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

## **ANNUAL REPORT 2005**



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

## 2005 Annual Report

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#### 1 INTRODUCTION

#### **FOREWORD**

The new European Commission set out with the lead of José Manuel Barroso, who was confirmed as European Commission President in November 2004, where David Byrne, the Irish Commissioner for Health and Consumer Protection was replaced by Cypriot Markos Kyprianou, and Margot Wallström, the Swedish Commissioner for the Environment, was replaced by the Greek Stavros Dimas. The Presidencies of the European Council were held first by Luxembourg (January to June) and then by the United Kingdom (July to December).

During 2005, EFA's 15<sup>th</sup> year, EFA continued to work on the implementation of its Policy Document 2005-2008. EFA was active and visible at EU policy level through a variety of meetings and notably through the launch of the *Fighting for Breath* report on severe asthma on World Asthma Day in Brussels in May, which UK MEP Liz Lynne, herself a severe asthma sufferer co-hosted with EFA. In June, EFA launched the results of the *European Patient Voice Allergy Survey* at the World Allergy Congress in Munich. The final results of the *Fighting for Breath* survey were launched at the European Respiratory Society (ERS) Congress in Copenhagen in September, where EFA also had a stand and co-hosted a post-graduate course on 'Improving Physician-Patient Communication', with ERS. In November, EFA attended and held a stand at the European Commission's Open Forum 2005 *Health Challenges and Future Strategy* in Brussels.

Two vital tools for communication, information dissemination, advocacy and capacity building for EFA in 2005 were: The newly designed website, which provides clear and up-to-the minute information; and the EFA monthly electronic newsletter or 'ezine', which was launched in July 2005.

EFA continued to advocate for improvements on indoor environment through the results of surveys such as the *Fighting for Breath* severe asthma survey. We look forward to working even more closely with other NGOs at European level who are working on to this same end in an effort to build support and advocate as a stronger, larger, pro-health and environment entity, but also to help widen EFA's message not only amongst EU decision and policy makers but also amongst our peers, many of whom may not, for example, realize how tackling all sources of indoor air pollution, not just partly is essential for our patients, and the society as a whole and how big a health threat COPD is for Europe.

Building and increasing capacity and interaction amongst EFA members and outside, as well as strengthening and growing the network has never been given greater priority than during 2005, through joint advocacy efforts surrounding policy issues or survey results, such as the *European Patient Voice Allergy Survey* and due to the launch of EFA's new website and ezine.

We are grateful for all the support and valuable input received by EFA members in various capacities during 2005. We look forward to interacting closely with our members in the coming year.

We would also like to thank our main sponsors, European Commission, European Academy of Allergology and Clinical Immunology, AstraZeneca, Boehringer Ingelheim, GlaxoSmithKline, Novartis and UCB Pharma for their continuous support.

Svein Erik Myrseth President Donna Covey Acting Vice-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:

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

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.

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**

President
Svein Erik Myrseth
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Executive Officer
Susanna Palkonen

Email: susanna.palkonen@efanet.org

Communications (since February 2005)

Sophie Kazan

Email: sophie.kazan@efanet.org

#### Membership and representation

The EFA membership 2005 consists of 23 allergy, asthma and/or COPD patient associations or their coalitions in 17 European countries, in which there are over 400.000 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.

During 2005 two new organisations applied for membership, which will be confirmed by the Annual General Meeting of Members 2006.

#### Austria

Österreichische LungenUnion (ÖLU)

#### Belaium

Coalition of Prevention des Allergies asbl

Astma-en Allergiekoepel v.z.w.

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

#### Bulgaria

Association of Bulgarians with Bronchial Asthma (ABBA)

#### Czech Republic

Czech Initiative for Asthma

#### Denmark

Astma-Allergi Forbundet

#### Finland

Allergia-ja Astmaliitto - Allergy and Asthma Federation

#### France

Coalition of Fédération Française des Associations et Amicales d'Insuffisants Respiratoires (FFAAIR) Association Française pour la Prévention des Allergies (AFPRAL)

#### Greece

**ANIKSI** 

#### Italv

Coalition of FEDERASMA

Associazione Italiana Pazienti BPCO (AIPBPCO)

#### Lithuania

Coalition of Association of Allergic Children Clubs

Association of Asthma Patient Clubs

#### Netherlands

Nederlands Astma Fonds (AF)

Coalition of Stichting VoedselAllergie - Dutch Food Allergy Organisation

Vereniging voor Mensen met Constitutioneel Eczeem (VMCE)

#### Norway

Norges Astma- og Allergiforbund (NAAF) Norwegian Heart and Lung Association (LHL)

Slovenia

Pulmonary and Allergy Patients' Association of Slovenia (DPBS)

#### Sweden

Astma- och Allergiförbundet - Swedish Asthma and Allergy Association

#### Switzerland

Coalition of aha! Schweizerisches Zentrum für Allergie, Haut und Asthma Lungeliga Schweiz - Swiss Lung Association

U.K.

Asthma U.K.

Allergy UK - British Allergy Foundation (BLF)

#### **Honorary members**

Mariadelaide Franchi, Italy Edith M.A.L. Rameckers, the Netherlands Erkka Valovirta, Finland Elizabeth Bell, U.K. Arne Heimdal, Norway

#### **Project members**

European Centre for Disease Control and Prevention (ECDC) Anna Doboszyńska, Poland

A Thematic Network on Air Pollution and Health (AIRNET)
Policy Interpretation Network on Children's Environment and health (PINCHE)
Edith M.A.L. Rameckers, the Netherlands

INFORMAII Communicating on Food Allergies Global Allergy and Asthma European Network (GA<sup>2</sup>LEN) Global Alliance against Respiratory Diseases and Allergies (GARD) Erkka Valovirta, Finland

Severe Asthma European Survey; Fighting for Breath – A European Patient Perspective on Severe Asthma Martin Dockrell, U.K.

