

Treasurer

Otto Spranger
Österreichische Lungen Union
Obere Augartenstrasse 26-28
Vienna, A1140, Austria
Tel./Fax. +43 1 3304286
Email: lungenunion@chello.at

Member-at-Large

Nikoleta Grigorova
Association of Bulgarians with Bronchial Asthma (ABBA)
3rd floor, Office 304
5B Treditza str
BG 1000 Sofia, Bulgaria
asthma@mail.bg

Co-opted Member-at-Large

Roland Efraimson
Swedish Asthma and Allergy Association
Box 49303
S-10029 Stockholm, Sweden
roland.efraimson@astmaoallergiforbundet.se

Board (as off 30 May 2007)

President

Svein Erik Myrseth
LHL Norwegian Heart and Lung Association
Postboks 4375 Nydalen
0402 Oslo, Norway
Tel +47 22 799300
Fax +47 22 225037
Email: sem@lhl.no

Vice President

Marianella Salapatias
ANIKSI
75, E. Venizelou
15561 Holargos, Greece
Tel +30 210 6134254
Fax +30 210 6134254
Email: sophia@hol.gr

Treasurer

Otto Spranger
Österreichische Lungen Union
Obere Augartenstrasse 26-28
Vienna, A1140, Austria
Tel./Fax. +43 1 3304286
Email: lungenunion@chello.at

Member-at-Large

Nikoleta Grigorova
Association of Bulgarians with Bronchial Asthma (ABBA)
3rd floor, Office 304
5B Triditza str
BG 1000 Sofia, Bulgaria
asthma@mail.bg

Member-at-Large

Jenny Versnel
Asthma UK
Summit House, 70 Wilson Street
London EC2A 2DB, U.K.
Tel +44 20 7786 4900
Fax +44 20 7256 6075

Central Office

The EFA Office was located at

35 Rue du Congrès
1000 Brussels, Belgium
Tel. +32 (0)2 227 2712
Fax. +32 (0)2 218 3141

Executive Officer

Susanna Palkonen
Email: susanna.palkonen@efanet.org

Policy Officer – consultant (as off April 2007)

Mariann Skar: mariann.skar@efanet.org

Membership and representation

The EFA membership 2007 consists of 34 allergy, asthma and/or COPD patient associations or their coalitions in 18 European countries, in which there are over 500.000 individual patients and carers as members. EFA represents its member associations on a European level, whereas the associations represent their individual members in their respective countries.

Austria

Österreichische LungenUnion (ÖLU) www.lungenunion.at

Belgium

Coalition of Prevention des Allergies asbl www.oasis-allergies.org

Astma-en Allergiekoepel v.z.w. www.astma-en-allergiekoepel.be

Fondation contre les affections respiratoires et pour l'éducation à la santé (F.A.R.E.S.) www.fares.be

Bulgaria

Association of Bulgarians with Bronchial Asthma (ABBA) www.asthma-bg.com

Czech Republic

Czech Initiative for Asthma www.cipa.cz

Denmark

Astma-Allergi Forbundet www.astma-allergi.dk

Finland

Allergia-ja Astmaliitto - Allergy and Asthma Federation www.allergia.com

Hengitysliitto Heli – Pulmonary Association Heli www.hengityслиitto.fi

France

Association Asthme & Allergies www.asmanet.com

Coalition of Association Française pour la Prévention des Allergies (AFPRAL) www.prevention-allergies.asso.fr

Fédération Française des Associations et Amicales d'Insuffisants Respiratoires (FFAAIR) www.ffaair.org

Greece

ANIKSI www.allergyped.gr

Italy

Coalition of FEDERASMA www.federasma.org

Associazione Italiana Pazienti BPCO (AIPBPCO) www.pazientibpco.it

Lithuania

Coalition of Association of Allergic Children Clubs

Association of Asthma Patient Clubs

Lithuanian Council of Asthma Clubs www.astmainfo.lt

Luxembourg

Satellite of Prevention des Allergies asbl, Belgium

Netherlands

Coalition of Nederlands Astma Fonds (AF) www.astmafonds.nl

Vereniging Nederlands Davos www.nederland-davos.nl and

Astmapatienten Vereniging www.astmapatientenvereniging.nl

Coalition of Stichting Voedsel Allergie - Dutch Food Allergy Organisation www.stichtingvoedselallergie.nl

