

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



European Federation of  
Allergy and Airways Diseases  
Patients Associations

**EFA Annual Report 2013**

**ENVIRONMENT**  
to tobacco  
**partner**  
oxygen  
healthcare  
air pollution  
**NETWORK**  
capacity building  
pollen  
**COPD**  
**PATIENT**  
europe  
**asthma**  
allergy  
labelling  
medicines



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## Foreword



This year was a landmark for EFA as we launched our Manifesto for the 2014 election to the European Parliament summarising our priorities for the upcoming years. EFA's place in EU health, environment and research policies and their implementation was tangible and valued by Members of the European Parliament, who committed to our Manifesto, and other stakeholders. Our vision for a Europe where people with allergy, asthma and COPD have the right for a good quality care, safe environment and participation in all decisions affecting their health was advanced especially through persistent advocacy on the EU tobacco products directive and medical devices regulation. Further achievements included our publication *'Minimum Standards of care for COPD patients in Europe'*, our booklet on *'Enabling Traveling with Oxygen in Europe'*, through the promotion and training for national programmes on allergy and asthma and a pilot project in Austrian pharmacies on early detection of respiratory allergy. We also partnered in five innovative EU research projects focused in advancing our knowledge and personalized care in allergy and respiratory diseases. We organised a landmark event at the European Parliament for a project on health based ventilation guidelines for Europe. Our annual training for EFA members on EU health related policy was once again a success and it demonstrated that EFA's role in capacity building is vital to increase our collective impact. Our contribution at the European Medicines Agency is now well-established and we look forward to empowering more members on medicines and pharmacovigilance issues. We joined the club of Brussels health non-governmental organisations active on Twitter, a tool that has proven to be a great direct channel to connect, inform and promote directly with policy makers, partners and our members. Perhaps the biggest challenge was the successful application and final agreement for the EU core funding for 2014, which supports our funding diversity and therefore sustainability. We were happy to welcome a new member from Portugal, RESPIRA who represents people with COPD and to have fostered relations with inactive and potential members in Croatia, Malta and Portugal.

I would like to thank especially our members for their invaluable contribution to the common goal of good quality care, safe environment, active patients and uncompromised lives for all those with allergy, asthma or COPD in a synergy of members' action at the national and local levels. In 2013, we strengthened our partnership with the European level groups of primary care, pharmacists, allergologists, pulmonary specialists, health and environment, tobacco control and of patients, which is highlighted throughout this report. Thank you partners. Thank you members.

This report gives an overview of our main actions this year. In addition, EFA co-authored several publications and took part either as a speaker or participant in 93 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, our office team, supporting EU policy makers at the Parliament, Commission and the Council, partners and last but never least, our ten sustainable funding partners. The EU action should support national goals for patient-centered care and prevention and that's what we are here for – united we are strong..

Breda Flood  
*EFA President*

## EFA in brief

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 with allergy and respiratory diseases in Europe. 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 35 patients' associations operating at a national level.

## Vision and mission

Our vision is that European patients with allergy, asthma and chronic obstructive pulmonary disease (COPD) live uncompromised lives, have the right and access to good quality care and a safe environment.

Our mission is to be the voice of allergy, asthma and COPD patients at European level and to be actively involved in the decisions impacting their health by:

- Advocating at EU and regional levels for the needs of people with allergy, asthma and COPD
- Enabling a powerful European network of patients' organisations
- Valuing all members equally
- Sharing knowledge and implementing best practices
- Creating patient driven projects
- Cooperating with health care professionals, scientists and other stakeholders/NGOs

## EFA's core values mechanism



## Activity report 2013

This report presents EFA's main activities, projects and EU policy and advocacy activities in 2013. EFA thanks in advance all our partnerships, whether they are funding partners or operational partners as well as members – we look forward to and count on your collaboration to work towards our common aims for a Europe with access to good quality care, safe environment and patient participation in an equal way across Europe.

### Advocating for patients' rights

Throughout the year, EFA constantly performed advocacy activities at the EU level for the rights of people with asthma, allergy and COPD in Europe. Several briefings, position papers and advocacy letter templates have been drafted for our members, with documents handed over to policy-makers, and best practices shared in Europe. EFA's visibility increased thanks to constant active participation, as speakers and participants in events related to our disease areas, in Brussels or elsewhere, and to EFA membership in European Commission's expert groups, working parties and other bodies.

### 1. Work towards a European Programme on Allergy and Respiratory Diseases & Strategic overarching approach by the EU on allergy, asthma and COPD

#### Public health

In January 2013, EFA prepared a briefing<sup>1</sup> for our members on the **2013 European Commission Work Plan** for implementing the second EU Health Programme to raise awareness about all funding opportunities for EFA and our members in the field of public health. For the first time, we applied for a European Commission operating grant and were notified we had been awarded with it in November. As a consequence, EFA will receive funding from the European Commission in 2014 to finance 60% of its core activities.

In 2013 EFA was awarded with a European Commission operating grant for 2014.

Throughout the year, EFA monitored the negotiations between the Council of the European Union and the European Parliament on the **third multi-annual programme of EU action in the field of health (2014-2020)**. The text was proposed by the Commission in November 2011 and was voted by Parliament in 2012. At the end of 2013, no further decision had been taken by the institutions on future funding for health projects and not -profit EU organisations.

#### Reflection process on chronic diseases

During 2013, EFA followed-up on the EU reflection process on chronic diseases and communicated latest developments in this field to members. Two main areas of EU actions were identified: chronic diseases' prevention and health promotion and management of chronic diseases, with a special focus on patients' empowerment. An EU summit on chronic diseases was announced for 2014. In this framework, EFA will continue to advocate for an EU strategy on chronic diseases with disease specific chapters and best practices.

In November, our Board member Lina Buzermaniene participated in the annual conference of the Health Forum "Sustainable Health Systems for Inclusive Growth in Europe" organised by the rotating Lithuanian Presidency of the European Union in November and advocated for the rights of patients with allergy, asthma and COPD to be taken into account in the final declaration of the conference.

## EU policy survey

In December, EFA launched its first policy survey<sup>ii</sup> with the objective of assessing members' satisfaction with our advocacy activities in EU policies and discovering their priorities and actions at the national level. On the basis of the results (expected for 2014), we will be able to tailor our future strategies to members' policy needs.

## 2. Food allergen labelling in the EU

Throughout the year, EFA communicated with the European Commission, the European Food Safety Agency (EFSA) and other relevant stakeholders on the implementation of the food information to consumers' regulation, due to enter into force in December 2014. Our members were in close contact with their national authorities and regularly shared views through the EFA Food Allergy Working Group. As a result of these discussions, EFA adopted an internal position that allergen should be bolded to allow differentiation from other ingredients in the ingredients' list and that written information on allergen in the case of non-pre-packed food should be compulsory. In July, EFA released a press release<sup>iii</sup> on the need to improve industry's guidance on food allergen management.

In February, our President Breda Flood participated in the Food Allergy and Anaphylaxis Meeting (FAAM) organised in Nice by the European Academy of Allergy and Clinical Immunology (EAACI), while in June, Executive Officer Susanna Palkonen presented the patient's perspective in the FIC and Food Labelling 2013 conference<sup>iv</sup>.

In 2014, EFA's activities will continue to observe the implementation of the new regulation and we will be organising an event on this topic to follow-up on the previous event from September 2012.



The EFA Food Allergy Working Group adopted a position on food allergen labelling during the 2013 Annual General Meeting.

### 3. EU tobacco control

Following the Commission proposal for the new directive on the manufacture, presentation and sale of tobacco products (published in December 2012), EFA has been actively advocating for strengthening public health and promoting patients' rights in the legislative text.

EFA strongly collaborated with other not-for-profit organisations working in the field of tobacco control and the protection of public health, increasing our visibility in Brussels' environment. In February, EFA participated in a strategic meeting on the new directive co-organised by Smokefree Partnership (SFP), European Health Network (EHN), European Cancer League (ECL), European Public Health Alliance (EPHA) and the European Network for Smoking and Tobacco Prevention (ENSP). During the year, we reinforced our collaboration with the organisers, through teleconferences, face-to-face meetings, preparing common templates for members and advocacy documents, including a flyer on new tobacco packages that was distributed to policy-makers before the plenary vote in Strasbourg, shown below by Health Commissioner Tonio Borg during the discussion, and published in Brussels' based newspapers.



