European Federation of Allergy and Airways Diseases Patients' Associations

# EFA Annual Report 2012



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# European Federation of Allergy and Airways Diseases Patients' Associations 2012 Annual Report

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#### Introduction

This year was year of growth for EFA with expanded multilingual and cultural team in place in the Brussels office. Our three projects on raising awareness respiratory allergy, driving policy action on COPD and oxygen availability in planes delivered and moved forward our agenda. Our partnership in EU research projects delivered a stronger patient perspective and patient friendly communication within and from the projects. EFA involvement and visibility in EU health policy expanded and became more consistent, helping to pave the way for a Europe where people with allergy, asthma and COPD have the right for a good quality care, safe environment and participation. The EU now has an ever increasing agenda on chronic diseases, which helps us in our journey towards EU strategy and national plans on allergy and respiratory diseases.

I would like to thank especially our members for their invaluable contribution whether as active members or supporting us more silently.

This report gives an overview of our main actions this year. In addition EFA co-authored several publications, was represented either as a speaker or participant in more than 55 events related to EU policy or to partnership with health care professional associations or other NGOs. I hope you enjoy reading it.

Thank you to all EFA members, supporting EU policy makers at the Parliament, Commission and the Council, partners and last but never least, our sustainable funding partners,

Breda Flood

**EFA** President

# **About EFA**

EFA is a European network of patients' organisations that was founded in 1991, prompted by the belief that an international organisation 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 patients' 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. In 2002, the representation of patients with chronic obstructive pulmonary disease (COPD) was added to EFA's mission. Currently, EFA's membership base is exclusively European with patient associations representing 20 EU Member States plus Switzerland and Norway. In total, EFA membership includes 33 patients' associations operating at a national level.

#### Vision

EFA is the leading reference point for people with allergy, asthma and COPD.

EFA is dedicated to making Europe a place where:

- People with allergy, asthma and COPD have the right to best quality of care and safe environment
- People with allergy, asthma and COPD live uncompromised lives.
- People with allergy, asthma and COPD are actively involved in all decisions influencing their health

#### Mission

EFA is aiming to be a powerful European network of allergy, asthma and COPD patients' organisations that:

- Advocates at EU level the needs of people with allergy, asthma and COPD
- Values all members equally
- Implements best practices
- Creates patient-driven projects
- Cooperates with health care professionals, scientists and other stakeholders/nongovernmental organisations (NGOs)

#### **Objectives by target audience**

- For member organisations
- Actively communicates with member organisations identifying their needs
- Develops projects to meet these needs
- For patients
- Provides transparent access to information and educational tools in patient-friendly language
- Provides opportunities to participate actively in projects
- <u>For healthcare professionals/scientists</u>
- Facilitates communication in patient-friendly language focusing on patient needs
- Develops and promotes long term partnership on equal level
- Insures active participation of patients in all decisions regarding their disease
- For policy-makers
- Acts as liaison between people with allergy, asthma and COPD and EU policy-makers
- Negotiates to raise standards of care, environment and research
- Communicates and updates about patient needs
- For NGOs and industry
- Develops and promotes long term partnership
- Ensures well defined conditions of partnership

#### **Central values**

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

# ORGANISATION

#### **Board**

President Breda Flood Asthma Society of Ireland E-mail: <u>breda.flood@efanet.org</u>



Vice President Christine Rolland Association Asthme & Allergies, France E-mail: <u>ch.rolland@asthme-allergies.asso.fr</u>



*Treasurer* Ondrej Rybnicek Czech Initiative for Asthma (CIPA) E-mail <u>Rybnicek.O@seznam.cz</u>



Board Secretary Per-Åke Wecksell Swedish Asthma and Allergy Association E-mail: wecksell@hotmail.com

Member-at-Large Lina Buzermaniene Lithuanian Council of Asthma Clubs E-mail: <u>lina.buzermaniene@efanet.org</u>





# Office

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Project and Fundraising Officer Antje Fink-Wagner E-mail: antje.finkwagner@efanet.org

EU Policy and Project Officer



EU Policy and Project Assistant (until 31 May) Junior EU Policy and Project Officer (from 1 June) David Brennan

E-mail: info@efanet.org



#### **Members**

Roberta Savli

The EFA membership 2012 consists of 34 allergy, asthma and/or COPD patient associations or their coalitions in 22 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 Lungen-Union Obere Augartenstrasse 26-28, A-1020 Wien +43 1 330 4286 +43 1 330 4286 office@lungenunion.at www.lungenunion.at

#### **Bulgaria**

#### Association of Bulgarians with Bronchial Asthma, Allergy and COPD 5B Triditza Str, BG-1000 Sofia +359 2 980 4546 +359 2 980 4546 asthma@mail.bg www.asthma-bg.com

#### <u>Belgium</u>

#### Astma-en Allergiekoepel vzw

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#### **Belgium/Luxembourg**

#### **Prévention des Allergies**

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#### **Czech Republic**

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#### <u>Denmark</u>

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#### **France**

#### **Association Asthme & Allergies**

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#### <u>Greece</u>

#### ANIKSI

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#### <u>Lithuania</u>

#### Lithuanian Council of Asthma Clubs

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#### Association of Allergic Children Clubs

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#### Association of Asthma Patient Clubs

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#### **Netherlands**

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#### **Stichting Voedselallergie**

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#### **Poland**

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#### **Portugal**

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#### <u>Spain</u>

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#### <u>Sweden</u>

#### Astma och Allergi Förbundet

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# Swedish Heart and Lung Association

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#### **Switzerland**

#### aha! Allergiezentrum Schweiz aha! Centre d'Allergie Suisse aha! Centro Allergie Svizzera

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## Lungenliga Schweiz (Swiss Lung Association)

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#### **United Kingdom**

#### Allergy UK

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#### **Project members**

Board lead for MeDALL project Board liaison for the GA<sup>2</sup>P<sup>2</sup> project Per-Åke Wecksell, Sweden

*Board lead for the U-BIOPRED project* Breda Flood, Ireland

Board lead for HealthVent project Christine Rolland *Medical Advisor & Editor of EFA Book on Respiratory Allergy* Erkka Valovirta, Finland

European Medicines Agency (EMA) patient experts Lina Buzermaniene, Lithuania Breda Flood, Ireland Marianella Salapatas, Greece Per-Ake Wecksell, Sweden

COPD Patient Advisor to the Board Michael Wilken, Patientenliga Atemwegserkrankungen, Germany

Allergy Patient Advisor at EFA Allergy Project Joanna Bottema, Netherlands Asthma Fonds

#### Working groups

COPD Working Group, chair Michael Wilken, Patientenliga Atemwegserkrankuungen, Germany Severe Asthma Working Group, chair Lina Buzermaniene, Lithuanian Council of Asthma Clubs Allergy Working Group, chair Christine Rolland, Association Asthme & Allergies Food allergy, chair Roberta Savli, EFA Secretariat