Vereniging voor Mensen met Constitutioneel Eczeem (VMCE) www.vmce.nl

Norway

Norges Astma- og Allergiforbund (NAAF) www.naaf.no

Norwegian Heart and Lung Association (LHL) www.lhl.no

Poland

Polish Federation of Asthma, Allergy and COPD Patients' Organisations

Slovenia

Pulmonary and Allergy Patients' Association of Slovenia (DPBS) www.astma-info.com

Sweden

Astma- och Allergiförbundet - Swedish Asthma and Allergy Association www.astmaoallergiforbundet.se

Swedish Heart and Lung Association www.hjart-lung.se

Switzerland

Coalition of aha! Schweizerisches Zentrum für Allergie, Haut und Asthma www.ahaswiss.ch

Lungeliga Schweiz - Swiss Lung Association www.lung.ch

U.K.

Asthma U.K. www.asthma.org.uk

Allergy UK www.allergyuk.org

Honorary members

Mariadelaide Franchi, Italy

Edith M.A.L. Rameckers, the Netherlands

Erkka Valovirta, Finland

Elizabeth Bell, U.K.

Arne Heimdal, Norway

Project members

Global Allergy and Asthma European Network (GA²LEN)

Marianella Salapatras, EFA Team leader, Leader work package 3.4 Dissemination of research to patients

Prevalence, Cost and Basis of Food Allergy in Europe (EuroPrevall)

Erna Botjes, the Netherlands

COPD Advisor

Mariadelaide Franchi, Italy

ERS Ethics Committee

Svein Erik Myrseth, Norway

Committees and working groups

Medical Advisor

Chairperson Erkka Valovirta, Finland

Conference 2008 Committee:

Svein Erik Myrseth, Norway

Todor A Popov, Bulgaria

Nikoleta Grigorova, Bulgaria

Marianella Salapatras, Greece

Erkka Valovirta, Finland

Susanna Palkonen, Belgium

Conference agency (logistics)

AIMS International Group Bulgaria, Lora Dobriyanova, Project Manager

Memberships

European Patients Forum (EPF)

Susanna Palkonen, Board Member (until June 2007), Vice President (as off June 2007)

European Public Health Alliance (EPHA)

European Network for Smoking Prevention (ENSP)

Health and Environment Alliance (HEAL)

Allergic Rhinitis and Its Impact on Asthma (ARIA) Advisory Committee

Member, Susanna Palkonen, Belgium

Global Alliance against Respiratory Diseases (GARD), Svein Erik Myrseth, Member of the Planning Group (as off May 2007)

International Coalition of COPD Organisations (ICC), representative Svein Erik Myrseth

DG Environment Consultative Forum on Environment and Health: representative Susanna Palkonen

DG SANCO EU Health Policy Forum: representative Susanna Palkonen

DG SANCO Expert Group on Indoor Air Quality: Susanna Palkonen, Member

European Centre for Disease Control and Prevention (ECDC), Substitute Member of Advisory Board, Anna Doboszyńska, Poland

Associate memberships

International Primary Care Respiratory Group (IPCRG)

STRATEGY AND PRIORITIES 2007

As highlighted in the Business Plan 2006-2008, EFA five key objectives for 2007 were:

1. **Building Sustainable Capacity**
 - More capacity for the office
 - Adopting and implementing EFA Code of Ethics and Conduct and competency framework
 - Governance meetings: board and the AGM
2. **Extending Funding Sources to deliver Capacity** including fundraising for extended office through
 - Diversifying industry funding – more industry partnerships
 - Preparations for EU funded project
3. **Policy Formulation & Advocacy** through
 - agreeing and implementing Framework for Policy Formulation outlining how EFA EU policy responses and positions are formulated and how membership is involved in a transparent and inclusive way
 - focusing on the following EU policy processes: Green Paper on smoke-free environments, ambient air pollution directive, health strategy and health services
 - campaign on the COPD Declaration at the European Parliament
4. **Membership Development** through
 - increasing membership and
 - capacity building and sharing best practices
5. **Building Sustainable Partnerships** through
 - agreeing and implementing new partnership frameworks for industry and non-industry partnerships
6. **Establishing effective Communications** through
 - agreeing and starting the implementation of the Communications Strategy, with the supporting communication tools

