

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



## EFA Annual Report 2014

**2014**, the year when EFA patients voted for **health and prevention**





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## Foreword



2014 has been of special importance for EFA and the European Union. EFA implemented for the first time an operating grant from the EU Public Health Programme and thanks to our efforts to strengthen the representation of allergy and airways diseases patients in Europe, we welcomed four new members from Croatia, Ireland, Latvia and the United Kingdom.

Pursuing a Europe where 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, guided our activities to translate evidence and policy into meaningful changes for patients. EFA efforts to increase the healthcare workforce to tackle allergy resulted in a lay version of our Allergy Alert! Paper. We also organised several meetings with airline and airport representatives to discuss the discriminatory practices that some airlines impose on passengers requiring oxygen. We launched a Capacity Building Project to empower EFA member organisations to run their own projects and improve their potential for future involvement in EFA projects.

2014 has been a year of significant developments in the European arena. With the election of the new European Parliament and European Commission for 2014-2019, we presented our Manifesto to the new institutions and got support by more than 1,000 individual patients and almost 50 policy-makers. We accompanied the adoption of the Tobacco Products Directive, a legislation that reflects our priorities to enhance rights of patients with allergy, asthma and COPD. Another crucial legislation aimed at increasing the right of people with food allergies to know what is on their food came into force in December.

In 2014, we gathered the research and respiratory community at the European Parliament to present U-BIOPRED, EARIP, MeDALL and AirPROM EU-funded projects, where we ensure the patient perspective is taken into account in the research process. In particular, we helped to create a Patient Input Platform (PIP) Framework Document within the U-BIOPRED Project that will build on the experience of patients in order to involve them more effectively in EU research.

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 2014, we strengthened our partnership with healthcare professionals, scientists, European respiratory patient groups and environmental organisations, through actions that are highlighted throughout this document.

This report gives an overview of our main activities in 2014. In addition, EFA co-authored several publications and took part either as a speaker or participant in 134 events related to EU policy or to partnership with health care professional associations or other NGOs.

Thank you to all EFA members, our office team, supporting EU policy makers, partners and last but not least, to our eight sustainable funding partners and the European Commission.

We are already looking ahead to opportunities and challenges that 2015 will bring and we will count on your patient expertise and voice to continue working for a Europe where allergy, asthma and COPD patients live healthier and uncompromised lives.

Breda Flood, EFA President

## EFA in brief

The European Federation of Allergy and Airways Diseases Patients' Associations (EFA) is an independent non-profit organisation representing 40 allergy, asthma and chronic obstructive pulmonary disease (COPD) patients' associations from 24 European countries.

Allergy, asthma and COPD are amongst the most common chronic diseases in Europe. Moreover, asthma and allergy are the most frequent chronic diseases in childhood, seriously affecting the quality of life of patients and carers.

Our vision is that European patients with allergy, asthma and COPD live uncompromised lives, have the right and access to the best quality care and a safe environment. Our mission is to be the voice of allergy, asthma and COPD patients at European level enabling patients 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 healthcare professionals, scientists and other stakeholders/NGOs.

EFA activities in 2014 followed our vision and mission with the aim of strengthening the overall position of allergy, asthma and COPD patients in Europe. We seek long-term and meaningful solutions to the issues that the patients we represent face every day. . Moreover, we work to contribute to the prevention of these diseases, bringing the patient perspective to European decisions. More information about our work is available on [www.efanet.org](http://www.efanet.org).

## EFA's core values mechanism



## Activity report 2014

This report showcases EFA's main activities, projects and EU policy and advocacy actions undertaken in 2014. EFA wishes to thank all our partners, whether they are funding or operational partners, as well as our members, for their partnership and support on the initiatives we accomplished in 2014. We look forward to continuing the collaboration towards our common aims to access good quality care, a safe environment and patient participation in an equal way across Europe.

### 1. Advocating at EU level for the needs of people with allergy, asthma and COPD

EFA's role is to ensure that allergy, asthma and COPD patients are involved in all decisions affecting their health at EU level. We empower people with allergy, asthma and COPD to understand, be informed and take active part in the decision making process, through news, briefings, advocacy materials, position papers, responses to consultations, and participation in EU committees. By coordinating our network of patients, EFA contributes to the EU policy making and implementation processes, and creates space for discussions that provide an opportunity for partners from other sectors to come together with a patient-centred agenda.

2014 was a special year due to the election of the new European Parliament and the designation of the new College of Commissioners for 2014-2019, which gave us the opportunity to launch additional campaigns and advocacy activities. Throughout the year, we presented our **Manifesto for the 2014 European Parliament elections** (produced in 2013) to key EU policy-makers, asking them to support EFA's policy priorities aimed to reduce the prevalence of allergy and chronic respiratory diseases, as well as to improve the health of those who already have allergy, asthma and/or COPD. As a result of our network efforts, more than 1,000 people from 30 different countries publicly supported EFA's policy priorities, including 50 candidates and Members of the European Parliament (MEPs), of which 27 were elected. In December, EFA sent out the Manifesto to all new MEPs and the new Commissioner for Health and Food Safety to familiarise them with the priorities of people with allergy and respiratory diseases for the period 2014-2019.

More than 50 candidates and MEPs supported our Manifesto for the EU Parliamentary Elections.



EFA Manifesto was widely supported by patients like Lina Buzermaniene (Lithuania) and Diana Hadzhiangelova (Bulgaria), on the right.  
©EFA/Isabel Proaño

## 1.1 Access to healthcare, improved safety and stronger pharmacovigilance

In 2014, EFA delivered strong input into the EU healthcare initiatives through our consistent involvement at the European Medicines Agency (EMA) and our contribution to the formulation and implementation of several EU legislative files.

Regarding EMA, in 2014 EFA nominated several patient experts to take part in one Scientific Advice procedure for medicines concerning our disease areas as well as in two workshops. We participated in all Patients' and Consumers' Working Party (PCWP) meetings and in the meeting with all eligible patients' and consumers' organisations. Moreover, one of our members took part in the annual EMA training for eligible organisations' representatives, as a means to ensure consistent input from people with allergy, asthma and COPD. In May, we joined the Common Position between Patients', Consumers' and Healthcare Professionals' Organisations on supply shortages of medicines<sup>1</sup> that provided policy recommendations to the European Medicines Agency, national authorities and the industry on the way to avoid shortages that puts patients at risk of a deteriorating health status.

### Contributing to the European Commission 3<sup>rd</sup> Health Programme

In 2014, the European Union adopted the **Third Health Programme** for the period 2014-2020 as the main tool to support the implementation of EU legislation on health and finance projects and not-for-profit organisations aimed at enhancing health in Europe. Built on the experience of the previous two EU programmes for health (2003-2008 and 2008-2013), the 3<sup>rd</sup> Health Programme focuses on reducing health inequalities across Member States by promoting health, encouraging innovation, increasing the sustainability of health systems and protecting Union citizens from serious cross-border health threats. At EFA, we informed patients about this new programme<sup>2</sup>, and we prepared internal briefings for members both on the programme and the implementing work programme for 2014.

We warmly welcomed the celebration of the first **EU Summit on Chronic Diseases** and launched a press release<sup>3</sup> prior to the summit calling for a strategy on chronic diseases with diseases specific best practices. During the event, EFA President and EFA EU Policy Advisor presented EFA priorities and Manifesto to several stakeholders, as well as to Members of the European Parliament and the Italian and Irish Ministers of Health.



EFA President Breda Flood handing EFA Manifesto to Irish Minister of Health James Reilly. ©EFA/Roberta Savli

In October, EFA actively participated **in the 17<sup>th</sup> European Health Forum Gastein**, with our President Breda Flood and EFA Director as speakers and EFA EU Policy Advisor taking part in the Eight Young Forum Gastein. Susanna Palkonen was a panellist in the section on balancing care coordination and patients' choice, organised by the Austrian Federal Ministry of Health and the Main Association of Austrian Social Security Institutions in cooperation with the European Observatory on Health Systems and Policies, where she underlined the patients' freedom of choice when it comes to healthcare professionals. Roberta Savli participated at the Young Gasteiners Forum and together with European Patients' Forum (EPF) Policy Officer Laurène Souchet, she presented the poster "EU Campaign 2014 – When Patients Voted For Health"<sup>4</sup>, showcasing the outcomes of EFA and EPF manifestos' campaigns ahead of the 2014 European Parliament's elections. EFA President presented on a session on EU Scientific Committees (see section 1.5).



Young Gasteiners had the opportunity to discuss with Commissioner-Designate Vytenis Andriukaitis about the future of EU health policies. ©EHFG

MHealth apps should be monitored by competent authorities to make sure they are safe to use.

EFA contributed to the International Primary Care Respiratory Group (IPCRG) submission to the European Commission's (EC) public consultation on the definition of "primary care". We also responded to **the EC consultation on mobile health<sup>5</sup> (mHealth)** to make sure that the interests of asthma, allergy and COPD patients are taken into account by the European Union. In our submission, we underlined that data used in mHealth apps is personal and sensitive, therefore its use should be regulated by advanced legislation. While mHealth has a great potential to empower patients and to reduce healthcare costs, mHealth apps should be monitored by competent authorities to make sure they are safe to use. Finally, research and tests of mHealth apps should involve patients to maximise apps' usefulness.

