

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

ANNUAL REPORT 2008



European Federation of Allergy and Airways Diseases Patients' Associations

2008 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 and effective communications, 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 2008. We would also like to thank our platinum sponsors: European Commission, GlaxoSmithKline and Novartis 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 25 June 2008)

President – on sick-leave since March 2008 and absence of leave

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 – Acting President since March 2008

Marianella Salapatas
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75, E. Venizelou
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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

Jenny Versnel
Asthma UK
Summit House, 70 Wilson Street
London EC2A 2DB, U.K.
Tel +44 20 7786 4900
Fax +44 20 7256 6075
Email: jversnel@asthma.org.uk

Board (as off 26 June 2008)

President - stepped down from October 2008

Svein Erik Myrseth
LHL Norwegian Heart and Lung Association
Postboks 4375 Nydalen
0402 Oslo, Norway
Tel +47 22 799300
Fax +47 22 225037
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Member-at-Large

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Summit House, 70 Wilson Street
London EC2A 2DB, U.K.
Tel +44 20 7786 4900
Fax +44 20 7256 6075
Email: jversnel@asthma.org.uk

Member-at-Large

Pål Johansen
Norwegian Asthma and Allergy Association (NAAF)
Akersveien 24 c, Postbox 2603
ST:Hanshaugen
0131 Oslo, Norway
Email: pal.johansen@naaf.no

Co-opted Member-at Large – from October 2008

Ondrej Rybnicek
Czech Initiative for Asthma (CIPA)
Sokolská 31
CZ 12000 Praha 2, Czech Republic
Email rybnicek@med.muni.cz

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

Project and Fundraising Officer – consultant (as of September 2008)

Antje Fink-Wagner
Email: antje.finkwagner@efanet.org

Membership and representation

The EFA membership 2008 consists of 36 allergy, asthma and/or COPD patient associations or their coalitions in 20 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

Hengityslititto Heli – Pulmonary Association Heli www.hengityslititto.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

Ireland – from 26 June

Asthma Society of Ireland www.asthmasociety.ie

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

Portugal from 26 June

Portuguese Asthma Patients Association APA www.apa.pt

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 Salapatas, 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

EFA European COPD Book Editor

Mariadelaide Franchi, Italy

EFA Patient Advisor in the GSK COPD Assessment Test (CAT) development

Mariadelaide Franchi, Italy

Member of the CAT International Steering Committee

Marianella Salapatas, Greece

ERS Ethics Committee

Svein Erik Myrseth, Norway

Phenotype "handprints" to identify severe asthma condition (U-BIOPRED) Project, Board Lead

Jenny Versnel, U.K.

EFA Board EU Policy Lead

Jenny Versnel, U.K.

EFA Conference 2008 Chair of the Scientific and Organising Committee
Anna Dobozyńska, Poland

Medical Advisor
Erkka Valovirta, Finland

Memberships

European Patients Forum (EPF)
Susanna Palkonen, Vice President

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
International Coalition of COPD Organisations (ICC)

DG Environment Consultative Forum on Environment and Health: representative Susanna Palkonen
DG SANCO EU Health Policy Forum: representative Jenny Versnel
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 Dobozyńska, Poland

Associate memberships

International Primary Care Respiratory Group (IPCRG)

STRATEGIC PRIORITIES 2008

1. **Building Sustainable Capacity**
2. **Extending Funding Sources to deliver Capacity** through new outreach to new partnerships
3. **Policy Formulation & Advocacy** – based on EFA Sofia Declaration (annex 1)
4. **Membership Development through** increasing membership base and capacity building and sharing best practices
5. **Building Sustainable Partnerships through effective collaboration with key partners**
6. **Establishing effective Communications** through high profile communication tools

2 MAIN ACTIVITIES

BUILDING SUSTAINABLE CAPACITY

EFA Office in Brussels has one full-time worker and since October 2008 part-time Project and Fundraising Officer to support outreach to new funding partners. In addition, EFA has project members. The rest of the work is voluntary, board members each having specific responsibilities, supported by the Office and EFA medical advisor and COPD advisor. The results of the outreach on new funding opportunities will only become known 2009.

Governance

EFA governance follows our Code of Ethics and Conduct, in line with our Statutes, and including the general principles according to which EFA operates and an expenses and honorarium policy that the Board agreed 2007. Guidelines for prioritising participation in meetings and conferences will be developed to help using resources effectively.

The EFA board met 4 times, one meeting was a strategic meeting. The Annual General Meeting (AGM) was held 25 June in Warsaw, Poland where the Vice-President and one board member were elected. Vice President continued as Acting President due to absence of leave, and eventual stepping down of the EFA President.

Our external auditor audited the accounts for the approval of the AGM 2009 as usual.

EXTENDING FUNDING SOURCES TO DELIVER CAPACITY

In 2008, EFA funding was based on membership fees 15%, European Commission Project funding (GA²LEN and EuroPrevall projects and KnowYourAirforHealth website) 35% and sustainable partnership with industry (GSK and Novartis) 45% and project funding by industry (GSK 5% COPD Book project).

Due to the need to expand our funding base and changes in external environment regarding funding, EFA invested in support in outreach on funding. Antje Fink-Wagner started in October as a consultant as EFA Project and Fundraising Officer.

The new EU Public Health Programme enables European level organisations to apply for core-funding, but unfortunately only those receiving less than 20% from corporate partners. It is unclear to which criteria this is based on. EFA had a meeting with the European Commission and it is possible that this will change in the future.