EU Commissioner for Health and Consumers Tonio Borg used partners' tobacco packages flyer at the voting of the Tobacco Products Directive in Strasbourg, 8 October 2013.

In January, EFA published a briefing<sup>v</sup> for our members, followed by a position paper<sup>vi</sup> and presented them to Members of the European Parliament (MEPs). In 2013, we had direct contacts with 30 MEPs and met with nine (April and September) to make the voice of patients with asthma, allergy and COPD heard. We sent voting recommendations from patients with asthma, allergy and COPD both before the vote in the Environment, Public Health and Food Safety (ENVI) committee<sup>vii</sup> (July) and in the plenary<sup>viii</sup> of the European Parliament (October), as well as template letters for our members to contact their MEPs and national authorities in their local languages. In October, EU Policy Officer Roberta Savli travelled to Strasbourg to follow the European Parliament plenary vote with other public health advocates.<sup>ix</sup>



We continued our advocacy activities ahead of the trialogue (European Parliament rapporteur, Commission representative and Lithuanian Presidency of the Council European Union) agreement on the text (reached in December) and in 2014, we will keep on fighting for patients' rights and public health concerns until the directive is not formally approved and becomes law.

During the "Meet and Greet the EU Institution" training EFA members had a role-play on the revision of the directive. Divided into two small groups, they portrayed the Council of the EU and the European Parliament plenary and, once they reached the respective positions, they had to fight for them in the trialogue. This role-play gave them the opportunity to understand better the legislative process in Brussels and to improve their knowledge on the dossier.



EFA Director Susanna Palkonen presenting at the "Meet and Greet the EU Institution" training.

We have been particularly active in social media, promoting our position on Facebook and especially Twitter, where we managed to get in contact with key policy-makers and be the first to release some news on the directive. Our experience was presented in European Patients' Forum (EPF) Regional Advocacy Forum<sup>x</sup> in Zagreb (October) and in ENSP Networking Meeting<sup>o</sup> in Brussels (November).

## 4. European Year of Air: Outdoor and indoor air pollution

### Outdoor air pollution

Identified by European Commissioner for Environment, Janez Potočnik, as the EU Year of Air, 2013 was a key year for EFA to present patients' perspective and needs regarding clean air. We closely collaborated with the Health and Environment Alliance (HEAL), of whom EFA is a member, and built relationships with other stakeholders, such as the European Environment Bureau (EEB). In June, we participated in Green Week, the biggest environmental conference in the EU entirely dedicated to the topic of air pollution, with a conference<sup>xii</sup> on how to empower the most vulnerable groups such as patients suffering from respiratory diseases in fighting air pollution. Throughout the year, we decided to revamp the website <http://www.knowyourairforhealth.eu/> that was created together with HEAL in 2008, and we will re-launch it in 2014.

In March, EFA responded<sup>xiii</sup> to the European Commission's public consultation on the review of the air pollution legislation and throughout the year we asked for a proposal without delays and with ambitious goals. In April, we signed a joint letter<sup>xiv</sup> on the priorities for the review of the Thematic Strategy on Air Pollution together with other 60 not-for-profit organisations. In September, in the framework of HEAL's Annual General Assembly, EFA presented the perspective of patients with allergy, asthma and COPD on the need to have clean air to Commissioner Potočnik. As the Commission proposed a communication, a revised directive on national emission ceilings, a decision to ratify an international Protocol and a new directive to reduce pollution from medium-sized installations, we will continue our advocacy activities in 2014.



EU Commissioner for Environment Janez Potočnik at the HEAL Annual General Assembly with EU Policy Officer Roberta Savli.

EFA advocated for a stronger Seventh Environment Action Plan (7 EAP, proposed in November 2012 by the Commission) that takes into account health and the needs of people with allergy and respiratory diseases, throughout the entire legislative process. In February, we published a briefing<sup>xv</sup> for our members and in April, we sent a letter<sup>xvi</sup> to all the Parliamentarians of the Environment, Public Health and Food Safety (ENVI) committee. We provided template letters to our members to contact their national policy-makers and Members of the European Parliament. The 7 EAP was finally signed into law by the European Parliament and Council in November and EFA's advocacy efforts were successful as for the first time the need to guarantee a good indoor air quality was mentioned and EU limit values as regards both indoor and outdoor air pollution will have to be in line with the World Health Organisation (WHO) guidelines.

## Indoor air quality

On the 20<sup>th</sup> of February, EFA organised the final event<sup>xvii</sup> of the HealthVent project at the European Parliament hosted by the Member of the European Parliament Mrs. Catherine Stihler. The occasion attracted more than fifty participants. It served as a unique opportunity to learn about the project's results for a wide variety of stakeholders, including patients' associations, policy-makers, industry, research institutions, technology focused organisations and non-governmental-organisations, that could additionally express and share their views and experiences on indoor air quality. The first half of the event consisted of plenary presentations by HealthVent partners. During the second half, the policy impacts of guidelines for health-based ventilation were discussed by two panels, one focusing on clean air policies and the second on energy policies.<sup>xviii</sup>



MEP Catherine Stihler and Jacques Remacle from the Executive Agency for Health and Consumers at the HealthVent project at the European Parliament.

EFA collaborated with various stakeholders, participated in numerous events, disseminated project results and presented patients' perspective on indoor air quality in several occasions. In April, during the stakeholders consultation meeting of the Sinfonie project at the European Parliament, in May, in the framework of the annual general meeting<sup>xx</sup> of the European Ventilation Industry Association (EVIA) and in October, in the 11<sup>th</sup> edition of Emissions and odours from materials conference<sup>xx</sup>.

## Pollen

Pollen concentrations remains out of the European Commission agenda for the moment.

In 2013, EFA followed-up on the position paper for real-time information on allergenic pollen in Europe and ways to secure funding for forecasting services and surveys, which was approved by the 2012 Annual General Meeting in Dublin. Taking up EFA's concerns, in February, the Italian Member of the European Parliament Mr. Andrea Zanoni asked a written question on the topic to the European Commission. In April, the Commissioner for Environment Potocnik replied that the Commission had no plans to widen EU air quality policy in order to account for pollen monitoring, information dissemination and financing of such activities. Environmental protection legislation should exclude pollen emissions because they were not man-made and hence could not be reduced by Member State actions. As a result, and with the objective of refuting Commission's arguments, in September, EFA issued a press-release in collaboration with our healthcare professional partners, European Academy of Allergy and Clinical Immunology (EAACI) and European Respiratory Society (ERS). Further actions on this topic will probably follow in 2014.

In October, EFA participated in the stakeholders' meeting<sup>xxiii</sup> of the EU project Atopica, expressing patients' concerns on the need to have pollen monitoring as the way to limit the epidemic of allergy in Europe.

## 5. Chemicals

Throughout 2013, EFA participated in several workshops and conferences on the topic of chemicals in Europe with the objective of improving the knowledge on this specific piece of legislation and start advocating for the protection of patients with allergy, asthma and COPD for 2014.

## 6. Medicines & Medical devices

### European Medicines Agency

Since 2010, EFA is a member of the Patients' and Consumers' Working Party (PCWP) of the European Medicines Agency (EMA). In 2013, we successfully renewed our application and provided an EFA representative and alternate there. Throughout the year, we have been continuously involved in the activities of the agency providing the perspective of people in our disease areas.

In particular, EFA representatives have been present in all four PCWP meetings (February, June, September and December), providing recommendations to EMA on all matters of interest to patients, and in the two periodical joint PCWP and Health Care Professionals' Working Group (HCPWG) meetings (June and September). EFA has participated in several conferences and workshops organised by EMA, as well as in their annual training for patients and consumers. 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, questions and answers, summaries of European Public Assessment Reports, and other documents.