Regarding access to healthcare, we prepared an internal briefing for members on the **Transatlantic Trade and Investment Partnership Agreement (TTIP)**. Through a public letter, we supported the European Public Health Alliance (EPHA) response to the EC public consultation on the modalities for investment protection and investor-to-state dispute settlement (ISDS) in the TTIP. We are concerned that consumer, health, and environmental regulations could be challenged as violations of "investor rights" by companies with the ISDS mechanism. We underlined the risk posed by the TTIP, that could lead to the harmonisation of safety rules by levelling down, reducing EU higher standards to adapt to US ones, especially as regards environment, health and consumer protection legislations. Finally, we fear that increased intellectual property right protection and enforcement

could result in challenging EMA new policy on publication of clinical trials results and the new EU regulation on clinical trial. Negotiations on the TTIP are still ongoing.

EFA Director Susanna Palkonen was re-elected as European Patients' Forum (EPF) Vice-President during **EPF Annual General Meeting**, in May.



EFA Director Susanna Palkonen and EPF Vice-President Anders Olason, EPF President. ©Michael Chia

## Medical devices

When in early September 2014 European Commission President Jean-Claude Juncker announced his decision to move back the competence for medicinal products and health technologies from the Health Commissioner to the Commissioner in charge of Internal Market and Industry, we were deeply concerned and took action. We believe that medicinal products and the health technology sector belong under the responsibility of the Commissioner for health and, in collaboration with other public health not-for-profit organisations at European level, we asked the President of the Commission to reconsider his decision<sup>6</sup>. As a result of this collaborative pressure, President Juncker kept these portfolios within the competence of the Commissioner responsible for Health.

We continued our advocacy in the process of the revision of the medical devices legislation, which started in 2012. In January, we sent a public letter on the proposal for a regulation on medical devices to Health Attaches on the Council, with the aim of supporting enhanced patients' safety, increased patients' involvement and greater transparency<sup>7</sup>. EFA presented patients' views on the new regulation under discussion at the European Parliament and the Council at two workshops on medical devices jointly organised in January and March by EPF and the MedTech industry association EUCOMED.

For the first time, we participated in the Patients-MedTech Dialogue sessions run by EPF and EUCOMED in March and October. We were also an active member of the EPF-EUCOMED taskforce on the need to have patient-centred medical technology companies: the final checklist was presented in the Seventh European MedTech Forum celebrated in October.

## Putting allergies on the European Union's agenda

Allergies and respiratory diseases are often neglected conditions. At EFA, we have defended for decades the need to adopt holistic approaches to address those diseases and in January 2014 EFA, together with our long-lasting partner European Academy of Allergy and Clinical Immunology (EAACI), issued a press release<sup>8</sup> calling on the European Commission to coordinate efforts to tackle allergy in Europe. The call was built on the European Parliament's Written Declaration on allergies that was proposed in 2013 by 11 Members of the European Parliament (MEPs). In our efforts to raise awareness about allergy prevalence in Europe, we joined EAACI's skin prick test action at the European Parliament in Brussels and we strongly called for actions to relieve the burden of allergic disease. This activity was reinforced by the attendance of two of our members to the January plenary in Strasbourg, where they campaigned for the Written Declaration, signed by 177 MEPs. Even though the document was not adopted, the mandate of almost two hundred MEPs was strong enough to continue efforts to make the lives of people with allergies better and uncompromised.

Almost 200 MEPs supported our written declaration on the burden of allergies.



In January, more than 350 people from the European Parliament were examined for sensitivity to the most common allergens, and 47% of them tested positively ©EFA/Jan Meissner

As a follow-up, one of the proposers of the written declaration, MEP Sirpa Pietikäinen (Finland, EPP) organised a lunch meeting on the 16th of July at the European Parliament in Strasbourg with other MEPs and interested stakeholders to set a European Parliament Interest Group on Allergy and Asthma. Since then, EFA and EAACI have worked for the establishment of the Interest Group that was formalised in December. EFA and EAACI will run the secretariat of the group.

## 1.2 Food labelling

In the near future, up to 17% of the European population could suffer from some kind of allergy to food and there are currently 3.5 million under 25 years old living with food allergy. In September, ahead of the entry into force of the new EU food information to consumers' regulation, EFA in collaboration with EAACI joined forces to advance on the means to prevent allergic reactions and organised an event at the European Parliament to bring attention to the food labelling novelties to improve allergens information provided to consumers. The event called "Eating safely: round-table on European best practices on allergens labelling ahead of the entry into force of the Food Information to Consumers regulation"<sup>9</sup>, was hosted by MEP Renate Sommer (Germany, EPP), rapporteur of the latest food labelling regulation at the European Parliament. The event gathered 60 participants from 15 countries including key representatives from the EU institutions, national food safety and health authorities, healthcare practitioners, food industry and patients, who presented the best practices and implementation of allergens labelling in different Member States. During the event, representatives from the EU and national institutions stated their commitment to better label allergens present in food and shown their willingness to better regulate the issue of cross-contamination of allergens in processed foods<sup>10</sup>. More than 10 EU umbrella organisations attended the meeting.

EU institutions and national representatives committed to better label allergens present in food.

The recommendations issued from the event at the European Parliament were brought to the 8th European Food and Feed Law (EFFL) conference in Vienna in October, where EFA Policy Advisor presented on the need to have better labelling in Europe to empower people living with food allergies<sup>11</sup>.



During the event MEP Sommer stressed that "People have the right to know if the ingredients they cannot eat are present in the food they eat". ©David Plas

### 1.3 Tobacco control

EFA continued its advocacy efforts to **get stricter tobacco control** legislations throughout 2014. We activated our network of national associations to urge the Members of the European Parliament from their home country to support the tobacco products directive (TPD) in the European Parliament plenary vote in February<sup>12</sup>. As a result of the joint efforts of our network of members and partners, the provisions of the new directive represent an important milestone for European public health<sup>13</sup>. Bigger combined health warnings, harmonisation of some aspects of cigarettes' packs and banning on all flavours are among the main changes introduced by this legislation aiming to better protect Europe's children from taking up the deadly habit of smoking. We prepared a briefing for our members following the entry into force of the directive in May<sup>14</sup>, encouraging them to monitor and influence the implementation of the new measures at national level.

Given that this new legislation leaves room to regulate some tobacco products, such as electronic cigarettes (e-cigarettes), EFA called for further legislation to ensure the patients and consumers' interests are protected from e-cigarettes marketing and consumption. We participated in the European Network for Smoking and Tobacco Prevention (ENSP) **Network Meeting and General Assembly** in Bucharest to discuss the implementation of article 20 of the TPD, which regulates e-cigarettes. Conscious of the challenges posed by the wider use of electronic cigarettes, EFA developed together with ENSP a guide with recommendations to Members States on the implementation at national level of the new rules on electronic cigarettes set out in the TPD<sup>15</sup>.



EFA Policy Advisor Roberta Savli (in green) brought the respiratory patients' views regarding electronic cigarettes to the ENSP AGM in Bucharest. ©ENSP

At national level, our contribution to make tobacco control a reality was materialised through our contribution to **the Irish Public Health (Standardised Packaging of Tobacco) Bill 2013**, submitted together with our member Asthma Society of Ireland in January<sup>16</sup>. Our concerns about tobacco use and marketing in Europe were fully embraced by the Irish authorities and we warmly welcomed the Irish legislative proposal that aims at protecting people, and especially children, from tobacco-related diseases and deaths. Moreover, the legislation foresees the introduction of plain standardised packaging in tobacco products sold in Ireland, something that we fully supported.

At global level, EFA was invited for the first time to present the patients' perspective at the Sixth European Conference on Tobacco or Health, celebrated in Istanbul in March 2014. EFA provided the patients perspective and the right of the most vulnerable groups to be protected from second-hand smoke at a pre-congress workshop on "**Smoke-free environments from the Human Rights perspective**" organised by ENSP<sup>17</sup>. During the Congress, we also presented our Manifesto to raise awareness on the need to improve the lives of people with allergy, asthma and chronic obstructive pulmonary diseases (COPD) in Europe, whose health is seriously affected by tobacco.

In 2014 we participated also in the drafting of the new edition of the **World Tobacco Atlas** by providing the patients' views on tobacco and health, and we also joined forces with the World Health Organisation (WHO) on the **World No Tobacco Day** to call on European leaders to use taxation measures to decrease tobacco consumption in the region.<sup>18</sup>

#### 1.4 Better air quality, indoors and outdoors

Following the European Commission's proposal of the new **Clean Air Policy Package**, in 2014 EFA continued advocating for improved air quality, outdoors and indoors in Europe. We multiplied our efforts to present the patients' perspective to several political bodies involved in the revision, such as our submission in May to the experts/stakeholders consultation launched by the Committee of Regions or the letters we shared with our members addressed to their Ministers of Environment before the May EU Environment Council meeting. We kept our Members informed and engaged in the discussions, through updates and briefings on the revision of the National Emission Ceilings (NEC) directive and we secured Parliament engagement on this issue through two advocacy meetings with MEP Piernicola Pedicini (Italy, EFDD and shadow-rapporteur for the EFDD political group for this dossier) and MEP Bart Staes (Belgium, Greens).

With the new College of Commissioners in place, the EU Clean Air Policy was threatened of withdrawal. To avoid this catastrophic scenario, we joined forces with other European umbrella organisations working on health, environment and climate change and called for the continuation of the revision of the **National Emissions Ceiling Directive** (NEC)<sup>19</sup>. The Commission responded positively and we expect that in 2015 allergy, asthma and COPD patients' air quality needs will be taken into account when reviewing the legislation.

[knowyourairforhealth.eu](http://knowyourairforhealth.eu) provides patient-friendly information on air quality to allergy, asthma and COPD patients.

