

European Federation of Allergy and Airways Diseases Patients' Associations

Annual Report 2009



www.efanet.org

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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) 2009. The main areas include building high profile projects, increasing funding partnership and capacity, working effectively and more with diverse membership and influencing European policy on allergy, asthma and COPD from patient perspective. In addition to work outlined here, EFA spoke at some 20 EU and other health events during the year, and was involved through our memberships and partnerships in several initiatives.

I am happy to be able to present this report to you, our role as advocates for a better deal for people with allergy, asthma and COPD no matter where they live in Europe is increasing and with your help we are stronger.

We are grateful for all the support and valuable input received by EFA members in various capacities during 2009. We would also like to thank our 5 star sponsors: European Commission, GlaxoSmithKline and Novartis for their continuous high level support and trust, new 3 star sponsors Boehringer Ingelheim and Merck for their commitment, 2 star sponsor Linde Gas and donator Nigaard for their support.



Marianella Salapatas
President

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 12 June 2009)

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
Email: sem@lhl.no

Vice President – Acting President from 26 June 2008

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

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

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

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

Board (From 12 June 2009)

President

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

Vice President

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

Member-at-Large and Treasurer 1st January 2010 until which time Otto Spranger acted as Interim Treasurer

Breda Flood
Asthma Society of Ireland
Email: breda.flood@efanet.org

Member-at-Large

Lina Buzermaniene
Lithuanian Council of Asthma Clubs
Email: lina.buzermaniene@efanet.org

Member-at-Large

Per-Ake Wecksell
Swedish Asthma and Allergy Association
Email: per-ake.ecksell@astmaoallergiforbundet.se

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

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

Meet and Greet EU Institutions training

Mariann Skar mariann.skar@efanet.org
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Membership and representation

The EFA membership 2009 consists of 36 allergy, asthma and/or COPD patient associations or their coalitions in 201 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

Germany from 12 June

Patientenliga Atemwegserkrankungen e.V. www.patientenliga-atemwegserkrankungen.de

Greece

ANIKSI www.allergyped.gr

Ireland

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 and
Vereniging Nederlands Davos www.nederland-davos.nl and

Coalition of Stichting Voedsel Allergie - Dutch Food Allergy Organisation www.stichtingvoedselallergie.nl
Vereniging voor Mensen met Constitutioneel Eczeem (VMCE) www.vmce.nl

Norway

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

Poland

Polish Federation of Asthma, Allergy and COPD Patients' Organisations

Portugal

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

Board lead for the Motion at the EFA AGM 2009
Per-Ake Wecksell, Sweden

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 COPD Assessment Test International Steering Committee

Marianella Salapatras, Greece

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

Jenny Versnel, U.K. until September, from thereon Breda Flood, Ireland

EFA Board EU Policy Lead until 12 June

Jenny Versnel, U.K.

Medical Advisor

Erkka Valovirta, Finland

European Medicines Agency (EMA) Patient experts

Lina Buzermaniene, Lithuania

Breda Flood, Ireland

Marianella Salapatras, Greece

Ondrej Rybnicek, Czech Republic

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), Otto Spranger, Austria, 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 until 12 June and Marianella Salapatras from 12 June

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

European Medicines Agency Patient and Consumer Working Party, representative Lina Buzermaniene, Lithuania, alternate Breda Flood, Ireland

Associate memberships

International Primary Care Respiratory Group (IPCRG)

STRATEGIC PRIORITIES 2009

- 1. Build high profile projects**
- 2. Increase funding partnership and capacity**
- 3. Work effectively and more with diverse membership**
- 4. Influence European policy on allergy, asthma and COPD from patient perspective**

2 MAIN ACTIVITIES

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 COPD advisor.

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.

The EFA board met 4 times, one meeting was a strategic meeting. The Annual General Meeting (AGM) was held 12 June in Rome, Italy where the President and two board members were elected. Our external auditor audited the accounts for the approval of the AGM 2010 as usual.