2 MAIN ACTIVITIES

BUILDING SUSTAINABLE CAPACITY

The Business Plan until 2008, developed 2006-2007 in **EFA Development Project** was approved by the AGM 2007 including five key areas for development were identified:

1. Building Sustainable Capacity
2. Funding Sources to deliver Capacity
3. Policy Formulation & Advocacy
4. Membership Development
5. Building Sustainable Partnerships

The Business Plan was accompanied by the following core strategic documents for consultation with the EFA membership for 2007, which were also approved by the AGM. They form the basis on how EFA works, partners and is governed. The EFA Board agreed on board leads for all of them (see above).

- Code of Ethics and conduct – Svein Erik Myrseth
- Communications Strategy – Marianella Salapatas
- Framework for Policy Development – Jenny Versnel, nominated as EFA EU Policy Lead
- Competency Framework for the Board and Secretariat – Svein Erik Myrseth
- Sustainable Partnership with Industry – Otto Spranger
- Sustainable Partnership with EU Institutions, Non-governmental organisations and foundations – Otto Spranger

In addition, Nikoleta Grigorova was nominated as board lead on membership development.

Mariann Skar was employed as independent consultant to support on part-time basis and interim in specific policy and capacity building actions, until more personnel could be employed.

EXTENDING FUNDING SOURCES TO DELIVER CAPACITY

In spring and autumn 2007, EFA did a major approach to more than 50 potential companies in line with the Framework for Sustainable Partnership with the Industry, and these were followed up. Our current corporate partners agreed on the new framework.

POLICY FORMULATION AND ADVOCACY

The new Framework for EFA Policy Formulation, that sets our the way we formulate policy positions together and on behalf of members was used for the first time in connection of the EFA response for the public consultation on the EU Green Paper on second hand smoke (SHS) – (see below).

Healthy air to breathe

During the year, EFA took part in three initiatives at EU level that have the potential to improve air quality; EU Expert Group on Indoor Air Quality, EU Green Paper on Smokefree Environments and legislative proposal in the framework of EU Thematic Strategy on Quality and accompanying Directive on ambient air quality. All of

these can be seen as part of the EU Environment and Health Action Plan, the so-called SCALE process, initiated 2004.

EFA took part in the work of the DG SANCO (Health and Consumer Protection Directorate General) Expert Group on **Indoor Air Quality**. The purpose of the Group is to advise the European Commission on EU initiatives and role in this field. The mandate includes indoor air pollution but excluding second hand smoke which is dealt with separately (see below). The group consists of independent scientific experts nominated by the Commission, experts nominated by the member states and policy experts nominated by health, environment and industry organizations and EFA represents the patients. The purpose is to come up with to a range of recommendations for integrated action to improve the IAQ across the EU, including all the actors: EU, member states, other stakeholders. Two pillars for action were identified for the Group's work plan¹:

1. 'buildings', including design, materials, construction products and household products, combustions appliances and outside environment and
2. 'occupants', including 'daily activities in the house', information, dialogue and advice

Four concrete work areas were agreed, and working groups formed on each of these:

- Information to the public, professionals and policy makers
- Working with manufacturers
- Working with member states
- Coordination between different relevant DG's, such as DG Enterprise (Construction products directive), DG Environment (Chemicals directive REACH) etc

EFA is a member of the first working group, and the first action is to set up EU website portal for credible information on IAQ, including the results of the EU funded projects in this area, such as the EFA THADE project.

The timeframe for delivering recommendations on a coordinated EU policy framework is end of 2009. For making such 'policy framework' credible, subject to public consultation, understandable for different audiences and endorsed by all stakeholders, including the Council of Ministers, the Parliament and the Commission (all policy areas), EFA and our partner HEAL believe that a Green Paper on IAQ need to be developed and published.