# **Memberships and Representation**

**Membership** at European and global levels is seen as a strategic asset for various organisations, which include:

- European Patients' Forum (EPF), for issues in EU health agenda that are common for all patients
- Health and Environment Alliance (HEAL), for indoor and outdoor air pollution, climate change and for chemicals
- European Network for Tobacco Control and Smoking Prevention (ENSP), for tobacco control and second hand smoke
- Global Asthma and Allergy Patient Platform (GA<sup>2</sup>P<sup>2</sup>), initiated by EFA in 2009

- Global Allergy and Asthma European Network (GA<sup>2</sup>LEN)
- International Coalition of COPD Organisations (ICC)
- WHO Global Alliance against Respiratory Diseases (GARD)

EFA also maintains ongoing **partnerships and cooperates** in its work with various other organisations, healthcare professionals and technical profession including:

- European Respiratory Society (ERS)
- European Lung Foundation (ELF)
- European Academy of Allergology and Clinical Immunology (EAACI)
- Allergic Rhinitis and its Impact on Asthma (ARIA)
- International Primary Care Respiratory Group (IPCRG)
- Union of European Medical Specialists (UEMS)
- Global Initiative for COPD (GOLD)
- Global Initiative for Asthma (GINA)
- Pharmaceutical Group of the European Union (PGEU)
- Federation of European Heating and Air-Conditioning Associations (REHVA)

EFA representatives are also active within partner organisations and occupying roles such as:

- Vice President of the European Patients Forum, Susanna Palkonen
- Executive Committee of HEAL, Roberta Savli
- Planning Group of GARD, Otto Spranger (Austria, EFA member)
- DG Health and Consumers Expert Group on Indoor Air Quality, Susanna Palkonen
- DG Environment Consultative Forum on Environment and Health, Susanna Palkonen
- European Medicines Agency Patient and Consumer Working Party, Lina Buzermaniene, Breda Flood (alternate), Susanna Palkonen (on behalf of EPF)
- AirPROM project Exploitation Committee, Breda Flood
- Silne Advisory Board (Tackling socioeconomic inequalities in smoking), Roberta Savli
- Advisory Group of the Integrated Exposure for Risk Assessment in indoor environments (INTERA) project, Susanna Palkonen
- Advisory Group of the Schools Indoor Pollution and Health Observatory Network (SINPHONIE) project, Susanna Palkonen
- User Advisory Board of the Renewing Health project, Susanna Palkonen
- Steering Group of the European Commission Ex Smokers Are Unstoppable Campaign, Breda Flood

- 1<sup>st</sup> Vice President of GA<sup>2</sup>P<sup>2</sup>, Per-Ake Wecksell
- Secretary of the Patient Organisations Committee of EAACI, Breda Flood
- EAACI Task Force on Primary Care, Christine Rolland
- ELF Executive Committee, Breda Flood
- ARIA Advisory Committee, Susanna Palkonen
- EPF Policy Advisory Group, Roberta Savli
- Editorial Board of the Italian Journal of Primary Care, Susanna Palkonen
- HEAL "The Unpaid Health Bill How coal power plants make us sick" Technical Review Group, Roberta Savli
- GSK European Health Advisory Board, Susanna Palkonen

# **Strategic Priorities 2012**

The EFA "niche" is being the only European level patient organisation for people with allergy, asthma and COPD, who are represented through EFA member organisations. To make EFA a powerful organisation at the service of patients and members, EFA will:

- Advocate at EU level the needs of people with allergy, asthma and COPD
- Work more and equally with members
- Implement best practice
- Create patient-driven projects
- Cooperate with health care professionals, scientists and other stakeholders/NGOs

The work priorities for 2012 are:

- High quality EFA owned projects where patients are at the core: COPD project, allergy project and oxygen harmonisation project
- EU project partnerships: delivering in U-BIOPRED, MeDALL, AirPROM and HealthVent
- EU policy
- Funding: development, growth, diversity
- New website as EFA ambassador and effective interactive information and advocacy tool

# **MAIN ACTIVITIES**

## Governance

#### AGM

The Annual General Meeting (AGM) was held 11 May in Dublin, Ireland. Our external auditor audited the accounts for the approval of the AGM 2012 (approved 15 June in EGM). During the AGM many important issues were discussed. During this year's elections two board members were re-elected to the Board. EFA welcomed back Christine Rolland as vice-president from Association Asthme &



Allergies and Lina Buzermaniene as member from the Lithuanian Council of Asthma Clubs.

The EFA board met 3 times in Brussels, one meeting was a combined strategic and regular meeting and one in Barcelona in connection of an EU project meeting. In addition the board had regular meetings via skype or teleconference to stay on top of the regular business and leave time in face-to-face meetings for the key board issues.

The AGM approved the application from FENAER

(Spain) to become EFA's newest member in 2012 and decided on EFA's short term strategy and work plan. Members also expressed their support in the EFA Board's proposal to apply for core funding from the European Commission for the year 2014, giving official approval to the EFA Secretariat to complete the application for March of 2013. They decided against joining the European COPD Coalition in 2012 and will revisit the decision for EFA to become a member in the future after they have demonstrated a compatibility with EFA's mission and goals while showing they have a patient-centred approach to their actions.

#### **Networking Meeting**

At EFA's second Networking Meeting, EFA members began with the Members' EU Programme. This began with a discussion of EFA members' feedback for the EFA Meet and Greet the European Institutions training session in Brussels in March 2013. The report for this training session was presented in brief with statistics highlighting the preferences of EFA members, helping to improve the session in the future. Afterwards, potential channels for EU funding opportunities to the EFA members were presented. The session was designed to inform members of their options as national patient associations to allocate EU funding for their core activities and projects, while also explaining why EFA is unable to obtain funding for them directly.

The EFA Members' Working Group Programme allowed for two ninety minute sessions where parallel sessions were held for the COPD Working Group and Food Allergy Working group as well as the Asthma Working Group and Allergy Working Group. Rapporteurs were selected by each group to present to all members future plans, activities and strategies discussed. In concluding the

Networking Day, EFA welcomed a special guest speaker, Professor Stephen Lane, who discussed the topic of sports and asthma as well as other respiratory diseases. This was organized thanks to the Asthma Society of Ireland and was an open event for the public to attend.

## Office

EFA Office in Brussels had an Executive Officer, part-time Project and Fundraising Officer and fulltime Junior EU Policy and Project Officer and since the end of the year, full-time EU Policy and Project Officer. In addition, EFA has project members/leaders dealing with different projects and uses external services as appropriate. The rest of the work is voluntary, board members each having specific responsibilities, supported by the Office and members contributing on voluntary basis to our projects and coordinated EU advocacy.