For the **World Asthma Day 2014**, we chose to provide patient-friendly information on air quality to allergy, asthma and COPD patients and carers together with our partner Health and Environment Alliance (HEAL). We issued a press release<sup>20</sup> to support the revamp of the [www.knowyourairforhealth.eu](http://www.knowyourairforhealth.eu) website that we updated with new information and translated into English, German, Italian, Polish and Spanish<sup>21</sup>.

EFA participated in **HEAL Annual General Meeting** in October where EFA EU Policy Advisor was re-elected in the HEAL Executive Committee and took over the function of Treasurer.



## 1.5 Chemicals

In 2014, EFA started working in the field of chemicals to limit the exposure of people with asthma, allergy and COPD, and therefore improve their daily life. As part of this new policy strategy we responded in May to the European Commission consultation on fragrance allergens in cosmetics<sup>22</sup>. To ensure a comprehensive approach on citizens' safety, we recommended including respiratory allergens contained on cosmetics, in addition to contact ones, and to focus not only on fragrances but also on preservatives. We also encouraged the Commission to further regulate the mix of fragrances that could be more problematic for allergic people than single products.

As a consequence of our active involvement on this topic, EFA President was invited to speak in the workshop "Building EU health policy for the future II", focused on the work of EU Scientific Committees and how civil society groups can contribute to their outcomes. The workshop was organised in October during the 17<sup>th</sup> European Health Forum Gastein by the European Commission Directorate-General for Health and Consumers.

## 1.6 Research

Patient participation in research projects ensures that scientific outcomes address patients' needs as their involvement in research helps finding common ground in the establishment of research priorities. EFA has participated in several EU-funded research projects over the years, and continued its involvement in 2014 by providing constant and increasing involvement of patients across the research processes.

### Patient's crucial role in EU research projects

The importance of patients' involvement in research was discussed in detail at a European Parliament event called "Does innovative research for allergy and respiratory diseases in the European Union benefit patients?"<sup>23</sup>, organised by EFA.

Hosted by MEPs Catherine Stihler (S&D, UK) and Petru Luhan (EPP, Romania), patients', policy-makers, healthcare professionals, industry, and research institutions discussed how patients and researchers can work together on EU research projects and how patients' needs and priorities can be incorporated in the new EU research framework.



Asthma, allergy and COPD patients from different countries participated in the European Parliament event presenting ongoing research on allergy and respiratory diseases. ©David Plas

The speakers provided an insight into the development of four EU-funded research projects (U-BIOPRED, MeDALL, AirPROM, and EARIP) where allergy and respiratory diseases patients are actively participating. The diversity of these respiratory research projects demonstrated the utility of EU-funded projects for patients and how patients can meaningfully shape projects to produce better outcomes that will positively impact their daily lives.

The added value of patient involvement can lead to further investment on research initiatives directly targeted to respond to patients' needs.

EU representatives involved in the discussion supported the integration of patient priorities in the EU research agenda and stated that the added value of patient involvement can lead to further investment on research initiatives directly targeted to respond to patients' needs.

### Patients' involvement setting the Horizon 2020 research agenda

Since 2014, EFA Director Susanna Palkonen is a patient representative in the strategic work of the Scientific Panel for Health (SPH) of the Horizon 2020 programme. The Scientific Panel for Health is a science-led stakeholder platform that elaborates scientific input concerning societal challenge. The panel will provide a scientific analysis of research and innovation bottlenecks and opportunities and will contribute to the development of future European health research and innovation policy so that research results translate into benefits of citizens. From 2014 Susanna Palkonen also participates in the ERACoSystMed Scientific Advisory Group, focused on systems medicine.

## 2. Creating patient driven projects and sharing best practices

EFA coordinates member organisations to work together on priority issues, exchange experiences and channel input into our activities through EFA's disease specific Working Groups (allergy and asthma, food allergy and COPD) as well as through EFA specific projects.

### 2.1 EFA working groups

EFA Working Groups (WGs) provide opportunities for members to network and exchange best practices, hold discussions on relevant but complex topics, build capacity, and remain updated on the activities and EFA projects and EU projects plans.

**EFA Food Allergy Working Group** provides guidance on the field of food allergy and patients' representation. Chaired by EFA EU Policy Senior Advisor Roberta Savli, the WG is composed of 13 active food allergy experts representing 10 EFA members. In 2014, the WG held a teleconference in May and two face-to-face meetings in June and September that guided the advocacy initiatives highlighted below.

Concerned about the European Commission approach to rapeseed, the group sent a letter to five MEPs – Renate Sommer (Germany, EPP), James Nicholson (UK, ECR), Frederique Ries (Belgium, ALDE), Pilar Ayuso (Spain, EPP) and Mark Demesmaecker (Belgium, ECR) – to express its disappointment with the Commission draft decision to label foods containing rapeseed protein (a novel food) with a statement highlighting that the products may cause allergic reaction to consumers who are allergic to mustard. In the views of food allergy patients, this labelling based on assumed cross-reactivity is not acceptable: either rapeseed protein is considered as an allergen and therefore treated according to the new food information to consumers' regulation's provisions or it is not and thus no special label is needed. In the position of the WG, information about possible cross-reaction is best handled as a patient education issue.



EFA Food Allergy Working Group is composed of 13 active food allergy experts representing 10 EFA members. ©EFA/Isabel Proaño

Regarding the European Food Safety Authority (EFSA) public consultation on the draft Scientific Opinion on the evaluation of allergenic foods and food ingredients for labelling purposes, EFA responded based on the WG recommendations<sup>24</sup>. Our contribution was focused on the need to establish thresholds to maximise consumers' safety and on precautionary labelling to be used only as an ultimate solution after the correct implementation of best-practices to avoid cross-contamination. In the same line, in December, we responded to the European Commission public consultation on the Guidelines relating to the provision of information on substances causing allergies or intolerances as listed in Annex II of the food information to consumers' regulation<sup>25</sup>. We reiterated that the ingredients' list should always be compulsory (irrespective of the size of the pack and both for pre-packed and non-pre-packed food) and we stressed that the names of the substances listed in Annex II should always be mentioned, with specific names used only as a useful addition (for instance, in brackets).

In 2014 we showed our concerns about the changes on the use of precautionary labelling by Alpro, one of the biggest suppliers of soya products in Europe, which could have resulted in decreased quality of life and life-threatening consequences for many people with food allergy<sup>26</sup>. The company decided in August to gradually remove the "may contain" labelling and established two production lines, one for soya products and the other for nuts, to eliminate any possible cross-contamination and avoidable risk for people with food allergy.

Over the course of 2014, **EFA joint Asthma and Allergy Working Group** held a teleconference in May and a face-to-face meeting in June. The group, chaired by EFA Board member Christine Rolland, is composed of 22 active asthma and allergy experts representing 18 EFA members.

In the framework of the EFA Allergy Awareness project, members of the Working Group discussed further steps in the implementation of the "Allergy risk check in pharmacy" survey at national and regional levels, after the success of the pilot project in Vienna. Following the example of Lungenunion (Austria), FederASMA e ALLERGIE Onlus (Italy) adapted and disseminated the survey in the Italian region of Liguria. Their experiences were shared in major healthcare events, to facilitate the process in other European countries (see section 2.2).



Giorgio Salerni (Federasma e Allergie Onlus) shares samples of the Allergy Risk Check questionnaire during the Allergy and Asthma Working Group meeting in June. ©EFA/Isabel Proaño

**EFA COPD Working Group** also met several times in 2014, in April via teleconference and face-to-face in June. The COPD Working Group gathers 10 active patient volunteers, representing nine EFA members, and is chaired by EFA Member Delegate Michael Wilken. This Working Group (WG) especially focuses on prevention and early diagnosis of COPD; healthcare access and care inequalities in Europe; rehabilitation; tobacco control and quitting support and the promotion of active lifestyles. In 2014, the WG members decided to focus their work and discussions on three out of the eight minimum standards that we identified in the EFA Minimum Standards of Care for COPD in Europe Book. The three standards will be further developed through EFA's harmonisation survey to be published in 2015 (see section 2.2).

The COPD Working Group also discussed EFA's Oxygen Harmonisation project. In 2014, EFA developed a passengers' complaint survey to get a better picture of where and how patients were experiencing discriminatory practices when travelling by plane with medical oxygen. The survey was developed together with the European Disability Forum (EDF), the European Organisation for Rare Diseases (EURORDIS) and EFA members, and it will serve as an indicator for the handling of medical oxygen of airline and airport staff (see section 2.2).

## 2.2 EFA projects on allergy, COPD, oxygen, and asthma

In 2014, EFA continued its commitment to implement patient-led projects to address specific gaps in each of our disease areas. The activities we initiated widely involved EFA members' input and participation and resulted in the creation of tools that serve to inform EFA advocacy actions and asks, as well as to raise awareness among EFA's target groups.

During the year 2014, we achieved high visibility through our **Allergy Awareness project**. The results of the Allergy Risk Check that we supported in 2013 in Austria, a project that provided an insight of the pharmacists' role delivering allergy treatments, were presented at the European Academy of Allergy and Clinical Immunology Congress (EAACI) and later published in the EAACI Atlas of Allergies<sup>28</sup>.



EFA Austrian Member Otto Spranger presented the results of the Allergy Risk Check at EAACI Congress in Copenhagen. ©EFA/Antje Fink-Wagner

In terms of European advocacy, we distributed a lay version of our Allergy Alert! Paper calling for a specialisation on allergology and the increase on the number of allergy professionals that was cascaded among national authorities<sup>29</sup>. Given the importance of investing more on clinical and medical capacities to tackle allergy, the paper was endorsed by the Allergic Rhinitis and its Impact on Asthma (ARIA), EAACI, the International Primary Care Respiratory Group (IPCRG) and the European Union of Medical Specialists (UEMS). The paper will be presented in several European countries to urge for the harmonisation of pre- and post-graduate medical education in the field of Allergology.