In January the European Commission published a **Green Paper on Smoke free environments**² for public consultation on the role of the European Union should take in smoke free indoor environments. The Paper included

- review of health effects of second hand smoke, including the EFA THADE project results – second hand smoke is the single most important indoor air pollutant and the only effective action is a ban and the results of the EFA Severe Asthma Survey Fighting for Breath – one of the top three wishes of people with severe asthma is banning smoking in public and workplaces,
- economic considerations,
- social considerations and
- public support for smoke free environments
- current regulations in different member states
- the regulations and initiatives at EU level (nonbinding resolutions and recommendations and workplace directives for specific areas and circumstances)

¹ The IAQ Expert Group workplan is available from the EFA Office upon request

² http://ec.europa.eu/health/ph_determinants/life_style/Tobacco/Documents/gp_smoke_en.pdf

- examined the pros and cons for different type of EU policy options including comprehensive ban and a ban with exceptions; for the licensed hospitality sector, for pubs and bars not serving food and enclosed separately ventilated smoking rooms.
- And identified total ban as the most effective option

EFA consulted members (9 responses were received, 30% of membership), using our Policy Formulation Framework and submitted a joint response with our partner, International Primary Care Respiratory Group (IPCRG) in support of the Paper³, but with following main comments:

- Binding legislation banning smoking in the workplace (with the argument that all enclosed public places are also workplaces) is the only realistic and effective measure to protect from second hand smoke and that this is particularly relevant for the patients with allergy, asthma, chronic obstructive pulmonary disease (COPD) and other vulnerable groups, such as children leading to social and work exclusion and unnecessary illness.
- For all of these groups their airways disease may be worsened by exposure to cigarette smoke and for asthma and COPD it may interfere with the ability of their treatment to work.
- The goal of a total ban is to protect everybody (including hospitality sector, technical and cleaning personnel) from SHS. It is also a signal for children and adolescents that smoking is an addiction and that it is socially unacceptable.
- EU not only has a mandate, but the responsibility to introduce binding legislation to put an end to exposure to SHS for all, no matter where they live in the EU, and thus help to protect their right to breathe healthy indoor air
- Binding legislation either based on existing directives (EU common market workplace legislation) or separate directives is the most cost-effective means, including recognising SHS as serious health hazard
- Although the legislative process may take some time, our aspiration must be for an enforceable smoke free Europe
- the need for consideration on effective enforcement and for a proper preparation and campaigning process prior to the introduction of new legislation
- Attention should also be paid to the need to have a well-funded and effective smoking cessation framework in place at Member State/sub national level, as appropriate, before the introduction of comprehensive legislation
- However, no Member States should wait for the EU regulations, but as quickly as possible start a process of implementing smoke-free environments.
- Provided additional data on SHS and allergy, asthma and COPD

The Consultation results would be published 2008 followed by impact assessment and proposals for action.

The discussions between the Commission, Parliament and the Council on the **Directive on Ambient Air Pollution**⁴, which accompanies the **Thematic Strategy on Air Pollution**⁵, which started 2005 continued.

The aim of the Strategy and the Directive is to bring all the separate directives on outdoor air pollution into one single act and update and upgrade the level of protection of citizens according to current knowledge, including from the small particles. During 2006 EFA and partners asked that the Parliament and the Council

³ <http://www.efanet.org/activities/documents/EUGreenPaperSmokefreeEFAandIPCRGResponse300507.doc>

⁴ http://ec.europa.eu/environment/air/cafe/pdf/cafe_dir_en.pdf

⁵ <http://ec.europa.eu/environment/air/cafe/index.htm>

to support the original Commission proposal - no roll-back of existing standards, particularly for PM10 and that legally binding standards for PM2.5 should be introduced in line with WHO air quality guidelines⁶.

Lead by the Health and Environment Alliance (HEAL), EFA joined Doctors for the Environment and the ERS 25 June in a letter campaign involving the MEPs to boost the weak ambition of the Parliament and the Council.