# Funding

In 2012, EFA funding was based on membership fees (3%), European Commission Project funding (4%) and 56% core-funding and 27% project funding from our 11 sustainable corporate partners representing all our disease areas. EFA funding increased from 2011 thanks to our ongoing outreach to potential partners and clear and transparent operation of our framework for partnership<sup>1</sup> based on trust. The partners are acknowledged at the end of this report.

EFA remains involved as partner in 4 projects both the Health Programme and the 7<sup>th</sup> Framework Programme for Research. In addition, EFA had a special meeting for our sustainable funding partners in March in Brussels to present EFA work done 2011 and outlook for the 2012. The meeting provided the opportunity for new and old partners also had the opportunity comment on their experience in supporting EFA.

To see EFA's Provisional Funding Table for the European Medicines Agency (EMA), disclosing the percentages of the overall budget per sponsor and funding source, please follow the link below:

http://www.efanet.org/wp-content/uploads/2013/03/EFA-Provisional-Funding-table-for-EMA-2012.pdf

<sup>&</sup>lt;sup>1</sup> <u>http://www.efanet.org/about/documents/FinalSustainableCorporatePartnershipArrangementsEFAJune09.doc</u>

# Membership



#### EFA-Spanish Patient Association Alignment Meeting – Barcelona, Spain

On January 25<sup>th</sup> 2012, EFA hosted a meeting with eight different Spanish patient associations working on the EFA disease areas of allergy, asthma and COPD in order to familiarize itself with the current state of play regarding cooperation between patient associations at a national level in Spain. The meeting provided an opportunity for EFA to present itself to these associations, and for the Spanish associations to become familiar with each other's activities in their disease areas. The goal of EFA for the meeting was to expand membership of patient associations in Spain, and although at that time there was no Spanish member of EFA, the meeting marked the beginning of increased communication on both sides. Ultimately the only patient association operating at a national level in Spain was FENAER, which exists as a federation of different patient associations representing patients with respiratory diseases. Following the meeting, FENAER expressed interest in EFA membership and consequently had its membership approved at the Annual General Meeting in Dublin on May 11<sup>th</sup> 2012. The meeting was conducted mostly in Spanish. The EFA President was also present for the meeting to represent the EFA Board.



#### EFA-RESPIRA Meeting – Lisbon, Portugal

EFA's Executive Officer and Assistant Policy and Programme Officer traveled to Lisboa, Portugal on October 24th, 2012 to meet with the Portuguese patient association RESPIRA, which represents patients with COPD and other chronic respiratory diseases in Portugal. EFA's representatives were warmly greeted by the entire RESPIRA Board, which is comprised entirely of volunteers. The aim of the meeting was for both sides to become more familiar with each other, identify areas for future cooperation and discuss the current problems existing for patient associations in Portugal. Each group presented its goals, activities and recent events and the RESPIRA Board explained that their membership has increased from 32 to 600 in the span of 5 years. This demonstrates clear interest from Portuguese patients to seek stronger representation and empowerment in society. The organisation has organized impressive public awareness campaigns in the past years, including the offering of spirometry tests for taxi drivers at Lisboa's airport, as the profession shows the highest prevalence of cigarette smokers in Portugal. RESPIRA continued its awareness efforts with a television campaign to make World COPD Day 2012. EFA and RESPIRA discussed reimbursement policies in Portugal and the difficulties of accessing liquid oxygen for patients in need while RESPIRA also taught EFA about the National Programme for Respiratory Disease in Portugal. This programme targets all chronic respiratory diseases and RESPIRA confirmed involvement in the government's efforts to tackle the increase in respiratory diseases in the country. The meeting concluded with RESPIRA expressing clear interest in becoming an EFA member at the Annual General Meeting in Rome, May 31<sup>st</sup> 2013.

#### EFA Working Groups on COPD, Food Allergy and Allergy/Asthma

EFA members continued to participate in the EFA working groups on COPD, food allergy, allergy and asthma in 2012. They continue to be opportune moments for EFA members to meet throughout the year outside of the Annual General Meeting and other external events. In addition, the EFA members regularly make contributions towards the implementation of EFA projects at these meetings when required. If face-to-face meetings are not possible, the EFA Secretariat polls its members and offers teleconferences as alternatives to discuss pressing agenda items.

To date, the Food Allergy Working Group has continued to meet the most regularly, with very high attendance and tangible outcomes, including an event at the European Parliament on the 19<sup>th</sup> of September on "Contains/May Contain – Food Allergen Labelling". For more information on the event and EFA's activity in food allergy, see the section below on advocacy.

The COPD Working Group convened throughout 2012 in March, May and November for face-to-face meetings to exchange updates on their activities and for providing patient perspective and guidance for the EFA COPD and Oxygen Harmonisation Projects. They aided the development of a draft report defining the absolute minimum baseline standards for COPD patient livelihood in Europe, which targeted its use for a disease-specific Own-Initiative Report on COPD at the European Parliament as an objective throughout the year.

In addition, the COPD Working Group members assisted the EFA Projects and Fundraising Officer, Antje Finkwagner, in developing specific actions on COPD in the planning for 2013. For instance, the decision to disseminate a questionnaire to EFA members for updating the information collected in the <u>EFA Book on COPD in Europe</u> was assisted by discussions in the COPD Working Group members exchanging their experiences with the status quo in their nations and desire to make the best information possible available to all COPD patients in Europe.

The Allergy Working Group, in contrast to the Food Allergy Working Group, primarily focused upon respiratory allergies in Europe with meetings primarily held by teleconference over 2012 apart from the working group meeting at the AGM. The EFA Allergy Awareness Project was promoted to members from the beginning of the 2012 due to EFA's pending plans concerning the Finnish Allergy Plan (FAP) Workshop to countries with EFA members in November. This opportunity was routinely stressed as an invaluable opportunity to promote best practice across Europe.

The Asthma Working Group, similarly to the Allergy Working Group, met primarily through teleconferences and at the AGM. Since there currently is no EFA project for asthma, the working group is updated on the EU Projects concerning asthma and activities of the Secretariat, Board and Members in this disease area. In November, the EFA Secretariat held a joint Asthma/Allergy Working Group teleconference to communicate results of the FAP Workshop in Helsinki and presents a proposal for a new EFA project on adolescents with asthma between 12 and 17 years old.

#### EFA "Meet and Greet the EU Institutions" training

On the 20<sup>th</sup> and 21<sup>st</sup> of March 2012, EFA organised its third "Meet and Greet the EU Institutions" training. It was built upon the experience of the previous two events. Based on the feedback received from these previous trainings, this was a combination of beginner and advanced training

The goal of the training was on the one hand to give the members a general overview of the EU functioning and policies directly or indirectly related to allergy, asthma and COPD patients in Europe, and on the other hand to gain better understanding of how EU policies channel the decisions of national governments and how EFA members can contribute to the EU decision-making process. The overall and long-term objective was to build capacity, involve and engage EFA members towards working at the EU level in the future.