A delegation formed by Giovanni Passalacqua, Sandra Frateiaci, Monica De Simone, Giorgio Salerni and Filomena Bugliaro presented the Allergy Alert! Paper to the Italian Ministry of Health.  
©Federasma/Roberta Savli

At national level, Italian EFA Member FederASMA e ALLERGIE Onlus organised a meeting with representatives from the Italian Ministry of Health in Rome in December to present them with the requests issued in the Allergy Alert! Paper. EFA Senior Policy Advisor, Roberta Savli, introduced EFA's work and the Allergy Awareness project, while FederASMA e ALLERGIE Onlus, together with representatives from ARIA, discussed the Allergy Alert! Paper recommendations, especially how they could be adapted to the Italian context and the pathways for promoting the action through the Italian institutions.

Norway, Italy and Bulgaria have shown interest in developing a national programme on allergy.

EFA members in Norway and Bulgaria were also active promoting the requests of the Allergy Alert! Paper. In Norway, authorities are willing to act at national level to establish a national programme on allergy and Norges Astma- og Allergiforbund (NAAF) took part in discussions and consultations. In Bulgaria, the Association of Bulgarians with Bronchial Asthma, Allergy and COPD (ABBA) organized a stakeholder meeting and approached the representatives of the newly elected government to introduce the request of the Allergy Alert! Paper.

Austrian COPD patient Guenter Hirsch explained the obstacles he faces when air travelling and pledged airlines and airports to facilitate and reduce the costs of medical oxygen on board.  
©EFA/Isabel Proaño



In the framework of EFA's 2013 **Oxygen Harmonisation project**<sup>30</sup> that was integrated within **EFA's 2014 COPD project**, EFA organised a meeting with patients, airlines and airport representatives in October to discuss the discriminatory practices that some European airlines enforce on passengers requiring oxygen therapy. To raise awareness about the inequalities and obstacles that affect COPD patients when travelling by plane needing supplemental oxygen, we presented the findings of the Oxygen Harmonisation booklet<sup>31</sup> at a COPD poster session during the European Respiratory Society Congress (ERS) Congress, a great opportunity to inform healthcare professionals about the social dimensions affecting COPD patients' lives. We also used the occasion of the 2014 World COPD Day to launch a press release<sup>32</sup> at EU and national level explaining the situation for COPD patients needing to travel in Europe and asking public authorities, airports and airlines for changes to enable air travel with medical oxygen.



EFA Corporate Relations Manager Antje Fink-Wagner presented EFA's research "Enabling air travel with Oxygen in Europe" at ERS Congress in Munich. ©EFA/Isabel Proaño

Building on the momentum created by the 2013 EFA Book Minimum Standards of Care for COPD Patients, we conducted a survey on "Harmonising prevention and other measures for COPD patients across Europe". A report of the survey will be published in 2015 to guide EFA Members advocacy efforts when meeting with national health insurance organisations with the aim to discuss the reimbursement policies existing to cover for the treatment of COPD patients.

In 2014, EFA launched two new projects. The **Asthma Health Literacy Project for Adolescents** aims at developing a set of recommendations and guidelines to improve treatment adherence of adolescents with asthma. In 2014, the Maastricht University produced a literature review on non-adherence to treatment among adolescents with asthma in the age of 12-17. Based on the literature review, we developed a pilot questionnaire focused on adherence, socio-demographic factors and personal characteristics to investigate the factors that hinder or enable young people between 12-17 years to adhere to their treatment. We then designed a wider survey that will be developed in four EU countries. The results of this research will be published soon and will be used to ensure better support to young people with asthma in Europe.

**EFA Capacity Building project** was launched in 2014 to increase expertise and capacity in EFA Member organisations. Throughout the year, EFA team organised three Capacity Building sessions targeted to several Members' needs in Italy, Lithuania and Portugal (see section 7.1).

### 3. Improving care and knowledge through partnerships and research

Our continuous cooperation with healthcare professionals, scientists, health and environment NGOs and other stakeholders strengthens EFA's voice towards policy-makers, patients and the public of the latest policy and scientific developments in our disease areas.

#### 3.1 Strengthening partnerships for policy change

EFA maintains numerous **partnerships** covering our disease areas and our policy priorities. In 2014, EFA continued its long-standing collaboration with partner organisations, such as the European Patients' Forum (EPF), European Academy of Allergy and Clinical Immunology (EAACI), the European Respiratory Society (ERS), Health and Environmental Alliance (HEAL) and the European Network for Smoking Tobacco Prevention (ENSP). Since 2006, EFA Director Susanna Palkonen has served as EPF Board Member and in 2014 she was re-elected as EPF Vice-President. Moreover, EFA EU Policy Advisor Roberta Savli is also member of the EPF Policy Advisory Group (PAG) and was re-elected Member of HEAL Executive Committee as Treasurer.



In 2014 we partnered among others with EPF, EAACI, ERS and IPCRG (from left to right).

In 2014, EFA reinforced its contacts with other health and environment non-governmental organisations, such as the European Environment Bureau (EEB) and the European Public Health Alliance (EPHA). In addition, our participation in events in Brussels and elsewhere has enabled EFA to be in contact with a wide range of partners and to start fruitful working relations with them.

Within the framework of **multiannual patient-centred EFA projects**, EFA collaborated with the European Disability Forum (EDF) and Rare Disease Europe (EURORDIS) on the transport of passengers that require assistive equipment and/or oxygen when travelling. Moreover, the European Academy of Allergy and Clinical Immunology (EAACI), the European Union of Medical Specialists (UEMS), Allergic Rhinitis and its Impact on Asthma (ARIA) and the International Primary Care Respiratory Group (IPCRG) jointly endorsed our Allergy Alert! Paper to promote its requests to national ministries of education and health, an EFA initiative (see section 2.2).

Also in 2014, EFA strengthened its relation with sister patients' organisations Cystic Fibrosis Europe (CF-Europe), Lung Cancer Europe (LuCE) and Pulmonary Hypertension Association (PHA) through a coordination meeting that aimed at joining efforts within the EU level respiratory disease patient community.

### 3.2 Ensuring the patients' perspective in EU-funded projects

In 2014, EFA continued to promote active patients' involvement in high-level research projects through Seventh Framework Programme on Research and Innovation (FP7) projects on better care and innovation. EFA aims at the inclusion of the patient perspective in all research activities and at the translation of research outcomes in meaningful benefits for patients. EFA's role in EU funded projects is mainly focused on communication, dissemination and exploitation of the project results and we actively participate and advice ethics/exploitation committees.



Within the **U-BIOPRED project** (Unbiased BIOMarkers in PREdiction of respiratory disease outcomes), EFA collected inputs from the project Patient Input Platform (PIP) on patient experts' participation in the development of project results. We analysed the data received and produced a framework document that showcases a collective storyline reflecting PIP members role within the platform as well as the patients' input at different stages of the project. This framework will guide patients' involvement in U-BIOPRED and other EU projects.



In the **MeDALL project** (Mechanisms of the Development of Allergy), EFA created a stakeholder database that will be key to the implementation of the Finnish Allergy Programme in other EU countries. We also participated in the MeDALL/AIRWAYS ICPS<sup>33</sup> meeting at the Ministry of Health and Care Services of Norway, where consortium partners presented MeDALL results to date and discussed the exploitation of the Finnish Allergy Project in other countries (Norway in particular) and the integration of the work done within MeDALL in other projects/initiatives.



Within the **AirPROM project** (Airway Disease Predicting Outcomes through Patient Specific Computational Modelling), EFA published a booklet<sup>34</sup>, launched at the European Respiratory Society Congress in 2014, presenting the project and lung modelling techniques applied. EFA also contributed to the promotion of AirPROM outcomes and findings through social media, and supported the creation of a series of interviews with other consortium partners on the outputs of the project and the future benefits it will bring to patients. These activities were reinforced by our continued involvement in the AirPROM Project Exploitation Committee through EFA President, Breda Flood.



Led by EFA Member Asthma UK, the **EARIP project** (European Asthma Research and Innovation Partnership) aims at pulling out efforts to fill in research asthma gaps in Europe. In 2014 EFA collected relevant literature on existing asthma programmes and compared them in the manuscript "National and regional asthma programmes in Europe: a systemic review". The manuscript has been submitted to the European Respiratory Review and will be published in 2015.



In addition, the proposal for the **myAirCoach project** to develop a mobile health device to improve self-management in asthma was successful. As part of the consortium we lead the dissemination package. The project will run from 2015-2017 and will be funded under the Horizon 2020 programme.



EFA Director Susanna Palkonen presented the European asthma programmes manuscript during EARIP Partners meeting celebrated in September in Munich. ©EFA/Isabel Proaño

### 3.3 Coordinating actions with other EU level respiratory patients' groups

Conscious of existing coordination and communication gaps between different European umbrella organisations representing chronic and rare respiratory diseases patients, EFA organised the first coordination meeting between EU-level respiratory patient groups with the objective of joining forces.

During the meeting organised in the framework of the European Respiratory Society Congress<sup>35</sup>, Cystic Fibrosis Europe (CF-Europe), Lung Cancer Europe (LuCE) and EFA demonstrated an interest in future collaboration and plans to strengthen the patients' voice at European level on cross-cutting issues. Given the success of this meeting, EFA plans to host similar events in 2015.