BUILDING HIGH PROFILE PROJECTS

Conferences

In June EFA held its statutory **Annual General Meeting** (AGM) in Rome, Italy followed by 13th **Conference 'The Future of Patient Organisations'**. The Conference was held at the Italian Ministry of Health and co-hosted by FEDERASMA and Associazione Italiana Pazienti BPCO. More than one dozen modern projects on allergy and asthma with EFA involvement and best practice examples were screened and by doing so, the Conference highlighted the conditions needed to manage future challenges of national and international allergy and asthma patient organisations. 35 patient leaders and partners took part.

As part of the Conference, one session was jointly



with the **WHO Global Alliance Against Respiratory Diseases General Assembly** that was running simultaneously . EFA members had been invited to send one slide of their recent best project, and these were presented to the global leaders and demonstrated the diversity of activities and the importance of the role of patient associations. EFA also made the call to global leaders for support of the global plans for a platform of allergy and asthma patient groups ‘GA²P Global Alliance of Allergy and Asthma Patient Organisations’, an initiative from EFA. EFA also sent out a joint press release with the GARD.

On the 14th followed **The First Conference of COPD Patients**, co-organised by the International COPD Coalition and EFA and in collaboration with the Associazione Italiana pazienti BPCO, International Primary Care Respiratory Group (IPRCG), World Organisation of Family Doctors (WONCA) and Global Initiative against Chronic Respiratory Diseases (GOLD). The purpose was to create a better understanding of global COPD management strategies, the unmet needs of COPD patients worldwide, and the development and implementation of COPD prevention strategies as well as approaches to found COPD patient organizations and for existing COPD patient organizations to successfully implement programs.

The Conference was attended by more than 100 patients, patient leaders, healthcare professional leaders and the WHO. As a result, the Global Bill of Rights of COPD Patients and Global Mandate for COPD Care were launched. EFA sent out a joint release with the ICC.

The presentations of the EFA Conference are available at <http://www.efanet.org/EFAConference2009.html> and the Abstracts Book at <http://www.efanet.org/documents/EFARomeConferenceAbstractBook.pdf> . EFA wishes to specifically acknowledge the support of Mariadelaide Franchi for all these events.

COPD Patient Global Bill of Rights¹:

the right to receive early and accurate diagnosis,
the right for information and education about COPD,
the right for support and understanding,
the right to receive care and treatment that will benefit them,
the right to their fair share of society’s involvement and investment in their welfare and improved care,
the right to advocate with other COPD patients and supporters for improved COPD care and COPD prevention
the right to safe air and environment

EFA Book on COPD in Europe – Sharing and Caring¹

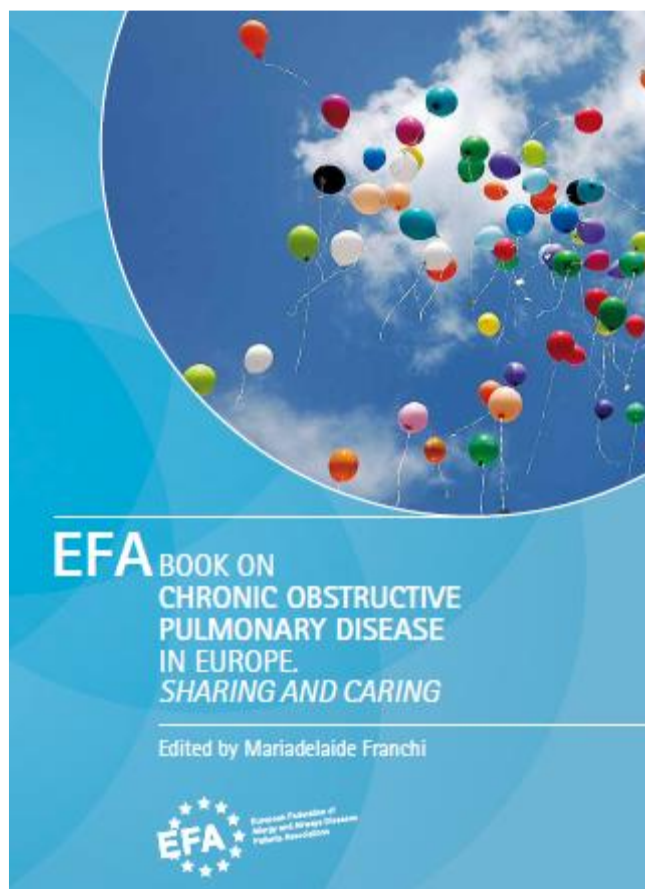
EFA’s ongoing priority is increased awareness and recognition of COPD as a public health priority in Europe that would lead to early diagnosis. On World COPD Day, 18 November EFA published an unprecedented collection of information on COPD in Europe. From patients to policy makers, the Book was based on information collided from patient groups and their partners in 12 countries and official statistics: Austria, Belgium, Czech Republic, Finland, France, Germany, Ireland, Italy, Netherlands, Portugal, Serbia, UK; The