EFA representatives were asked to present during the annual training (December) and a workshop organised by the Agency on a project dealing with vaccination in Europe (October), and EFA submitted its comments<sup>xxiv</sup> to the EMA concept paper on the need for a reflection paper on quality aspects of medicines for older people (June). We have used materials and videos prepared by EMA in our social media, website and communication with members.

## Medicines & treatments

In June, EFA sent an advocacy letter<sup>xxv</sup> to the members of the ENVI committee of the European Parliament asking to support a clear exemption from a regulation aiming to phase out fluorinated greenhouse gases for medical applications as hydrofluorocarbons-based metered dose inhalers are necessary to guarantee adequate treatment of some people with respiratory diseases, especially children, elderly people and those in the severe stages of these diseases. The letter was drafted in collaboration with our partner organisation, the International Primary Care Respiratory Group (IPCRG). The collaboration continued and widened with the participation of the European Hospitals and Healthcare Federation (HOPE) in a second letter<sup>xxvi</sup> addressed to the Council. The text was agreed upon by the Parliament and the Council in December and the medical exemption was accepted, and it will be formally adopted in 2014.

In 2013, EFA has been working with EPF on the clinical trials regulation (proposed by the Commission in July 2012), supporting its position that requested more transparency, patients' participation, a coordinated approach on information to patients and ethics reviews. We sent template letters to members to advocate with their national policy-makers ahead of the Council meeting. In June, EU Policy Officer Roberta Savli took part in the summer school for patient advocates in clinical trials and drug development organised by the European Rare Disease Organisation (Eurordis), in Barcelona. In October, Executive Director Susanna Palkonen was a speaker in the event organised by the European Federation of Pharmaceutical Industries and Associations (EFPIA) on discussing clinical trial data.

**An exemption for fluorinated greenhouse gases for medical applications was accepted by the European Parliament and the Council.**

In September, EFA released a press release<sup>xxvii</sup> in collaboration with IPCRG on ten easy steps to defeat difficult-to-manage asthma.



Participants at the Eurordis summer school for patient advocates in clinical trials and drug development.

## Medical devices

Following the European Commission proposal for the new medical devices regulation (published in November 2012), EFA has been actively advocating for enhanced patients' safety and involvement as well as greater transparency in the legislative text. EFA frequently collaborated with European Patients' Forum (EPF) and met other stakeholders such as Eucomed, the association of medical technology industry in Europe, to present patients' perspective on this topic.

In January, EFA published a briefing<sup>xxviii</sup> followed by a position paper and amendments that were presented to Members of the European Parliament (MEPs) both via e-mail and during face-to-face meetings (in February and April, EFA met with three key MEPs, rapporteurs or shadow-rapporteurs of the regulation).

We sent voting recommendations from patients with asthma, allergy and COPD both before the vote in the Environment, Public Health and Food Safety (ENVI) committee<sup>xxix</sup> (September) and in the plenary<sup>xxx</sup> of the European Parliament (October), as well as template letters for our members to contact their MEPs in their national languages. As the Council has still not reached its position on the topic before the end of 2013, advocacy activities will continue throughout 2014.

We have been particularly active in social media, promoting our position on Facebook and especially Twitter, where we managed to get in contact with key policy-makers and be the first to release some news on the regulation.

## 7. EFA Manifesto for European Parliament Elections 2014

In view of European Parliament elections that will take place during the week of May the 22nd-25th in 2014, EFA decided to adopt a Manifesto to raise awareness for asthma, allergy and COPD, present patients' concerns and needs among current and future policy-makers, and put their rights at the top of their political agenda.

EFA Manifesto was prepared by EFA with the active input of members during summer. We officially launched it on the 17<sup>th</sup> of October<sup>xxxi</sup> and some EFA members had the pleasure to be the first ones to use the Manifesto and ask their national Members of the European Parliament to sign it during the "Meet and Greet the EU Institutions" training. The Manifesto website<sup>xxxi</sup> went live for signatures and the hashtag #EFAManifesto was also created. The Manifesto was translated by EFA members in three different languages (Finnish, Bulgarian and Polish) and used for advocacy activities.

A campaign paper was distributed to members, together with advocacy templates letters they could use with their national policy makers. EFA sent the Manifesto to all current Members of the European Parliament, it was constantly present in a banner on EFA's website and advertised in all our newsletters, presentations and internal events and external conferences. We used it in our social media and e-mail signatures. Since Members of the European Parliament presented a Written Declaration on recognising the burden of allergic disease in Europe on October 11<sup>th</sup>, a rationale on the complementarity of our Manifesto with the Written Declaration was sent to members. A press release<sup>xxxi</sup> to mark the Written Declaration was published in collaboration with European Academy of Allergy and Clinical Immunology (EAACI).

By the end of 2013, more than 500 concerned people supported our three priority areas and fourteen actions to improve the health and quality of life of people with asthma, allergy and COPD, including four Members of the European Parliament. Actions will continue in 2014 and intensify before the European Parliament elections.



## EFA Manifesto for 2014 European Parliament Elections

We are calling on you to commit yourselves to the following priorities in the area of health:

**1. Develop an EU strategy on chronic diseases with disease specific chapters**

As an outcome of the EU reflection process on chronic diseases, dating back to 2010, an EU strategy with disease specific chapters should be developed. The strategy would enable us to effectively tackle incidence and risk factors, while helping us deal with negative consequences for the health of affected people, their families and the economies of the EU and its Member States.

**2. Invest in prevention – tackle health determinants**

- 2.1. Reduce tobacco consumption through a stricter tobacco products directive
- 2.2. Implement the smoke free Europe recommendations
- 2.3. Introduce a better strategy on outdoor air pollution with limit values in line with WHO recommended levels
- 2.4. Adopt a strategy on indoor air quality that includes the home and the workplace
- 2.5. Include pollen monitoring under the Clean Air Programme for Europe
- 2.6. Reduce exposure to chemicals in everyday life
- 2.7. Introduce labelling of all ingredients in the ingredients list of

**3. Help ensuring equal access to care for each patient**

- 3.1. Eliminate discrimination of patients based upon their disease or condition
- 3.2. Reduce health inequalities as regards access to care and quality of treatment within and between Member States
- 3.3. Initiate or boost patients' participation in decision-making in all areas relating to their health and wellbeing, particularly concerning the placement of medicinal products and medical devices on the market and their reimbursement, priority setting for studies, trials and research, through promotion, facilitation and support of programmes in Member States, ensuring funding for patients' organisations
- 3.4. Strengthen patients' safety
- 3.5. Improve accuracy and quality of information to patients and boost health literacy
- 3.6. Ensure early and accurate diagnosis of allergies and chronic respiratory diseases, such as asthma and COPD, through increased training for healthcare professionals, development of national programmes, set up of registers and spirometry testing
- 3.7. Ensure that more funds are allocated for EU health policy and programmes and prioritise investments in research of allergic and respiratory diseases

## Implementing best practices through patient driven projects

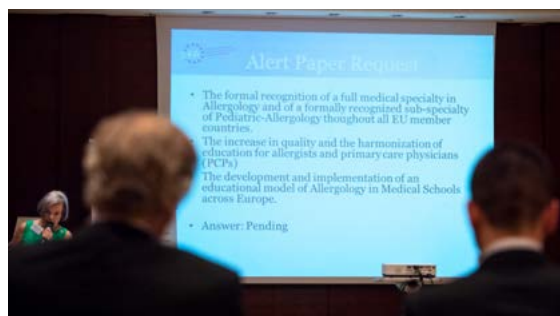
### Allergy Awareness Project

Following the landmark workshop<sup>xxxiv</sup> to introduce the Finnish Allergy Programme (FAP) in Helsinki, Finland in November 2012, EFA continued to support its members with efforts to establish national allergy programmes. As a first step, EFA finalized educational slides<sup>xxxv</sup> targeting policymakers which could be used by members in their efforts to advocate for national programmes.