From left to right, Mogens Ekelund (LuCE), Hilde de Keyser (CF-Europe), Isabel Saraiva (EFA), Breda Flood (EFA), Susanna Palkonen (EFA) participated in the alignment meeting. ©EFA/Isabel Proaño

## 4. Increasing awareness through targeted communications

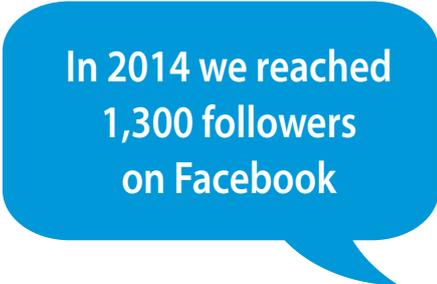
EFA strives to generate and disseminate health information and knowledge, and to promote health within the European region. In 2014, EFA communication activities continued to be focused on these objectives to ensure the right of people with allergy, asthma and COPD to the highest level of healthcare quality and life.

With the incorporation of a Communications Officer in 2014, EFA launched a self-assessment process to evaluate the pertinence, use and impact of each of its communication tools. A Visual Identity survey was circulated among all members and partners and, as a result, EFA decided to reshape its branding and communication tools to raise visibility at EU and national level and to provide more user-friendly tools to its members.

EFA's core dissemination tool is the **website** ([www.efanet.org](http://www.efanet.org)). During the course of the year, EFA published 91 new web articles showcasing EFA's own activities (projects, publications, events), and providing the latest insights on European-related policy. EFA's website served as a directory for asthma, allergy and COPD patients' associations in Europe, and visitors increased by 25.32%.

By using social media, EFA aims at interacting directly with patients, carers as well as with other organisations representing patients. In 2014 we shared events, publications and photos of our activities through EFA **Facebook page** (<https://www.facebook.com/EFAPatients>). As a result, by the end of 2014 EFA Patients had a total of 1,300 followers.

Since February 2013, EFA uses a **Twitter account** ([https://twitter.com/EFA\\_Patients](https://twitter.com/EFA_Patients)) to raise the profile of allergy, asthma and COPD patients' needs at European level. In 2014, our hashtag #EFAManifesto served as a tracking tool to call on Members of the European Parliament (MEPs) to support our Manifesto for the European Parliament elections. We also used Twitter to flag our vision during public events in real time, through the hashtags #patientsvoice, #EFAEvent and #EFAMeeting. By communicating about EU developments in relation to our diseases areas, in 2014 alone we managed to increase our followers by 175%, half of them being official corporate accounts.



In 2014 we reached  
1,300 followers  
on Facebook



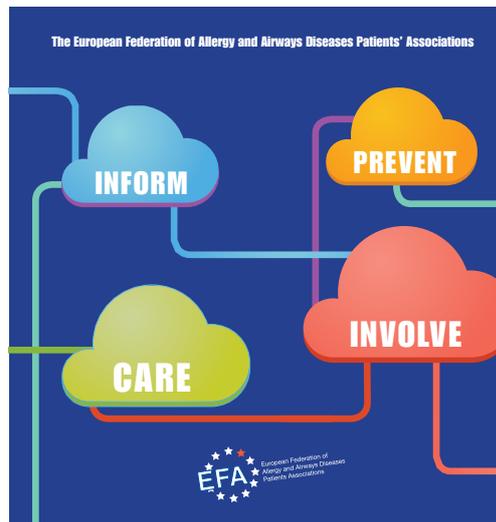
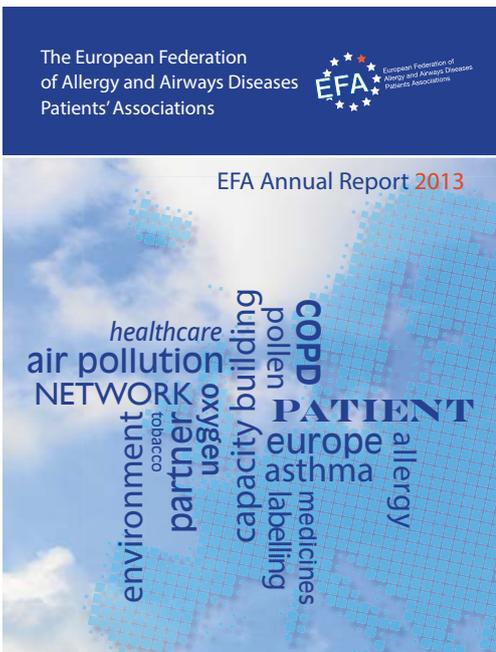
Our followers  
on Twitter increased  
175% in 2014

We also used our monthly **EFA newsletter** to update on EU policy developments, EFA's projects, the evolution of EU funded projects, sharing members' success stories and informing about EFA's representation in key events.

In 2014, EFA revised and redesigned its corporate leaflet and the accompanying folder<sup>36</sup>. In addition, we published our 2013 Annual Report with the approval of the Annual General Meeting held in June in Brussels. This is the first EFA report that has been distributed also with hard copies<sup>37</sup>.

EFA also prepared visual materials for the EU projects event (web banner, poster, invitations) and the food labelling event (web banner poster, invitations), held at the European Parliament.

Finally, in 2014 published eight press releases, either alone or in partnership with other organisations to bring attention to the asthma, allergy and COPD patients' perspective on ongoing policy discussions and events, international days or developments of interest to European patients.



## 5. Governance: strengthening our voice

In 2014, EFA extended its office capacity and developed expertise in communication and financial management. This added significant value to the implementation of EFA's European Commission operating grant and the development and implementation of EFA's communication and dissemination strategy.

EFA's Board met face-to-face four times, reviewed progress and prepared for the Annual General Meeting (AGM). In interim, the Board had one hour teleconferences to deal with urgent issues, as well as by email.

The AGM provided a platform for a strategic planning workshop with EFA members. Complemented with the outcomes of an external evaluation procedure of EFA's core-programme, the exercise established the foundation for EFA's Strategic Plan 2015-2020. The Network Meeting that followed this session fostered dialogue, exchange and collaboration among EFA's network of members to support the development of members' capacity and motivation.

### 5.1 Annual General Meeting and Network Meeting

The 2014 **Annual General Meeting (AGM)** took place in Brussels on June 16<sup>th</sup> and was attended by 31 EFA Member Delegates representing 57,9% of EFA membership<sup>38</sup>. Five organisations from different EU countries applied for EFA membership, and four were accepted by Members (from Croatia, Latvia, Ireland, UK). In 2014, EFA's membership increased to 38 associations in 24 countries, including two new countries from lower EU gross domestic product rates (GDP). A new Board was elected, consisting of both experienced and new EFA Board members, crucially including a patient with COPD.



From left to right, Lina Buzermaniene (EFA outgoing Board Member), Isabel Saraiva (upcoming EFA Board Member), Silvio Sanko (Association of Parents of Asthmatic Children of Zagreb), Rita Paeglite (Latvian Asthma and Allergy Association), Damien Peelo (COPD Support Ireland), Christine Rolland (EFA Vice President), D'Arcy Myers (representing Asthma UK), Breda Flood (EFA President), Per-Ake Wecksell (EFA Board Secretary) and Ondrej Rybnicek (EFA Board Treasurer). ©EFA/Isabel Proaño

EFA's 2014 Network Meeting in Brussels<sup>39</sup> served to have a strategic planning session to facilitate the work of the delegates and to increase transparency. Members Delegates discussed EFA's overarching strategic goals that would shape the basis for a strategic plan for 2015-2020, with the flexibility for adjustment according to emerging issues and priorities.



Through the strategic planning session the AGM defined access to good quality care, a safe environment and patient involvement EFA's objectives until 2020. ©EFA/Isabel Proaño

The outcomes of the SWOT analysis were subjected to a computerised qualitative data analysis (NVivo) and quantitative data analysis (Excel). The overarching themes that came out from the coding process are the following:

- **EFA Secretariat and EFA Board**

The internal functioning of the EFA Secretariat and EFA Board were mainly assessed as a strength; the dedication of staff and EFA's positioning within Europe are examples listed as EFA *fortes*. The Secretariat's limited human capacity, on the other hand, was perceived as a weakness, although to a lesser extent.

- **Representation**

The majority of responses in connection to EFA's representation of patients' organisations that cover allergy, asthma or COPD was positive. However, participants pointed out the difficulty of representing organisations from different European countries that cover three different (and specific) disease areas.

- **Collaboration/Partnerships**

Collaboration with other stakeholders (key opinion leaders, other European level organisations, industry and other health or research organisations) was indicated as an area that requires further improvement.

- **EFA members**

EFA represents a strong base of solid member organisations, but the current membership base does not yet represent a balanced EU geographical coverage of people with allergy, asthma and COPD.

- **Advocacy initiatives**

Raising awareness was listed as a key opportunity for EFA in coming years; the increasing focus on patients' empowerment and personalised medicines in the European research agenda, as well as promotion of self-care, will be considered key areas for EFA's involvement in the near future.

## 5.2 Dedicated expertise on financial management and communications

In 2014, EFA strengthened its internal capacity by increasing the number of people working in the Secretariat, one of the imperatives that arose from the Members strategic planning session at the AGM 2014 and by developing new dedicated expertise on financial management and communications.

### Welcome to EFA!

Throughout 2014, Francis Grogna took care of **EFA financial management** on a consultant basis, professionalising this activity. In April 2014, EFA recruited the first **EFA Communications Officer**, Isabel Proaño Gómez, to streamline EFA's internal and external communications, implement a dissemination strategy, improve our visibility and ease communications with members.

EFA Membership and Programme Manager, David Brennan, left EFA at the end of August and was replaced by **EFA Project Manager**, Giuseppe De Carlo as of September, who also took over the membership activities planned in the operating grant.