¹ <http://www.efanet.org/documents/EFACOPDBook.pdf>
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information covered basic facts on COPD, access to and quality of care as judged and reported by patient groups and a snapshot of the patient group activities to highlight their fundamental role.

The purpose of the Book, that will be represented at the European Parliament in 2010, is to share best practices and highlight the gaps to make policy both at European and country level to serve patients interest. EFA wants to sincerely thank our members and others who took part and our late Editor Mariadelaide Franchi and Jean Ann Gilder Scientific Communications who coordinated the data collection and writing. The Book could serve as a model for allergy and asthma as well. The project was supported by equal grants from GSK and Boehringer Ingelheim.

The main conclusions are that while a lot of progress has been made, the awareness of COPD is still alarmingly low and that patients across Europe are either diagnosed in late stages or do not have adequate access to the care and support they need.



Conclusion from the EFA Book on COPD in Europe:

There is an urgent need to recognise COPD as a public health priority and rather than dispersing initiatives, a need to develop comprehensive programmes on COPD both at European and at national level and in partnership with all stakeholders including patient groups.

Global Allergy and Asthma Patient Platform

EFA has recognised that there is no global platform for the organisations representing people with allergy and asthma. The idea for a global platform was discussed with patient leaders from different continents at EFA Patient Summit organised at the World Allergy Organisation Conference in Buenos Aires, Argentina in December. It was agreed to set up GA²P² gradually and the 'Declaration of Buenos Aires' was signed by the attending patient groups to highlight the global problem of allergy and asthma and the goals of the GA²P².

We, allergy and asthma patients, patient care givers and patient advocates from xy countries around the world declare

- Global networking of allergy and asthma patient organizations is needed.
- All patients with allergies and asthma have a right to comprehensive health care.
- Access to education including information, training and self management plans is mandatory in best practice therapy.
- Patients with allergies and asthma demand to live in healthy unpolluted air and smoke-free environments.

EFA Annual Report 2009. Patients with allergies and asthma have the fundamental responsibility to take an active role in managing their disease and to lead a healthy life style. Page 13 of 28

INCREASING FUNDING PARTNERSHIP AND CAPACITY

In 2009, EFA funding was based on membership fees 15%, European Commission Project funding 15% and 70% sustainable partnership with and project funding by the industry.

There still are no possibilities for EFA to apply for core-funding from the European Commission, and therefore EFA has invested in Project and Fundraising Officer who's task is outreach to corporate funders and build projects that deliver on our mission and objectives but at the same time attract funding.

Increasing industry partnerships

Industry is a natural partner of patient organisations and EFA collaboration is based mutual trust and transparency, in line with our Corporate Partnership Framework² and Code of Ethics and Conduct³. The EFA Board approved an updated Framework for EFA Sustainable Corporate Partners. The updated Framework is more precise on the benefits and responsibilities both for EFA and partners. For example in order to support a project, partner needs to commit to sustainability of EFA through an unrestricted grant to support our core operations at the service of people with allergy, asthma and COPD. It also includes new categories to acknowledge the level of partnership: 5 star, 4 star, 3 star, 2 star and 1 star. 3 new partners signed up in 2009. The partners are acknowledged at the end of this report.

During our conference in June EFA had a special meeting for our sustainable funding partners in Rome to present EFA work done 2008 and outlook for the 2010. All partners attended the meeting. Our funding partners 2009 are listed at the end of this report.