In May, commemorating World Asthma Day, EFA published the *Allergy Alert! Paper*<sup>xxxvi</sup>, accompanied it with a press-release<sup>xxxvii</sup>, and then presented it in person to the coordinator for the European Conservatives and Reformists group (ECR), and to the European Commission Directorate General for Health and Consumers. The paper was sent to Commissioners for Health and Education and Culture and to the chair of the ENVI committee and political coordinators. In collaboration with European Academy of Allergology and Clinical Immunology (EAACI), the European Union of Medical Specialists (UEMS) and Allergic Rhinitis and Its Impacts on Asthma (ARIA), EFA calls for the following fundamental changes to healthcare systems across Europe regarding pre- and post-graduate medical education:

- the formal recognition of a full medical specialty in Allergology and of a formally recognised sub-specialty of Pediatric-Allergology throughout all EU Member States;
- the increase in quality and the harmonisation of education for allergists and primary care professionals;
- the development and implementation of an educational model of Allergology in medical schools across Europe.

At the 2013 EAACI Congress, EFA participated in a symposium with policymakers and medical specialists presenting the Allergy Awareness Project and Call to Action while other partners outlined key arguments from the Allergy Alert! Paper. In addition, at the EAACI Congress 'Call to Action' posters<sup>xxxviii</sup> were made available in all the same languages as the *EFA Book on Respiratory Allergy In Europe: Raising Awareness, Relieving the Burden*<sup>xxxix</sup>. These were designed to be collected by medical specialists and general practitioners to hang on the walls of waiting rooms for their patients.



Presentation of policy demands from the Allergy Alert! Paper at the 2013 EFA Annual General Meeting in Rome.

EFA member Österreichische Lungenunion successfully conducted an Allergy Risk Check pilot project in Vienna during spring. They sent allergy kits to all pharmacies in Vienna for the peak allergy season. Pharmacy customers filled out quick questionnaires and then reviewed their results with pharmacists to determine whether or not they suffer from allergic symptoms. In a sign of its success, the head of the Pharmaceutical Group of the European Union (PGEU) invited EFA to present to its assembly of members for the following year.





From left to right Pascale Demoly, Nikos Papadopolous, Cezmi Akdis, EFA Vice President Christine Rolland.

### COPD Project

EFA continued its work with MEP Kadenbach to adopt a resolution on COPD before the 2014 European elections. To support this objective, EFA partnered with Miguel Román Rodríguez, former President of the International Primary Care Respiratory Group (IPCRG) and produced an article entitled *‘Real World Burden of COPD: Employed vs Not in Paid Employment Patients’*.<sup>xi</sup> The foreword was signed by four key policymakers in the Committee on the Environment, Public Health and Food Safety (ENVI) Committee of the European Parliament: Matthias Groote (Chairman), Dr. Peter Liese (Co-coordinator of the EPP Group), Dr. Richard Seeber (Co-coordinator of the EPP Group) and Dr. Antoniyia Parvanova (Member). The article builds an evidence base for the resolution and was later published in *Journal of Health and Productivity* for December 2013. Despite these efforts to directly insert COPD into the agenda of European policymakers, the objective of a resolution was unachievable and any additional efforts will need to wait until the new European Parliament is elected in 2014.

Following up on the COPD working group’s decision to establish minimum standards of care, a publication was planned for release in November 2013 to coincide with World COPD Day. As a result, over the spring and summer of 2013 EFA members representing people with COPD were asked to complete a survey to help identify common deficiencies in care for COPD patients which commonly appear across Europe. In the *‘EFA Book on Minimum Standards of Care for COPD Patients in Europe’*<sup>xii</sup> EFA members identify eight minimum standards of care for COPD patients in all European countries with the COPD Working Group agreeing upon three for concentration of efforts in 2013:

1. Ensure early diagnosis of COPD by using spirometry testing in primary care for current and ex-smokers older than 35 years old;
2. Coordination should be increased between primary care, specialists and hospitals to increase efficiency of treatment and quality of life for patients;
3. Smoking cessation services and pulmonary rehabilitation should be made available for all COPD patients in need, regardless of their employment status;



The publication was presented at a public event in Brussels, *What role for diseases and patients in shaping Horizon 2020? A COPD case study of patient involvement*, co-hosted with the European COPD Coalition under the auspices of the EU Lithuanian Presidency. The event highlighted research of COPD and the best practices of patient involvement, particularly the newest EFA publication, presented by COPD Working Group Chair, Michael Wilken, while publically attracting attention to the significance of COPD and its harmful effects upon societies and healthcare systems in Europe.



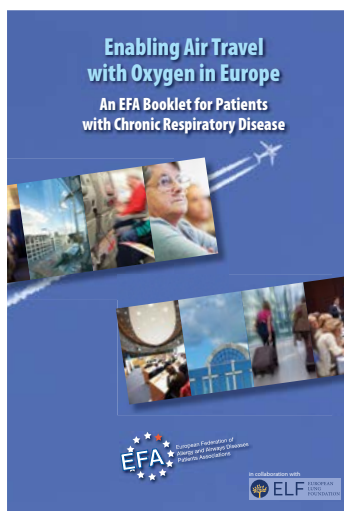
From left to right, ERS Representative Dr. Sylvia Hartl, EFA President Breda Flood and EPHA Secretary General Monika Kosinska (presenting).

## Oxygen Harmonisation Project

Over the course of 2013, EFA completed its single year Oxygen Harmonisation Project, which strived to create a lay-friendly booklet for both patients with chronic respiratory disease requiring oxygen for air travel and flight crews for airlines as primary audiences. After collecting patient testimonies in collaboration with the European Lung Foundation (ELF) EFA examined the accessibility of information to patients through the collection of policies for oxygen therapy use on airplanes for air carriers of each national airline in Europe, including Russia and Turkey. The results of this search were compiled with the patient testimonies into the *Enabling Air Travel with Oxygen in Europe: An EFA Booklet for Patients with Respiratory Disease*,<sup>xiii</sup> which includes an endorsement from the Member of European Parliament (MEP) Keith Taylor from the Tourism and Transport Committee, who led an own-initiative report for passengers rights in air travel.

The booklet evidences ongoing discrimination against passengers requiring the use of oxygen therapy as the research of airline websites clearly reveals certain European airlines may charge up to seven times the normal price of a ticket for even a continental European flight. The booklet, published in September, demonstrates that fees are unnecessary examples of exploitation along the same basis as the previous case of wheelchairs, where handicapped individuals were required to pay additional fees to bring their wheelchairs on board airplanes until 2006.

EFA met with MEP Taylor in October to present the book and patients' concerns as regards their need to fly with oxygen free of charge. MEP Taylor proposed an amendment to a legislative text under discussion at the European Parliament underlining this necessity and signed EFA Manifesto. The 02 Booklet was later presented on World COPD Day at the same public event<sup>xiv</sup> in Brussels as EFA's newest COPD publication. The booklet's findings were presented by Isabel Saraiva, from EFA's Portuguese member RESPIRA, whom as a COPD patient expressed her frustration and outrage at the unjustifiable high costs added to airfares. EFA will continue using the booklet in 2014 and beyond in its fight for ending discrimination against patients.



Discrimination against passengers requiring the use of oxygen therapy is ongoing within the EU.

## Improving care and knowledge through innovative research partnerships

EFA collaborates in key EU research projects in partnership with a wide range of partners. Our role includes ethics, dissemination to patients and policy makers, based on best practice.

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

EFA is a partner in the MeDALL<sup>xlv</sup> 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.

Allergy often starts in childhood and so children are the focus of MeDALL. Information from previous birth cohorts, including 42,000 children in Europe are looked at, and 18,000 are re-examined using similar methods. The annual general meeting of the project was held in Berlin on the 14<sup>th</sup> and 15<sup>th</sup> of January.

EFA's role for 2013 was defined as assisting to communicate and disseminate the project's information, such as article publications, and research results to a wider audience (including policy-makers at the EU level) while preserving a patients' perspective. EFA will also be a contributor in a task led by Professor Tari Haahtela aiming for the development of a template for creating national allergy programme in European countries making a clear link with EFA's own allergy project. While Prof Haahtela will provide a basis for stakeholder collaboration between healthcare practitioners, EFA will be able to contribute to the inclusion of policymakers and patients in the process.