COPD Advisor Mariadelaide Franchi, Italy

ARIA Advisory Committee Erkka Valovirta, Finland Susanna Palkonen, Belgium

#### Committees and working groups

Asthma Peer Support Working Group (until January 2005)
Carine Alders, the Netherlands
Knut Magne Ellingsen, Norway
Marianella Salapatas, Greece
Otto Spranger, Austria
Erkka Valovirta, Finland

Long Range Planning Committee (until June 2005) Chairperson Svein Erik Myrseth EFA, Norway Coordinator Anemone Bögels, the Netherlands Secretary Liesbeth Vredeling, the Netherlands Donna Covey, UK Robert Hejdenberg, Sweden Nikolaos Papadopoulos, Greece Zoltan Ronay, Hungary

Medical Committee Chairperson Erkka Valovirta, Finland

Programme Committee EFA Conference 2005 Anemone Bögels, the Netherlands Trudy Prins, the Netherlands Susanna Palkonen, Belgium

#### Memberships

European Patients Forum (EPF)
European Public Health Alliance (EPHA)
EPHA Environment Network (EEN)
EU Consultative Forum on Environment and Health
EU Health Policy Forum
European Network for Smoking Prevention (ENSP)
Global Alliance against Respiratory Diseases (GARD)
International Coalition of COPD Organisations (ICC)

#### STRATEGY AND PRIORITIES 2005

In March 2005, EFA produced an internal document entitled: EFA Forecast and Planning 2005-2008 – 'Dare to dream the possible', which attempted to bridge the gap from the vision of the EFA Policy Document 2005-2008, with its long range objectives, visions, its SWOT analysis and goals into action. This resulted in the creation of an Action Plan for 2005 with three main points<sup>1</sup>:

#### Forecast for 2005

#### 1 Influencing European Policy

- identifying and enlisting to the most important EU policy forums, sources of information and partnerships on EU policies regarding EFA policies and setting up a practical system to follow the priority developments in coordinated fashion
- improving visibility by organizing at least one coordinated European media campaign with focus on policy
- organizing a 'meet and greet' with member representatives and European level policy makers (MEPs, national representatives to the EU etc.) in Brussels
- promoting and disseminating THADE Towards Healthy Indoor Air in Dwellings project results in the SCALE EU Environment and Health Action Plan process

#### 2 Strengthening infrastructure

- finalizing EFA incorporation in Belgium
- finalising the long range planning process for 2005-2008 and developing a long range budgeting with targets and priorities
- employing more qualifications and human resources (information and PR)
- preparing to apply for an EC grant from the EU Public Health Programme 2003-2008 to support the policies 2005-2008 and to increase independent funding
- defining and developing EFA member services by establishing a membership and services committee
- recruiting new members with focus on new EU member states
- establishing a system to gather regularly member feedback

#### 3 Empowering member organisations

- developing IT and information services via the website through: re-structuring the navigation, regular updating of the information, creating members-only section with possibility for interaction and publishing electronic newsletter e-zine, EFA e-news instead of EFA Newsletter
- producing and publishing new patient focused information on EFA disease areas by conducting two European surveys
- capacity building by organizing a conference focused on capacity building and at least one smaller workshop with possibility for networking

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<sup>1</sup> http://www.efanet.org/members/documents/Annex7EFAPIan2005.doc

#### **2 MAIN ACTIVITIES**

#### INFLUENCING EUROPEAN POLICY

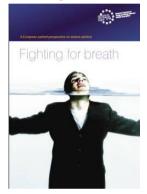
#### Objective:

Influencing European Union policy making on

- indoor and outdoor air
- healthcare
- societal participation
- research

#### Fighting for Breath - a European Patient Perspective on Severe Asthma Survey and Campaign

Following the success of the Asthma UK survey on severe asthma in the UK 2004 - Living on a Knife Edge,



Fighting for Breath Report

EFA conducted a survey on severe asthma in Europe, supported by an educational grant from Novartis. The objective was to gain insight on the first hand experience and hopes for the future of patients living with severe asthma, to communicate, for the first time, the seriousness and reality of living with severe asthma and empower patient groups to shape future health policy. The results served in supporting EFA policies on influencing European policies.

The survey involved 1,300 people with severe asthma symptoms in countries were the incidence of asthma is high; France, Spain, Germany, Sweden and the UK. The field work was conducted by NOP World Health on behalf of EFA, and survey coordinated and results analysed by the Asthma UK. An independent research agency, LAIA, was commissioned to provide an epidemiology for a statistical backdrop to the main patient focus of the survey. Significant gaps in currently available data also highlighted the need for a greater prioritisation of asthma and

greater availability of information in order to shape healthcare policy.

The survey revealed that millions of Europeans suffer from asthma symptoms that are so intense that they not only significantly impact on their quality of life, including working and social life, but also that they can cause fear, isolation and exclusion, strengthening the case for the need of higher prioritising of asthma by governments.

The results were launched in three stages to maximise impact and keep the momentum: in connection of World Asthma Day 3 May 2005 in a policy focused campaign in Brussels at proximity of the European Parliament, final report in medical media focused campaign at the annual European Respiratory Society Congress in Copenhagen and through report mailing campaign.

World Asthma Day Event and campaign was co-hosted by UK MEP Liz Lynne, herself a severe asthma sufferer. A press pack was created for the event and coordinated media action kit for members and patient groups in countries who participated in the survey. Posters including pictures and quotations from patients were also produced, for visual emphasis during this launch. 22 European members of parliament, EU member state permanent representatives, and European level and Belgium press and health and environment non-governmental organizations took part in the event. Media coverage was widespread and included television interviews (e.g. BBC Breakfast News) online (e.g. CNN and BBC), newsprint (the Belgian newspaper Le Soir and The European Voice) to name but a few.



Launch poster

The final report, Fighting for Breath – European Patients' Perspective on Severe Asthma<sup>2</sup> was officially launched in a press conference at the European Respiratory Society (ERS) congress in September 2005.

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<sup>&</sup>lt;sup>2</sup> http://www.efanet.org/activities/documents/Fighting\_For\_Breath1.pdf

This was attended by around 19 members of the international press. 400 copies were distributed to attending health care professionals at EFA Stand at the Conference exhibition.

Finally, the report with accompanying letter, which highlighted the main policy focused results of the survey was distributed in collaboration with Ms Lynne to over 500 NGOs, MEPs, Commission members and officials, permanent representatives of health and work unions and at EFA stand at the 2005 Health Policy Open Forum in Brussels.