Partnering in EU projects

Unbiased BIOmarkers for the PREDicting disease progression and medication efficacy U-BIOPRED



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 partners in **Unbiased BIOmarkers for the PREDicting disease progression and medication efficacy U-BIOPRED** -project. The project started in

² <http://www.efanet.org/about/documents/FinalSustainableCorporatePartnershipArrangementsEFAJune09.doc>

³ <http://www.efanet.org/about/documents/EFACodeofEthicsandConduct.pdf>

October 2009 and the it was prested to members at our conference in June. U-BIOPRED will address the issue that 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. EFA has a role in the ethics, consensus generation and dissemination of the project and research results in lay language through our network.

Health Based Ventilation Guidelines for Europe

EFA partnered in a project proposal to the EU Public Health Programme on indoor air quality 'HealthVent'. The purpose of the project lead by scientists is to develop health based ventilation guidelines for Europe that can be used as a policy making and practise tool by the EU member states. EFA would represent the interest of people with allergy, asthma and COPD in the project if it will be accepted for funding.

Mechanisms in the development of allergy

In 2009 there was an important call for project proposals from the EU Framework Programme for Research on the prevention and understanding allergy. EFA was asked by 4 different consortia to represent patients in their bid and decided to take part in all in order to be part of the winning bid.

WORKING EFFECTIVELY AND MORE WITH DIVERSE MEMBERSHIP

Increasing membership

One new member and new country joined and was warmly welcomed to EFA at our Annual Meeting; Patientenliga Atemwegserkrankungen e.V. representing people with COPD, asthma and emphysema in Germany increasing our membership-base into 34 associations in 23 countries. The objective of Patientenliga is to inform and train patients suffering from COPD and asthma in general and especially in their local groups.

Increasing member engagement and improve outcomes at European level

The AGM 2009 decided based on a motion from members that EFA needs to find ways to improve the motivation and number of members to be involved in order to have better joint outcomes at the European level and it was decided to set up an interactive discussion group of members lead by EFA board member to take this forward. The first plan should be presented at the EFA AGM 2010.

Working groups

EFA produced terms of reference to start working with members in a different way, and to provide possibilities for interaction through working groups. The food allergy working group was started 2009, but had to be left for a while due to lack of human resources to coordinate it. Never-the-less, the working groups

on food allergy, severe asthma and COPD are to be set up when possible. The terms of reference are in appendix 3 of this report.

Meet and Greet EU Institutions Training

In December EFA organised our second 'Meet and Greet EU institutions Training' for members in Brussels. The purpose was not only to introduce the main EU institutions: Parliament, Council and the Commission but to take members to meet and discuss with them in person. The two day intensive training was judged by the participants that it is good to visit the institutions and get an insight in how they function. The programme needs to give more space for communication among members and there could be two kinds of programs; one for beginners – like this and an additional program building on the knowledge that has been given. The event was supported by an unrestricted educational grant from Novartis. The evaluation report is available from EFA Office.

INFLUENCING EUROPEAN POLICY ON ALLERGY, ASTHMA AND COPD FROM PATIENT PERSPECTIVE

The EFA Book on COPD in Europe is a major policy tool for EFA, and campaigning will continue 2010. What we are striving for is comprehensive EU programmes with strategic view on our disease areas as already exist in rare diseases, alzheimers and cancer. This may be best achieved through programme on 'Allergic and respiratory diseases either jointly, or separately that would support national programmes, implement health in all policies and share best practices in care and prevention.

EU Health Strategy⁴

EFA through its' membership in the EU Health Policy Forum, a consultation and dialogue forum of the Directorate General Public Health (SANCO), EFA represented the perspective of patients with allergy, asthma and COPD in the two meetings of the Forum and the EU Health Policy Open Forum in June on 'Young People and Health', annual conference of 400 participants in Brussels where the Forum opens to wider audience. At the end of the 2009, EFA was one of the two patients groups invited to join the Steering Group of the next Open Forum 'Health in All Policies' to be held in June 2010 and specifically to coordinate a workshop on 'Environment and Health'. 'Health in all policies is one of the horizontal priorities in the EU Health Strategy, and particularly important for EFA because of the impact environment and various EU policies that have impact on environment affect the health and wellbeing of people we represent and their role in prevention.