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

AirPROM<sup>xlvi</sup> is a five-year EU-funded project from the FP7, 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 build up a bank of information that can be used to provide patients with a personalised treatment plan through creating a computer model of the lungs to help individual treatment choices.



AirPROM Work Package 9 meeting with Breda Flood, Neil Fitch, Sarah Dowsland, Tereza Reznakova and David Brennan (from left to right).

In April, EFA representatives attended the annual general meeting of the project in Barcelona. EFA is co-leading the project's dissemination work package together with the European Lung Foundation (ELF) and European Respiratory Society (ERS). Activities included the continued dissemination of two distinct AirPROM leaflets targeting scientific and patient audiences respectively. EFA continues with the management of the AirPROM LinkedIn group page.<sup>xvii</sup> EFA also participates in the project teleconferences and EFA's President is the patient representative in the project's Exploitation Committee, which developed the first draft of an exploitation plan for the project results. This is key for patients, whom ultimately the research should serve. In coming years when further interesting results will be revealed EFA will become more involved with communication to the general public to raise the profile of the project among policymakers and patients.



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

U-BIOPRED<sup>xviii</sup> 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 for personalized healthcare.

The annual general meeting was held in Barcelona on the 21<sup>st</sup> and 22<sup>nd</sup> of January and patients had a visible role. An additional face-to-face meeting of the work packages where EFA is a partner (dealing with dissemination and ethics) took place during the 2013 ERS Congress. EFA Board Member Lina Buzermanienė presented U-BIOPRED as a case study for patient involvement at an ERS Congress symposium concerning engagement with patients in healthcare and the media. In 2013, President Breda Flood was invited by the IMI to several of their meetings to highlight patient involvement in U-BIOPRED.



U-BIOPRED Consortium at the 2013 Annual General Meeting.

EFA assisted the dissemination work package (WP9), ethics work package (WP10) and U-BIOPRED Patient Input Platform (PIP) to create an exit questionnaire for participants in the U-BIOPRED clinical trial. The objective would be to ask study participants about their experiences in the clinical trial and identify specific positive and negative aspects of their participation to reflect upon for future initiatives. EFA continued its participation in monthly teleconference calls.

## European Asthma Research and Innovation Partnership (EARIP)

The EARIP<sup>ix</sup> project began in September after its successful proposal to a call from the 7<sup>th</sup> Framework Programme (FP7). With 30 million people suffering from asthma in Europe and treatment costs approaching €20 billion annually, this project aims to reduce asthma attacks, emergency healthcare utilisation and asthma deaths through a coordinated pan-European activity. The result will be a roadmap for asthma research in Europe and a sustainable innovation partnership on asthma to support patient-centred care and innovation.



EFA is a partner in this project, which is led by Asthma UK. EFA attended the consortium kick-off meeting during the European Respiratory Society (ERS) Congress 2013 in Barcelona and is the leader of Work Package 4 (WP4) which concerns recommendations for effective models in health and care system change for asthma. In 2013, EFA already begun to work on the first deliverable with its WP4 partners to engage with an author for a literature review surveying existing national asthma programmes in Europe. In November, with the assistance of Professor Tari Haahtela, leader of the Finnish asthma and allergy programmes, EFA identified Dr. Olof Selroos as a preferred candidate for this task, due for publication in peer-reviewed journal by autumn 2014.

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

The HealthVent<sup>l</sup> 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, we provided patients' perspective and drafted the dissemination plan of these guidelines.



In February, the last consortium meeting took place in Brussels to finalise the findings that were presented at a final event in the European Parliament.

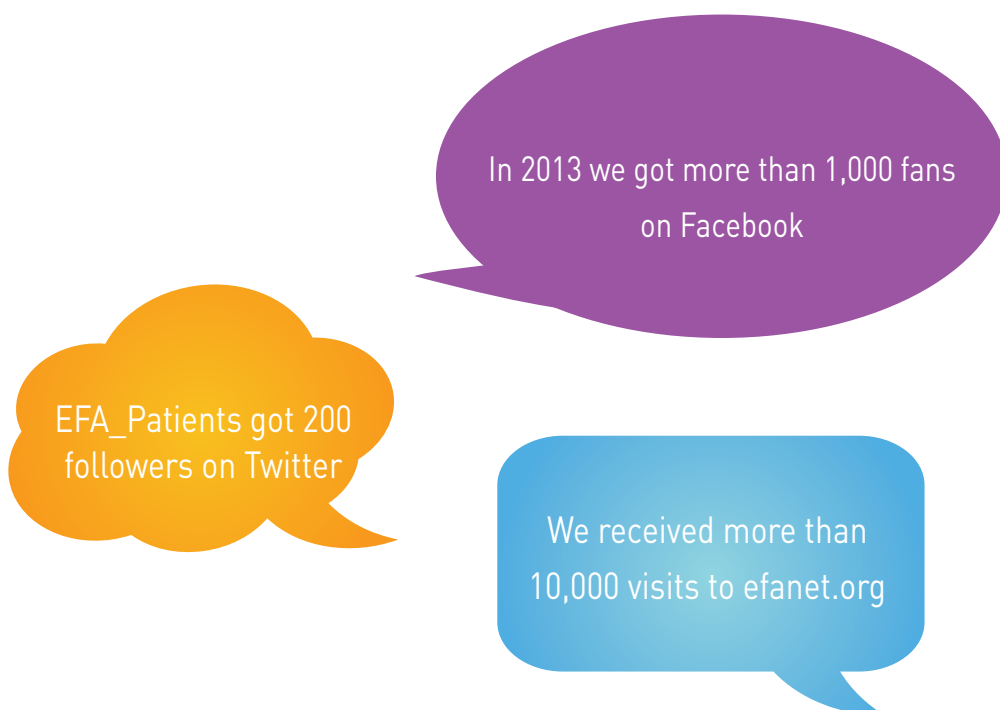
## Increasing awareness through targeted communications

In 2013 EFA continued to disseminate its monthly newsletter, which included a special “summer edition” covering multiple months. EFA also disseminated 9 press releases in connection with our most important work.

We continued this work with the webhost Directbrand and worked on a Social Media Strategy. As a result, EFA actively and steadily increased its participation and visibility in social media, creating a LinkedIn<sup>®</sup> page, opening a Twitter<sup>®</sup> account, establishing a YouTube<sup>™</sup> channel and boosting our Facebook<sup>™</sup> page with a month-long campaign in the Spring targeting a specific profile of Facebook users. As a result, our follower basis experienced a 10 fold increase. EFA also opened an online community for respiratory allergy, food allergy, asthma and COPD with Health Unlocked<sup>lv</sup>; however, its utilization has been limited to date and requires more sophisticated development in coming years.

The [www.efanet.org](http://www.efanet.org) website is the hub of EFA communication and interaction and we managed to capture 11,018 users in that period that stayed an average of 2:16 minutes on our website. As a landmark, EFA created the EFA Manifesto website for the 2014 elections campaign ([www.manifesto.efanet.org](http://www.manifesto.efanet.org)) to promote commitment to the Manifesto and collect signatures from Members of the European Parliament, stakeholders and patients themselves in the run up to the elections.

At the 2013 Networking Day in Rome, Italy, a presentation highlighted uses for EFA members such as a Dropbox for sharing documents, a forum for strengthening internal correspondence between members and a Google calendar application for all members to use if they want to share events. Nevertheless, in 2013 there was no considerable increase in the use of these features and it will need to be further developed and integrated into regular EFA activities before it reaches its potential.



## Strengthening our voice

### Annual General Meeting

The Annual General Meeting (AGM) was held on the 31st of May in Rome, Italy. Our external auditor audited the accounts for the approval of the AGM. During the AGM many important issues were discussed, including the outcomes and feedback on EFA trainings on the EU policy and national allergy programmes, the challenges in applying for core funding from the EU and the draft EFA Membership Strategy. The annual report, workplan and accounts were approved after discussion. During this year's elections three board members were re-elected to the Board. EFA welcomed back Breda Flood President from the Asthma Society of Ireland, Ondrej Rybnicek as Treasurer from CIPA and Per-Åke Wecksell as member from the Swedish Allergy and Asthma Association.