Top three wishes of Europeans with severe asthma:

- Further research into innovative treatment and finding the cure
- Access to expert care where I live
- Clean air to breathe indoors and out

Total media impressions: 30 million, exceeding the original target by 10 million (50%).

- 59 pieces of print coverage
- 35 pieces of online coverage
- 21 pieces of radio coverage
- 11 pieces of television coverage
- 7 pieces of newswire coverage
- Full oral presentation of data to ERS scientific session
- Final results and full EU report launched to media at press briefing attended by 19 international journalists
- Over 400 copies of the report distributed to healthcare professionals
- Final report presented to over 600 EU policy adviser policy makers, NGOs, WHO members and MEPs by EFA

The success of the survey has inspired EFA members and patient groups in other countries, and a tool-kit to empower repeating the survey locally is under production for 2006.

#### **COPD** campaign

For the first time, COPD was now object of a more targeted action in the 2005 Call of proposals for the EU Public Health Programme, published in February, which can be considered a milestone in our efforts of

advocacy for this little known and underestimated disease in European health policy.

EFA coordinated a European campaign for World COPD Day in November 2005. This involved the production of a COPD fact booklet and a press release promoting awareness of and need for action on COPD in European level. The press release, COPD fact booklet and a COPD pin were sent to members of the European Parliament's Environment and Health Committee, to councilors responsible for health, all 25 European Member State permanent representatives to the EU,



COPD Flipper booklet

working at European Council level, as well as to contacts at the European Commission, the WHO and fellow NGOs working on issues related to indoor air and respiratory health. A 'COPD Day' pack to members to promote coordinated action on World COPD Day was also sent to members.

#### Air quality

The SCALE EU Environment and Health Action Plan process, initiated 2004 showed little progress 2005, in particular in relation to EFA priority, the indoor air. The SCALE Consultative Forum, in which EFA is represented, had one meeting during the year. However, a paper suggesting EU action this field is expected in January 2006. Information generated by the two EFA EC funded projects Towards Healthy Indoor Air in Dwellings in Europe and Indoor Air Pollution in Schools are used as reference in this context. This paper should be available for stakeholder consultation in January 2006.

The Sixth Environment Action Programme: *Environment 2010: Our Future, Our Choice,* sets out to improve our environment as a whole, through a structured approach and focussing on a variety of priority issues, actions and key concerns in order to bring about change. One of the key environmental issues that the European Council and Parliament set out to approve seven key environmental issues by 2005, was the Air

Pollution Initiative entitled 'Clean Air for Europe' (CAFÉ). CAFÉ sets out a structured path of analysis and policy discussion towards the adoption of a thematic strategy on air pollution under the 6<sup>th</sup> EAP by mid 2005. Since this had not been published by May 2005, EFA, in collaboration with the European Public Health Alliance (EPHA) and with the lead of the EPHA Environment Network (EEN) co-signed a letter to the European Commission President Barosso, pointing out that the Commission was under a legislative obligation under the 6<sup>th</sup> Environmental Action Programme to come forward with a Thematic Strategy on air pollution in 2005 to help improve European air quality and pointing out that this had not yet taken place.<sup>3</sup>

In September 2005, the European Commission Proposal including The Thematic Strategy on Air Pollution (COM 2005 (447)) was published, aiming to cut the annual number of premature deaths from air pollution-related diseases by almost 40% by 2020 from the 2000 level, whilst at the same time reducing the area of forests and other ecosystems suffering damage from airborne pollutants.

In November 2005, EFA again sent a joint letter with other NGOs with the lead of EEN to EU Environment Ministers, expressing our disappointment on the lack of ambition in the European Commission Proposal, and accompanied directive which does not take into consideration the WHO 5 recommendations on vulnerable populations, as required under the Clean Air for Europe programme and conclusions of the Commissions own impact assessment. EFA also provided an opportunity to members, in advance of a debate due to take place in the European Council on 2 December 2005, asking them to support this action.<sup>4</sup>

A report on the Proposal is still being prepared by the European Parliament and since the European Council debate, no political agreement has been reached. Therefore, the next steps are for the European Parliament to adopt its report and come to a decision and for the European Council to come to a common position, which is forecasted to happen by mid-Summer 2006.

#### **Paediatric Medicines**

The use of unlicensed and off-label medicine for children is widespread in the EU, fifty per cent or more of medicines used for children have never been actually studied in this population. This is of major concern in allergy and asthma, the most common chronic childhood diseases. The EU Paediatric Medicines Initiative<sup>5</sup> was initiated 2000 and a resolution was adopted by the European Parliament on 7 September 2005 on the proposal for a regulation of the European Parliament and of the Council on Medicinal Products for Paediatric Use, which EFA has supported by responding to the Commission/EMEA consultation on the Regulation in 2004, which will improve the availability of high quality medicines tested for use in children.

In their 9 December 2005 meeting, European Health Ministers reached political agreement on the Regulation; the Council agreed on a combination of incentives and obligations for the pharmaceutical industry. The main obligation is that a paediatric plan must be submitted as part of the procedure for marketing authorisation of a medicine. There will also be broader public access to information on paediatric clinical trials and three representatives from patient organisations will be invited to take part in the Paediatric Committee, which according to the regulation will be created with expertise in all aspects related to medicines for children is central to the proposal and its operation. Though this Proposal is already in its second reading in the European Parliament, it still has to be discussed in the European Council.

#### Food labelling

The new labelling rules for foodstuffs (Council Directive 2000/13/EC)<sup>6</sup> in the EU finally entered into force 25 November 2005. Following a successful coordinated action by EFA and members, the directive aims to ensure that all ingredients in foodstuffs will have to be included on the label, which will enable consumers suffering from food allergies take better control of the treatment of their disease. The new Directive also establishes a list of ingredients liable to cause allergies or intolerances, which always have to be labelled with clear reference to their name and that this list will be updated according to latest evidence. In July 2005 the Commission had published guidelines drafted together with the member states on how to label the allergens listed in practice to accompany the legislation.