EFA was also invited to submit two articles in the European Parliament Magazine in connection of the 'Allergy Road show by GA²LEN' in December: A role for Europe, EU needs to take a strategic approach on allergy and

⁴ http://ec.europa.eu/health/ph_overview/strategy/health_strategy_en.htm
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respiratory diseases, Parliament Magazine January 2010:
<http://viewer.zmags.com/publication/8119c6af#/8119c6af/60>

Where is the vision? EU must develop patient centred action plan on allergy and respiratory diseases:
Parliament Magazine <http://viewer.zmags.com/publication/357a4a63#/357a4a63/10>

This was a great opportunity for EFA to present our goal and the need for comprehensive EU strategy and programmes on allergic and respiratory diseases that would take into consideration 'health in all policies', promote and share best practices on comprehensive national programmes on allergy, asthma and COPD.

Medicines

At the end of 2009 EFA applied and was accredited to work with the European Medicines Agency (EMA) in London. EFA was chosen as a member of the EMA Patient and Consumer Working Party (PCWP), which is one working party of the EMA Committee on Human Medicines. 15 European level patient and consumer organisations are members and the purpose is to have a permanent dialogue with the EMA on their policies and activities. All medicines in Europe are currently reviewed by the EMA for marketing authorisation. EFA also nominated 4 patient experts to review medicines package leaflets (PLs), European Public Assessment Reports (EPAR) on medicines so on our disease areas that they will be understandable for patients. EFA proposed experts may also be invited into Scientific Committee meetings when specific medicines are evaluated. EMA is truly a best practice example on involving patient representatives and patients.⁵

This is a new policy area for EFA and work intensive and it is likely that EFA members will be invited as experts as well.

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 had launched 2008 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 was translated in Finnish by Finnish Allergy and Asthma Federation, Italian by BPCO and FEDERASMA and into Lithuanian by the Lithuanian Council of Asthma Clubs. More language versions are to follow in 2010.

ANNUAL ACCOUNTS

⁵ http://www.ema.europa.eu/htms/general/contacts/CHMP/CHMP_PCWP.html

Financial report 2009

1. The Financial Report is in Euro.

2. Bank Accounts

EFA has four Bank Accounts:-

- A current (sight) account in Luxembourg in Euro. The balance at 31:12:09 was 13.519,51 Euro.
- A deposit (term) account also in Luxembourg. The balance at 31:12:09 was 0,00 Euro.
- A Visa account in Luxembourg in Euro. The balance at 31:12:09 was 18.738,80 Euro.
- A Swedish Currency Account in Euro. The balance at 31:12:09 was 50.356,74 Euro.

The total balance in the four Bank Accounts and Petty Cash at 31:12:09 was 83.562,26 Euro.

	<u>31-12-08</u>	<u>31-12-09</u>
Luxembourg 1	478,13	13.519,51
Luxembourg 2	20.155,44	0,00
Luxembourg 3	8.367,57	18.738,80
Sweden	50.302,63	50.356,74
TOTAL	79.335,06	83.562,26



Breda Flood
EFA Treasurer 2010



Otto Spranger
EFA Interim Treasurer 2009



Marianella Salapatras
EFA President

**BALANCE SHEET
IN EURO**

	31-dec-09	31-dec-08	31-dec-07
ASSETS			
VII. DEBTORS	61.975,33	70.090,71	17.408,57
Debtors ⁽¹⁾	61.975,33	70.090,71	17.408,57
IX. LIQUIDITIES	83.562,26	79.335,06	171.796,09
Bank Account 0038/4174-7	13.519,51	478,13	68.368,49
Handelsbanken 41 402 669	50.356,74	50.302,63	48.808,60
Bank Account 0038/8721-9	-	20.155,44	46.293,15
Bank Account 5912/7917-1	18.738,80	8.367,57	8.115,89
Petty Cash Account	947,21	31,29	209,96
X. DEFERRED CHARGES AND ACRUED INCOME	0,00	0,00	0,00
Deferred Charges	0,00	0,00	0,00
TOTAL ASSETS	145.537,59	149.425,77	189.204,66
LIABILITIES			
IV. RESERVE	107.701,71	96.465,57	155.292,77
Reserve last year	96.465,57	155.292,77	165.354,27
Excess of income over expenditure from current year	11.236,14	(58.827,20)	(10.061,50)
IX. DEBTS	37.835,88	52.960,20	33.911,89
Creditors ⁽²⁾	37.835,88	52.960,20	33.911,89
Received grants for next year ⁽³⁾			
TOTAAL DER PASSIVA	145.537,59	149.425,77	189.204,66