POLICY FORMULATION AND ADVOCACY

The priorities for influencing European level policy were based on priorities as identified in EFA Sofia Declaration (see annex 1). EFA also had a specific meeting with the European Commission, DG SANCO to introduce ourselves and our priorities.

ALLERGY

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

The status of **allergology** is fragmented in Europe. From the patient perspective this means that the competence in and quality of allergy care throughout different health care providers that they meet in their patient journey can be poor leading to wrong or partial diagnosis and therefore unsatisfactory and unsuccessful care. Despite the growing awareness of allergy, allergology has not been strengthened – in some countries even worsened.

EFA explored with the European Academy of Allergology and Clinical Immunology (EAACI) on possibilities to prepare for a project proposal for funding: 'There is no allergy care without experts in allergy', but it was decided that this may not be feasible and the first step is to know the status, in which EAACI is lending its' support.

In the EFA-GA²LEN-EuroPrevall workshop (see page 19) the new way of collaborating with members in disease specific working groups, and the need and objectives for the first working group on food allergy were discussed¹² to plan and lead European patient collaboration to improve the management of food allergy through improved networking, sharing best practices and information, influencing policy and practice and joint project development. People with food allergy have to rely entirely on the content information of food products to be empowered to take care of their disease and the EU has a specific powers in labelling and the European Commission put forward in 2008 a proposal on labelling³, including obligatory allergen labelling for non-packed food⁴. The first topics suggested by the participants included 'may contain', follow up EU legislation, novel foods, genetically modified foods and influencing air travel companies.

¹ The working group was set up 2009

² The Terms of reference for working groups are available from EFA Office upon request

³ Proposal for a Regulation of the European Parliament and of the Council on the provision of food information to consumers 2008/0028(COD) <http://www.europarl.europa.eu/oeil/file.jsp?id=5592852>

⁴ Proposal for a Regulation of the European Parliament and the of the Council on the provision of food information to consumers <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM:2008:0040:FIN:EN:PDF>

ASTHMA

- High standards of regulation for indoor and outdoor air pollution (*cross cutting issue* – see page ?)
- Funding for research

In 2007, EFA and members were successful in including respiratory diseases and allergies as priority diseases in the new European Commission Framework Programme for Research (FP7). 2008 our goal was to take part and represent patient interest in project proposals that are in line and incorporate the EFA FP7 project partnership requirements approved by the Board 2007, annex 2.

Severe Asthma



At the public-private partnership research programme of the DG Research (FP7) and the European Federation of Pharmaceutical Industries and Associations (EFPIA), called the Innovative Medicines Initiative (IMI) that was launched in April 2008; one priority was ‘understanding severe asthma’. The objective of IMI is to get pharmaceutical companies to work together and in collaboration with scientists, clinicians and patient organisations across Europe to remove the bottlenecks which currently exist in developing new treatments. EFA partnered in two expressions of interest of the research community, one of which was successful, **U**nbiased **BI**Omarkers for the **PRED**icting disease progression and medication efficacy U-BIOPRED.

The project is to start 2009, subject to successful contract negotiations with the European Commission. New treatments are needed for severe asthma but limitations exist in terms of identifying those patients who will benefit from a particular drug and identifying sufficient numbers of patients to participate in clinical trials. By bringing together all relevant groups with an interest in severe asthma it is believed that significant steps can be taken to overcome these bottlenecks and identify new treatments for severe asthma. Patient/patient representative participation through EFA, Asthma UK and Netherlands Asthma Fonds in Ethics Board, Safety Monitoring Board, dissemination of the results, in consensus building on the definition of severe asthma and U-BIOPRED patient platform is pivotal that real needs of patients are addressed and to help in identifying patients. All EFA members with interest will have an opportunity take part.

COPD

- Total ban of smoking in all public and workplaces (*cross cutting issue*, page 18)
- Access to and awareness and understanding of early diagnosis

COPD Declaration Campaign

EFA's ongoing priority is increased awareness and recognition of COPD as a public health priority in Europe that would lead to early diagnosis.

The Campaign launched on World COPD Day 2007 with the European Respiratory Society (ERS) and European Lung Foundation (ELF) continued for signing of the **Written COPD Declaration, annex 3 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 23 February 2008 and EFA and members contacted their MEPs to sign. In January spirometry was organised at the European

10 reasons to sign
written declaration 0102/2007 on
Chronic Obstructive Pulmonary Disease

1. By 2020, COPD will be the **third-largest cause of death** worldwide.
2. COPD **killed 2.7 million people** in 2000.
3. Up to three-quarters of people with COPD have **difficulty with simple tasks** such as walking upstairs.
4. COPD is **more common in men than women**, although this may be changing.
5. COPD is **associated with many other health problems**, including heart disease, diabetes and cancer.
6. Because **COPD is under-diagnosed**, it is hard to know exactly how many people suffer from it.
7. A recent global study found that about a **quarter of 62-60-year-olds** in Salzburg, Austria and Krakow, Poland have COPD.
8. Smoking is not the only risk factor: **environmental tobacco smoke and pollution** are also linked to COPD, as is the common genetic disease α_1 -antitrypsin deficiency.
9. **As the population ages**, COPD will become a bigger problem.

10. *"I try to live as normally as possible and have oxygen with me wherever I go. I can do the groceries, but can no longer take care of my youngest grandchild as I do not have the strength to take her in my arms any more."*
Gurilla, 64, Sweden

The deadline to sign is
February 28, 2008

This advertisement was prepared by



MEPs to promote lung health and the Declaration. 60 MEPs took the test. 220 MEPs signed the Declaration, 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.

