

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

# Annual Report 2010



*In memory of Mariadelaide Franchi*

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

*In Memoriam*  
Mariadelaide Franchi



EFA Honorary Member and COPD Advisor  
Founder and President of the Italian Association of COPD Patients  
Honorary President of FEDERASMA Italy  
Co-Chairwoman of International COPD Coalition  
Initiator, leader, FRIEND

## European Federation of Allergy and Airways Diseases Patients' Associations 2010 Annual Report

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## 1 INTRODUCTION

### FOREWORD and SUMMARY

Dear Colleagues and Friends,

This report is dedicated to Mariadelaide Franchi who passed away in January 2010. Lally's departure was a shock for all of us, since decades she has been involved in EFA in various leading capacities as board member, treasurer, EU project coordinator, editor, COPD adviser, honorary member and a dear friend. Lally moved mountains where the rest of us were kicking rocks. Lally's contribution is not measurable, she is irreplaceable and I hope we can keep up with her spirit, the spirit of EFA of collaboration, partnership, solidarity and a strong focus on goals and always patient perspective.

2010 was the year of the lung<sup>1</sup> and EFA joined this initiative. EFA dedicated this year 'In Memory of Mariadelaide Franchi'. The aim of the year of the lung was raising awareness about lung health through better information on prevention, risks and symptoms. The main objective was to make lung health a priority on political agendas and EFA very much shares this objective and our target is the European Union. Throughout this report you will see that EFA was busy doing just that, from patient perspective and in partnership with health care professionals and other NGOs. Our goal is overarching, strategic and action focused European programme on our disease areas and our new powerful vision decided by our general meeting in May, which states that EFA is dedicated making Europe a place where people with allergy, asthma and COPD have the right to best quality of care and safe environment, live uncompromised lives and are actively involved in all decisions influencing their health is driving us.

Our highlights of the year were our event at the European Parliament in June where the EFA Book on COPD in Europe 'Sharing and Caring' was presented, culminating to a call to action on COPD for Europe to place COPD as a public health priority, workshop on environment and health that EFA organised on behalf of the European Commission focusing on health in all policies and our conference for members in May on reimbursement and health technology assessment. Three very important EU research projects went on or started, on severe asthma, indoor air quality and mechanisms in the development of allergy in which EFA is patient partner. Our member steering committee scrutinised EFA's way of involving members, and the working group on food allergy spearheaded our biggest ever campaign to influence EU food allergen labelling rules.

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<sup>1</sup> <http://www.2010yearofthelung.org/1366-partners.htm>

EFA attended 57 external important meetings and events, gave 25 presentations or chaired in external conferences and events represented either by board or staff members or by our members. Our investment in fundraising has paid off, and EFA is expanding and planning ahead.

On the wider political level, the coming into force of the EU Lisbon Treaty<sup>2</sup> offers new opportunities for action by the European Union in the field of health. It preserves the competence of Member States on public health policy, but when common safety concerns in public health are identified, the EU shares competence and can introduce legally binding legislation. Secondly, the treaty makes the well-being of people an objective of the EU. The Article 9 and 168 of the Treaty on the functioning of the European Union puts in place ‘horizontal clauses’ about health. This means that the European Commission will have to take into account the impact on health in each of its proposal for legislation. Thirdly, the treaty also strengthens cooperation and coordination of Member States’ health policies, and sharing of best practice, in order to make the Member States health services more complementary in cross-border areas. Fourthly, the EU is now allowed to adopt incentives to “protect and improve human health”. Finally, the Lisbon Treaty makes the Charter of Fundamental Rights of Citizens<sup>3</sup> legally binding (except for the three countries which opted out: Czech Republic, UK, Poland). This charter includes a right to preventive healthcare and to Medical treatment.

With the leadership of the Global Alliance against Respiratory Diseases, of which EFA is a member, the United Nations adopted a Resolution on non-communicable disease, including chronic respiratory diseases, Resolution on the prevention and control of non communicable diseases<sup>4</sup> on 13th of May and the 7th of December, EU Belgium President prompted the Employment, Social Policy, Health and Consumer Affairs Council of the Council of the EU to adopt conclusions on “Innovative approaches for chronic diseases in public health and healthcare systems”<sup>5</sup>. The conclusions – which are policy statements that are non-binding but which enable and legitimize common measures to be taken by one or more or all 27 EU Members States – followed a Ministerial level conference held in Brussels on the 20th of October. All of these are very good news for people with allergy, asthma and COPD, the stage is set for allergy, asthma and COPD.