INCOME AND EXPENDITURE ACCOUNT
IN EURO

	31-dec-09	31-dec-08	31-dec-07
Income	326.969,71	199.287,57	217.747,81
Fees	31.500,00	31.500,00	27.000,00
Grants	233.000,00	120.000,00	134.946,82
EU Project	2.100,00	586,52	17.120,00
EFA Conferences	16.367,00	8.868,00	0,00
EFA Other Meetings	0,00	0,00	8.069,77
Europrevall	4.724,25	17.565,10	25.393,81
COPD Book	30.000,00	0,00	0,00
Secr.	0,00	136,87	0,00
GALEN	0,00	14.254,00	858,68
Bank Interests	269,90	3.468,29	4.358,73
Other meetings	9.008,56	2.908,79	0,00
Expenditure	315.733,57	258.114,77	227.809,31
Board Meetings	8.323,53	12.475,10	15.905,76
EFA Conferences	38.755,22	48.050,68	29.030,88
EU Project	3.300,00	0,00	15.020,26
Other Meetings	44.189,59	34.006,44	24.852,54
EFA Net	285,60	0,00	2.880,00
U-BIO	812,25		
Secretariat	152.380,53	103.159,33	55.799,88
Europrevall	14.737,95	11.532,50	27.295,53
Gard	120,00		
COPD book	9.686,05		
GALEN	0,00	9.656,44	21.530,57
Exec. Officer	38.400,00	38.400,00	35.200,00
Membership fees/Publicity	4.616,46	570,00	70,00
Bank Charges	126,39	264,28	223,89
Difference	0,00	0,00	0,00
Devaluation on Debtors ⁽³⁾			
Result of the Year	11.236,14	-58.827,20	-10.061,50

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

(1) Boehringer Ingelheim	60.000,00
Mundipharma	1.628,00
EPF	347,33
<hr/>	
Total Debtors	61.975,33
(2) Susana Palkonen : advance petty	2.171,95
bankcharges	10,50
Burotel	2.194,10
Polak Carline	1.000,00
Skar-Health & Educ	4.000,00
Botjes	11.640,06
Net Federation	285,60
Interel	9.686,05
DODS	2.833,33
Salapatas	2.178,67
AMC Med Research	600,00
Health & Environment	250,00
Breda Flood	653,53
Salemi	332,09
<hr/>	
Total Creditors	37.835,88

AUDITORS REPORT

**AUDITING OF WORKING-ACCOUNTS AND BALANCE
FOR THE FINANCIAL YEAR 2009
OF THE EUROPEAN FEDERATION OF
ALLERGY AND AIRWAYS DISEASES PATIENTS ASSOCIATIONS**

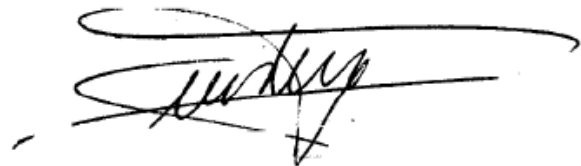
As appointed EFA Auditor by the Assembly General Meeting, I checked the annual accounts of the year 2009 of the European Federation of Allergy and Airways Diseases Patients Associations.

The financial statements for the year 2009 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 107.701,71 Euro. The net result of the year 2009 amounts to 11.236,14 Euro and the balance-total to 145.537,59 Euro.

It is my opinion that the balance sheet and the profit and loss account as at 31 December 2009 gives a fair view of the financial situation of the organisation.