<sup>&</sup>lt;sup>3</sup> http://www.efanet.org/activities/documents/AirgualityletterBarroso3006051.doc

<sup>4</sup> http://www.efanet.org/activities/documents/EUAirQualityLetterEFA-EENMinisters.pdf

http://europa.eu.int/eur-lex/lex/LexUriServ/site/en/com/2004/com2004\_0599en01.pdf

<sup>6</sup> http://europa.eu.int/comm/food/food/labellingnutrition/foodlabelling/comm\_legisl\_en.htm

#### **Health Information**

Health information, the quality and providers of information has been under increasing discussion on European level especially prompted by the review of Pharmaceutical legislation and associated debate on information to patients on prescription medication. Through EFA membership in the EU Health Policy Forum (HPF) which is a multi-stakeholder group of health actors established by DG SANCO, EFA took part in preparation of the Policy Recommendation Paper on Health Information<sup>7</sup>.

The aim of the paper was to make a contribution of wide variety of stakeholders in the framework of the Health Policy Forum to feed in the debate. Published in May, the paper recognizes that health information covers an extensive range of issues, it comes from a wide range of providers – family, peers, professionals and industry, public bodies and authorities and includes information on products, services, treatments, and health promotion and prevention. The paper encompasses all types of information, from scientific publication to commercial advertising. It rejects commercial advertising on information on prescription medicines, but recognises the right to access of any relevant information and education to make an informed health choice, which is one of the perquisites also for the empowerment of allergy, asthma and COPD patients.

The European Commission has established a baseline standard (COM(2002)667) for quality criteria for health information of which the following ethical standpoints can give guidance for providers; transparency, objectivity, timeliness, relevance and confidentiality.

The paper recommends that a policy mapping exercise should be undertaken by the Commission to identify all initiatives and policies addressing the different aspects of health information as part of current EU activities. On the basis of the outlined mapping exercise, the Commission should initiate a stakeholder consultation to include the range of providers and users of health information. Finally the paper suggests that provision of good quality health information could greatly be improved by a dedicated European Health Information Programme, because the current Public Health Programme only gives limited emphasis on provision of health information to citizens and responsibilities for health information at EU level is fragmented.

#### **European centre for Disease Control and Prevention**

The European Centre for Diseases Control and Prevention (ECDC)<sup>8</sup> was created by the European Parliament Resolution (No. 851/2004) of the 21<sup>st</sup> April 2004 and inaugurated in May 2005 in Stockholm. The purpose of this new centre is to strengthen and organise the EU capacity, surveillance, including data on diseases, advice the Commission, and to respond to health threats on communicable diseases, such as severe acute respiratory syndrome (SARS) in the enlarged EU without borders, in collaboration with other European and global organisations. Mrs. Zsuzsanna Jakab from Hungary was nominated as the ECDC Director.

The ECDC Advisory Forum was established, and EFA representative Anna Doboszyñska invited among the 5 other independent civil society experts, pharmacists, doctors, and patient groups. The other members of the Advisory Forum, whose task is to advice and monitor the work and progress of the centre, are delegates from EU Member States, Norway, Lichtenstein and Iceland.

The following units of ECDC have been established: Scientific and Technical Advice, Surveillance and Communication, Preparedness and Response, Administration and Management. 2005, the work focused on setting up the centre, agreeing on data access, developing technical systems storing and accessing data and developing strategy among others.

The scope of the centre will be evaluated in 2007 to examine the need for expanding its remit, including other public health issues, such as diseases of respiratory tract, allergy, asthma and COPD. It is the hope of EFA that the Centre in future will recognise and contribute to addressing the health threat of these diseases for European public health.

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<sup>&</sup>lt;sup>7</sup> http://www.europa.eu.int/comm/health/ph\_overview/health\_forum/hforum\_information\_en.pdf

<sup>8</sup> http://www.ecdc.eu.int/

#### STRENGHTENING INFRASTRUCTURE

#### Objective:

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.

#### Developing and increasing membership base

Internal transition to the new EFA Statutes (approved 2004) was completed during the activity year. This involved renewal of membership of all the existing members according to our new membership criteria. Completion of this process by the EFA AGM in June enabled starting actively recruiting new members.

EFA statutes now establish clear membership criteria and improved transparency of the organisation. For this purpose, new detailed membership application form was produced, filled in by all members, signed by chairperson and returned to EFA accompanied by their registered statutes and copy of latest annual accounts. Organisations could now opt for joining on their own behalf, or in coalition of other organizations in their country and thus sharing the membership fee and vote allowing greater flexibility and choice instead of the previous country membership.

In order to be accepted as EFA member, the organization must fulfill the following criteria, which reflects their patient focus, accountability, legitimacy, independence, transparency and democracy:

- be a patient or carer organization with the membership or participation of patients;
- should reflect the views and opinions of their membership in statements and opinions;
- be working towards EFA's aim and objectives and willing to co-operate with other organizations within the framework of EFA:
- have registered statutes in its country of origin and have a status of non-profit making;
- shall be self-governed;
- shall disclose its sources of funding and generally make available its financial accounts in accordance with the laws of their country of origin;
- in membership based organizations, have governing bodies elected by members or their elected representatives, and in non-membership based organizations, have patient perspective incorporated in policy making in a democratic way.

During 2005 letters and accompanying information packs for 10 potential members to join were sent, and by the end of the year EFA received the nomination of two new members, The Finnish Hengitysliitto Heli (Pulmonary Association Heli) and the newly established Polish Federation of Asthma, Allergy and COPD Patients' Organisations, thereby exceeding the target of membership increase 2005 2%, to 3%. These nominations will be confirmed by the General Meeting of Members 2006. There is an increasing interest to join EFA and we will continue the membership raising efforts 2006 in order not miss opportunity to extend the representation.

In December 2005, EFA called on members to nominate persons to form a Membership and Services Committee, which, it was hoped would help to define and develop EFA member services, grow membership – with a particular focus on new EU member states and establishing a system for gathering membership feedback. Nominations are due in early 2006.

#### Increasing capacity

In February 2005, EFA employed a freelance communications consultant, Sophie Kazan, whose previous role was Director of Strategy and Communications at the European Network for Smoking Prevention (ENSP). Sophie Kazan's responsibilities include communication and PR, among others the re-design of the EFA website.