At the same time the economic crisis hit Europe hard. On the 3<sup>rd</sup> of March, the EU launched a so-called EU 2020 strategy<sup>6</sup> to overcome the crisis by a Europe with smart, sustainable and inclusive growth. On the surface, health is a the great absent in the strategy, but there is no sustainability, no growth and inclusion in long term without health and access to good quality care and healthy environment for people.

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<sup>2</sup> <http://eur-lex.europa.eu/JOHtml.do?uri=OJ:C:2008:115:SOM:EN:HTML>

<sup>3</sup> [http://www.europarl.europa.eu/charter/default\\_en.htm](http://www.europarl.europa.eu/charter/default_en.htm)

<sup>4</sup> [http://www.un.org/ga/search/view\\_doc.asp?symbol=A/64/L.52&Submit=Search&Lang=E](http://www.un.org/ga/search/view_doc.asp?symbol=A/64/L.52&Submit=Search&Lang=E)

<sup>5</sup> [https://www.consilium.europa.eu/uedocs/cms\\_data/docs/pressdata/en/lisa/118282.pdf](https://www.consilium.europa.eu/uedocs/cms_data/docs/pressdata/en/lisa/118282.pdf)

<sup>6</sup> [http://ec.europa.eu/europe2020/index\\_en.htm](http://ec.europa.eu/europe2020/index_en.htm)

Ladies and gentleman, this report summarises the main activities, outcomes and progress of EFA towards our mission and objectives a better-good deal for people with allergy, asthma and COPD no matter where they live in Europe. I would like thank all members, the board, staff and partners for their involvement and support.

I thank all our sustainable corporate partners for placing their trust on us, who are acknowledged at the end of this report and the European Commission for their support. You have made our work possible. Thank you.

A handwritten signature in black ink, appearing to read 'MS', with a small mark below it.

Marianella Salapatas  
President

## ABOUT EFA

EFA is a European network of patient organizations that was founded in 1991, prompted by the belief that an international organization formed by European patients associations that share the same aims would be a more effective way to serve the needs and safeguard the rights of patients and their carers.

EFA was created to combine the forces of national patient associations on asthma and allergy for results at European level and to improve the health and quality of life of people in Europe with those diseases. Serving the interests of allergy and airways patients at the national level is the primary responsibility of individual members and EFA supports member organisations by facilitating the sharing of knowledge and experiences.

### **New and strengthened vision, mission and objectives**

#### Vision

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

EFA is dedicated to making Europe a place where:

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

#### Mission

EFA is aiming to be a powerful European Network of allergy, asthma and COPD patients organizations that:

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

#### Objectives by target audience

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

## Central Values

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



## ORGANISATION

### Board (until 28 May 2010)

*President - stepped down from October 2008*

Marianella Salapatas

ANIKSI, Greece

Email: [msalapatas@gmail.com](mailto:msalapatas@gmail.com)

*Acting Vice President*

Ondrej Rybnicek

Czech Initiative for Asthma (CIPA)

Email [Rybnicek.O@seznam.cz](mailto:Rybnicek.O@seznam.cz)

*Treasurer*

Breda Flood

Asthma Society of Ireland

Email: [breda.flood@efanet.org](mailto:breda.flood@efanet.org)

*Board Secretary*

Per-Ake Wecksell

Swedish Asthma and Allergy Association

Email: [per-ake.ecksell@astmaoallergiforbundet.se](mailto:per-ake.ecksell@astmaoallergiforbundet.se)

*Member-at-Large*

Lina Buzermaniene

Lithuanian Council of Asthma Clubs

Email: [lina.buzermaniene@efanet.org](mailto:lina.buzermaniene@efanet.org)

### Board (From 28 May 2010)

*President*

Marianella Salapatas

Email: [msalapatas@gmail.com](mailto:msalapatas@gmail.com)

*Vice President*

Christine Rolland

Association Asthme&Allergies, France

Email: [ch.rolland@asthme-allergies.asso.fr](mailto:ch.rolland@asthme-allergies.asso.fr)