Brussels 28 April 2010
Sara CEUSTERS
Accountant

BUDGET

Budget 2010

Income (Credits)	in €
Membership Fees	37.500,00
EUProject UBIOURED	20.000,00
GA ² LEN	-
Other Projects	20.000,00
Sponsors long term	160.000,00
Sponsors short term	50.000,00
EFA Annual Congress	-
Total	287.500,00

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
EUProject UBIOURED	20.000,00
GA ² LEN	-
Logistics	1.500,00
P,P&P	-
PR-Activities	
Meet & Greet	18.000,00
Booth-Material	-
Membership Fees	4.500,00
Reserve	-
Total	280.880,00
Balance	6.620,00

EFA thanks our sustainable funding partner who have made our work possible:

5 star
GSK
Novartis

3 star
Boehringer Ingelheim
Merck

2 star
Linde Gas

Donator
Nigaard

and

the European Commission DG Research

Detailed information on the EFA funding is available at: www.efanet.org/about

Annex 1

COPD Patients Global Bill of Rights

Adopted at the International COPD Coalition (ICC) and EFA First International Conference of COPD Patients 14 June 2009, Rome, Italy

1. The right to receive early and accurate diagnosis

Early and accurate diagnosis is essential for COPD patients to take the necessary steps to improve their quality of life and lung health. Physicians and national health services have a responsibility to provide this early and accurate diagnosis. National health services should have reliable information about the number of COPD patients in their country. Physicians should be willing and able to diagnose COPD.

2. The right for information and education about COPD

People in each country should know what COPD is, its risk factors, especially smoking, and what symptoms it causes. COPD patients should be taught what state-of-the-art care for COPD involves.

3. The right for support and understanding

Friends, family, communities, health care providers, and health services need to provide support and understanding to COPD patients for this difficult disease.

4. The right to receive care and treatment that will benefit them

Proper care and treatment will benefit patients, improve their breathing and quality of life, and will help them contribute more to others. Effective medicines, smoking cessation counseling and treatment, and good health care are essential to provide this right, as is long-term follow up. Medical care for COPD patients should have both continuity and comprehensiveness.

5. The right to their fair share of society's involvement and investment in their welfare and care

COPD patients have worked throughout their lives to earn their fair share of society's involvement and investment in their welfare.

6. The right to advocate with other COPD patients and supporters for improved COPD care and COPD prevention

COPD patients know how important good care is to their lives. They also know that every effort should be made to prevent others from suffering from this disease. It is their right and responsibility to advocate at every level for improved COPD care and prevention.

7. The right to safe air and environment

Unsafe air and environment are particularly harmful to COPD patients. All health care professionals have an obligation to protect their patients from conditions that are unsafe to their health. Patients and health care providers have an obligation to fight for their rights to safe air and environment

Annex 2

GA²P² Declaration of Buenos Aires*

*Global Allergy and Asthma Patient Platform

We, allergy and asthma patients, patient care givers and patient advocates from xy countries around the world declare

- **G**lobal networking of allergy and asthma patient organizations is needed. We will establish a network to empower the patient voice. We demand to be equal partners involved in decision making, from inception to conclusion, with global health care organizations such as ARIA*, GINA**, GOLD***, WAO****, and WHO- GARD*****.
- **A**ll patients with allergies and asthma have a right to comprehensive health care. Best practice therapy includes early diagnosis, patient centred care, access to medication, regular follow-up and rehabilitation. These must be globally agreed, locally adapted, widely disseminated and implemented.
- **A**ccess to education including information, training and self management plans is mandatory in best practice therapy. Participation in decisions of their own care is essential for allergy and asthma patients to facilitate adherence.
- **P**atients with allergies and asthma demand to live in healthy unpolluted air and smoke-free environments. They have the right to accurate information on allergens and other substances that aggravate their disease.
- **P**atients with allergies and asthma have the fundamental responsibility to take an active role in managing their disease and to lead a healthy life style to allow no limitations to their life and daily activities.

Patients' families, caregivers and health professionals must be empowered to support patients to manage their allergies and asthma.

We as GA²P² will work for this on a global level. Action is needed and our network will work unceasingly to achieve this goal.