During March and April 2005, EFA prepared to apply for an EC grant from the EU Public Health Programme 2003-2008 to support the policies 2005-2008 and to increase independent funding. The public health programme was initially proposed by the European Commission in 2000<sup>9</sup> and it is based on Article 152 (4) of the EU Treaty and it was set up as a means of Community action to actively promote co-operation and co-ordination between Member States both generally, as an 'incentive measure designed to protect and improve human health', and to set high standards of quality and safety of tissues and blood, measures in the veterinary and phytosanitary fields, the areas on which the EU may legislate directly. The European Commission works with a Committee representing members of the EU Members States to implement the public health programme decide the annual Work Plan and assess the projects. This is both a painstaking and often lengthy application and evaluation process on the part of applicants and assessors alike.

EFA identified the following key areas eligible for Commission co-financing, which also fit EFA objectives: Health Information (Strand 1) which could enable EFA to complete and surpass objectives dealing with awareness raising of allergic and respiratory diseases, the exchange of information and knowledge about these diseases; Health Determinants (Strand 3) which includes elements of capacity building and advocacy, on which EFA could build in order to empower members and grow a stronger network.

This exercise together with additional outside support will feed in to enable the organisation submit a successful project proposal in the 2006 call for proposals for the programme.

In August the EFA Board initiated an internal team building effort in order to strengthen the 'team work nature' of board membership and defining and taking action towards the realization of EFA Policy Document 2005-2008. The Board thereby developed an internal vision for EFA, which reflects how they believe the organization is to develop. This reads: 'to become a single and effective European voice for allergy, asthma and COPD patients, which adds value to the role of member organisations and other stakeholders'.

#### **EMPOWERING MEMBER ORGANISATIONS**

#### Objective:

Empowering member organizations to reach a comparable level of serving the interests of patients by exchanging experiences on:

- influencing national policymaking
- products and services for people with allergies, asthma and COPD
- increasing awareness

#### New re-launched www.efanet.org and eZine

Developing IT and information services are a key challenge and priority for EFA, and therefore target of major effort for the activity vear. EFA website went through a complete make over: look. navigation and content. The aim was to produce an attractive, capacity building tool which visible, informative and up-to-date would serve and communicate our mission effectively. The site is now structured with main sections on; general information about the organisation, its activities, electronic news and sections on diseases specific information and links, in short, one stop shop information resource on EFA, allergy, asthma and COPD and related policies. Members benefit of the 'members only' section with exclusive information and a discussion platform as well as many other features, which can be built upon on the future. The site now also enables the EFA staff to have direct control on the look and contents.



Home page www.efanet.org

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<sup>9</sup> http://europa.eu.int/eur-lex/en/com/pdf/2000/en 500PC0285.pdf

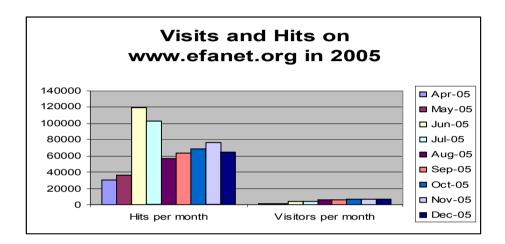
EFA printed newsletter was replaced in July by a monthly electronic newsletter, EFA eZine, incorporated with the website. The eZine enables fast, flexible, summarized, tailored and up-to-date news delivery and serves



EFA eZine

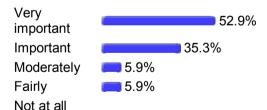
as capacity building tool. The eZine features news of EFA activities and campaigns, on EU health issues related to our policy priorities and EFA member news.

As part of the launch of the website in Summer 2005, an 'invitation' to visit the new website and subscription invitation to the new eZine to a wide variety of policy makers, environment and health and patient groups and the industry was sent out Autumn 2005. As a results, the overall 'mailing list' at the end of the year counts 150 subscribers of which 20% are EFA members and the site has around 7000 visitors and between 3000 and 15000 hits a month, which is an increase by over 500% compared to the old EFA website – see graphic below.



### **Annual General Meeting and Conference**

In May 2005 EFA held its statutory Annual General Meeting (AGM) in Amsterdam. The AGM was due to be organised in connection of the planned capacity building conference for members; Allergy, asthma and COPD - Breaking through barriers. Device: start with possibilities in stead of limitations, which was subsequently cancelled due to low subscriptions/over ambitious estimates for participation. Consequently, the AGM assigned EFA to conduct a survey among membership on the preferred EFA conference concept and reasons for low participation and participation. The results were as follows, and feel feed into future planning of EFA conferences.



70% of members answered the survey. For those who did not register, funds were the most important reason, followed by 'other activities that took priority'. For those who did register, having people available, the AGM and meeting other EFA-members had the highest priority, directly followed by budget availability and the conference programme. As to how many delegates would go to the conference, 71.4% voted one delegate, 14.3% two, 7.1% three and 7.1% more than three.

That the EFA Conference is viewed important is clear, because 88.2% say it is important or very important.

According to members, the ideal Conference is held every year, and is combined with the AGM. As for the content and target audience of the conference, it is clear that the conference should be about medical information and innovations, targeted to patient organisations' representatives. Workshops are also highly appreciated, for instance on how to develop a patient organisation and lobbying, as is including patients as another target audience. The ideal conference is 2 days long. And according to this survey, organisations would send more delegates to their Ideal EFA Conference.

#### The European Patient Voice Allergy Survey

The EFA European Patient Voice Allergy Survey was initiated to gain first hand insight from patients on living with and managing allergic rhinitis and the perceived burden of allergic rhinitis among patients living with the disease. <sup>10</sup>

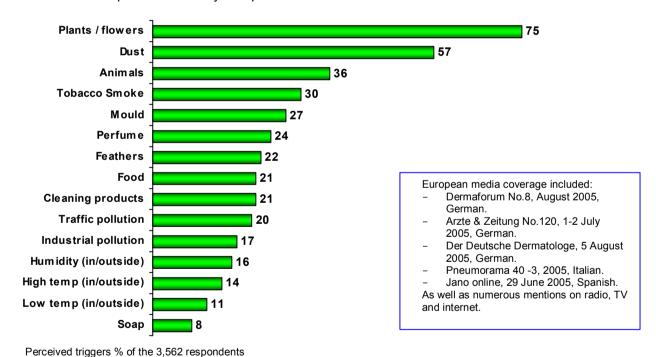


The survey, supported by an educational grant from UCB Pharma, involved over 3,500 members of EFA member organisations and other allergy patient groups 11 European countries (Belgium, Czech Republic, Finland, France, Germany, Greece, Italy, the Netherlands, Spain, Switzerland and the UK) who reported having symptoms of allergic rhinitis. The field work was conducted by the participating patient groups and data compiled by ... on behalf and analysed together with EFA.