*Treasurer*

Breda Flood

Asthma Society of Ireland

Email: [breda.flood@efanet.org](mailto:breda.flood@efanet.org)

*Board Secretary*

Per-Ake Wecksell

Swedish Asthma and Allergy Association

Email: [per-ake.ecksell@astmaoallergiforbundet.se](mailto:per-ake.ecksell@astmaoallergiforbundet.se)

*Member-at-Large*

Lina Buzermaniene  
Lithuanian Council of Asthma Clubs  
Email: [lina.buzermaniene@efanet.org](mailto:lina.buzermaniene@efanet.org)

**Office**

The EFA Office was located at 35 Rue du Congrès  
1000 Brussels, Belgium  
Tel. +32 (0)2 227 2712  
Fax. +32 (0)2 218 3141

*Executive Officer*

Susanna Palkonen  
Email: [susanna.palkonen@efanet.org](mailto:susanna.palkonen@efanet.org)

*Project and Fundraising Officer*

Antje Fink-Wagner  
Email: [antje.finkwagner@efanet.org](mailto:antje.finkwagner@efanet.org)

*EU Policy and Project Assistant*

Laurene Souchet  
Email: [info@efanet.org](mailto:info@efanet.org)

*Meet and Greet EU Institutions training*

Mariann Skar [mariann.skar@efanet.org](mailto:mariann.skar@efanet.org)

**Membership and representation**

The EFA membership 2010 consists of 36 allergy, asthma and/or COPD patient associations or their coalitions in 21 European countries, in which there are over 500.000 individual patients and carers as members. EFA represents its member associations on a European level, whereas the associations represent their individual members in their respective countries.

*Austria*

Österreichische LungenUnion (ÖLU) [www.lungenunion.at](http://www.lungenunion.at)

*Belgium*

Coalition of Prevention des Allergies asbl [www.oasis-allergies.org](http://www.oasis-allergies.org)  
Astma-en Allergiekoepel v.z.w. [www.astma-en-allergiekoepel.be](http://www.astma-en-allergiekoepel.be)  
Fondation contre les affections respiratoires et pour l'éducation à la santé (F.A.R.E.S.) [www.fares.be](http://www.fares.be)

*Bulgaria*

Association of Bulgarians with Bronchial Asthma (ABBA) [www.asthma-bg.com](http://www.asthma-bg.com)

*Czech Republic*

Czech Initiative for Asthma [www.cipa.cz](http://www.cipa.cz)

*Denmark*

Astma-Allergi Forbundet [www.astma-allergi.dk](http://www.astma-allergi.dk)

*Finland*

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Allergia-ja Astmaliitto - Allergy and Asthma Federation [www.allergia.com](http://www.allergia.com)  
Hengityслиitto Heli – Pulmonary Association Heli [www.hengityслиitto.fi](http://www.hengityслиitto.fi)

*France*

Association Asthme & Allergies [www.asmanet.com](http://www.asmanet.com)

Coalition of Association Française pour la Prévention des Allergies (AFPRAL) [www.prevention-allergies.asso.fr](http://www.prevention-allergies.asso.fr)

Fédération Française des Associations et Amicales d'Insuffisants Respiratoires (FFAAIR) [www.ffaair.org](http://www.ffaair.org)

*Germany*

Patientenliga Atemwegserkrankungen e.V. [www.patientenliga-atemwegserkrankungen.de](http://www.patientenliga-atemwegserkrankungen.de)

*Greece*

ANIKSI [www.allergyped.gr](http://www.allergyped.gr)

*Ireland*

Asthma Society of Ireland [www.asthmasociety.ie](http://www.asthmasociety.ie)

*Italy*

Coalition of FEDERASMA [www.federasma.org](http://www.federasma.org)

Associazione Italiana Pazienti BPCO (AIPBPCO) [www.pazientibpco.it](http://www.pazientibpco.it)

*Lithuania*

Coalition of Association of Allergic Children Clubs and  
Association of Asthma Patient Clubs

Lithuanian Council of Asthma Clubs [www.astmainfo.lt](http://www.astmainfo.lt)

*Luxembourg*

Satellite of Prevention des Allergies asbl, Belgium

*Netherlands*

Coalition of Nederlands Astma Fonds (AF) [www.astmafonds.nl](http://www.astmafonds.nl) and