Thanks to this event, 12 EFA members had the opportunity to come to Brussels for one and a half day. They were given presentations by EU public affairs professionals and EFA staff in Brussels, they dug deeper in a case study, a legislative text under review, they met and greeted EU officials from the EP and the Commission and MEPs from their countries.

After the meeting an evaluation form was circulated and feedback collected by EFA secretariat. During the Network meeting held in Dublin on the 12<sup>th</sup> of May 2012, a presentation on the inputs received and the possibilities for the future was given. The final evaluation report is available online at <u>EFA website</u>, as well as the <u>presentation</u> of the report held during the Networking Day in Dublin. In general, the participants considered the training very valuable.

#### **EU Structural Funds for patient groups**

During the 2012 Networking Day that took place on the 12<sup>th</sup> of May in Dublin, EFA staff members Roberta Savli and David Brennan made a presentation introducing the different channels through which patient associations can apply for EU funding through their national governments and through EFA. The presentation is available online at EFA website: <u>http://www.efanet.org/wp-content/uploads/2012/10/EU-funding-for-EFA-members.pdf</u>.

The presentation was given in the framework of a more general capacity building programme for our members. The aim was to explain them all the possible funds available at the EU, so that they would be able to apply in the future either through EFA or in conjunction with us (under the research and public health programmes) or through their national governments (structural funds).

In 2013, EFA is planning a follow-up on this second part of the presentation, with an in-depth focus on structural funds.

#### **Advocacy**

Throughout the year, EFA has constantly undergone advocacy activities at the EU level for the rights of people with asthma, allergy and COPD in Europe. Several briefings have been drafted for our members, documents handed over to policy-makers, best practices shared in Europe. The visibility of

the organisation was increased thanks to constant participation in conferences and events related to our disease areas (such as the high-level <u>European Health Forum Gastein</u>), in Brussels or elsewhere, and to EFA membership in European Commission's expert groups or agencies' working parties and other groups. An overview of our advocacy activities in the field of EU policy is available <u>here</u>.

#### Public health

In January 2012, EFA prepared a <u>briefing</u> for our members on the 2012 Work Plan for implementing the second EU Health Programme to make them aware of all possible funding opportunities for EFA and our members in the field of public health.

For the same purpose, EFA started to focus on the proposal for "The Third Multi-Annual programme of EU Action in the Field of Health" (2014-2020) (proposed by the Commission in November 2011). We developed first <u>briefing</u> on the proposal for our member, a <u>letter</u> that was sent to the *rapporteur* of the text at the European Parliament asking to consider our disease areas in the report she was going to draft, and another <u>letter</u> was subsequently sent to all members of the ENVI committee of the EP asking them to specifically support some amendments of the text.

#### **Reflection process on chronic disease**

In April 2012, EFA (with the valuable input of our members and in collaboration with IPCRG, International Primary Care Respiratory Group) responded to the European Commission public consultation on the EU reflection process on chronic diseases required by the Council Conclusions on "Innovative approaches for chronic diseases in public health and healthcare systems".<sup>2</sup> The response can be downloaded from <u>EFA website</u> and covers all the consultation questions required by the Commission from our disease areas perspective.

As a conclusive remark, EFA recommends the development of an **EU strategy on chronic diseases** that will tackle their incidence, the determining risk factors, the negative consequences for the health of affected people, their families and the economies of the EU and MSs. This strategy should include disease specific best practices and national programmes, such as the Finnish allergy, asthma and COPD programmes and the Danish COPD prevention programme. In elaborating this approach, the European Commission and the MSs should take into account the perspective of all relevant stakeholders and especially of patients' groups as they can offer a unique expertise.

This was a follow-up of the Council conclusions on "Prevention, early diagnosis and treatment of chronic respiratory diseases in children" from 2011<sup>3</sup>.

#### European Year of Active Ageing and Solidarity between Generations

EFA has followed the activities and results of the European Year of Active Ageing and Solidarity between Generations 2012, writing a briefing for our members (available <u>here</u>) and participating in official conferences of the year.

<sup>&</sup>lt;sup>2</sup> Available at: <u>http://www.consilium.europa.eu/uedocs/cms\_Data/docs/pressdata/en/lsa/118282.pdf</u>.

<sup>&</sup>lt;sup>3</sup> Available at: <u>http://www.consilium.europa.eu/uedocs/cms\_Data/docs/pressdata/en/lsa/126522.pdf</u>.

An important debate for our disease areas at the European Union Parliament was held on the 13<sup>th</sup> of November 2012 on the "Impact of early diagnosis and control of chronic respiratory diseases on Active and Healthy Ageing". It was organised by the Région Languedoc-Roussillon, in collaboration with EFA and other relevant stakeholders, under the auspices of the Cyprus Presidency of the Council of the European Union that has then adopted the Council conclusions on "Healthy Ageing across the Lifecycle".<sup>4</sup>



#### Medicines

Since 2010 EFA is a member of the Patients' and Consumers' Working Party (PCWP) of the European Medicines Agency (EMA) and throughout 2012 we have been continuously involved in the activities of the agency providing the perspective of people with allergy, asthma and COPD in our disease areas. In particular, EFA representatives have been present in all PCWP meetings, providing recommendations to EMA on all matters of interest to patients, and in the periodical joint PCWP and Health Care Professionals' Working Group (HCP) meetings (February and September). EFA has then participated in several conferences organised by EMA, as well as in their annual training for patients and consumers (November). Throughout the year, we provided patients to take part in Scientific Advisory Groups (SAGs) and ad hoc meetings in our disease areas, reviewed EMA information on medicines, commented on press releases, question and answer- and other documents.

EFA responded to the <u>European Commission consultation on the introduction of fees to be charged</u> by EMA for pharmacovigilance (together with other organisations taking part in the PCWP) and to EMA consultation on the concept paper on the involvement of children and young people at the Paediatric Committee (PDCO).

EFA has been working with EPF on the clinical trials regulation (proposed by the Commission in July 2012)<sup>5</sup> supporting its position that requested more transparency, patients' participation, coordinated approach on information to patients and ethics' reviews. We have been advocating as well on the new medical devices regulation (proposed in November 2012).<sup>6</sup> Further activities on these topics will follow in 2013.

#### Food allergen labelling

For food allergy patients, along with people who have hypersensitivities and intolerances, there are significant and numerous issues with the labelling of food items in Europe. Inaccurate, unavailable or misleading information, low readability, untrustworthy precautionary labelling for cross contamination, recipe changes or strange ingredients and language barriers are all equally concerning and can result in poor quality of life or nutrition, fear, restrictions, social isolation and even death.

<sup>&</sup>lt;sup>4</sup> Available at: <u>http://consilium.europa.eu/uedocs/cms\_data/docs/pressdata/en/lsa/134097.pdf</u>.

<sup>&</sup>lt;sup>5</sup> Available at: http://ec.europa.eu/health/files/clinicaltrials/2012 07/proposal/2012 07 proposal en.pdf.