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
- 220 MEPs signed – showing their support for COPD
- 60 MEPs had their lung function tested

COPD Book project

EFA started to build major policy and best practice sharing project for 200 that would map and communicate how Europe is doing, from patient perspective on COPD and in partnership with EFA members and other COPD patient groups in 2009. The questionnaire was developed during the year, and GSK signed up as our funding partner.

Cross cutting issues

- healthy indoor and outdoor air
- total ban of smoking in all public and workplaces

Indoor air quality

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 advice 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 purpose is to come up with to a range of recommendations for integrated action to improve the IAQ across the EU.

The timeframe for delivering recommendations on a coordinated EU policy framework is end of 2009. The developments in this area are not very fast, in fact disappointing⁵. 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, ERS and HEAL believe that a Green Paper on IAQ need to be developed and published.

Second Hand Smoke - Green Paper on Smoke free environments⁶

EFA participated together with the IPCRG in the impact assessment of the European Commission following the public consultation 2007 and consultation report from 2008 on the Green Paper on SHS⁷. We again highlighted the need for comprehensive EU ban on exposure to second hand smoke in public and workplaces to support in particular people with respiratory diseases and children in countries where nothing is planned, or only partial bans only exist. The final Commission proposal for action at EU level is still pending. The likely option is updating EU workplace legislation (tobacco smoke classified as carcinogen) complemented by EU Council Recommendation (non-binding measure).

⁵ http://www.inive.org/members_area/medias/pdf/Inive%5CEnVIE%5CKephalopoulos.pdf

⁶ http://ec.europa.eu/health/ph_determinants/life_style/Tobacco/Documents/gp_smoke_en.pdf

⁷ <http://www.efanet.org/activities/documents/EUGreenPaperSmokefreeEFAandIPCRGResponse300507.doc>

Air pollution - www.knowyourairforhealth.eu

In the follow up of the new EU Directive and Strategy on Ambient Air Pollution and Clean Air for Europe, EFA and Health and Environment Alliance (HEAL), partly funded by the DG Environment, launched a project entitled 'Communicating EU air quality information and alerts to allergy, asthma & COPD Patients in Europe'. This included a policy campaign and website on the implementation of the Directive from patient perspective and with patient participation. The website is tailored to the needs of people with COPD and other respiratory diseases to check national and local air quality and to learn the steps they can take to minimise any adverse effects. The website also provides information about the current action of the European Union to improve air quality. EFA members from Denmark, Finland,

Ireland, the Netherlands and Italy signed up for follow up. The website was launched on World COPD Day in November (see below), and had a good online coverage. EFA also wrote to the Commissioners on Environment and Health asking how they aim to provide targeted information 'free of charge' for people with respiratory diseases and their organisations and whether these groups qualify as 'vulnerable populations' as specified in the Directive. Letters⁸ were also sent to EU environment and health ministers about the entry into force of the new ambient air quality directive (2008/50/EC), highlighting how patients' groups could significantly contribute to the implementation of this regulation.

Know your air for health

Health affects Your right to cleaner air Useful links



This website provides citizens with information on national and local air pollution in Europe. It also offers useful links and references on how to find information about action aimed at improving air quality at the national level and in your local area. The text is particularly intended to meet the needs of those considered susceptible to air pollution.

Find your local respiratory health forecasts:



⁸ <http://www.efanet.org/enews/documents/EFALetterEUEnvironmentandHealthMinisters.pdf>



European Federation of Allergy and Airways Diseases Patients' Associations

PRESS RELEASE 19 November 2008

World COPD Day

Know Your Air for Health - EU air pollution forecasts offered to those with breathing problems

People with respiratory diseases such as chronic obstructive pulmonary disease (COPD) suffer more than others when air pollution levels are high. The new website launched today by EFA and Health and Environment Alliance (HEAL) www.knowyourairforhealth.eu is a resource centre for air pollution forecasts across EU, steps to take to protect your health and learning about rights for healthier air.

Up to one in 10 European adults have COPD and many fear leaving their homes on a day of high air pollution. "It is unacceptable that the most susceptible people cannot be guaranteed clean air at all times - but at least now they can better plan their activities in periods when air pollution is high," Susanna Palkonen of EFA says.

"Air quality within the European Union is still not good enough to protect health," says Christian Farrar-Hockley, Senior Policy Advisor at HEAL. "The WHO estimates that the average person within the EU is losing one year of life as a result of poor air quality. The website helps explain the different policies and thus provides opportunity to become involved in the debate."

Although European Union has a "Thematic Strategy on Air Quality", the new ambient air quality directive (2008/50/EC) needs to be effectively implemented if it is to bring significant benefits to people with respiratory diseases.

EFA and its national members who are partnering in the website project, are writing to health and environment ministers in all EU countries about the entry into force of the new ambient air quality directive, highlighting how patients' groups could significantly contribute to the implementation of this regulation.

By providing people with COPD or other respiratory diseases with air pollution forecasts, EFA and HEAL hope to reduce unnecessary suffering, illness, exacerbations and hospital admissions due to air pollution. [Click for full release and more...](#)
www.knowyourairforhealth.eu

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Tobacco control

In April EFA took part in a stakeholder consultation meeting organised by DG SANCO on renewing⁹ the **EU Tobacco products directive**¹⁰ that regulates the manufacture, presentation and sale of tobacco products in the EU. Our main messages were: ultimate objective should be banning the sale of tobacco products in the EU, specific warning on COPD to tobacco packs to improve awareness and helpline numbers for quitting published in packs.