The results disclose the significant, disruptive impact of allergic rhinitis on patients' lives with daily activities,

emotional wellbeing, work and studies all severely affected by the condition – which strengthens the case of taking it seriously by patients and the public, and need for higher prioritising by governments, and adds to the evidence that an increasing number of patients are perceive that they are suffering throughout the year instead of only seasonal hay fever. Interestingly, attempts to reduce allergen load at home by those who had done so were perceived to be mostly inadequate.

The results, which offer a valuable source of patient focused information for the countries involved, and tool for policy influencing, were launched at the World Allergy Congress in Munich on 28 June 2005 in a press conference. The event was well-attended by 30 journalists from European medical and consumer press. EFA sent out a press release/call to action entitled: *Allergic Rhinitis Patients Speak Out* to accompany the launch. The final report of the survey is expected 2006.



### GA<sup>2</sup>LEN – Global Allergy and Asthma European Network

The GA<sup>2</sup>LEN<sup>11</sup> Network of Excellence, project funded under the EU Framework programme for Research FP6, and where EFA partners was introduced to members in a workshop in Athens, hosted by the ANIKSI in December. 24 members and other patient group representatives from 14 countries took part in the workshop, which also scoped the expectations for GA<sup>2</sup>LEN, potential role of members and information needs of

http://www.ga2len.net

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http://www.efanet.org/enews/documents/AllergysummaryreportFINALdata220605-onsitea.doc

patients. The main messages included; Producing knowledge is only part of the process. Information must be relevant and assessed, synthesised and adjusted to the needs of different target groups. It then has to be disseminated. Communicating research results to patients that may have an impact on their lives is particularly important. Patients' organisations need up-to-date information on these research results to convey to members so that they can better manage their disease. At present, no integrated system exists to disseminate new scientific information on allergy and asthma to patient organisations in Europe. In some countries, patient information dissemination is effective but in others the process is haphazard or non-existent. Working groups at the meeting therefore proposed that GA²LEN should create a system that would provide a flow of evaluated, reliable and reviewed research findings, including uncertainties, from the partner centres and work packages.

Patients also needed to know what topics are currently being researched, and when the results might be available. The information would be selective and brief, and basic as well as more specific. It should be written in clear and simple language and tailored to target groups of patients. Translation would be important to ensure fast dissemination to different language groups. An information tool that could be used is the "enews alert", which would be linked to fact sheets on the GA²LEN website.

Participants considered that printed information materials continue to be an important tool in patient education; not all patients have access to e-mail and internet. These should be adapted for intended target groups, adapted to local conditions and quality marked by GA<sup>2</sup>LEN and local EFA member.

To avoid duplication of efforts, a survey should map the existing patient information tools of EFA member associations and GA<sup>2</sup>LEN centres. It might also identify the need for different types of patient information, the topics and target groups, and the need for adaptation and translation into different languages. The survey should also review information channels, such as newsletters, to avoid duplication in dissemination.

EFA also has a role in helping to incorporate the view of the patient in research policy in GA<sup>2</sup>LEN. Patient input in could be achieved by ensuring patient representation in each work package, and regular exchange of ideas between GA<sup>2</sup>LEN centres and local patients' associations.

Finally, the question of how to reach the general public, including the patient. undiagnosed was addressed. The media could play a crucial role and therefore local collaboration patients of associations and GA2LEN centres GA<sup>2</sup>LEN within campaigns mandatory for success. Although GA2LEN is first and foremost a tool for integrating research, ensuring the same messages to the public, patients and patient organisations across Europe is equally important.

## EFA member needs for GA<sup>2</sup>LEN Information:

- Production, assessment, summarizing, adjusting and communicating research results including uncertainties for EFA members
- Scoping of information material needs, existing tools and channels in countries
- Production of tools for patients (needs based)

#### Participation:

- Patient representation in scientific work packages
- Collaboration between GA<sup>2</sup>LEN centres and EFA members

#### PINCHE - Policy Interpretation Network on Air Pollution and Children's Health and Environment



In 2005 the PINCHE project was finalized. The data collection was presented in large final reports of the six Work packages on: Exposure, Epidemiology, Toxicology, Risk and Health Impact Assessment, Socioeconomic Factors and Science – Policy Interface, which are available online<sup>12</sup>.

Additionally, Report Seven contains the summary of PINCHE's policy recommendations, a tool for policy making and advocacy on European and national level and a folder was created containing an overview of the set-up and results in summary.

EFA had a project member in the Socioeconomic Factors and Science-Policy Interface working parties and contributed to these reports. The third PINCHE Conference took place in Brussels on 23-25 November 2005. EFA was invited to participate in the programme and present the

consumer and patients' point of view on the Science-Policy interface.

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<sup>12</sup> http://www.pinche.hvdgm.nl/

#### InformAll - Communicating about Food Allergies

Informall, the two year EU funded project from the EU 5<sup>th</sup> Framework Programme for Research in which EFA is a partner, came to an end in December 2005. The objective of the project was to promote the provision of visible, credible food allergy information sources to allergic consumers, agro-food industry, health professionals and regulators. As a result, valuable web resources for allergic patients and experts were launched to EFA members to publish at their website as a service for their target groups.