<sup>&</sup>lt;sup>6</sup> Available at: <u>http://ec.europa.eu/health/medical-devices/files/revision\_docs/proposal\_2012\_542\_en.pdf</u>.

Throughout the year, EFA has had meetings with the DG SANCO unit at the Commission responsible for the implementation of the recently adopted EU regulation on food information to consumers (a briefing on the results of the vote was drafted for our members and available <u>here</u>). EFA Food Allergy Working Group has worked diligently to specify the topic of allergen labelling as warranting a broader public dialogue in the context of the new EU regulation.

To help industry implementing the provisions (and especially those related to the provision of information on allergen for non pre-packed food, one of the main novelties of the new legislation), EFA has had meeting with three associations (Food and Drink Europe, European Modern Restaurant Association – EMRA, and European Vending Association – EVA) to insert the patient perspective in their actions.

EFA participated in the EAACI Food Allergy Summer School in Vienna on the 23<sup>rd</sup>-25<sup>th</sup> of August 2012, an event that attracted young healthcare professionals, nurses, dieticians and patient representatives dealing with food allergy and anaphylaxis. EFA submitted an abstract<sup>7</sup> and presented a poster<sup>8</sup> on "Better labelling is necessary to empower people with food allergy in Europe".



Continuing the collaboration with EAACI, on the 19<sup>th</sup> of September 2012 at the European Parliament, EFA organised an event specifically addressing "Contains/May Contain – Food Allergen Labelling." It was hosted by Mrs. Renate Sommer, Member of European Parliament (MEP), *rapporteur* of the Regulation at the European Parliament. The event attracted approximately eighty participants, serving as a unique opportunity for a wide variety of stakeholders, including patients, policy-makers, industry and NGOs to share experiences and learn about best practices from around Europe. The discussions were divided into two distinct segments focused on separate topics. The first half of the

<sup>&</sup>lt;sup>7</sup> Available at: <u>http://www.efanet.org/wp-content/uploads/2012/10/Food-allergy-abstract-EAACI.pdf</u>.

<sup>&</sup>lt;sup>8</sup> Available at: <u>http://www.efanet.org/wp-content/uploads/2012/10/EAACI-Poster.pdf</u>.

event consisted of a plenary with presentations from experts on food allergy and the new EU regulation on the provision of food information to consumers.

The second half consisted of two panels with short and informative presentations on best practices towards achieving compliance to the new regulation. The <u>report</u> is available online, as well as most of the <u>presentations</u> from the speakers. With this event, EFA was able to raise our and our members profile as patient leaders in this topic.

## Tobacco control

A major risk factor for people with allergy, asthma and COPD is related to tobacco consumption and exposure to second-hand smoke. Therefore, throughout the year, EFA has been participating in conferences on the topic of tobacco control and smoking prevention. EFA President Breda Flood has been a member of the Steering Group of the European Commission <u>Ex Smokers Are Unstoppable</u> campaign.

Being the revision of the directive 2001/37/EC on the approximation of the laws, regulations and administrative provisions of the Member States concerning the manufacture, presentation and sale of tobacco products<sup>9</sup> included in the European Commission's work plan for 2012, EFA has been advocating with other NGOs active in the field of tobacco control (and especially with ENSP, European Network for Tobacco Control and Smoking Prevention, to which EFA is an associated member) for this to happen.

The proposal was delayed by the facts surrounding the <u>resignation of former Commissioner for</u> <u>health and consumers, John Dalli</u>, and the <u>appointment of his successor</u>, <u>Tonio Borg</u>. Together with other NGOs dealing with transparency and tobacco control, EFA sent a <u>letter to the President of the</u> <u>European Commission</u>, <u>José Manuel Barroso</u>, in October to call for immediate progress on the tobacco products directive dossier and for greater transparency and stronger ethics rules.

We were happy to see that the proposal was finally released before the end of the year and EFA has immediately started an advocacy campaign with the main objectives of making compulsory pictorial warnings and plain packaging.

#### Outdoor and indoor air pollution

Air pollution is especially harmful to people who already suffer from lung diseases: not only because poor air quality may result in increased risks (especially for children) of developing asthma and respiratory allergies; but also because people with asthma, allergy and COPD are the first to react and the symptoms of their diseases may worsen (exacerbation) in case of poor air quality. Patients with asthma suffer more on or after days with higher pollution levels. Living near polluted roads could be responsible for about 15-30% of all new cases of asthma in children; and of COPD in adults 65 years of age and older.<sup>10</sup>

<sup>&</sup>lt;sup>9</sup> Available at: <u>http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2001:194:0026:0034:EN:PDF</u>.

<sup>&</sup>lt;sup>10</sup> Data from the APHEKON project, available at: <u>http://www.aphekom.org/</u>.

For this reason, throughout the year, EFA has always followed the topic and participated in conferences on the issue. EFA is represented in the EU Expert Group on Indoor Air Quality (IAQ) created in 2006 by DG SANCO, which meets regularly (the documents of the annual meeting that took place in October 2012 are available <u>here</u>) to discuss the subject of indoor air quality in the European Union.



The patients' perspective was presented in the framework of the EU

Sustainable Energy Week in the conference <u>"Energy Efficient Buildings - Healthy People"</u> (20/06/2012) and in the open policy workshop "EU Year of Air – how can we reduce air pollution to improve health?" (13/09/2012) organised by HEAL (Health and Environment Alliance).

Being a member of this association (and Roberta Savli, EU Policy and Project Officer, one of the Executive Committee members since September), a joint advocacy campaign has been carried out focused both on indoor and outdoor air pollution. In particular, in April 2012, a <u>letter</u> was sent out to Mr. Janez Potočnik, the EU Commissioner for Environment, together with other NGOs active in the field of health and environment, calling the Commission to enforce the EU air quality limit values. Throughout the year, HEAL and EFA advocated for indoor air quality to be taken into consideration into the new energy efficiency directive<sup>11</sup> and for a second EU environment and health action plan to be adopted. These attempts were unfortunately unsuccessful, but common efforts are in place to make sure that the newly proposed 7<sup>th</sup> Environment Action Programme<sup>12</sup> (proposed in November 2012 by the Commission) takes into account health and the needs of people with allergy and respiratory diseases. EFA staff has been part of the technical review group for a report on the unpaid health bill of coal that has been prepared by HEAL throughout 2012.

These actions will continue in 2013, together with an advocacy strategy on the expected revision of the EU ambient air legislation, expected for September.

#### Climate change

Climate change is also a crucial topic for EFA. Hot nights prevent recovery from high daytime temperatures and have further impacts on health, through the effects of sleep deprivation. High humidity impairs sweating, which helps people keep cool and this results in worsening for asthma patients<sup>13</sup>. In addition, global warming is extending the pollen season, therefore affecting people with respiratory allergies.