EU Health Strategy¹¹

EFA Board EU Policy Lead took part and represented people with allergy, asthma and COPD in the new working group on strategic priorities of the EU Health Policy Forum (EUHPF)¹², which started to set up a plan for the Forum. This included strategic priorities and action plan for 2009 and the overall framework is the new EU Health Strategy. The Plan will be ready and published 2009.

Other policy issues

Through EFA membership and board membership in the European Patients' Forum (EPF), we were specifically involved in EU policies regarding **information to patients**, as EFA Executive Officer is EPF Vice President, and their representative at the European Commission High Level Pharmaceutical Forum working group on information to patients¹³. High Level Pharmaceutical Forum 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. The Forum finalised during 2008 a number of practical resources to support improving information:

1. [Recommendations to enhance access to information on diseases and treatment options in healthcare settings and examples of good and innovative practices](#)
2. [a set of examples of good and innovative practices in several Member States](#)
3. [Core Quality Principles on information to patients](#) and [detailed practical methodology of use](#)
4. [The key elements for core information on disease and treatment](#)
5. [Summary of research on patients tools to distinguish good health information quality](#)
6. [Introduction to Public Private Partnerships and other Collaborative Approaches Delivering Information to Patients on Diseases and Treatment Options in Europe illustrated by an overview of existing initiatives](#)
7. [Ethical guidance as to collaborations and public private partnership among partnering organisations](#)
8. [Wider Health Aspects.](#)

The Legislative proposal on information to patients was launched 2008 by the DG Enterprise. 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, but with a context of a Comprehensive European Information to Patients Strategy, where patients are key players, that should be developed.

EFA EU Policy Advocacy 2008 – main actions :

- www.knowyourairforhealthwebsite.eu
- Signing Campaign of Declaration at the European Parliament on Combating COPD

⁹ Second Report on the Application of the Tobacco Products Directive :

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

¹⁰ Directive 2001/37/EC of the European Parliament and of the Council on the approximation of the laws, regulations and administrative provisions of the Member States concerning the manufacture, presentation and sale of tobacco products

¹¹ http://ec.europa.eu/health/ph_overview/strategy/health_strategy_en.htm

¹² http://ec.europa.eu/health/ph_overview/health_forum/policy_forum_en.htm

¹³ http://ec.europa.eu/pharmaforum/information_en.htm

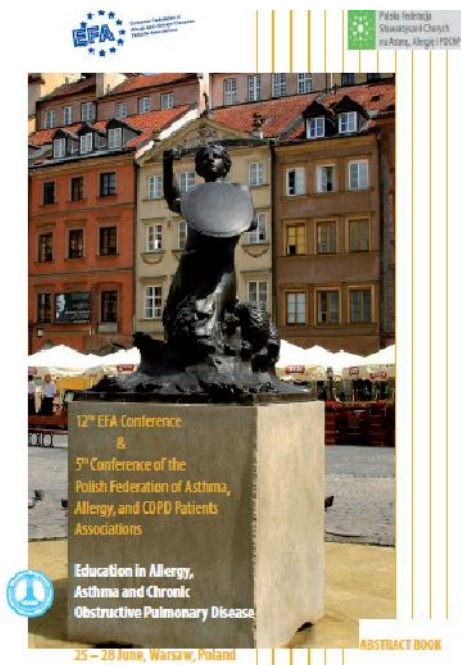
MEMBERSHIP DEVELOPMENT

Increasing membership base

Two new members joined and were warmly welcomed to EFA at our Annual Meeting; Irish Asthma Society and Portuguese Asthma Association (APA), increasing our membership-base into 34 associations in 22 countries.

Capacity building and sharing best practices

In May EFA held its statutory **Annual General Meeting (AGM)** in Warsaw, Poland followed by 12th **Conference** 'Education in Asthma, Allergy and COPD', jointly with our Polish member Polish Coalition of Asthma, COPD and Allergy Patient Organisations annual conference. The rationale was that there is growing evidence that patient education is not only beneficial, but crucial for effective management of chronic disease and that education is a process, not a one-time event and in fact – who is educating whom? The aim was to update on the latest knowledge and look into the future of care, treatments, environment and smoking cessation with special focus on patient education.



The Programme was twofold; firstly it introduced hot topics on all of our disease areas with the aim to update patients, patient representatives and healthcare professionals on state-of-the-art. Secondly separate sessions for doctors, nurses and patient leaders discussed patient education in theory and practice. The feedback from members was that sharing best practices in patient education among patient groups could even deserve its' own conference.

There were almost 500 participants at the Conference. Simultaneous translation into Polish enabled wide local participation. The abstracts of the Conference are available at <http://www.efanet.org/activities/documents/EFAAbstractBook20081.pdf>

The Prevalence, Cost, and Basis of Food Allergy across Europe EuroPrevall¹⁴, project (IP) launched 2005 in the context of the EU Framework Programme of Research FP6 The main objective is to improve the quality of life for food allergic people, and it is therefore EFA is partner in the project.

2008 EuroPrevall published copyright-free material for primary care professionals and food allergic persons or parents to allergic children; Food allergy: Basic facts and how to live with it¹⁵. The material aims to help to

¹⁴ <http://www.euoprevall.org/>

¹⁵ <http://www.ga2len.net/index.cfm?action=viewPublicPage&pageID=2217>

understand what food allergy is about, how it is diagnosed and handled. EFA collaborated to create the material which is available for members to use as they wish.