EFA members met in Rome and work together at European level.

The AGM welcomed the application from Respira (Portugal) to become EFA's newest member in 2013 and decided on EFA's short term strategy and work plan. The EFA board met 2 times in Brussels and once in Barcelona in connection of an EU project meeting. In addition, the board had regular meetings via teleconference to keep up with regular business and to give input to the EU core-funding application.

### Networking Meeting

At EFA's third Networking Meeting, held on June 1<sup>st</sup> in Rome, there was an open floor discussion for EFA members to discuss updates of activities from their previous year. Members from Austria, Denmark, Finland, Germany, Greece, Ireland, Norway, Poland, Portugal, Spain, Sweden and the UK shared updates on their newest projects, recent events and awareness raising initiatives. The members were provided with a tutorial on how to use the Members Area of its new website (<http://members.efanet.org>). This session was planned to increase discussions and experience among members.

EFA members also participated in parallel working group sessions on COPD and food allergy, which were later followed by a joint asthma and allergy working group. In the Food Allergy working group, EFA members and EU Policy Officer Roberta Savli discussed potential legislative changes and confirmed a second Food Allergy workshop at the European Parliament in 2014. In the COPD Working Group, the Norwegian Allergy and Asthma Federation presented its case study of COPD patients where personal trainers were assigned to keep patients active with the help of a 'motivator' – another COPD patient – to improve quality of life. Project and Fundraising Officer Antje Fink-Wagner overviewed the fate of the European Parliament's resolution on COPD and facilitated members' discussion of the questionnaire disseminated to collect information for EFA's upcoming publication on *Minimum*

*Standards of Care for COPD Patients in Europe.* Lastly she encouraged members to collect stories for EFA's upcoming publication *Enabling Air Travel with Oxygen in Europe* to have a robust number of testimonies from patients reflecting on the difficulties encountered when traveling with oxygen therapy. During the joint Asthma and Allergy Working Group, members were introduced to the Alert! Paper as well as the Allergy Check pilot project in Vienna, which had been implemented by Otto Spranger of the Österreichischer Lungenunion. He succeeded in rallying pharmacists in Vienna to help their customers correctly manage and seek attention from healthcare professionals for their allergy problems. Giorgio Salerni from Federasma e Allergie expressed interest in following up on this success in Italy for 2014.



EFA member representative from Austria, Otto Spranger presenting at the 2013 Annual General Meeting in Rome.

## Office

In 2013, EFA Office in Brussels had an Executive Officer, part-time Project and Fundraising Officer, full-time EU Policy Officer, full time Membership and Programme Officer and an EU Policy and Programme Intern. 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.

## Expanding EFA's membership

### EFA Meeting with the Maltese Asthma Society – St Julien's, Malta

On September 28th, EFA arranged a meeting with the Maltese Asthma Society (MAS) in St Julien's, Malta after President Breda Flood and Executive Officer Susanna Palkonen were invited to attend an EAACI workshop in the same location. Membership and Programme Officer David Brennan joined for the meeting where EFA presented its core values, most recent activities and future plans in the coming years. The MAS shared their experience in addressing asthma in Malta, where the disease





is both highly stigmatized by the general public and highly prevalent among a large percentage of the society. Although it is a common ailment in Malta, participants believed there is reluctance among patients to address the problem or discuss it openly even with healthcare professionals. MAS confirmed an interest to join EFA in the future and also to potentially expand to unite the patient associations for asthma and allergy while considering to make efforts for including COPD patients as well in the future.

### **EFA Meeting with the Association for Portuguese Asthmatics – Vale do Lobo, Portugal**

EFA's Executive Officer and Membership and Programme Officer traveled to Vale do Lobo, Portugal on October 12<sup>th</sup> 2013, when Susanna Palkonen was invited to give a presentation by the Association for Portuguese Asthmatics (APA) at the annual Portuguese Society of Allergology and Clinical Immunology (SPIAC) conference. The organisations had a meeting which provided EFA with the opportunity to meet members of the APA Board and staff to help reactivate their interest and involvement in EFA's activities following a prolonged period of infrequent interactions. EFA was able to update the APA representatives on its recent work and future plans, while answering their questions and discussing related topics. APA showed EFA its most recent activities with the public most of which were organised locally in Porto. It was also confirmed that close collaboration continues with asthma specialists and researchers at the University of Porto.



### **EFA Meeting with the Association of Parents of Asthmatic Children of Zagreb – Zagreb, Croatia**

In conjunction with a regional meeting of the European Patients Forum (EPF), Roberta Savli used the opportunity of traveling to Zagreb to meet with a patient association representing children with asthma and allergy. The two organisations exchanged information about their recent activities and the participants from Zagreb revealed a similar local organisation is known to exist in Dubrovnik. The organisations are both run by volunteers and they have scarce financial resources. Both associations would feel very grateful to be members of EFA as they currently believe they are quite isolated in their activities and do not know much about what other organisations do in other parts of Europe. They have an interest in pollen monitoring and could be interested to help influence the development of a national programme for respiratory disease as EFA has attempted to promote through its Allergy Awareness Project.



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

EFA continued to provide opportunities for EFA members to participate in the EFA working groups on COPD, food allergy, allergy and asthma throughout 2013. They continue to be opportune moments for EFA members to meet or discuss topics specific to their areas of interest throughout the year outside of the Annual General Meeting and other external events. In addition, the EFA staff regularly updates members and highlights their contributions towards the implementation of EFA projects where applicable. When face-to-face meetings are not possible, the EFA Secretariat continues to poll EFA members to offer a teleconference as an alternative to discuss agenda items.

In 2013, the **Food Allergy Working Group** continued to communicate regularly, with very high attendance and tangible outcomes. In particular, an EFA position on how allergen should be differentiated in the ingredients' list has been adopted (they should be bold) while enhancing the

position on how to provide information on allergen in the case of non-pre-packed food (written information is preferable unless the allergic person is able to speak directly with the person that prepared the food). Finally, a press release<sup>vi</sup> on the need to improve industry's guidance on food allergen management was released in July.

The **COPD Working Group**, chaired by Michael Wilken (PLA-Hannover) convened once by teleconference in April 2013 and twice for face-to-face meetings at the Networking Day in June and in conjunction with an EFA public event on COPD in November. These working group meetings were used as opportunities to exchange updates on their activities and for providing patient perspective and guidance for EFA's COPD and Oxygen Harmonisation Projects. They aided the collection of patient testimonies for the Oxygen Harmonisation Project's publication and encouraged the completion of the patient-centred questionnaire on COPD standards of care for EFA's COPD Project publication in autumn of 2013. At the November meeting, participants prioritized three of the eight minimum standards for COPD patient livelihood in Europe of the eight identified in the publication to focus activities for 2014.

In 2013, the **Allergy and Asthma Working Groups** were coordinated jointly with co-chairs Christine Rolland (Association asthme et allergies) and Lina Buzermanienė (Lithuanian Council of Asthma Clubs). A joint teleconference took place in April, which was followed by a joint meeting during the Networking Day in June. An update of the Allergy Awareness Project activities was provided to members, including EFA member activities such as the Allergy Risk Check pilot project in Austria and briefings of progress in establishing national allergy programmes in Bulgaria, Italy and Norway. The working group also reviewed EFA actions in current EU projects on allergy and asthma, providing information where members could become involved directly. EFA's involvement in a successful proposal for the European Asthma Research and Innovation Partnership (EARIP) was also announced to the working group and advertised ways EFA members could become involved in the future. A new EFA project, such as one focusing on asthma in adolescents between 12 and 17 years old, was also confirmed to be unable to proceed due to low interest from sustainable funding partners, but EFA will still continue to try and run the project in coming years.