<sup>&</sup>lt;sup>11</sup> Available at: <u>http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2012:315:0001:0056:EN:PDF</u>.

<sup>&</sup>lt;sup>12</sup> Available here: <u>http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM:2012:0710:FIN:EN:PDF.</u>

<sup>&</sup>lt;sup>13</sup> E. M. Fischer, C. Schär, *Consistent geographical patterns of changes in high-impact European heatwaves*, in Nature Geoscience, vol. 3, pages 398-403, 2010, available at: <u>http://www.nature.com/ngeo/journal/v3/n6/pdf/ngeo866.pdf</u>.

To make sure that the levels of pollen in the air are monitored, EFA has drafted a <u>position paper</u> that was approved by the Annual General Meeting in Dublin on the 11<sup>th</sup> of May on real-time information on allergenic pollen in Europe and the way to secure funding for forecasting services and surveys. Further actions on this topic will follow in 2013 and 2014.

In June, EFA has responded to the European Commission public consultation on the preparation of the EU adaptation strategy to climate change (available <u>here</u>), where the need to protect vulnerable people with asthma, allergy and COPD was emphasized.

# Implementation of best practices through patient driven projects

#### Allergy Awareness Project

Following the success of the launch event at the European Parliament for the <u>EFA Book on</u> <u>Respiratory Allergy In Europe: Raising Awareness, Relieving the Burden</u> and EFA <u>Call to Action</u> on Respiratory Allergies in Europe, EFA returned to the European Parliament in January 2012 to disseminate copies of the book and invitation letters to the mailboxes for all Members of European Parliament (MEPs). In addition, EFA requested all its event and project partners to share the Call to Action and increase the signatures collected to strengthen the list of signatories in quantity and prestige. Over the course of the spring 2012, the EFA Secretariat negotiated and conferred with translation services to assure the <u>EFA Book on Respiratory Allergies in Europe</u> was available in languages other than English. By the summer of 2012, EFA had finished <u>translations</u> for 14 European languages which are: Bulgarian, Czech, Danish, Dutch, Finnish, French, German, Greek, Italian, Lithuanian, Polish, Portuguese, Spanish and Swedish.

At the European Respiratory Society (ERS) Congress 2012 in Vienna, the EFA stand continued to distribute the English version of the <u>EFA Book on Respiratory Allergies in Europe</u> and had a computer available to collect signatures for the <u>Call to Action</u>. On the final day of the ERS Congress, September 4<sup>th</sup> 2012, EFA co-hosted a symposium on 'Patient views on respiratory allergies' with the European Lung Foundation (ELF) with EFA's Board Secretary co-chairing the event. During the symposium, subjects for discussion included best practices in coping with respiratory allergy and main patient concerns, among others. Primary questions of interest addressed how politicians can act to increase political awareness of the disease area, how to promote national prevention and awareness programmes, how to improve training in allergy for healthcare professionals and how to best align healthcare reimbursement policies to support the proactive self-management of respiratory allergy among patients.

From November 8<sup>th</sup> – 9<sup>th</sup> 2012, three EFA Members brought delegations from Bulgaria, Italy and Norway for a <u>Workshop</u> to Introduce the Finnish Allergy Programme (FAP). The delegations attended a two day educational programme to introduce the FAP through presentations from Finnish stakeholders who participated in its development and implementation firsthand. They learned how the programme was initiated and how it has been run in view of initiating similar programmes within their own national contexts. The EFA report on the workshop is available to the public on the EFA website (<u>http://www.efanet.org/wp-content/uploads/2013/01/Report-on-the-EFA-Finnish-Allergy-Programme-Educational-Meeting.pdf</u>).

#### **COPD** Project

Following up on the successful COPD workshops of 2011, the EFA COPD Project in 2012 sought the achievement of an Own Initiative Report (OIR) at the European Parliament. With the support of EFA COPD Working Group actions in early 2012, a draft by patient representatives was created while brainstorming necessities for minimum standards of care guidelines for COPD patients in Europe. EFA promoted an OIR on COPD at the Environment, Public Health and Food Safety (ENVI) Committee of the European Parliament with success gaining support from several Members of European Parliament (MEPs); however, the key policymaker at the ENVI Committee, MEP Linda McAvan, was unwilling to confirm her support. This was perceived to be a result of a scandal in the past when she agreed to support an OIR on a different chronic disease and it turned out to be written by industry. As a result, MEP McAvan was unwilling to commit to any OIR on a specific chronic disease.

As a result of the inability to get an OIR passed, the EFA Board decided upon favoring the recommendation of EFA Programme and Fundraising Officer, Antje Fink-Wagner, to refocus on passing a resolution on COPD before the 2014 MEP elections instead. Ms. Fink-Wagner confirmed the support of <u>MEP Karin Kadenbach</u> in the ENVI committee to sponsor a resolution on COPD, which could then be used at a national level to demand changes for COPD healthcare standards within national healthcare systems. To assist in building an evidence base for the resolution, EFA partnered with former International Primary Care Respiratory Group (IPCRG) President Miguel Román Rodríguez, who wrote an article discussing COPD real life data and the effect of COPD on the working population of Europe as a whole.

#### **Oxygen Harmonisation Project**

The EFA Oxygen Harmonisation Project was first launched in 2012 with support from the members of the COPD Working Group, who consistently brought up the issue of oxygen provision to COPD patients and other patients with chronic respiratory diseases. This has particularly been problematic with air travel as airlines have different policies on oxygen provision across Europe and the World. A stakeholder's meeting at the Commission and report on the rights of passengers for air travel did not provide clarification of oxygen provision for travel, so EFA met with the International Air Transport Association (IATA) to discuss the matter.

However, since bottled oxygen is considered a 'hazard' on airplanes, EFA discovered it would also need to meet with representatives from the European Aviation Safety Agency (EASA) and the International Civil Aviation Organisation (ICAO). EFA representatives approached EASA and were informed the issue was not at the top of the agenda; in fact, there were no employees assigned to address the problem specifically. As a result, EFA was recommended to collect 100 testimonies from patients across Europe who had difficulties traveling by plane with oxygen. The story collection would be performed simultaneously as EFA would receive questions from patients, in their native languages, and forwarding them onwards to EASA. These tasks were scheduled to be performed in 2013.

# **Collaboration and Partnerships**

EFA always collaborates with those who have a complementary perspective and expertise that we do not have. During the year, the following were partner of our allergy, oxygen harmonisation or COPD projects, including primary and secondary care representatives: ARIA, ELF, ERS, GOLD, PGEU and IPCRG. In addition, EFA has represented patients in four EU funded projects, with vast scientific and academia partnership.