To complement the lay State-of-the-Art papers based on EuroPrevall and other latest research published last year, which are available for EFA members to use and publish: Sexy research on food allergy (food allergy and gender)¹⁶, Food allergy diagnosis today and in the future¹⁷ and The impact of food allergy on quality of life¹⁸, EuroPrevall published the following new ones in collaboration with GA²LEN:

- The percentage of people with food allergy in the community and Why is it important to know about it¹⁹
- What amounts of foods may trigger food allergy symptoms? And why do we need this information?²⁰

EFA members were invited to the fifth 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 on 10 - 12 April in Paris, France.

EFA organised a joint workshop with GA²LEN and EuroPrevall '**Asthma and Allergy Selected and Food for Thought - Thought for Food**' focusing on EuroPrevall and GA²LEN research results, their significance for patient care and tools developed for the general public/patients. The presentations given are available for EFA members at <http://www.efanet.org/members/index.html>

The topics included severe asthma; aspirin hypersensitivity; severe asthma; pet ownership and exposure, sports and asthma and the need to set up EFA members working group on food allergy. 14 members from 12 countries took part.

The GA²LEN Public Day for the French patients, **Les Allergies.. Pensez vous être à l'abri?** was held this year in collaboration with EFA French members.

¹⁶ <http://www.efanet.org/activities/documents/EuroPrevallGenderResearchFoodAllergy.pdf>

¹⁷ <http://www.efanet.org/activities/documents/EuroPrevallFoodAllergyDiagnosisTodayandFuture.pdf>

¹⁸ <http://www.efanet.org/activities/documents/EuroPrevalltheimpactoffoodallergyinQoL.pdf>

¹⁹ http://www.ga2len.net/files_new/filesPublic/EuroPrevall%202009_Percentage%20of%20people%20with%20food%20allergy.pdf

²⁰ http://www.ga2len.net/files_new/filesPublic/EuroPrevall%202009_What%20amounts%20of%20foods%20may%20trigger%20food%20allergy.pdf

BUILDING SUSTAINABLE PARTNERSHIPS

Partnership with NGOs

During the year EFA partnered with several non-governmental organisations as highlighted throughout this report, that support and share parts of our mission and objectives, and in particular EU policy priorities.

These included:

- Global Alliance Against Respiratory Diseases (GARD), founding member and planning group membership
- International COPD Coalition (ICC) - member
- European Patients Forum (EPF), member and vice presidency
- European Respiratory Society (ERS), Ethics Committee membership
- European Lung Foundation (ELF)
- International Primary Care Respiratory Group (IPCRG), associate member
- Health and Environment Alliance (HEAL), membership
- European Network for Smoking Prevention (ENSP), membership
- World Organisation of Family Doctors (WONCA)
- Allergic Rhinitis and Its' Impact on Asthma (ARIA), membership in Advisory Committee
- Global Alliance for COPD (GOLD) - World COPD Day
- Global Initiative for Asthma – World Asthma Day

First links were also been made and exchange of information started with European Academy of Dermatology and Venereology (EADV) through providing a patient speaker for their press conference on eczema in June.

Corporate partnership

For the first time, EFA had a special meeting for our sustainable funding partners in Brussels to present EFA work done 2007 and outlook for the 2008 and future. Our sustainable industry partners 2008 were GSK and Novartis and we are grateful for their ongoing support. Industry is a natural partner of patient organisations and EFA collaboration is based mutual trust and transparency, in line with our Corporate Partnership Framework²¹ and Code of Ethics and Conduct²². From October onwards when our Project and Fundraising Officer started, liaising with potential new partners for 2009 and beyond started (see page 11).

EFA continued to take part in the THINK TANK between industry and patient organisations organised by the EFPIA, the new EuropaBio (European bio-medical industry organisation) Patient Advisory Board and the GSK Health Advisory Board.

²¹ <http://www.efanet.org/about/documents/EFASustainableCorporatePartnershipFramework.pdf>

²² <http://www.efanet.org/about/documents/EFACodeofEthicsandConduct.pdf>

ESTABLISHING EFFECTIVE COMMUNICATIONS

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.

A new partnership website targeted for people with allergy, asthma and COPD with the HEAL www.knowyourairforhealth.eu is a new resource centre on air pollution and related legislation (see page).

World Asthma Day



On World Asthma Day 6 May EFA sent out a media alert²³ in support of the IPCRG and World Organisation of Family Doctors (WONCA) campaign 'Spring into Action' highlighting that two thirds of people with asthma do not lead a full life because of

their condition and that they want to know more and top tips for people with asthma, healthcare professionals and policy makers. The EFA members activities were collated in a summary²⁴.

World COPD Day – 19 November launch of the Know Your Air for Health website - see page 16

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 EFA Patient Voice in Allergy survey 2005, in collaboration with members and other patient groups in 11 countries were published in an article '**Allergic Rhinitis in Not a Trivial Disease**'²⁵ in Current Opinion in Allergy and Clinical Immunology Journal in January. It highlights the impact allergic rhinitis is having to patients daily life, and thereby still unmet needs by patients that could be solved with proper management, improved communication with treating healthcare professionals and good quality and comprehensive patient information, education and support, including issues relating healthy indoor environment. Therefore future management guidelines for allergic rhinitis must promote relief from the emotional burden of allergic rhinitis and from the negative impact on daily activities, encourage patient

²³ <http://www.efanet.org/enews/documents/EFAMediaAlertSpringintoActiononAsthma.doc>

²⁴ <http://www.efanet.org/enews/documents/WADEFAMembersactivities.doc>

²⁵ <http://www.ncbi.nlm.nih.gov/pubmed/18188010>

education, and maintain and build on the strong partnership between patients and healthcare professionals. The evidence was also used as an example in EPF policy response on Information to Patients.