The requests were the same as 2006 and 2007:

- Standards must offer a protection for all, including those most vulnerable and based on WHO Air Quality Guidelines published 2006
- There must be no weakening on existing standards on PM10
- A new legally binding limit value or strongest possible % reduction of PM2.5 exposure is needed

The Directive should be finalised in 2008, and EFA will follow up through the HEAL.

COPD Declaration Campaign



The Campaign launched 15 November 2006 – World COPD Day (WCD) in partnership with the European Respiratory Society (ERS) and European Lung Foundation (ELF) continued for signing of the **Written COPD Declaration at the European Parliament**, launched by Scottish Member of the European Parliament (MEP) Catherine Stihler to launch a debate at the EP, Commission and European Council of Ministers calling upon the EU to pay more attention to this under-recognised and under-funded disease. The Declaration was available for MEPs to sign until the 21 February 2007 and EFA and members contacted their MEPs to sign. 120 MEPs signed, which was not enough for the Declaration to pass (half of the MEPs should sign), but the support from MEPs was encouraging, and the awareness of policy makers improved. It was therefore decided to re-launch a declaration on the WCD 14 November, with more investment on advocacy activities.

On WCD EFA, ERS and ELF organised a launch and press conference at the EP in Strasbourg and produced a leaflet to raise awareness⁷. The advocacy campaign will continue 2008, with a deadline for signatures 23 February 2008.

The COPD Declaration called for the EU and the Member States to

- promote prevention and ensure equal access to early diagnosis, correct treatments and mobility of COPD patients;
- facilitate long-term research into the causes, prevalence and treatments for COPD;
- implement comprehensive smoke free policies and to develop smoking cessation strategies;
- publish a Green Paper on indoor air quality

⁶ http://www.who.int/phe/health_topics/outdoorair/en/index.html

⁷ <http://www.efanet.org/enews/press.html>

Improving care and patient participation

Through EFA membership and board membership in the European Patients' Forum (EPF), we were specifically involved in EU policies regarding **information to patients**. EPF is a member of the High Level Pharmaceutical Forum⁸, joint initiative of DG SANCO and DG Enterprise. It is member state and stakeholder forum to look at collaboration on and improving information to patients, relative effectiveness evaluations of medicines and pricing and reimbursement of medicines. Another related process is the forthcoming proposal from the Commission on information on prescription medicines in the EU for citizens.

The EPF aim is to improve access to patient friendly information through credible and patient centred legal proposal on improving access to information on prescription medicines in the EU and called for a comprehensive EU strategy on information to patients – not only on medicines. On relative effectiveness, EPF called for quality of life evaluations alongside with other effectiveness evaluations.

EFA also specifically endorsed the EPF response to the DG SANCO consultation of the **Community action on health services**⁹ that was a follow up on the Commission aim to find legal certainty on the free movement of EU citizens that also applies to health services according to the rulings of the European Court of Justice. The response emphasized that access to sustainable good quality health services is a fundamental right for all patients in the EU regardless of where they live, and what their social status is, though the priority must be care close to home. EU can play a role to achieve this by supporting the member states. The consultation should be followed by further proposals by the EU.

Through membership in both EPF and the HEAL, EFA was involved in a consultation on **future EU Health Strategy**: Health in Europe: a Strategic Approach 2008-2013 by endorsing their responses. EPF emphasized in particular meaningful involvement of patients in EU policies, including core funding for patient groups and access to patient centred care as key elements for an inclusive health strategy. HEAL supported the 'health in all policies' component in the Strategy, in particular in policies affecting the environment. On basis of the Consultation, a White Paper Together for Health: A Strategic Approach for the EU 2008-2013¹⁰ was published by the Commission, DG SANCO in October, which took on board the comments above.

EFA EU Policy Advocacy 2007 – main actions : http://www.efanet.org/activities/eu_policy.html

- Consultation response on the Green Paper on EU policy on Smoke free Environments
- Signing Campaigns of Declaration at the European Parliament on Combating COPD

MEMBERSHIP DEVELOPMENT

Increasing membership base

Four potential new EFA members were involved in the EFA activities through the COPD Declaration campaign (see page 15) and the GA²LEN workshop (see page 21), demonstrating value to join in practice.