#### Understanding Allergy – Mechanisms in the development of allergy (MeDALL)



EFA is delighted to be a partner in the <u>MeDALL</u> project – Mechanisms of the Development of Allergy – a research project that is investigating the causes of allergy. MeDALL is funded by the EU Seventh Framework Programme for Research and Technological Development (FP7). EFA collaborates with 22 scientific partners in order to provide better answers to why and how allergy develops, and to design, clarify and target prevention opportunities and innovation in treatment. Patients have high hopes for the project.

Allergy often starts in childhood and it is children who are the focus of MeDALL. Information from previous birth cohorts, including 42,000 children in Europe are looked at, and 18,000 re-examined using similar methods. The annual general meeting of the project was held in Paris on the 23<sup>rd</sup> and 24<sup>th</sup> of January 2012.

EFA's role in the project is communicating and disseminating project's information and (preliminary) results to a wider audience (including policy-makers at the EU level), as well as offering a patients' perspective. EFA will also help MeDALL to contribute to EU policy by shaping together with other partners a model in the prevention and treatment of allergy that could be adapted and used at the national level.

# Personalised treatment for people with respiratory disease – Airway Disease Predicting Outcomes through Patient Specific Computational Modeling (AirPROM)



<u>AirPROM</u> is a five-year EU-funded project, which aims to develop tools enabling personalised treatments for people with asthma and COPD. Current methods of treatment adopt a "one size fits all" approach rather than tailoring treatments to patient's individual requirements. AirPROM will help building up a bank of information that can be used to provide patients with a personalised treatment plan.

The annual general meeting of the project was held in Barcelona on the 19<sup>th</sup> and 20<sup>th</sup> of April 2012. Together with the European Lung Foundation (ELF), EFA is co-leading on project dissemination to patients and public and a further face-to-face meeting of our work plan dealing with eexploitation, training and dissemination was held in Vienna on the 3<sup>rd</sup> of September 2013 in the framework of the European Respiratory Society (ERS) annual congress.

At the congress, 500 dissemination kit USB sticks were distributed with <u>complete information about</u> <u>the project</u>, including summary booklets for <u>professionals</u> and the <u>general public</u>. Over the course of the project, the researchers will use a number of techniques from image analysis, bioengineering, computation modeling and more, to develop virtual models of the whole airway system. These models will help to shed light on the optimum treatment that people with asthma or COPD should receive in order to live as normal a life as possible. A <u>Twitter account</u> was created by ELF, while EFA developed a <u>LinkedIn group page</u> with the objective of linking the projects to other relevant activities and increase visibility and dissemination of results.

# Understanding severe asthma – Unbiased Biomarkers in the Prediction of Respiratory Disease (U-BIOPRED)



<u>U-BIOPRED</u> is a five-year project funded by the Innovative Medicines Initiative (IMI), a public-private partnership between the European Commission and the European Federation of Pharmaceutical Industry Associations (EFPIA). The project aims to understand more about severe asthma by gathering patients, scientists, and other stakeholders to collaborate in pioneering asthma research.

The annual general meeting was held in Barcelona on the 23<sup>rd</sup> and 24<sup>th</sup> of January 2012. An additional face-to-face meeting of the work packages EFA is involved in (dealing with dissemination and ethics) took place on the 3<sup>rd</sup> of September 2012 in Vienna in conjunction with the ERS congress.

At the congress, an U-BIOPRED stand was set up. A <u>Twitter account</u> was created by ELF, while EFA developed a <u>LinkedIn group page</u> with the objective of linking the projects to other relevant activities and increase visibility and dissemination of results. A <u>press-release</u> on the updates of the project was released on the World Asthma Day on the 1<sup>st</sup> of May to help researchers with the recruitment of patients and healthy volunteers willing to take part in the study.

#### Indoor air quality – Health Based Ventilation Guidelines for Europe (HealthVent)



The <u>HealthVent</u> project started in July 2010 with the purpose of developing health-based ventilation guidelines for Europe that can be used as a policy making and practice tool by the EU Member States. It was funded by the Second Programme of Community Action in the Field of Health. EFA is involved, together with other stakeholders having a multidisciplinary background, in the implementation and impact assessment of the guidelines.

Two consortium meetings took place in 2012: one in Brussels (hosted by EFA) on the 12<sup>th</sup> and 13<sup>th</sup> of April, and the other one in Copenhagen on the 8<sup>th</sup> and 9<sup>th</sup> of October. During the year, EFA took part in the state-of-the-art review of existing knowledge and drafted part of the executive summary of the projects presenting the patients' perspective. In addition, we have had a leading role in the organisation of the final workshop at the European Parliament to present the results of the project that will be held in February in the framework of the EU Year of Air 2013.

# **Communications**

At EFA's 2012 AGM in Dublin, Ireland the EFA Secretariat unveiled a first glimpse into the future of communications at EFA through its arrangements with Irish web service providers, <u>Directbrand</u>, for a new EFA website and newsletter. At a meeting with Directbrand the day prior to the AGM, a strategic foundation was laid for the launch of EFA's new website in the summer of 2012. The new site features a homepage banner rotating the most recent publications and public awareness campaigns from EFA's core activities and projects. In addition, it provides a much improved structure for posting events, EFA news items and project information. The new website will also be compatible for the integration of

The <u>first EFA newsletter</u> after the summer break also featured a new template and more attractive feature for the external dissemination of information from both the EFA Secretariat and EFA's members to those interested in following EFA's activities and disease areas. The monthly newsletter has continued to feature EFA's events, relevant EU policy developments and EFA members' news. The release of the first newsletter was subsequently followed by the launch of EFA's new Facebook page to start its strategic movement towards using social media to reach policymakers, patients, EFA members and others with an interest in EFA activities. The launch of this page was a critical step towards a Social Media Strategy for EFA, which will be implemented in 2013.

EFA also published a leaflet of its work and mission that was distributed throughout the year in events.

#### Financial report 2012

**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 31:12:12 was 438,436.51 Euro.
- b. A deposit (term) account also in Luxembourg. The balance at 31:12:12 was 159,928.47 Euro.
- c. A Visa account in Luxembourg in Euro. The balance at 31:12:12 was 0,00 Euro.
- d. A Swedish Currency Account in Euro. The balance at 31:12:11 was 50.444,81 Euro.

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

TOTAL	227,971.93	462,129.25	362,505.69
Sweden	50,356.74	50,444.81	50,444.81
Luxembourg 3	0,00	0,00	0,00
Luxembourg 2	57,674.89	158,631.83	159,928.47
Luxembourg 1	119,940.30	253,052.61	152,132.41
	<u>31-12-10</u>	<u>31-12-11</u>	<u>31-12-12</u>

Ouding Am

Ondrej Rybnicek EFA Treasurer

Brede Filood

Breda Flood EFA President

# AUDITING OF WORKING-ACCOUNTS AND BALANCE FOR THE FINANCIAL YEAR 2012 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 2012 of the European Federation of Allergy and Airways Diseases Patients Associations.

The financial statements for the year 2012 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 80.192,46 Euro. The net result of the year 2012 amounts to 419.759,89 Euro and the balance-total to 448.413,97 Euro.