EFA was also co-author of a GA²LEN review article: **Primary care: the cornerstone of diagnosis of allergic rhinitis**²⁶, highlighting the important and raising role of primary care and best practice in diagnosis, which was part of the GA²LEN Campaign Does Rhinitis Lead to Asthma²⁷ and the **Allergic Rhinitis and Its Impact on Asthma Update (ARIA) guidelines update**²⁸

EFA publications 2008:

- **Annual Report 2008**
- **Abstracts Education in Allergy, Asthma and COPD** from the EFA Conference 2008
- **Allergic rhinitis is not a trivial disease.** Current Opinion in Allergy and Clinical Immunology. 2008 Feb;8(1):1-9. Valovirta E, Palkonen S, Myrseth E,
- Partner in: **Primary care: the cornerstone of diagnosis of allergic rhinitis.** Allergy. 63(8):981-989, August 2008. Ryan, D. 1,2; van Weel, C. 3; Bousquet, J. 4,*; Toskala, E. 5,*; Ahlstedt, S. 6,7; Palkonen, S. 8; van den Nieuwenhof, L. 3; Zuberbier, T. 9,*; Wickman, M. 10,11,*; Fokkens, W. 12,*
- Partner in: Bousquet J, Khaltaev N, Cruz A, et al. **ARIA update.** Allergy 2008; 63: 8-160. 2008, 8: 1-9

²⁶ <http://www.ncbi.nlm.nih.gov/pubmed/18691300>

²⁷ <http://www.efanet.org/activities/DoesRhinitisleadtoAsthma.html>

²⁸ http://www.guidelines.gov/summary/summary.aspx?doc_id=12177

3 ANNUAL ACCOUNTS

FINANCIAL REPORT

Financial report 2008

1. The Financial Report is in Euro.

2. Bank Accounts

EFA has four Bank Accounts:-

- a. A current (sight) account in Luxembourg in Euro. The balance at 31:12:08 was 478,13 Euro.
- b. A deposit (term) account also in Luxembourg. The balance at 31:12:08 was 20.155,44 Euro.
- c. A Visa account in Luxembourg in Euro. The balance at 31:12:08 was 8.367,57 Euro.
- d. A Swedish Currency Account in Euro. The balance at 31:12:08 was 50.302,63 Euro.

The total balance in the four Bank Accounts and Petty Cash at 31:12:08 was 79.335,06 Euro.

	<u>31-12-08</u>	<u>31-12-08</u>
Luxembourg 1	478,13	68.368,49
Luxembourg 2	20.155,44	46.293,15
Luxembourg 3	8.367,57	8.115,89
Sweden	50.302,63	48.808,60
TOTAL	79.335,06	171.796,09



Otto Spranger
EFA Treasurer



Marianella Salapatas
EFA Acting President

Financial Balance of the Bank Accounts in Euro

	Luxemburg			Petty Cash	Handelsbanken	Subtotal =	Changes	Total
	Sight Account	LU 5912 7917 1	LU 0038 8721 9	EUR	EUR	Spread Sheets		
Income								
Fees	31.500,00					31.500,00		31.500,00
Main sponsorship	66.237,06					66.237,06	53.762,94	120.000,00
EU Project	586,52					586,52		586,52
EFA Other Meetings						0,00		0,00
EFA Conference	8.868,00					8.868,00		8.868,00
EFA News						0,00		0,00
GALEN	14.254,00					14.254,00		14.254,00
Aimet						0,00		0,00
Pinche						0,00		0,00
Europrevall	17.565,10					17.565,10		17.565,10
SAFE						0,00		0,00
Secr.	136,87					136,87		136,87
Bank Interest	71,76	253,18	1.649,32		1.494,03	3.468,29		3.468,29
Other Meetings	3.989,59					3.989,59	-1.080,80	2.908,79
Transfer	27.787,03		-27.787,03			0,00		0,00
Total	170.995,93	253,18	-26.137,71	0,00	1.494,03	146.605,43	52.682,14	199.287,57
Expenditure								
Board Meetings	12.046,10					12.046,10	429,00	12.475,10
Other Meetings	32.117,27			1.477,17		33.594,44	412,00	34.006,44
EFA Conferences	45.844,72					45.844,72	2.205,96	48.050,68
EFA News						0,00		0,00
Europrevall	27.361,13					27.361,13	-15.828,63	11.532,50
EU Project						0,00		0,00
Aimet						0,00		0,00
GALEN	14.309,27			87,50		14.396,77	-4.740,33	9.656,44
LRPC						0,00		0,00
PINCHE						0,00		0,00
Membership fees/Publicit	570,00					570,00		570,00
Secr.	64.663,45			314,00		64.977,45	36.735,84	101.713,29
P&P	1.511,57					1.511,57	-65,53	1.446,04
Logistics						0,00		0,00
Exec. Officer	38.400,00					38.400,00		38.400,00
Misc.	1.800,00					1.800,00		1.800,00
Bank Charges	262,78	1,50				264,28	0,00	264,28
Total	238.886,29	1,50	0,00	1.878,67	0,00	240.766,46	19.148,31	259.914,77
Result	(67.890,36)	251,68	(26.137,71)	(1.878,67)	1.494,03	(94.161,03)	33.533,83	(60.627,20)