Annex 3**EFA WORKING GROUPS****Terms of Reference*****Background***

EFA is the European Network of allergy, asthma and COPD patient associations that represents its members on European Level, provides a platform for members to exchange best practices, capacity building and collaboration. Representing 3 diseases, it has become evident that clear mechanisms for disease specific collaboration is needed. The EFA AGM in May 2008 agreed to start setting up working groups. The working groups do not exclude other interaction between EFA and members, but complements it.

The first working group is food allergy, and asthma (severe) and COPD are to follow. Others may be set up according to need and resources, such as atopic eczema.

The work and outcomes of the working groups are complementary and the EFA board and staff members involved in each will have specific responsibility for ensuring optimum exchange of information and synergy.

EFA Mission and Objectives

EFA mission is a European community of patient organizations that share the responsibilities of

- reducing the frequency and severity of allergies, asthma and COPD,
- minimizing their societal implications
- improving health related quality of life
- ensuring full citizenship of people with these diseases and
- pursuing equal health opportunities in the field of allergy and airways in Europe.

EFA Objectives are

- To influence European Union policy making
- To support 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.
- To empower member organizations to reach a comparable level of serving the interests of patients by exchanging experiences

Members

Working group is composed of people working or volunteering at EFA member organisations, with specific interest in the topic of the group and willingness to collaborate with colleagues around Europe and one representative from the staff/board. There is no limit for the number of participants.

Objectives of the Working Group

Overall objective: through setting up a working group of members working on specific disease area to plan, lead and engage in European patient collaboration and to provide a working mechanism for patient leaders to share best practices and collaborate in support of national efforts improve the management of allergy, asthma and COPD

Specific objectives:

- Provide a practical flexible transparent and cost-effective way of working with members
- Improve input of members in EFA activities whether projects or influencing European policy and practice
- Improving EFA access to member expertise
- Engaging more people with diverse skills and expertise at member associations in EFA activities (not only one contact person)
- Improve the ownership of members on EFA products, and thus their use at national level and making sure they correspond to real needs of patients
- Networking and improving colleague peer contact

- Sharing tools, actions, experience and information with colleagues
- Support in developing new interesting EFA projects
- Provide a patient collaboration mechanism and sounding board for European projects EFA is partnering in
- Ensure and provide patient expertise
- Campaign on EU policy
- Patient consensus building on a specific topic
- Serve as mechanism to ensure, provide and mobilise patient experts support and expertise on a national or European issue
- Attract new members

Working Methods

- The participation is voluntary.
- The group will select a coordinator among themselves to lead the group
- Nominating 'ad hoc' leaders on a specific topic/project/campaign is possible
- The main working methodology will be through email – list server, skype or telephone call and other means enabled by the internet
- Face-to-face meetings are possible in connection of other meetings and where a budget can be allocated for example in connection of a specific project
- The group will set up a work plan proposal for short and long term to be approved by the Board, but the work is flexible and adjustable
- The Working Group reports to the Board quarterly
- To start, the WG will hold a telephone/web conference to get started

Timeline and actions

- **Food allergy** working group
 - nominations and start May 2009,:
 - topics suggested so far:
 - Influence EU food labelling legislation: food labelling directive advocacy and campaign work with the new European Parliament elected 7 June 2009
 - Prevalence, Cost and Basis of Food Allergy in Europe EuroPrevall –project outcomes sharing and dissemination
 - Novel foods, genetically modified foods (GMO)
 - Joint letter to IATA (International Air Transport Association) asking to replace nuts with other appetizers on flights
- **Asthma (severe) working group:** when U-BIOPRED severe asthma project and budget comes through and after presentation of the at EFA Conference in Rome
- **COPD working group:** build on EFA European COPD Book outcome and dissemination
- **At the EFA Conference in Rome, there is a possibility to sign up**

Measuring outcome and evaluation

- Expectations of participants mapped in the starting phase of a specific WG
- Questionnaire to WG members at the end of running year mapping 1. Whether expectations were fulfilled 2. Advancing in specific objectives
- Number of participants involved
- Number of countries involved
- Conclusions for continuation/amendment
- Criteria for closing a working group: no regular reports, less than 3 active participants, no joint actions