Showing excellent progress and valuable contributions during their work as interns, Jelena Malinina (Policy Intern March-September) and Joke de Vocht (Projects Intern May-November) were hired in 2014 as **Junior EU Policy Officer** (September-December) and **Junior Project Officer** (November-December).

EFA's office at the end of the year was therefore structured and composed of two main teams: one dealing with EU policy and the other one with EU and EFA projects and membership, and of a cross-cutting one that included general and financial management and communications.

### Goodbye and good luck!

- David Brennan, Project Manager from 2012 to 2014
- Jan Meissner, Policy and Projects Intern from January to March 2014
- Marina Schmidt, Projects Intern from March to April 2014

### 5.3 Evaluation of EFA's core-programme

Throughout the year, EFA conducted continuous evaluations addressing governance/operations, effectiveness of the dissemination and work programme in achieving objectives, contribution to the European Union health programme through our policy work, events execution and participant/membership satisfaction. This process included dedicated evaluation questionnaires and SWOT analysis (Strengths, Weaknesses, Opportunities and Threats) to EFA membership, and dedicated questionnaires for participants of all key internal and external meetings, events and trainings organised by EFA. The quantitative evaluation was done through the participation rates to events, social media followers/subscribers, google analytics, publications and outreach. As a result, it can be said that EFA work programme has reached its objectives, but there are number of key recommendations for EFA arising to develop governance, new kinds of partnerships, marketing, streamline communication and tighten the strategic focus of the organisation.

## 6. Expanding EFA's membership

Based on EFA Membership Strategy, in 2014 EFA worked to increase its representativeness in Europe through Alignment Meetings that involved EFA members and new potential members. The meetings allowed us to get a better insight of the situation of allergy, asthma and COPD patients in different countries and provided the opportunity for participants to share activities, experiences and to establish contacts for future collaboration at national and European levels. We paid particular attention to patients' organisations from Eastern Europe.

### 6.1 Alignment meetings

EFA organised the **Baltic alignment meeting** (15<sup>th</sup> of February 2014, Vilnius, Lithuania) to discuss with EFA Members the Lithuanian Council of Asthma Clubs, the Association of Allergic Children Clubs, and the Association of Asthma Patient Clubs, together with the Latvian Asthma and Allergy Association about how to strengthen our collaboration. The Latvian Allergy and Asthma Association expressed interest in establishing a closer collaboration with EFA in the future and applied for membership. The Latvian Allergy and Asthma Association was accepted as EFA member by the Annual General Meeting 2014.



Meeting with Baltic patients, from left to right David Brennan, Lina Buzermaniene, Inga Zalnerauskiene, Inese Vīcupe, Egle Kvederaite, Rita Paeglīte. ©EFA/Jan Meissner

EFA **United Kingdom alignment meeting** with associations representing people with allergy and respiratory diseases (24<sup>th</sup> of November 2014, London, UK) gathered EFA Members from Asthma UK and Allergy UK, and representatives from Action Against Allergy. Action Against Allergy shown an interest in EFA activities and applied for EFA membership in February 2015.

## 6.2 Targeted visits to patients organisations

EFA organised a visit to the **German Allergy and Asthma Association (DAAB)** on the 10<sup>th</sup> of September, in Mönchengladbach, Germany. DAAB is the eldest European patient organization focused on allergy and asthma, existing since 1897. After the meeting, DAAB expressed interest to resume collaboration with EFA. DAAB applied for EFA membership in February 2015.



From left to right, Antje Fink-Wagner (EFA), Andrea Wallrafen (DAAB) and Breda Flood (EFA). ©EFA/Joke de Vocht

On 27<sup>th</sup> October 2014, EFA **Hungarian membership meeting** gathered the Hungarian Asthma and Allergy Patients Association (ABOSZ) and the Hungarian Allergy Association. Both ABOSZ and the Hungarian Allergy Association shown an interest in strengthening their collaboration with EFA and applying for membership.

In addition, and as a result of EFA's general membership outreach, Food Allergy Italia also submitted a membership application in February 2015.

## 7. Building expertise and capacity with EFA Members

In order to support the creation of a European network of strong and professional national organisations of people with allergy, asthma and COPD, EFA organises specific trainings for its members within the framework of EFA Capacity Building Programme.

### 7.1 EFA Capacity Building project for patients organisations

Conscious that EFA Members encounter similar needs and limitations within their associations, EFA decided to establish the first Capacity Building project aimed at leveraging members' capacity to run their own projects and organisations and to increase their involvement in EFA projects.

Based on a survey of interest, we selected three members that complied with the selection criteria: FederASMA e ALLERGIE Onlus (Italy), Lithuanian Council of Asthma Clubs (Lithuania) and RESPIRA (Portugal). EFA travelled to each member country between October and November 2014.



The Capacity Building meetings took place in Florence, Vilnius and Lisbon and involved 46 participants. In the picture, participants in Florence. ©EFA/ Antje Fink-Wagner

The capacity building meetings helped both Members and EFA to identify gaps in the structure of the organisations and served to propose actions to overcome them. EFA informed participants how to identify and maintain fundraising opportunities and how to involve and motivate volunteers. During the sessions, experts from the hosting countries guided an internal discussion to analyse the strengths, weaknesses, opportunities and threats (SWOT) for each organisation. Overall, participants expressed their satisfaction with the Capacity Building meetings and requested more training opportunities.

### 7.2 European Medicines Agency (EMA) training

On the 18<sup>th</sup> of February 2014, EFA organised its first training for patient experts on allergy, asthma and COPD with the aim to strengthen EFA patient expertise and members' participation at the European Medicines Agency (EMA), as well as to support EFA's involvement at EMA. The training was attended by 15 participants representing 10 EFA Member associations including EFA President and EFA representative at EMA Patients' and Consumers' Working Party Lina Buzermaniene.

Through the training, they had the opportunity to discover EMA's work and how patients can be involved throughout the process of evaluation, and communication about medicines. Thanks to this opportunity, EFA Members could learn from patient experts already involved with EMA, as well as from EMA Secretariat.



The EMA training served 10 EFA Members to increase their knowledge about the role and the involvement of patients in the development on medicines. ©EFA/ Jan Meissner

### 7.3 EFA “Meet and Greet EU institutions” training

EFA organises the **Meet and Greet EU Institutions training** for its members annually. The objective of the training is to give members an overview of the functioning of the EU and EU policies that are related to EFA disease areas. Although the topics discussed vary every year depending on the EU institutional and policy developments, the training enables a better understanding of how national policies are affected by the EU and how members can contribute to the EU policy process through EFA.

In 2014, the training attracted 11 patients' representatives from seven EFA members associations and one partner patients' organisation<sup>41</sup>. Conceived as a combination of beginners and advanced training, participants learnt about the composition, powers and functioning of the newly elected European Parliament and European Commission, the main developments in EU health policy, and EFA's collaboration with other Brussels' stakeholders. Members were also presented EFA's communication strategy and could better experience European policy dossiers through a role-play and a workshop. They also had the opportunity to meet and greet officials from the European Commission and the Members of the European Parliament (MEPs) from their home countries: Marjana Petir (Croatia, EPP), Biljana Borzan (Croatia, S&D), Carlos Coelho (Portugal, EPP), Soledad Cabezón (Spain, S&D), Seb Dance (UK, S&D), Andrey Kovatchev (Bulgaria, EPP), and Francisco Sosa Wagner (Spain, NI). As a result of these meetings, two more MEPs supported EFA Manifesto<sup>42</sup>.

The role play on the medical devices directive organised during the Meet and Greet the EU Institutions training proved successful to learn more about EU functioning and mechanisms. ©EFA/ Isabel Proaño



## Secretariat and Governance

### EFA Board



**President**

Breda Flood  
Asthma Society of Ireland  
42-43 Amiens Street  
1 Dublin  
Ireland  
breda.flood@efanet.org



**Vice President**

Christine Rolland  
Association Asthme & Allergies  
66 Rue des Tilleuls  
92100 Boulogne Billancourt  
France  
ch.rolland@asthme-allergies.asso.fr



**Treasurer**

Ondrej Rybnicek  
Czech Initiative for Asthma  
Sokolská 31  
12000 Praha 2  
Czech Republic  
Rybnicek.O@seznam.cz



**Board Member**

Per-Åke Wecksell  
Swedish Asthma and  
Allergy Association  
Rosenlundsgatan 52  
Box 170 69 - Sweden  
wecksell@hotmail.com

### EFA Office



**Director**

Susanna Palkonen  
susanna.palkonen@efanet.org



**Membership**

**and Project Manager**

Giuseppe De Carlo  
giuseppe.decarlo@efanet.org



**Deputy Director  
& Senior EU Policy Adviser**

Roberta Savli  
roberta.savli@efanet.org



**EU Junior Policy Officer**

Jelena Malinina  
jelena.malinina@efanet.org



**Communications Manager**

Isabel Proaño Gómez  
isabel.proano@efanet.org



**Junior Projects Officer**

Joke de Vocht  
joke.devocht@efanet.org



**Project and  
Fundraising Manager**

Antje Fink-Wagner  
antje.finkwagner@efanet.org

## EFA Members

### Austria

#### Österreichische Lungen-Union

Obere Augartenstrasse 26-28,  
A-1020 Wien  
+43 1 330 4286  
office@lungenunion.at  
<http://www.lungenunion.at/>  
Delegate: Otto Spranger, Managing Director

### Bulgaria

#### Асоциация на Българите Боледуващи от Астма

5B Triditza Str BG -1000 Sofia  
+359 2 980 4546  
asthma@mail.bg  
<http://www.asthma-bg.com/>  
Delegate: Diana Hadzhiangelova, President