Annexe 1

<u>BALANCE SHEET</u>			
<u>IN EURO</u>			
	31-déc-08	31-déc-07	31-déc-06
<u>ASSETS</u>			
VII. DEBTORS	70.090,71	17.408,57	90,71
Debtors ⁽¹⁾	70.090,71	17.408,57	90,71
IX. LIQUIDITIES	79.335,08	171.796,09	184.378,86
Bank Account 0038/4174-7	478,13	68.368,49	45.159,52
Handelsbanken 41 402 668	50.302,63	48.808,60	47.353,40
Bank Account 0038/8721-9	20.155,44	46.293,15	83.702,58
Bank Account 5912/7917-1	8.367,57	8.115,89	7.884,86
Petty Cash Account	31,29	209,96	278,50
Transfert	0,00	0,00	0,00
X. DEFERRED CHARGES AND ACRUED INCOME	0,00	0,00	0,00
Deferred Charges	0,00	0,00	0,00
TOTAL ASSETS	149.425,77	189.204,66	184.469,57
<u>LIABILITIES</u>			
IV. RESERVE	96.328,70	155.292,77	156.697,27
Reserve last year	155.292,77	165.354,27	94.656,94
Excess of income over expenditure from current year	(58.964,07)	(10.061,50)	62.038,33
IX. DEBTS	52.960,20	33.911,89	19.115,30
Creditors ⁽²⁾	52.960,20	33.911,89	19.115,30
Received grants for next year ⁽³⁾			-
TOTAAL DER PASSIVA	149.288,90	189.204,66	175.812,57

INCOME AND EXPENDITURE ACCOUNT
IN EURO

	<u>31/12/208</u>	<u>31-déc-07</u>	<u>31-déc-06</u>
Income	199.150,70	217.747,81	315.917,88
Fees	31.500,00	27.000,00	30.750,00
Grants	120.000,00	134.946,82	200.000,00
EU Project	586,52	17.120,00	0,00
EFA Conferences	8.868,00	0,00	8.000,00
EFA Other Meetings	0,00	8.069,77	0,00
Europrevall	17.565,10	25.393,81	14.319,10
Pinche	0,00	0,00	5.007,69
GALEN	14.254,00	858,68	50.000,00
Bank Interests	3.468,29	4.358,73	3.551,89
Other meetings	2.908,79	0,00	4.289,20
Expenditure	258.114,77	227.809,31	253.879,55
Board Meetings	12.475,10	15.905,76	7.238,51
EFA Conferences	48.050,68	29.030,88	44.471,16
EU Project	0,00	15.020,26	7.800,00
Other Meetings	34.006,44	24.852,54	27.613,69
EFA News	0,00	2.880,00	0,00
Secretariat	103.159,33	55.799,88	47.052,37
Airnet	0,00	0,00	104,00
Europrevall	11.532,50	27.295,53	9.750,00
GALEN	9.656,44	21.530,57	31.174,48
PINCHE	0,00	0,00	2.659,40
Exec. Officer	38.400,00	35.200,00	72.536,25
Membership fees/Publicity	570,00	70,00	3.180,49
Bank Charges	264,28	223,89	299,20
Result of the Year	-58.964,07	-10.061,50	62.038,33

**FOOTNOTES RELATED TO BALANCE SHEET AND
INCOME AND EXPENDITURE ACCOUNT**

(1) Mr Myrseth : advance 735 NOK	90,71
GSK Sponsoring	70.000,00
Shire Health : reimbursement	
<hr/>	
Total Debtors	70.090,71
(2) Susana Palkonen : advance petty	1.700,00
bankcharges	10,50
Salapatas	841,00
Botjes	12.086,29
Fink Wagner	36.495,84
Myrseth	1.586,57
Net Federation	240,00
<hr/>	
Total Creditors	52.960,20
(3)	
<hr/>	
Total Received for next year	0,00

Missing justifications :

AUDITORS REPORT

AUDITING OF WORKING ACCOUNTS AND BALANCE
FOR THE FINANCIAL YEAR 2008
OF THE EUROPEAN FEDERATION OF
ALLERGY AND AIRWAYS DISEASES PATIENTS ASSOCIATIONS


As appointed EFA Auditor by the Assembly General Meeting, I checked the annual accounts of the year 2008 of the European Federation of Allergy and Airways Diseases Patients Associations.

The financial statements for the year 2008 are established in Euro.

Like last year, the bookkeeping is held on a cash-basis. All the documents I verified enabled me to match every receipt and expenditure to a supporting document.

The financial year closes at a profit brought forward of 96.465,57 Euro. The net result of the year 2008 amounts to – 58.827,20 Euro and the balance-total to 149.425,77 Euro.

It is my opinion that the balance sheet and the profit and loss account as at 31 December 2008 gives a fair view of the financial situation of the organisation.



Brussels 29 May 2009
Filip MOEYKENS
Accountant

BUDGET

Revised budget 2009

Income (Credits)	in €
Membership Fees	36.000,00
EU-Projects (EuroPrevall U-BIOPRED)	open
GA ² LEN	open
Other Projects (COPD) Book	10.000,00
Sponsors long term	200.000,00
Sponsors short term	15.000,00
EFA Annual Congress	15.000,00
Total	276.000,00

Expenditure (Debits)

EFA-Net	2.880,00
Staff	70.000,00
Secretariat/Administration	60.000,00
EFA-Board Meetings	9.000,00
Projects (COPD Book)	10.000,00
EFA-Conference	20.000,00
Other Meetings	25.000,00
EU-Projects (EuroPrevall, U-BIOPRED)	open
GA ² LEN	open
Logistics	1.500,00
P,P&P	-
PR-Activities	10.000,00
Part-time worker	60.000,00
Booth-Material	-
Membership Fees	4.500,00
Reserve	-
Total	272.880,00
Balance	3.120,00