These resources include Database on allergenic foods<sup>13</sup> with information on food allergens targeted for the general public and technical information for specialists, Food allergens information portal (FAIP) with easy to read information on food allergy to consumers, food processing and regulation information to the industry and on diagnosis and management to health professionals.<sup>14</sup> In addition it serves as a portal to worldwide and credible information (in several languages) on food allergy to consumers, specialists and industry that has been assessed by experts.<sup>15</sup>

In addition, recommendations in form of easy-to-read leaflets for reproduction for different target groups; food industry, general public, health professionals, patients, food authorities, and caterers and food-service industry, on how to best communicate food allergy information to them were launched.<sup>16</sup>

#### EuroPrevall - The Prevalence, Cost, and Basis of Food Allergy across Europe



EuroPrevall<sup>17</sup> is a new integrated project (IP) launched 2005 in the context of the EU Framework Programme of Research FP6 and aims are to deliver improved quality of life for food allergic people through research activities.

One of the great achievements for EuroPrevall in 2005 was the publication of the Work Package 4 report<sup>18</sup> on Consumer preferences regarding food allergen information. The report reveals, amongst other things, research showing that though consumers would like more information on food labels, the current information is already considered overwhelming. And so, new strategies to provide clear, targeted information to allergic patients are vital. Scoping of tools available for allergic consumers (EFA members), health care professionals and industry started this year with the aim to summarise and analyze the results and fill the gap of information and it's availably in close collaboration with the GA<sup>2</sup>LEN project. EFA is the leader of allergic consumer stakeholder group in the project, and as such has influence through Executive Committee membership in all research and dissemination of research within the project, and to disseminate to and involve members.

<sup>13</sup> http://foodallergens.ifr.ac.uk/

<sup>14</sup> http://www.foodallergens.info

http://www.foodallergens.info/portal.html

http://www.informall.eu.com/informationleaflets2005.htm

http://www.europrevall.org/

http://www.efanet.org/activities/documents/REPORTEuroprevallreport4.pdf

#### **3 ANNUAL ACCOUNTS**

#### FINANCIAL REPORT

#### 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 31:12:05 was 61.604,18 Euro.
- b. A deposit (term) account also in Luxembourg. The balance at 31:12:05 was 41.360,05 Euro.
- c. A Visa account in Luxembourg in Euro. The balance at 31:12:05 was 7.736,68 Euro.
- d. A Swedish Currency Account in Euro. The balance at 31:12:05 was 46.404,64 Euro.

Note: EFA is a Charity still registered in Sweden so a Swedish Account is necessary.

The total balance in the four Bank Accounts and Petty Cash at 31:12:05 was 157.605,55 Euro.

	<u>31-12-04</u>	<u>31-12-05</u>
Luxembourg 1	18.802,22	61.604,18
Luxembourg 2	50.491,38	41.360,05
Luxembourg 3	7.642,56	7.736,68
Sweden	45.811,56	46.404,64
TOTAL	122.747,81	157.105,55

#### 3. Membership Fees

The Annual Membership Fee remained at 1,500 Euro per Member or Coalition Member. All Members paid.

This report includes all EFA's Accounts.

Otto Spranger EFA Treasurer Svein-Erik Myrseth EFA President Donna Covey EFA Acting Vice President

### **BALANCE SHEET IN EURO**

	31-déc-05	31-déc-04	31-déc-03
<u>ASSETS</u>			
VII. DEBTORS	3.362,47	44.808,79	6.000,00
Debtors (1)	3.362,47	44.808,79	6.000,00
IX. LIQUIDITIES	157.605,55	123.136,81	225.557,26
Bank Account 0038/4174-7	61.604,18	18.802,22	20.295,27
Handelsbanken 132 152 398			
Handelsbanken 41 402 669	46.404,64	45.811,56	9.346,05
Bank Account 0038/8721-9	41.360,05	50.491,38	187.552,68
Bank Account 5912/7917-1	7.736,68	7.642,65	7.549,78
Petty Cash Account	500,00	389,00	813,48
Transfert	0,00		0,00
X. DEFFERRED CHARGES AND ACRUED INCOME	0,00	0,00	0,00
Deferred Charges	0,00	0,00	0,00
TOTAL ASSETS	160.968,02	167.945,60	231.557,26
LIABILITIES			
IV. RESERVE	103.315,94	67.829,38	195.585,71
Reserve last year	67.829,38	195.585,71	112.742,60
Excess of income over expenditure from current year	35.486,56	(127.756,33)	82.843,11
IX. DEBTS	57.652,08	100.116,22	35.971,55
Creditors (2)	7.652,08	100.116,22	35.971,55
Received grants for next year (3)	50.000,00		
TOTAAL DER PASSIVA	160.968,02	167.945,60	231.557,26
	0,00	0,00	0,00

## INCOME AND EXPENDITURE ACCOUNT IN EURO

	31-déc-05	31-déc-04	31-déc-03
Income	232.628,75	198.953,04	470.691,39
Fees	25.500,00	21.500,00	27.000,00
Grants	195.000,00	123.308,79	267.109,59
EU Project	0,00	36.194,75	110.706,96
EFA Conferences	0,00	30.194,73	40.428,35
EFA Other Meetings	1.423,31		3.110,00
EFA News	1.420,01		0,00
Alpha Day			0,00
Airnet	8.657,00		21.060,00
SAFE	3.331,33		,
Secr.			
GALEN	324,98	10.000,00	
Bank Interests	1.723,46	2.353,51	1.273,57
Other meetings	ŕ	5.595,99	,
Difference			2,92
Expenditure	197.142,19	326.709,37	387.848,28
Experiance	101.142,10	020.700,07	001.040,20
Board Meetings	6.891,59	8.448,61	3.249,58
EFA Conferences	45.238,04	102.864,66	31.661,46
EU Project	2.664,00	34.629,61	166.974,17
Other Meetings	25.337,64	18.691,78	33.734,40
SAFE			
Expenditures Swedish Account			
EFA News	8.208,00	8.535,00	21.360,00
Secretariat	29.829,33	32.526,16	23.824,99
Alpha Day			
Airnet	0,00	24.749,31	24.736,70
EFA Net	6.461,33	3.285,00	2.225,00
ENCPA			13.585,65
GALEN	285,94	17.941,10	
LRPC	0,00	28,59	5.138,58
PINCHE	0,00	8.370,31	
Exec.Officer	70.474,80	57.782,54	59.213,09
Membership fees/Publicity	1.200,00	3.259,70	
Bank Charges	551,52	562,00	2.144,66
Pres. Exps	0.00	05.00	
Difference	0,00	35,00	
Devaluation on Debtors <sup>(3)</sup>		5.000,00	
Result of the Year	35.486,56	-127.756,33	82.843,11