### Belgium

#### Asthma-en Allergiekoepel vzw

Staatsbaan 165, 3460 Bekkevoort,  
Vlaams Brabant  
+32 800 843 21  
info@astma-en-allergiekoepel.be  
<http://www.astma-en-allergiekoepel.be/>  
Delegate: Erika Colen, Secretary

#### FARES - Fond d'Affections Respiratoires

Rue de la Concorde, 56, 1050 Bruxelles  
+32 2 5122936  
bibliothèque@fares.be  
[www.fares.be](http://www.fares.be)  
Delegate: Martine Spitaels

#### Prévention des Allergies

Rue de la Concorde 56, 1050 Bruxelles  
+32 2 5116761  
fpa@oasis-allergies.org  
[www.oasis-allergies.org](http://www.oasis-allergies.org)  
Delegate: Nadia Steenbeek, President

### Croatia

#### Udruga Roditelja Djece Astmatičara Grada Zagreba

Srebrnjak 100, 10000 Zagreb  
+358 922 858 177  
astma.udruga@gmail.com  
[www.astma-udruga.com](http://www.astma-udruga.com)  
Delegate: Silvio Šanko, President

### Czech Republic

#### CIPA - Česká iniciativa pro astma

Sokolská 31, 12000 Praha  
+42 0 224266229  
cipa@volny.cz  
[www.cipa.cz](http://www.cipa.cz)  
Delegate: Ondrej Rybnicek

### Denmark

#### Asthma-Allergi Forbundet

Universitetsparken 4 DK-4000 Roskilde  
+45 43 435 911  
tk@astma-allergi.dk  
[www.astma-allergi.dk](http://www.astma-allergi.dk)  
Delegate: Thorkil Kjaer, Director

### Finland

#### Allergia-ja Astmaliitto

Paciuksenkatu 19, FIN-00270 Helsinki  
+358 9 473351  
international@allergia.fi  
[www.allergia.fi](http://www.allergia.fi)  
Delegate: Ilkka Repo, Director

#### Hengityslitto

Oltermannintie 8, PL 40, FIN-00620 Helsinki  
+358 207 575 134  
mervi.puolanne@hengityslitto.fi  
[www.hengityslitto.fi](http://www.hengityslitto.fi)  
Delegate: Mervi Puolanne,  
Organisation Director

## France

### **Association Asthme & Allergies**

66 Rue des Tilleuls, 92100 Boulogne  
Billancourt  
+33 1 4131 6160  
ch.rolland@asthme-allergies.asso.fr  
www.asthme-allergies.org  
Delegate: Christine Rolland, Director

### **FFAAIR - Fédération Française des Associations et Amicales de malades, Insuffisants ou handicapés Respiratoires**

66 Boulevard Saint Michel, 75006 Paris  
+33 1 55 42 50 40  
ffaair@ffaair.org  
www.ffaair.org  
Delegate: Liliya Gentet

### **AFPRAL - Association Française pour la Prévention des Allergies**

84 La Ruche, Quai de Jemmapes, 75010 Paris  
+33 1 7023 2814  
secretariat@afpral.asso.fr  
<http://allergies.afpral.fr/>  
Delegate: Pascale Couratier, President

## Greece

### **ANIKSI**

75, El. Venizelou, Holargos, 115 61 Athens  
+30 210 7726160  
irini@allergyped.gr  
www.allergyped.gr  
Delegate: Elomida Visviki

## Germany

### **Patientenliga**

#### **Atemwegserkrankungen**

84 Berliner Strasse, 55276 Dienheim  
+49 61 333 543  
pla@patientenliga-atemwegserkrankungen.de  
<http://www.patientenliga-atemwegserkrankungen.de>  
Delegate: Michael Köhler, Chairman

## Ireland

### **Asthma Society of Ireland**

42-43 Amiens Street, 1 Dublin  
+353 18 178 886  
office@asthmasociety.ie  
www.asthmasociety.ie  
Delegate: Sharon Gosgrove, Director

### **COPD Support Ireland**

Brookfield House, Brookfield Terrace,  
Blackrock, Co. Dublin  
+353 12 833 500  
damienpeelo@copd.ie  
www.copd.ie  
Delegate: Damien Peelo, Manager

## Italy

### **FederASMA e ALLERGIE Onlus – Federazione Italiana Pazienti**

33 Via Ser Lapo Mazzei, 59100 Prato (PO)  
+39 5741 821 033  
segreteria@federasmaeallergie.org  
www.federasmaeallergie.org  
Delegate: Giorgio Salerni, delegate to relations with supranational associations

## Latvia

### **Latvijas Astmas un Alerģijas Giedrība**

54 – 11Pernavas iela, 1009, Riga  
+371 7 278 608  
astmaalergija@inbox.lv  
www.astmaalergija.lv  
Delegate: Rita Paeglite, Chairperson

## Lithuania

### **LAKT - Lietuvos Astmos Klubų Taryba**

Vilnius City University Hospital, 57 Antakalnio  
Str., LT -10207 Vilnius  
+370 652 78126  
info@astmainfo.lt  
www.astmainfo.lt  
Delegate: Lina Buzermaniene, President

## Luxembourg

### Prévention des Allergies

+352 26431968

fpa@oasis-allergies.org

www.oasis-allergies.org

Delegate: Suzanne van Rokeghem

## Norway

### Norges Astma- og Allergiforbund

Postbox 2603, St Hanshaugen,

N-0131 Oslo

+47 23 353 535

anne@naaf.no

www.naaf.no

Delegate: Anne Elisabeth Eriksrud,

Secretary General

## Netherlands

### Longfonds

Stationsplein 127, 3818 LE Amersfoort

+31 33 434 1295

info@longfonds.nl

www.longfonds.nl

Delegate: Michael Rutgers, Director

### Stichting Voedselallergie

Postbus 207, NL-3860 AE Nijkerk

+31 33 4655098

info@voedselallergie.nl

www.voedselallergie.nl

Delegate: Erna Botjes, President

### VMCE - Vereniging voor Mensen met Constitutioneel Eczeem

Postbus 26 NL-3860 AA, Nijkerk

+31 33 2471044

efa@vmce.nl

www.vmce.nl

Delegate: Bernd Arents, President

## Poland

### Polska Federacja Stowarzyszeń Chorych na Astmę i POChP

ul. Swietokrzyska 20 pok. 316, 00-002

Warsaw

+48 22 5054409

astma.federacja@gmail.com

www.astma-alergia-pochp.pl

Delegate: Piotr Dabrowiecki, President

## Portugal

### APA - Associação Portuguesa de Asmáticos

Rua Arnaldo Gama 64, 2, 4000-094 Porto

+351 965416733

informa@apa.org.pt

http://www.apa.org.pt

Delegate: Luís Miguel Vieira de Araujo

### RESPIRA - Associação Portuguesa de Pessoas com DPOC e Outras Doenças Respiratórias Crónicas

R. Infante D. Pedro, nº 10-B,

1700-243 Lisboa

+351 96 492 67 08

direcao@respira.pt

www.respira.pt

Delegate: Luisa S. Branco, President

## Spain

### FENAER - Federación Nacional de Asociaciones de Enfermedades Respiratorias

7 Ingeniero de la Torre Acosta, 5M,

29007 Málaga

+34 609 130 276

presidencia@fenaer.es

www.fenaer.es

Delegate: Victoria Palomares, President

## Slovenia

### DPBS - Društvo pljučnih in alergijskih bolnikov Slovenije

ZD Rudnik, Rakovniška cesta 4, 1000

Ljubljana

+386 1 427 4444

dpbs@siol.net

www.dpbs.si

Delegate: Nadja Trillerm

## Sweden

### **Astma och Allergi Förbundet**

44 St. Eriksgatan, 5tr, Box 49303, SE 100 29,  
Stockholm  
+46 8506 2800  
info@astmaoallergiforbundet.se  
www.astmaoallergiforbundet.se  
Delegate: Ulf Brändström, Secretary General

### **Riksförbundet HjärtLung**

Box 9090 SE 102 72, Stockholm  
+46 8 55 606 201  
lars.edborg@hjärt-lung.se  
www.hjärt-lung.se  
Delegate: Lars Edborg,  
Operations Strategist / International Secretary

## Switzerland

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

Scheibenstrasse 20, 3014 Bern  
+41 31 359 9000  
info@aha.ch  
www.aha.ch  
Delegate: Georg Schaeppi, CEO

### **Lungenliga Schweiz**

Südbahnhofstr. 14c 3000 Bern  
+41 31 378 2050  
info@lung.ch  
www.lungenliga.ch  
Delegate: Sonja Bietenhard, Manager

## United Kingdom

### **Allergy UK**

Planwell House, LEFA Business Park, Edgington Way DA14 5BH, Sidcup, Kent  
+44 1322 611655  
info@allergyuk.org  
www.allergyuk.org  
Delegate: Lindsey McManus,  
Deputy Chief Executive

### **Asthma UK**

18 Mansell St, E1 8AA London  
+44 20 7786 4900  
info@asthma.org.uk  
www.asthma.org.uk  
Delegate: Samantha Walker,  
Deputy Chief Executive

## Auditors' report 2014

### CONTRACTUAL AUDITOR'S REPORT ON THE FINANCIAL STATEMENTS OF THE EUROPEAN FEDERATION OF ALLERGY AND AIRWAYS DISEASES PATIENTS' ASSOCIATIONS (EFA) FOR THE YEAR ENDED 31 DECEMBER 2014

As required by law and the association's by-laws, we report to you in the context of our appointment as the association's contractual auditor. This report includes our opinion on the financial statements. The financial statements include the balance sheet as at December 31, 2014, the income statement for the year then ended, and the disclosures.