Vereniging Nederlands Davos [www.nederland-davos.nl](http://www.nederland-davos.nl) and

Coalition of Stichting Voedsel Allergie - Dutch Food Allergy Organisation [www.stichtingvoedselallergie.nl](http://www.stichtingvoedselallergie.nl)

Vereniging voor Mensen met Constitutioneel Eczeem (VMCE) [www.vmce.nl](http://www.vmce.nl)

*Norway*

Norges Astma- og Allergiforbund (NAAF - Norwegian Asthma and Allergy Association)

*Poland*

Polish Federation of Asthma, Allergy and COPD Patients' Organisations

*Portugal*

Portuguese Asthma Patients Association APA [www.apa.pt](http://www.apa.pt)

*Slovenia*

Pulmonary and Allergy Patients' Association of Slovenia (DPBS) [www.astma-info.com](http://www.astma-info.com)

*Sweden*

Astma- och Allergiförbundet - Swedish Asthma and Allergy Association [www.astmaoallergiforbundet.se](http://www.astmaoallergiforbundet.se)

Swedish Heart and Lung Association [www.hjart-lung.se](http://www.hjart-lung.se)

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## Switzerland

Coalition of aha! Schweizerisches Zentrum für Allergie, Haut und Asthma [www.ahaswiss.ch](http://www.ahaswiss.ch)  
Lungeliga Schweiz - Swiss Lung Association [www.lung.ch](http://www.lung.ch)

## U.K.

Asthma U.K. [www.asthma.org.uk](http://www.asthma.org.uk)  
Allergy UK [www.allergyuk.org](http://www.allergyuk.org)

## Honorary members

Edith M.A.L. Rameckers, the Netherlands  
Erkka Valovirta, Finland  
Elizabeth Bell, U.K.  
Arne Heimdal, Norway  
Mariadelaide Franchi, Italy – *passed away in January 2010*

## Project members

Adviser to the Treasurer  
Otto Spranger, Austria

*Board lead for the Motion at the EFA AGM 2009*  
*Board lead for MeDALL Project*  
*Board liaison for the GA<sup>2</sup>P<sup>2</sup> project*  
Per-Ake Wecksell, Sweden

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

*Member of the COPD Assessment Test International Steering Committee*  
Marianella Salapatras, Greece

*Medical Advisor*  
Erkka Valovirta, Finland

*European Medicines Agency (EMA) Patient experts*  
Lina Buzermaniene, Lithuania  
Breda Flood, Ireland  
Marianella Salapatras, Greece  
Ondrej Rybnicek, Czech Republic  
Per-Ake Wecksell, Sweden

## Memberships

*European Patients Forum (EPF)*  
Susanna Palkonen, Vice President – re-elected in May 2010

*European Network for Smoking Prevention (ENSP)*

*Health and Environment Alliance (HEAL)*

*Global Alliance against Respiratory Diseases (GARD)*, Otto Spranger, Austria, Member of the Planning Group

*International Coalition of COPD Organisations (ICC)*

*DG Environment Consultative Forum on Environment and Health: representative Susanna Palkonen*

*DG SANCO EU Health Policy Forum*

*DG SANCO Expert Group on Indoor Air Quality: Susanna Palkonen, Member . Substituted by Giorgio Salerni, Italy in two meetings*

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

*Advisory Group of the Integrated Exposure for Risk Assessment in indoor environments (INTERA) project  
Advisory Group of the Schools Indoor Pollution and Health Observatory Network SIMPHONIE project from  
EU Public Health Programme <http://www.sinphonie.eu/>*

*Allergic Rhinitis and Its Impact on Asthma (ARIA) Advisory Committee*

*Editorial Board of the Italian Journal of Primary Care*

*European Medicines Agency Patient and Consumer Working Party on behalf of the EPF*

*Scientific Committee of the 19<sup>th</sup> International Conference on Health Promoting Hospitals and Services*

*User Advisory Board of the [Renewing Health project](#) from the EC ICT Policy Support Programme*

*GSK European Health Advisory Board*

*Susanna Palkonen, Member*

#### **Associate memberships**

*International Primary Care Respiratory Group (IPCRG)*

## **STRATEGIC PRIORITIES 2010**

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

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

### **The work priorities for 2010 are:**

1. Working on member involvement horizontally through each EFA action
2. Building and executing EFA owned and initiated projects
3. Professional and effective Involvement at the European Medicines Agency
4. Fundraising

## 2 MAIN ACTIVITIES

EFA Office in Brussels has one full-time Executive Officer, part-time Project and Fundraising Officer and full-time EU Policy and Project Assistant. 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.