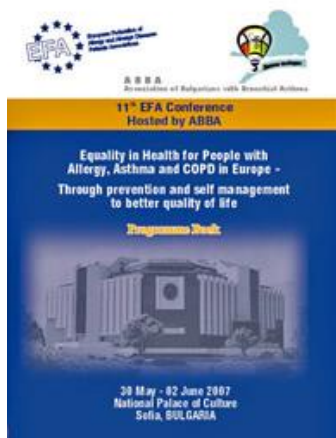
⁸ http://ec.europa.eu/health/ph_overview/other_policies/pharmaceutical/forum_en.htm

⁹ http://ec.europa.eu/health/ph_overview/co_operation/mobility/community_framework_en.htm

¹⁰ http://ec.europa.eu/health/ph_overview/Documents/strategy_wp_en.pdf

Developing a membership development plan in accordance with the Business Plan was started, and more concrete actions are planned for 2008.

Capacity building and sharing best practices



In May 2008 EFA held its statutory **Annual General Meeting** (AGM) in Sofia, Bulgaria followed by 11th **Conference** 'Equality in Health for People with Allergy, Asthma & COPD in Europe - Through prevention and self management to better quality of life', which was this year jointly organised and hosted by the Bulgarian ABBA.

The Programme was three fold; firstly it featured presentations from professionals and volunteers working in EFA member organisations on their programmes, projects, campaigns, services and products, policies and influencing policy making in country and local level on allergy, asthma and chronic obstructive pulmonary disease (COPD). The purpose was to share best practices in this field. Secondly, speakers from the European Union institutions and non-governmental organisations presented the main EU policies, programmes and initiatives that affect our patients, including indoor and outdoor air quality, research, services and patient information. Thirdly, scientists presented the latest trends in research into allergy, asthma and COPD.

There were 71 participants from 19 European countries, including 67 patient representatives, of which 35 Bulgarian and delegates from the European Commission, Bulgarian Ministry of Health, ERS and GA²LEN. The participants agreed on '**EFA Sofia Declaration**' on which are the urgent priorities for action for people with allergy, asthma and COPD on European level that EFA should work on, and on the national level:

ALL patients with allergy, asthma & COPD

Comprehensive European and national programmes on

- Access to good, equal standards of **care**, no matter where you live in Europe
- High standards of and access to patient & professional **education, information and new knowledge**
 - Healthy, unpolluted **air** to breathe indoors and out

ALLERGY – first priorities

- European and national level
- Allergology recognised as a medical speciality across Europe
 - Safe food: clear and understandable food labelling (packaged, unpackaged, catering, restaurants)

ASTHMA – first priorities

- European level
- High standards of regulation for indoor and outdoor air pollution
 - Funding for research
- National level
- Reimbursement of medication

COPD – first priorities

- European level
- Total ban of smoking in all public and workplaces
 - Access to and awareness and understanding of early diagnosis
- National level
- Access to and awareness and understanding of early diagnosis
 - Access to rehabilitation close to home

The conference presentations are available at

<http://www.efanet.org/activities/EFAConference2007EqualityinHealthforPeoplewithAllergyAsthmaandCOPDinEurope.html>

The two-day training for members **Meet and Greet EU institutions** was organized in Brussels 29-30 of November. The aim was to inform about the opportunities and challenges the EU poses to public health and how it all works and by increasing knowledge at local level, more engagement and participation in activities at EU level. This is needed in order to make EU public health activities good for our patients and us as NGOs play a crucial role in bridging the gap between citizens and decision-makers.

The Programme¹¹ included presenting an overview on ongoing activities at EU level related to public health and especially people with allergy and airway diseases, face-to-face meetings in Brussels and Luxembourg with the responsible officials on health determinants (environment and health), tobacco control, food labelling, EU Public Health Programme and health and safety at work and the HEAL and visit to the European Parliament.

11 members of maximum 12 took part. According to the evaluation, they found it very useful, but suggested some changes in future trainings to develop the Programme.