## Building capacity for Members

### EFA “Meet and Greet the EU Institutions” training

On the 15<sup>th</sup> and 16<sup>th</sup> of October, EFA organised its fourth “Meet and Greet the EU Institutions” training with a combination of beginner and advanced training, built upon the experience of the previous three events in 2007, 2009 and 2012. The beginner programme covered the decision making process in the EU, main developments in the health policy at the European level and introduced to different roles stakeholders play here in Brussels. Together with advanced participants, the beginners met and greeted key actors from the Commission and the Council working on issues important to them, and also selected Members of the European Parliament (MEPs) from their home countries to present EFA Manifesto for the European Parliament elections for the first time. In total, members met with eleven MEPs and/or people from their staff. A role-play enabled all participants to dig deeper in the EU Tobacco Products Directive case-study and replay the legislative process. Thanks to a workshop on air pollution they got a first-hand experience of the European decision making process on the Commission’s proposal for the revision of the EU Thematic Strategy on Air Pollution.<sup>lvii</sup>



EFA Member representatives Inga Zalnerauskiene, Javier Contreras, Marivy Palomares, Artur Badyda and Giorgio Salerni at the European Parliament.

The goal of the training was on the one hand to give the thirteen members participating 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 patients’ associations can contribute to the EU decision-making process. The overall and long-term objective was to involve, engage and empower EFA members towards advocating for their interests and taking part in the EU legislative process in the future.

The evaluation report is available online on the EFA website<sup>lviii</sup>, while the pictures taken during the training that are uploaded on the EFA Facebook page.<sup>lix</sup> In general, the participants considered the training very valuable and complimented EFA for its organisation.

### **Follow-up Presentation on EU funding for patients groups**

During the 2013 Networking Day on the 1<sup>st</sup> of June in Rome, a guest speaker from the European Patients' Forum (EPF), Walter Atzori, followed up on EFA's presentation at the Networking Day 2012 in Dublin on applying for funding from the European Commission. He emphasised EFA members should not look for EU funding as a way to "raise income" since it will never cover the full costs for an organisation, but it is a way which can help each organisation meet their goals. An EU budget can also offer two key opportunities, which are directly managed EU programmes or structural funds (indirectly managed EU programmes). He confirmed patients' associations can have a role investigating topics related to their interest, recruitment and/or coordination of patients, assurance of patient-centred methodologies, translations into local and lay friendly languages and the discussion of ethical issues. While the presentation encouraged patient associations to become involved in EU funded initiatives, they were also advised to be aware of the heavy workload this involvement would entail.

### **EFA Membership Survey**

In November 2013, the EFA Secretariat disseminated EFA's first Membership Survey<sup>ix</sup> to be completed by each individual member for an updated snapshot into each organisation's current obstacles, expectations from EFA and internal composition. The survey questions range from requesting an estimate of their members, confirming the size of their staff and evaluating their satisfaction with EFA correspondence and activities. An analysis of the survey will be completed into a report and presented at the Annual Meeting in Brussels 2014.

## Secretariat and Governance

### Board

*President*

**Breda Flood**

Asthma Society of Ireland  
E-mail: breda.flood@efanet.org



*Vice President*

**Christine Rolland**

Association Asthme & Allergies, France  
E-mail: ch.rolland@asthme-allergies.asso.fr



*Treasurer*

**Ondrej Rybnicek**

Czech Initiative for Asthma (CIPA)  
E-mail: Rybnicek.O@seznam.cz



*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: lina.buzermaniene@efanet.org



### Office

*Executive Officer*

**Susanna Palkonen**

E-mail: susanna.palkonen@efanet.org



*Project and Fundraising Officer*

**Antje Fink-Wagner**

E-mail: antje.finkwagner@efanet.org



*EU Policy Officer*

**Roberta Savli**

E-mail: roberta.savli@efanet.org



*Membership and Programme Officer*

**David Brennan**

E-mail: david.brennan@efanet.org



*EU Policy and Programme Interns*

George Koukoulakis (February – March 2013)

Tereza Reznakova (March – September 2013)

Jan Meissner (September 2013 –December 2013)

E-mail : info@efanet.org

## EFA Members

The EFA membership 2013 consists of 35 allergy, asthma and/or COPD patient associations or their coalitions in 23 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.

<b>Austria</b>		
Österreichische Lungen-Union		<a href="http://www.lungenunion.at">www.lungenunion.at</a>
<b>Bulgaria</b>		
Association of Bulgarians with Bronchial Asthma, Allergy and COPD		<a href="http://www.asthma-bg.com">www.asthma-bg.com</a>
<b>Belgium</b>		
Astma-en Allergiekoepel vzw		<a href="http://www.astma-en-allergiekoepel.be">www.astma-en-allergiekoepel.be</a>
Fonds des Affections Respiratoires (FARES)		<a href="http://www.fares.be">www.fares.be</a>
<b>Belgium &amp; Luxembourg</b>		
Prévention des Allergies		<a href="http://www.oasis-allergies.org">www.oasis-allergies.org</a>
<b>Czech Republic</b>		
Czech Initiative for Asthma		<a href="http://www.cipa.cz">www.cipa.cz</a>
<b>Denmark</b>		
Asma-Allergi Forbundet		<a href="http://www.astma-allergi.dk">www.astma-allergi.dk</a>
<b>Finland</b>		
Allergia-ja Astmaliitto		<a href="http://www.allergia.fi">www.allergia.fi</a>
Hengityslitto Heli (Pulmonary Association Heli)		<a href="http://www.hengityslitto.fi">www.hengityslitto.fi</a>
<b>France</b>		
Association Asthme & Allergies		<a href="http://www.asthme-allergies.org">www.asthme-allergies.org</a>
Fédération Française des Associations et Amicales de malades, Insuffisants ou handicapés Respiratoires (FFAAIR)		<a href="http://www.ffaair.org">www.ffaair.org</a>
Association Française pour la Prévention des Allergies (AFPRAL)		<a href="http://www.prevention-allergies.asso.fr">www.prevention-allergies.asso.fr</a>
<b>Greece</b>		
Aniksi		<a href="http://www.allergyped.gr">www.allergyped.gr</a>
<b>Germany</b>		
Patientenliga Atemwegserkrankungen e.V.		<a href="http://www.patientenliga-atemwegserkrankungen.de">www.patientenliga-atemwegserkrankungen.de</a>
<b>Ireland</b>		
Asthma Society of Ireland		<a href="http://www.asthmasociety.ie">www.asthmasociety.ie</a>
<b>Italy</b>		
Federasma e Allergie Onlus		<a href="http://www.federasma.org">www.federasma.org</a>
Associazione Italiana Pazienti BPCO (AIP-BPCO)		<a href="http://www.pazientibpco.it">www.pazientibpco.it</a>
<b>Lithuania</b>		
Lithuanian Council of Asthma Clubs		<a href="http://www.astmainfo.lt">www.astmainfo.lt</a>
Association of Allergic Children Clubs		<a href="mailto:jolantakudzyte@gmail.com">jolantakudzyte@gmail.com</a>
Association of Asthma Patient Clubs		<a href="mailto:astma@takas.lt">astma@takas.lt</a>
<b>Netherlands</b>		
Longfonds		<a href="http://www.longfonds.nl">www.longfonds.nl</a>
Stichting Voedselallergie		<a href="http://www.stichtingvoedselallergie.nl">www.stichtingvoedselallergie.nl</a>
Vereniging voor Mensen met Constitutioneel Eczeem		<a href="http://www.vmce.nl">www.vmce.nl</a>