### Governance

EFA governance follows our Code of Ethics and Conduct, in line with our Statutes, and including the general principles according to which EFA operates.

The EFA board met 4 times in Brussels, one meeting was a strategic meeting. The Board started in autumn regular one hour skype meetings to deal with ongoing issues where board guidance is needed and to save monies, time and be more effectively concentrated on key board issues in face-to-face meetings.

The Annual General Meeting (AGM) was held 28 May in Vilnius, Lithuania. Our external auditor audited the accounts for the approval of the AGM 2010 as usual. During the AGM many important issues were discussed. During this year's elections the vice president and one board member were elected. EFA welcomes its new Vice President Christine Rolland from French association "Association Asthme et Allergies" and welcomes back Lina Buzermaniene from Lithuanian Council of Asthma Clubs. Also EFA would like to thank Ondrej Rybnicek from Czech Initiative for Asthma, ex Vice President for his dedication and work in [the EFA board](#).

The AGM decided on a new powerful vision, mission and objectives, see page 6. The rationale was that vision, mission and objectives need to speak to people, to patients and objectives defined by target our target audiences: patients, members, policy makers, health professionals, scientists and other non-governmental organisations. At the end of the AGM the members through a networking process shared best practices of their own member associations.

### Funding

In 2010, EFA funding was based on membership fees 10%, European Commission Project funding 25% and 65% sustainable corporate partnership and project funding by the industry. EFA funding increased one third thanks to our ongoing outreach to potential partners.

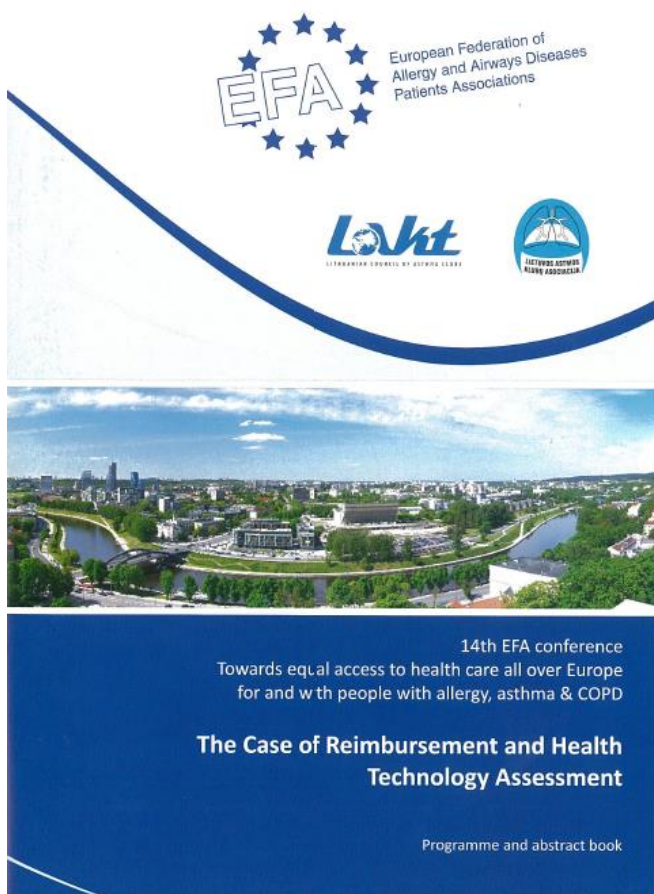
There still are no possibilities for EFA to apply for core-funding from the European Commission.

Industry is a natural partner of patient organisations and EFA collaboration is based mutual trust and transparency, in line with our Corporate Partnership Framework<sup>7</sup> and Code of Ethics and Conduct<sup>8</sup>. acknowledge the level of partnership: 5 star, 4 star, 3 star, 2 star and 1 star. 3 new partners signed up in 2009. The partners are acknowledged at the end of this report.