The Prevalence, Cost, and Basis of Food Allergy across Europe EuroPrevall¹² is an integrated project (IP) launched 2005 in the context of the EU Framework Programme of Research FP6 and aims are to deliver improved quality of life for food allergic people through research activities. EuroPrevall is the largest project ever funded by the European Union. More than 60 partners are involved. The project has been running for 24 months and will be finished in May 2009. The main objective is to improve the quality of life for food allergic people, and it is therefore EFA is partner in the project.

All the data and tools of the project will feed into the development of better strategies to manage allergens in foods, from understanding how different food manufacturing processes may affect allergenicity to how to best convey allergen information to consumers via food labelling. 2007 EuroPrevall produced the following lay State-of-the-Art papers based on EuroPrevall and other latest research, which are available for EFA members to use and publish:

- Sexy research on food allergy (food allergy and gender)¹³
- Food allergy diagnosis today and in the future¹⁴ and
- The impact of food allergy on quality of life¹⁵

EFA members were invited to the third annual Conference of **Global Allergy and Asthma European Network of Excellence (GA²LEN)**, funded from the EU 6th Framework Programme for Research, in which EFA is a partner representing the European patient took place on 18-20 April in London.

EFA organised a joint workshop with GA²LEN 'What's in it for Patients' to introduce the first GA²LEN public **Pan-European campaign 'Does Rhinitis Lead to Asthma?'** and discuss members involvement and discuss patient involvement in research. 20 members from 12 countries took part.

¹¹ <http://www.efanet.org/activities/documents/EFAMeetandGreetEUProgramme1.doc>

¹² <http://www.europrevall.org/>

¹³ <http://www.efanet.org/activities/documents/EuroPrevallGenderResearchFoodAllergy.pdf>

¹⁴ <http://www.efanet.org/activities/documents/EuroPrevallFoodAllergyDiagnosisTodayandinFuture.pdf>

¹⁵ <http://www.efanet.org/activities/documents/EuroPrevalltheimpactoffoodallergyinQoL.pdf>

The objective of the Campaign is to alert healthcare professionals and patients of the importance of the link between rhinitis and asthma for the management of one or both these allergic diseases. Evidence shows that rhinitis and asthma are intimately linked, and management of one disease can be improved by taking the other into account. The Campaign is based on peer-reviewed scientific publication of the GA²LEN review committee¹⁶ and follows the recommendations of the International guidelines on the management of Allergic Rhinitis and Its Impact on Asthma (ARIA) update which will be published in 2008.

It was agreed that members will be sent the text for the planned leaflet for patients for comments, limited support is available for translations and that they together with the local GA²LEN scientific centres have the right use the leaflets in their country.

The second part of the Workshop explored **patient participation in research** in general: sharing best practices, why is patient participation needed and ethical issues and in particular in GA²LEN. Prior to the workshop, the interest of members in research topics was mapped: members are most interested in issues that have direct impact in treatment or general themes such as prevention, but 12 expressed interest in taking part in GA²LEN scientific work packages as patient representatives. The GA²LEN research focuses mostly on very specific issues. It was discussed with the GA²LEN scientific work packages leader, whether members could be nominated to different work packages. No definite conclusion was made, and EFA was requested to explore this further with him.

On the 20 April, during the Public Day, organised in collaboration with Asthma UK and Allergy UK, EFA Vice President launched the *Does Rhinitis Lead to Asthma Campaign* in Pan-European level, including the EFA Campaign website¹⁷.



During the year, two leaflets were produced, one to the primary care physicians and the other to patients 'Does Sneezing Lead to Wheezing'. 17 EFA members were involved in commenting the patient leaflet and 14 in translations to their language and 9 in preparation for national launches.

Both leaflets are now available in 12 languages: Danish, Dutch, English, French, German, Greek, Italian, Lithuanian, Macedonian, Polish, Spanish and Catalan. The campaign has been launched at national level in Belgium, France, Austria. Events are planned in several other countries

including Italy and Poland.

EFA-GA²LEN Campaign 2007 Does Rhinitis lead to asthma?