#### Report on the financial statements – Unqualified opinion

We have audited the financial statements of the "European Federation of Allergy and Airways Diseases Patients' Associations (EFA)" (the "Organisation") for the year ended December 31, 2014, which show a balance sheet total of € 642.657,18 and a loss for the year of € 8.876,06.

#### Responsibility of the board of Directors for the preparation of the financial statements

The board of Directors is responsible for the preparation of financial statements that give a true and fair view in accordance with the financial-reporting framework applicable in Belgium, and for such internal control as the board of Directors determines is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

#### Responsibility of the statutory auditor

Our responsibility is to express an opinion on these financial statements based on our audit. We conducted our audit in accordance with International Standards on Auditing (ISAs). Those standards require that we comply with the ethical requirements and plan and perform the control to obtain reasonable assurance about whether the financial statements are free from material misstatement.

An audit involves performing procedures to obtain audit evidence about the amounts and disclosures in the financial statements. The procedures selected depend on the statutory auditor's judgment, including the assessment of the risks of material misstatement of the financial statements, whether due to fraud or error. In making those risk assessments, the statutory auditor considers the association's internal control relevant to the preparation of financial statements that give a true and fair view, in order to design control procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the entity's internal control. An audit also includes evaluating the appropriateness of valuation rules used and the reasonableness of accounting estimates made by board of Directors, as well as evaluating the overall presentation of the financial statements.

We have obtained from board of Directors and association officials the explanations and information necessary for our audit.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

### **Unqualified opinion**

In our opinion, the financial statements of the European Federation of Allergy and Airways Diseases Patients' Associations give a true and fair view of the association's equity and financial position as at December 31, 2014, and of the results of its operations for the year then ended, in accordance with the financial-reporting framework applicable in Belgium.

### **Other matter**

The financial statements of the European Federation of Allergy and Airways Diseases Patients' Associations for the year ended December 31, 2013, were audited by another auditor who expressed an unqualified opinion on those statements on June 14, 2014.

### **Report on other legal and regulatory requirements**

The board of Directors is responsible for the compliance with the law of 27 June 1921 on non-profit organisations, international non-profit organisations and foundations, with the by-laws and with the legal and regulatory requirements regarding bookkeeping.

In the context of our mandate and in accordance with the Belgian standard which is complementary to the International Standards on Auditing (ISAs) as applicable in Belgium, our responsibility is to verify, in all material respects, compliance with certain legal and regulatory requirements.

On this basis, we make the following additional statements, which do not modify the scope of our opinion on the financial statements:

- Without prejudice to certain formal aspects of minor importance, the accounting records are maintained in accordance with the legal and regulatory requirements applicable in Belgium.
- EFA is registered as Not-for-Profit Organisation in Sweden. EFA is currently working on its full registration in Belgium and ensuring compliance with the law and regulations. Based on our assessment there are no effect on the financial statements. There are no other transactions undertaken or decisions taken in breach of the by-laws or of the Law of 27 June 1921 on non-profit organisations, international non-profit organisations and foundations that we have to report to you.

Londerzeel, May 15, 2015  
Jean Bernard PIEULI-TAKOU  
Registered auditor

## Financial report 2014

### Balance sheet at 31<sup>st</sup> December 2014 (€)

ASSETS	2014 (€)	2013 (€)	2012 (€)
<b>LIQUIDITIES</b>	<b>424,523.00</b>	<b>704.132,20</b>	<b>362.505,69</b>
Current account	211,827.02	292.222,11	152.132,41
Current account	50,444.81	50.444,81	50.444,81
Deposit account	162,251.17	361.465,28	159.928,47
Petty cash account	0,00	0,00	0,00
<b>FURNITURE</b>	<b>4,356.91</b>	<b>2.423,77</b>	<b>908,28</b>
<b>DEBTORS</b>	<b>0,00</b>	<b>0,00</b>	<b>0,00</b>
<b>DEFERRED CHARGES AND ACRUED INCOME</b>	<b>213,777.27</b>	<b>2.789,40</b>	<b>85.000,00</b>
Accrued Incomes	209,412.27	0,00	85.000,00
Deferred Charges	4,365.00	2.789,40	0,00
<b>TOTAL ASSETS</b>	<b>642,657.18</b>	<b>709.345,37</b>	<b>448.413,97</b>
<b>LIABILITIES</b>	<b>2014 (€)</b>	<b>2013 (€)</b>	<b>2012 (€)</b>
<b>RESERVE</b>	566,094.32	574.970,38	419.759,89
Reserve last year	574,970.38	419.759,89	339.567,43
Excess of income over expenditure from current year	(8,876.06)	155.210,49	80.192,46
<b>DEBTS</b>	<b>76,562.86</b>	<b>134.374,99</b>	<b>28.654,08</b>
Creditors	25,243.21	24.306,25	28.654,08
VAT payable on IC deliveries/services	7,048.58		
Taxes on salary	8,477.50	27.226,53	
Social security	(4,368.89)	51.583,21	
Salaries employees	8,920.46		
Other social debts	742.00	259,00	
Received grants for next year	30,000.00	30.000,00	
Received fees for next year	500.00	1.000,00	
<b>TOTAL LIABILITIES</b>	<b>642.657,18</b>	<b>709.345,37</b>	<b>448.413,97</b>

## Income Account (€)

	31/12/2014	31/12/2013	31/12/2012
<b>INCOME</b>	<b>664,944.39</b>	<b>659.820,35</b>	<b>556.721,68</b>
<b>Operating programme</b>			
EC Operating Grant	221,524.27		
Grants	64,000.00	360,000.00	395,000.00
Membership Fees	12,512.00	12,012.00	12,000.00
<b>Projects</b>			
Grants	179,407.48		
<b>EFA Projects</b>			
Allergy	50,000.00	75,000.00	50,000.00
Asthma	30,000.00		
Capacity Building	62,000.00		
COPD	40,000.00	98,000.00	30,000.00
Oxygen		25,000.00	40,000.00
<b>EU Projects</b>			
AirPROM (EU Project)		44,711.50	
EARIP (EU Project)		36,850.00	
U-BIOPRED (EU Project)		2,494.70	24,000.00
MeDALL (EU Project)	3,247.72	2,809.16	2,809.16
Recovery Miscellaneous	1,459.44	1,393.15	1,599.90
Financial Income	793.48	1,549.84	1,312.62

## Expenditure Account (€)

	31/12/2014	31/12/2013	31/12/2012
<b>EXPENDITURE</b>	<b>673,820.45</b>	<b>504,609.86</b>	<b>476,529.22</b>
<b>Operating Programme</b>			
Office	67,249.48	47,471.07	50,577.72
Staff	150,959.66	205,677.18	96,732.00
Fundraising	64,301.98	40,658.05	28,311.47
Financial Management	13,031.70		
Working Groups		6,095.77	4,996.37
Events	51,641.49	40,713.38	62,813.39
AGM & Network Meeting	29,907.21	31,939.12	19,434.06
Membership fees	1,750.00	1,900.00	2,550.00
Communications	24,108.27	16,407.24	33,741.66
<b>Projects</b>			
Staff	83,319.94		
<b>EFA Projects</b>			
Allergy	30,908.31	40,208.62	86,242.86
Asthma	12,363.16		
Capacity Building	39,079.31		
COPD	58,705.85	49,170.64	62,490.46
Oxygen		13,534.43	23,705.84
Project Programme	1,713.42	2,021.87	
<b>EC Projects</b>			
AirPROM	3,986.41	1,247.79	1,015.51
EARIP	16,071.27		
Europrevall - 2013	9,331.45		
U-BIOPRED	1,457.65	5,117.56	1,174.51
MeDALL	1,814.12	1,284.99	448.29
Health Vent	(-143,10)	562.20	1,252.73
Financial charges	12,262.87	599.95	1,042.35
<b>Result of the year</b>	<b>-8,876.06</b>	<b>155,210.49</b>	<b>80,192.46</b>

## Acknowledgements

**EFA thanks sincerely our funding partners who have made our work possible:**

### **European Commission**

Operating grant European Agency for Health and Consumers 221.524,27

DG Research FP7 project: MEDALL 3.247,72

### **Sustainable partnership with industry**

#### **Operating programme sustainability**

Air Liquide Sante International 8.000,00

ALK Abello 8.000,00

Almirall 8.000,00

Boehringer Ingelheim International 8.000,00

GSK 8.000,00

Novartis 8.000,00

Sanofi Pasteur MSD 8.000,00

Stallergenes 8.000,00

#### **Project programme sustainability**

Air Liquide Sante International 20.000,00

ALK Abello 20.000,00

Almirall 20.000,00

Boehringer Ingelheim International 20.000,00

GSK 20.000,00

Novartis 20.000,00

Sanofi Pasteur MSD 20.000,00

Stallergenes France 20.000,00

Donations: Chiesi Farmaceutici 15.000,00

Donations: Mundipharma International 4.407,48

#### **EFA Allergy Project**

ALK Abello 25.000,00

Stallergenes France 25.000,00

#### **EFA Asthma Project**

Novartis 30.000,00

#### **EFA Capacity Building Project**

Boehringer Ingelheim International 32.000,00

Novartis 30.000,00

#### **EFA COPD Project**

Novartis 40.000,00

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35 Rue du Congrès  
1000 Bruxelles, Belgium

Phone +32 (0)2 227 2712 • Fax +32 (0)2 218 3141  
[info@efanet.org](mailto:info@efanet.org)



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[www.efanet.org](http://www.efanet.org)



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