In April EFA had a special meeting for our sustainable funding partners in Brussels to present EFA work done 2009 and outlook for the 2010. All but two partners attended the meeting. New and old partners also had the opportunity present on their experience in supporting EFA . Our funding partners 2010 are listed at the end of this report.

## CREATING PATIENT DRIVEN PROJECTS

### Conference - Patients, health technology assessment and reimbursement



In May EFA held its statutory **Annual General Meeting (AGM)** in Vilnius, Lithuania followed by **14<sup>th</sup> Conference** for patient representatives: **Towards equal access to healthcare for and with people with allergy, asthma and COPD - The Case of Reimbursement and Health Technology Assessment (HTA)**. The Conference was hosted by EFA Lithuanian member associations.

The first day was dedicated to the AGM and the second day was a half a day conference.

Are organizations representing people with allergy, asthma and COPD involved in reimbursement and health technology assessment processes? How are decisions made? What is health technology assessment, are patients involved, how? and the best practice in patient involvement. These were the questions answered and discussed during the Conference through case studies, best practice examples and overviews

from government officials, academia and of course patient groups. We had the opportunity to hear about

<sup>7</sup> <http://www.efanet.org/about/documents/FinalSustainableCorporatePartnershipArrangementsEFAJune09.doc>

<sup>8</sup> <http://www.efanet.org/about/documents/EFACodeofEthicsandConduct.pdf>



reimbursement policies in different European countries as well as what HTA is and how patient organizations can contribute.

EFA would like to thank Lina Buzermaniene and the Lithuanian council of Asthma Clubs and Egle Kvederaite from the Association of Asthma Patient Clubs for a superb organization of the conference.

The presentations of the EFA Conference are available at

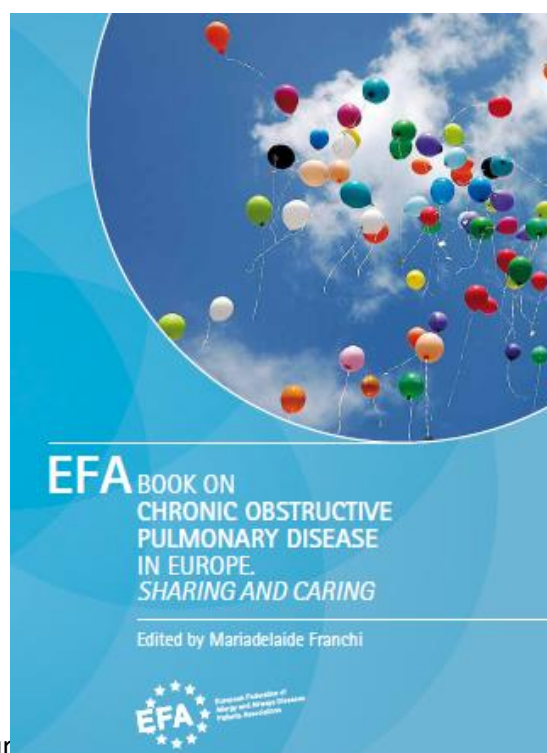
<http://www.efanet.org/activities/EFAconferencepresentations.html> and the Abstracts Book upon request from EFA Office [info@efanet.org](mailto:info@efanet.org).

## **EFA COPD Project Launch of Call to Action for Europe on COPD at the European Parliament**

EFA's ongoing priority is increased awareness and recognition of COPD as a public health priority in Europe that would lead to early diagnosis. On the 30 June, following the EU Health Policy Forum Conference on Health in All Policies, our Book on COPD in Europe – Sharing and Caring<sup>9</sup>, unprecedented collection of information on COPD in Europe from patients to policy makers, was presented the European Parliament. Based on the results of the Book<sup>10</sup>, Call to Action on COPD<sup>11</sup> for Europe was launched in the event that was hosted by MEP Catherine Stihler, see Annex 1.

The purpose of the Book is to share best practices and highlight the gaps to make policy both at European and country level to serve patients interest. The main conclusions were that while a lot of progress has been made, the awareness of COPD is still alarmingly low and that patients across Europe are either diagnosed in late stages or do not have adequate access to the care and support they need. Therefore the Call to Action highlighted the need and actions for European strategic and concerted approach on COPD, early diagnosis as the priority.