Preliminary budget 2010

Income (Credits)	in €
Membership Fees	30.000,00
EU-Projects	-
GA ² LEN	-
Other Projects	20.000,00
Sponsors long term	160.000,00
Sponsors short term	50.000,00
EFA Annual Congress	-
Total	260.000,00
Expenditure (Debits)	
EFA-Net	2.880,00
Staff	45.000,00
Secretariat/Administration	100.000,00
EFA-Board Meetings	9.000,00
Projects	20.000,00
EFA-Conference	35.000,00
Other Meetings	25.000,00
EU-Project	-
GA ² LEN	-
Logistics	1.500,00
P,P&P	-
PR-Activities	
Meet & Greet	17.000,00
Booth-Material	-
Membership Fees	4.500,00
Reserve	-
Total	259.880,00
Balance	120,00

EFA thanks our

Platinum sponsors

European Commission DG Research

GlaxoSmithKline

Novartis

Annex 1

**EFA European Allergy, Asthma & COPD Patient Sofia Declaration
2 June 2007**

Agreed at the 11th EFA Conference *Equality in Health for People with Allergy, Asthma and COPD in Europe - Through prevention and self management to better quality of life*, Sofia, Bulgaria, 30 May – 2 June 2007

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

Conference Participants

Allergy and Asthma Federation, Finland
 ANIKSI, Greece
 Association of Allergic Children Clubs, Lithuania
 Associazione Italiana Pazienti BPCO
 Association of Bulgarians with Bronchial Asthma ABBA
 Astmafonds, the Netherlands
 Asthma UK
 Astma-Allergiforbundet, Denmark
 Association Asthme & Allergies, France
 Austrian Lung Association
 Czech Initiative for Asthma
 Lithuanian Council of Asthma Clubs
 Norwegian Asthma and Allergy Association
 Norwegian Heart and Lung Associations
 Pulmonary and Allergy Patients' Association of Slovenia
 Swedish Asthma and Allergy Association
 Swedish Heart and Lung Association
 Vereniging Nederland-Davos, the Netherlands

Annex 2

EFA FP7 partnership

The European Federation of Allergy and Airways Diseases Patients Associations (EFA) is a non-profit network of 32 European **allergy**, **asthma** and **chronic obstructive pulmonary disease (COPD)** patient organizations from 20 countries, in which there are over 500.000 patient/carer members.

Rationale: One of our key goals is patient centered demand driven research and following that, communication of the results of research to patients, in a format they can understand and access it, including discussing of the results in practice and addressing uncertainties.

This requires appropriate patient/patient representative partnership and participation in defining the research agenda, in research itself and in communicating the results.

Any partnership must address one or more of our overall priorities, which are

- indoor and outdoor air quality,
- greater access to and quality of medical and social care and prevention
- patient centred research and
- meaningful patient participation in research, involvement in policies, commissioning of patient care services & society and having a voice in care delivery & society

Role: our role in a project could be one or combination of the following:

- Participate in development of any project proposal and especially EFA role in a project
- Member in the Steering Committee or similar of a project
- Recruiting/providing expert patients for various purposes in a project
- Review reports and participate in drafting of recommendations
- Lead/contribute to the coordination of the patient organization participation in the project
- Contribute/lead in producing materials containing outcomes of a project for patients (leaflets, web etc)
- Contribute/lead in communicating the results, discussing on progress and dissemination of material via meetings (EFA Annual Conference and/or specific meetings on the project results for patient representatives) and other media (website, monthly electronic newsletter) to patient representatives and the public at large
- Overall coordination of the EFA network input in the project
- Lead a work package on patient involvement and/or dissemination

Daily rates for EFA:

- EFA Project Member: 480€
- EFA Board Member/Executive: 640 €

Expenses: reimbursement of

- Travel
- Accommodation
- Subsistence
- Administrative expenses

EFA reserves the right to withdraw from a project if it contradicts our core values which are

- Patient involvement is central
- Sharing knowledge and experience
- Partnership and cooperation

While EFA will through its network and communication tools promote and disseminate the project results, EFA cannot be held responsible for the wider dissemination by its members who are independent, through their dissemination channels, unless their work paid for.

Annex 3

Written Declaration 0102/2007 on Combating COPD

The European Parliament,

- having regard to Rule 116 of its Rules of Procedure,
- A. whereas chronic obstructive pulmonary disease (COPD) is a common and costly lung disease whose advanced stage is chronic respiratory failure,
- B. whereas COPD is a under-recognised, under-diagnosed and under-treated disease neglected by healthcare providers and the public,
- C. whereas COPD is increasing worldwide as a result of the epidemic in tobacco use, the global demographics and indoor and outdoor air pollution,
- D. whereas COPD causes approximately 200,000-300,000 EU deaths yearly and is projected to move from the sixth to the third most common cause of death worldwide by 2020,
 1. Calls on the Member States to raise awareness of COPD by promoting prevention and ensuring equal access to early diagnosis, correct treatment and mobility of COPD patients;
 2. Calls on the EU to facilitate long-term research into the causes, prevalence and treatments for COPD;
 3. Urges the EU Member States to implement comprehensive smoke free policies and develop smoking cessation strategies;
 4. Calls on the EU to publish a Green Paper on indoor air under the EU Environment and Health Action Plan;
 5. Instructs its President to forward this declaration, together with the names of the signatories, to the Council and the Commission.