Norway	
Norges Astma- og Allergiforbund (NAAF)	<a href="http://www.naaf.no">www.naaf.no</a>
Poland	
Polish Federation of Asthma, Allergy and COPD Patients' Organisations	<a href="http://www.astma-alergia-pochp.pl">www.astma-alergia-pochp.pl</a>
Portugal	
Portuguese Asthma Patients Association (APA)	<a href="http://www.apa.org.pt">www.apa.org.pt</a>
RESPIRA - Associação Portuguesa de Pessoas com DPOC e outras Denças Respiratórias Crónicas	<a href="http://www.respira.pt">www.respira.pt</a>
Spain	
Federación Nacional de Asociaciones de Enfermedades Respiratorias (FENAER)	<a href="http://www.fenaer.es">www.fenaer.es</a>
Slovenia	
Pulmonary and Allergy Patients' Association of Slovenia (DPBS)	<a href="http://www.dpbs.si">www.dpbs.si</a>
Sweden	
Astma och Allergi Förbundet	<a href="http://www.astmaoallergiforbundet.se/">www.astmaoallergiforbundet.se/</a>
Swedish Heart and Lung Association	<a href="http://www.hjart-lung.se">www.hjart-lung.se</a>
Switzerland	
aha! Allergiezentrum Schweiz aha! Centre d'Allergie Suisse aha! Centro Allergie Svizzera	<a href="http://www.aha.ch">www.aha.ch</a>
Lungenliga Schweiz (Swiss Lung Association)	<a href="http://www.lungenliga.ch">www.lungenliga.ch</a>
United Kingdom	
Allergy UK	<a href="http://ww.allergyuk.org">ww.allergyuk.org</a>

## Project members

Board lead for the MeDALL project	Per-Åke Wecksell, Sweden
Board lead for the U-BIOPRED project	Breda Flood, Ireland
Medical Advisor & Medical leader for EFA Respiratory Allergy Project	Erkka Valovirta, Finland
Medical Advisor of EFA Book on Minimum Standards of Care for COPD Patients in Europe	Professor Jorgen Vestbo, Denmark
European Medicines Agency (EMA) patient experts	Lina Buzermaniene, Lithuania
	Breda Flood, Ireland
	Per-Ake Wecksell, Sweden
	Martine Puhl, the Netherlands
	Michael Wilken, Germany
COPD Patient Advisor to the Board	Otto Spranger, Austria
	Michael Wilken, Patientenliga Atemwegserkrankungen, Germany
Allergy Patient Advisor at EFA Allergy Project	Joanna Bottema, Netherlands Asthma Fonds

## EFA Working groups

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



## Auditors report

As appointed EFA Auditor by the Assembly General Meeting, I checked the annual accounts of the year 2013 of the European Federation of Allergy and Airways Diseases Patients Associations. The financial statements for the year 2013 are established in Euro. Like last year, the bookkeeping is held on a cash-basis. All the documents I verified enabled me to match receipt and expenditure to a supporting document. The financial year closes at a profit brought forward of 574.970,38 Euro. The net result of the year 2013 amounts to 155.210,49 Euro and the balance-total to 709.345,37 Euro. It is my opinion that the balance sheet and the profit and loss account as at 31 December 2013 gives a fair view of the financial situation of the organisation.

Brussels, 15<sup>th</sup> June 2014

Sara CEUSTERS  
Accountant

## Financial report 2013

### Balance sheet at 31<sup>st</sup> December 2013

ASSETS	2013 (€)	2012 (€)	2011(€)
<b>LIQUIDITIES</b>	<b>704.132,20</b>	<b>362.505,69</b>	<b>426.129,25</b>
Current account	292.222,11	152.132,41	253.129,25
Current account	50.444,81	50.444,81	50.444,81
Deposit account	361.465,28	159.928,47	158.631,83
Petty cash account	0,00	0,00	0,00
<b>FURNITURE</b>	<b>2.423,77</b>	<b>908,28</b>	<b>1.816,56</b>
<b>DEBTORS</b>	<b>0,00</b>	<b>0,00</b>	<b>0,00</b>
<b>DEFFERRED CHARGES AND ACRUED INCOME</b>	<b>2.789,40</b>	<b>85.000,00</b>	<b>0,00</b>
Accrued Incomes	0,00	85.000,00	0,00
Deferred Charges	2.789,40	0,00	0,00
<b>TOTAL ASSETS</b>	<b>709.345,37</b>	<b>448.413,97</b>	<b>463.945,81</b>

LIABILITIES	2013 (€)	2012 (€)	2011(€)
<b>RESERVE</b>	<b>574.970,38</b>	<b>419.759,89</b>	<b>339.567,43</b>
Reserve last year	419.759,89	339.567,43	209.56,14
Excess of income over expenditure from current year	155.210,49	80.192,46	130.021,29
<b>DEBTS</b>	<b>134.374,99</b>	<b>28.654,08</b>	<b>124.378,38</b>
Creditors <sup>1</sup>	24.306,25	28.654,08	124.378,38
Taxes on salary	27.226,53		
Social security	51.583,21		
Other social debts	259,00		
Received grants for next year	30.000,00		
Received fees for next year	1.000,00		
<b>TOTAL LIABILITIES</b>	<b>709.345,37</b>	<b>448.413,97</b>	<b>463.945,81</b>

## Income and Expenditure Account (€)

	31/12/2013	31/12/2012	31/12/2011
<b>INCOME</b>	<b>659.820,35</b>	<b>556.721,68</b>	<b>605.930,50</b>
Membership Fees	12.012,00	12.012,00	29.800,00
Partnerships and representation		1.599,90	406,00
Grants	360.000,00	395.000,00	350.000,00
Projects			
EARIP (EU Project)	36.850,00		
U-Biopred (EU Project)	2.494,00	24.000,00	10.412,00
Medall (EU Project)	2.809,16		
Airprom (EU Project)	44.711,50		
GALEN (EU Project)			20.000,00
HealthVent (EU Project)			4.264,00
COPD (EU Project)	98.000,00	30.000,00	140.000,00
Oxygen (EU Project)	25.000,00		
Allergy (EU Project)	75.000,00	50.000,00	50.000,00
EU Project		42.809,16	
Recovery Miscellaneous	1.393,15		
Bank Interests	1.538,31	1.298,14	1.046,51
Difference	11,53	14,48	0,59
<b>EXPENDITURE</b>	<b>504.609,86</b>	<b>476.529,22</b>	<b>475.909,21</b>
AGM & Network Meeting	31.939,12	19.434,06	25.440,46
Board and Membership	12.914,45	28.158,32	17.557,36
Working Groups	6.095,77	4.996,37	2.610,20
Partnerships and representation	16.991,46	16.570,39	13.868,86
Fundraising and communication	51.692,49	51.893,33	54.854,74
Projects			
U-BIOPRED (EU Project)	5.117,56	1.174,51	302,60
MeDALL (EU Project)	1.284,99	448,29	808,10
AirPROM (EU Project)	1247,79	1.015,51	700,81
Health Vent (EU Project)	562,20	1.252,73	1.916,64
COPD (EFA Project)	49.170,64	62.490,46	160.877,36
Oxygen (EFA Project)	13.534,43	23.705,84	
Allergy (EFA Project)	40.208,62	86.242,86	99.914,57
Meet and Greet (EFA Project)	10.807,47	11.311,78	
Other projects	2.021,87		
Food Allergy EP event		6.772,90	
Office costs	52.843,87	60.737,52	29.453,94
Staff	205.677,18	96.732,00	46.000,00
Membership fees	1.900,00	2.550,00	342,68
Bank charges	594,61	930,70	342,68
Difference	5,34	111,65	4,37
<b>Result of the year</b>	<b>155.210,49</b>	<b>80.192,46</b>	<b>130.021,29</b>

## Acknowledgements

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### European Commission

DG Research FP7 projects:	AIRPROM 44.711,5 EARIP 36.850 MEDALL 2.809,16 U-BIOPRED 2.494,7
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### Sustainable industry partnerships

5 Star*****	GlaxoSmithKline – EUR 55.000 Novartis – EUR 55.000
3 Star***	ALK Abelló – EUR 30.000 Almirall – EUR 30.000 Air Liquide Healthcare – EUR 30.000 BoehringerIngelheim – EUR 30.000 Boston Scientific – EUR 30.000 Chiesi – EUR 30.000 Stallergenes – EUR 30.000
1 Star*	Vifor – EUR 10.000

### EFA projects

COPD Project	Almirall EUR 15.000, Air Liquide EUR 12.000 BoehringerIngelheim EUR 12.000 Chiesi EUR 12.000 Novartis EUR 12.000
Allergy project	ALK Abelló EUR 25.000 Stallergenes EUR 25.000
Oxygen Project	Almirall EUR 25.000 Air Liquide EUR 25.000
Meet & Greet the EU Institutions Project	Novartis EUR 15.000

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