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

(1) France Membership fee 2005 (cheque received in 2006)	1.500,00
Svein Erik Myrseth: 15.000 NOK advance	1.862,47
Total Debtors	3.362,47
(2) Susana Palkonen : advance petty cash account	1.109,92
Bank	9,60
Palkonen	3.200,00
Palkonen	1.856,39
Palkonen	1.476,17
Total Creditors	7.652,08
(3) Main Sponsorship fee 2006	50.000,00
Total Received for next year	50.000,00

## 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	27.000,00					27.000,00	-1.500,00	25.500,00
Main sponsorship	288.308,79					288.308,79	-93.308,79	195.000,00
EU Project	200.000,10					0,00	00.000,10	0,00
EFA Other Meetings	1.423,31					1.423,31		1.423,31
EFA Conf'rence						0,00		0,00
EFA News						0,00		0,00
GALEN	324,98					324,98		324,98
Airnet	8.657,00					8.657,00		8.657,00
SAFE	,					0,00		0,00
Secr.						0,00		0,00
Bank Interest	166,18	95,53	868,67		593,08	1.723,46		1.723,46
Other Meetings			·			0,00		0,00
Transfer	2.883,92		-10.000,00	7.116,08		0,00		0,00
Advance Creditors						0,00		0,00
Difference						0,00		0,00
Total	328.764,18	95,53	-9.131,33	7.116,08	593,08	327.437,54	-94.808,79	232.628,75
Expenditure								
Board Meetings	7.259,16					7.259,16	-367,57	6.891,59
Other Meetings	35.651,48					35.651,48	-10.313,84	25.337,64
EFA Conferences	85.109,64					85.109,64	-39.871,60	45.238,04
EFA News	15.235,20					15.235,20	-7.027,20	8.208,00
Europrevall	6.461,33					6.461,33	7.027,20	6.461,33
EU Project	2.664,00					2.664,00		2.664,00
Airnet	8.218,84					8.218,84	-8.218,84	0,00
GALEN	8.670,94					8.670,94	-8.385,00	285,94
LRPC	2.0.0,01					0,00	2.333,30	0,00
PINCHE	3.957,02					3.957,02	-3.957,02	0,00
Membership fees/Publicity	3.409,70					3.409,70	-2.209,70	1.200,00
Secr.	23.212,18			2.688,99		25.901,17	-435,22	25.465,95
P&P	3.876,01			1.476,63		5.352,64	-1.396,30	3.956,34
Logistics	7.325,04			,		7.325,04		407,04

Exec.Officer	79.397,22			1.449,38		80.846,60	-10.371,80	70.474,80
Difference						0,00		0,00
Bank Charges	556,62	1,50				558,12	-6,60	551,52
Total	291.004,38	1,50	0,00	5.615,00	0,00	296.620,88	-99.478,69	197.142,19

Result	37.759,80	94,03	(9.131,33)	1.501,08	593,08	30.816,66	4.669,90	35.486,56

tft leverancier vanuit kasboek

(2.500) (999)

1euro = 9,05800 SEK 1euro = 1,611923 CHF 9,058001951

### AUDITING OF WORKING-ACCOUNTS AND BALANCE FOR THE FINANCIAL YEAR 2005 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 2005 of the European Federation of Allergy and Airways Diseases Patients Associations.

The financial statements for the year 2005 are established in Euro.

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

The financial year closes at a positive cumulative outstanding of 103.315,94 Euro. The net result of the year 2005 amounts to 35.486,56 Euro and the balance-total to 160.968,02 Euro.

It is my opinion that the balance sheet and the profit and loss balance as at 31 December 2005 gives a fair view of the financial situation of the organisation.

Brussels 16 March 2006 Filip MOEYKENS

Accountant

## BUDGET

## Revised budget 2006

Income (Credits)		in €	
Memberghip Fees			27.000,00
EU-Projects GA²LEN			50.000,00
Other Projects Sponsors long term			10.000,00 200.000,00
Sponsors short term			-
EFA Annual Congress	Total		8.000,00 <b>295.000,00</b>
Expenditure (Debits)			
Printing			-
EFA-Net			4.600,00
Staff			85.000,00
Secretariat/Administration			38.600,00
EFA-Board Meetings			9.000,00
Projects			58.000,00
EFA-Conference			35.000,00
Other Meetings			20.000,00
EU-Project			-
GA <sup>2</sup> LEN (Conference, WS)			25.000,00
Logistics			5.000,00
P,P&P			4.000,00
PR-Activities Parttime worker			1.500,00
Booth-Material			-
Membership Fees			4.400,00
Reserve			+. <del>+</del> 00,00
. (333) 73	Total		290.100,00
	Balance		4.900,00

## Budget 2007

Income (Credits)		in €
Memberghip Fees		30.000,00
EU-Projects		25.000,00
GA²LEN		50.000,00
Other Projects		10.000,00
Sponsors long term		200.000,00
Sponsors short term		-
EFA Annual Congress		20.000,00
	Total	335.000,00
Expenditure (Debits)		
Printing		-
EFA-Net		4.700,00
Staff		90.000,00
Secretariat/Administration		53.600,00
EFA-Board Meetings		9.000,00
Projects		35.000,00
EFA-Conference		35.000,00
Other Meetings		20.000,00
EU-Project		34.000,00
GA <sup>2</sup> LEN (Conference, WS)		25.000,00
Logistics		5.000,00
P,P&P PR-Activities		4.000,00
Parttime worker		1.500,00
Booth-Material		-
Membership Fees		4.500,00
Reserve		4.500,00
I AGGGI V G	Total	321.300,00
	Balance	13.700,00

**EFA thanks our main sponsors:** European Commission European Academy of Allergology and Clinical Immunology (EAACI) AstraZeneca Boehringer Ingelheim GlaxoSmithKline Novartis UCB Pharma