It is my opinion that the balance sheet and the profit and loss account as at 31 December 2012 gives a fair view of the financial situation of the organisation.

Brussels 28 May 2013 Sara CEUSTERS Accountant

Annexe 1

	BALANCE SHEET IN EURO			
	31-dec-12	31-dec-11	31-dec-10	31-dec-09
ASSETS				
III. FURNITURE	908,28	1.816,56	0,00	61.975,33
Office Appliances Depreciation of office appliances	2.724,84 (1.816,56)	2.724,84 (908,28)		61.975,33
VII. DEBTORS	0,00	0,00	0,00	61.975,33
Debtors				61.975,33
IX. LIQUIDITIES	362.505,69	462.129,25	227.971,93	83.562,26
Bank Account 0038/4174-7 Handelsbanken 41 402 669 Bank Account 5912/7917-1 Petty Cash Account	152.132,41 50.444,81 159.928,47	253.052,61 50.444,81 158.631,83	119.940,30 50.356,74 57.674,89	13.519,51 50.356,74 18.738,80 947,21
X. DEFFERRED CHARGES AND ACRUED INCOME	85.000,00	0,00	0,00	0,00
Acrued Incomes Deferred Charges	85.000,00 0,00	0,00	0,00	0,00
TOTAL ASSETS	448.413,97	463.945,81	227.971,93	145.537,59

#### LIABILITIES

IV.	RESERVE	419.759,89	339.567,43	209.546,14	107.701,71
	Reserve last year Excess of income over expenditure from current year	339.567,43 80.192,46	209.546,14 130.021,29	107.701,71 101.844,43	96.465,57 11.236,14
IX.	DEBTS	28.654,08	124.378,38	18.425,79	37.835,88
	Creditors (1)	28.654,08	124.378,38	18.425,79	37.835,88
	TOTAAL DER PASSIVA	448.413,97	463.945,81	227.971,93	145.537,59

Annexe 2

# INCOME AND EXPENDITURE ACCOUNT

	31-dec-12	31-dec-11	31-dec-10	31-dec-09
Income	556.721,68	605.930,50	361.093,29	326.969,71
Membership Fees	12.000,00	29.800,00	26.250,00	31.500,00
Partnerships and representation	1.599,90	406,00		
Grants <sup>(2)</sup>	395.000,00	350.000,00	330.122,59	233.000,00
Projects (3)				
COPD	30.000,00	140.000,00		30.000,00
U-Biopred	24.000,00	10.412,60		,
Allergy	50.000,00	50.000.00		
EU Project	42.809,16	,		2.100,00
Bank Interests	1.298,14	1.046.51	136,09	269,90
Difference	14,48	0,59	44,61	,
Expenditure	476.529,22	475.909,21	259.248,86	315.733,57
Board	24.549.73	17.557,36	12.876,44	8.323,53
Partnerships and representation	16.570,39	13.868,86	4.359,52	,
Fundraising	28.311,47	51.132,04	79.912,95	
AGM & Network Meeting	19.434,06	25.440,46	26.169,00	38.755,22
COPD Project	62.490,46	160.877,36	56.384,32	9.686,05
U-BIOPRED	1.174,51	302,60	551,78	812,25
Medall Project	448,29	808,10	242.00	,
Health Vent Project	1.252,73	1.916,64	1.160,61	
Meet and Greet Project	11.311,78	,	595,32	
Working Groups	4.996,37	2.610,20		
Allergy Project	86.242,86	99.914,57		
AirProm	1.015,51	700,81		
Website	23.581,86	3.722,70	2.972,49	285,60
Membership	3.608,59	,	,	,
Oxygen	23.705,84			
Food Allergy	6.772,90			
Office	50.577,72	27.902,74	34.229,05	152.380,53
Staff	92,732,00	42,000,00	39,600,00	38,400,00
Communication	10.159,80	1.551,20	,	,
Intern	4.000,00	4.000,00		
Membership fees	2.550,00	800,00		4.616,46
Bank Charges	930,70	342,68	174,55	126,39
Difference	111,65	4,37	20,83	0,00
Result of the Year	80.192,46	130.021,29	101.844,43	11.236,14

Annexe 3

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

(1)	Susana Palkonen	- 211,00
	Spranger Otto	720,86
	Hotel du Congres	- 432,55
	Hotel Royal Centre	436,00
	Erkka Valovirta	254,00
	Wagner Henriettefink Antje	18.197,00
	Wilken Michael	- 14,00
	Flood Breda	463,90
	Rybnicek Ondrej	307,93
	Visa	- 2.228,32
	Allergia - ja astmalitto	536,99
	Buzermaniene Lina	395,08
	Rolland Christine	531,33
	Scientific Communication SRL	5.685,00
	Price John	24,00
	Hotel Floris Louise	68,55
	Kamphuis J.A.E.	52,00
	Savli Roberta	155,09
	Astma- & Allergiförbundet	781,85
	Brennan David	135,96
	Sodexho	- 471,57
	Hadzhiangelova Petrova Diana	721,50
	Groettum Hlle	56,55
	Eriksud Anne Elisabeth	1.989,13
	SL Studio	1.200,00
	Federasma Onlus	269,90
	NH Hotels Italia	- 971,10
	Total Creditors	28 654 08

Total Creditors

28.654,08

Smithkline Beecham 2011       75.000,00         Chiesi Farmaceutici Spa       30.000,00         Pfizer       30.000,00         Novartis Pharma (received in 2013)       55.000,00         BoehringerIngelheim (received in 2013)       30.000,00         Stallergenes       30.000,00         ALK-Abello       30.000,00         Almirall       30.000,00         Vifor Internationaztional       30.000,00	
Total Sponsoring 395.000,00	
	OPD OPD
AMC Medical Research 24.000,00 U-	-biopred
5	lergy lergy
Inserm 2.809,16 Me	edall
•	xygen xygen
Total Projects 146.809,16	

# **Acknowledgements for funders**

#### EFA thanks our funding partners who have made our work possible:

#### **European Commission**

DG Research 26.809,16

#### Sustainable industry partnerships

#### 5 Star\*\*\*\*

- GlaxoSmithKline 55.000
- Novartis 55.000

#### 3 Star\*\*\*

- ALK Abelló 30.000
- Almirall 30.000
- BoehringerIngelheim 30.000
- Chiesi 30.000
- Pfizer 30.000
- Stallergenes 30.000
- Vifor 30.000

#### **COPD Project**

15.000 – GSK (at the time of closing the accounts, the other sponsorships for this project was not received)

#### **Allergy project**

50.000 ALK Abelló, Stallergenes 25.000 each

#### **Oxygen Project**

40.000 Almirall. 25.000, AirLiquide 15.000 each

To see EFA arrangements with funders, please follow the link below: <u>http://www.efanet.org/our-values/</u>