- Launch event 20 April in London
- Campaign website <http://www.efanet.org/activities/DoesRhinitisleadtoAsthma.html>
- Translations of the leaflets for patients and primary care available in 12 languages

¹⁶ Van 17 members in Poland in Commenting the patient leaflet Durham, ...M Salapatas et al. and members of GA²LEN work packages and in 'Does Rhinitis lead to asthma?' Rhinology 2007, 45, 112-121

¹⁷ <http://www.efanet.org/activities/DoesRhinitisleadtoAsthma.html>
 ▪ 9 members involved in preparation for national launches

BUILDING SUSTAINABLE PARTNERSHIPS

The new EFA Frameworks for industry and non-industry partnerships form the basis for sustainable funding arrangements with the industry, foundations, European institutions and the NGOs. The first step for implementation was outreach for more industry partners (see page 11).

The credible and effective partnership with the EU institutions comes through good working relation and visibility, and our advocacy efforts, membership in the EU working groups and partnership in EU funded projects affirmed and strengthened the partnership.

EFA continued collaboration and strengthened partnerships with other non-governmental organisations through joint advocacy, board membership and membership (see pages 11-16), in particular with the HEAL, ERS, ELF, EPF and IPCRG.

ESTABLISHING EFFECTIVE COMMUNICATIONS

The EFA Communications strategy, approved in the AGM 2007 sets out the strategic objectives to ensure that our target audiences, external and internal understand who we are, how we work, what the products of our work are, and how they are available to those who want them, when they want them, in the format that they can use them. For the comprehensive implementation, a Communications Officer's post will need to be founded. The following communication tools were used and publications published 2007:

Communication tools

www.efanet.org



EFA main communication tool is our website, where all events, news releases and policy responses are

published either on the public zone or at the members-only section which requires a password when only targeted for members. The website was updated regularly; however the EFA monthly eZine, launched in 2005 and featuring EFA activities and campaigns, EU health issues related to our policy priorities and EFA member news and incorporated with the website was not published regularly due to the lack of communications support.

Publications

One scientific manuscript was published and one submitted and accepted for publication for 2008. These were Pan European surveys highlighting the impact of severe asthma and allergic rhinitis as voiced by

patients themselves and have produced invaluable patient focused information for EFA, members and other stakeholders for informed policy and solid argument in advocacy.

The results of the EFA Fighting for Breath Survey were finally published in *Allergy*: **The limitations of severe asthma: the results of a European survey** in partnership with the Asthma UK¹⁸ and on the 3 March EFA had a press conference '*Fresh perspective on severe asthma in Europe -Understanding & Addressing Patient's Needs*' in Brussels¹⁹ in collaboration with the EFA Belgium members. The authors presented the survey results and a young patient from Germany was invited to share her experiences on growing up and living with severe asthma. Media materials were also available to EFA members, in particular for the countries where the survey was conducted. For example Asthme&Allergies in France had their press conference later in March to publish the results for France and Asthma UK led the media outreach in the UK. The event was well attended by 20 journalists and there was blanket coverage in the Belgium newspapers.

A kit has been prepared for EFA members to repeat the survey in their countries, and the Norwegian Asthma and Allergy Association and FEDERASMA in Italy have started preparations.

One EFA manuscript was accepted for publication in January 2008 '**Allergic Rhinitis in Not a Trivial Disease**'. It is based on EFA Patient Voice Allergy Survey 2005, in collaboration with members in 11 countries.

EFA publications 2007:

- Results of the Fighting for Breath Survey: Dockrell M, Partridge MR, Valovirta E. The limitations of severe asthma: the results of a European survey. *Allergy* 2007;62:134-141
- Annual Report 2006
- Leaflet for MEPs with ERS and ELF 'Why you should sign the Written Declaration on COPD'
<http://www.efanet.org/enews/documents/COPDLeafletMEPs.pdf>
- Leaflet for patients Does Rhinitis Lead to Asthma - Does Sneezing Lead to Wheezing with GA²LEN
<http://www.efanet.org/activities/documents/DoesRhinitisLeadtoAsthmaBrochureforPatient.pdf>

¹⁸ Dockrell M, Partridge MR, Valovirta E. The limitations of severe asthma: the results of a European survey. *Allergy* 2007;62:134-141.
http://www.efanet.org/activities/documents/fighting_For_Breath1.pdf.2005

¹⁹ <http://www.efanet.org/enews/press.html>

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