The speakers of the event included patient with COPD, European Parliament President, Jerzy Buzek<sup>1213</sup>, European Respiratory Society and EFA representatives. The participants were MEPs and all key stakeholder groups on COPD.



<sup>9</sup> <http://www.efanet.org/documents/EFACOPDBook.pdf>

<sup>10</sup> <http://www.efanet.org/enews/documents/EFAMediaAnnouncement30June2010.doc>

<sup>11</sup> <http://www.efanet.org/enews/documents/COPDCalltoActionFinal.doc>

<sup>12</sup> <http://www.efanet.org/enews/PresidentBuzekForward.pptx>

<sup>13</sup> [http://www.efanet.org/enews/documents/100520ForewordCOPD\\_3692\\_final.doc](http://www.efanet.org/enews/documents/100520ForewordCOPD_3692_final.doc)

EFA wishes to thank our partners who signed and launched together with us<sup>14</sup> the Call to Action: pulmonary specialists: ERS and European Lung Foundation, primary care: International Primary Care Respiratory Group, global COPD community: International COPD Coalition, environment and health community: Health and Environment Alliance and the tobacco control community: European Network for Smoking Prevention and Tobacco Control representing key communities in the fight against COPD and fight for the rights of people with COPD. The Programme of the event and the presentations are available at:

<http://www.efanet.org/enews/press.html>

<http://www.efanet.org/activities/documents/COPDEventAgenda30June2010FINAL.doc>

The call to action and a copy of the book were distributed to all 700+ members of the European Parliament. In connection of the event, EFA had the opportunity to write in the European Parliament Magazine on COPD<sup>15</sup>, alongside with Catherine Stihler, see page Communications.

Video<sup>16</sup> of the event promoting the Call to Action and raising awareness of COPD was launched on World COPD Day in November, see also page Communications. <http://www.efanet.org/video.html>

In a further action to mark World COPD Day 2010, EFA President spoke at the European Parliament representation in Scotland, at an event hosted by Catherine Stihler on why COPD is such a silent killer in Scotland, and what we can do about it.

**EFA 7 point Call to Action for Europe on COPD:**

*We assert that the following actions should be supported by the European Parliament, European Commission and European Council:*

- 1. Make COPD a political priority**
- 2. Increase awareness of COPD**
- 3. Prioritize the early diagnosis of COPD**
- 4. Support an integrated and multidisciplinary patient-centered approach to the treatment of COPD to improve the care and management of COPD**
- 5. Prevent COPD**
- 6. Improve Air Quality**
- 7. Support better understanding and management of COPD through research**

## **Global Allergy and Asthma Patient Platform**

Last year, EFA project 'Global Allergy and Asthma Patient Platform' the GA<sup>2</sup>P<sup>2</sup> was kick-started to establish a global platform for the organisations representing people with allergy and asthma and the GA<sup>2</sup>P<sup>2</sup> 'Declaration of Buenos Aires'<sup>17</sup> was launched. Its five main points centre on the need for global networking of asthma and

<sup>14</sup> <http://www.efanet.org/enews/COPDCalltoActionJointPressrelease.docx>

<sup>15</sup> <http://www.theparliament.com/digimag/issue310>

<sup>16</sup> <http://www.youtube.com/watch?v=cw3OXsXltc0>

<sup>17</sup> <http://www.efanet.org/enews/documents/DeclarationofBuenosAires112ComplefinalincludingDecember2010.doc>

allergy patient organisations; the right for asthma and allergy patients to comprehensive healthcare; their right to have access to education including information, training and self-management; their right to live in healthy, unpolluted air and smoke-free environments; and their responsibility to lead and be empowered to lead healthy lifestyles and manage their disease.

By the end of the 2010, 17 patient groups from across the world had signed it. The second meeting was held at the ERS conference in September. The GA<sup>2</sup>P<sup>2</sup> decided on its constitution and started planning for its first global project, board elections and website. EFA was also invited to write a forward, including our global work on GA<sup>2</sup>P<sup>2</sup> to World Allergy Organisations forthcoming White Book on Allergy<sup>18</sup> on the status of allergy in the world.

### **Project planning**

Significant project planning work for 2011 took place to launch EFA Allergy project and a follow up project on COPD. These plans were presented and welcomed at the EFA AGM in Vilnius.

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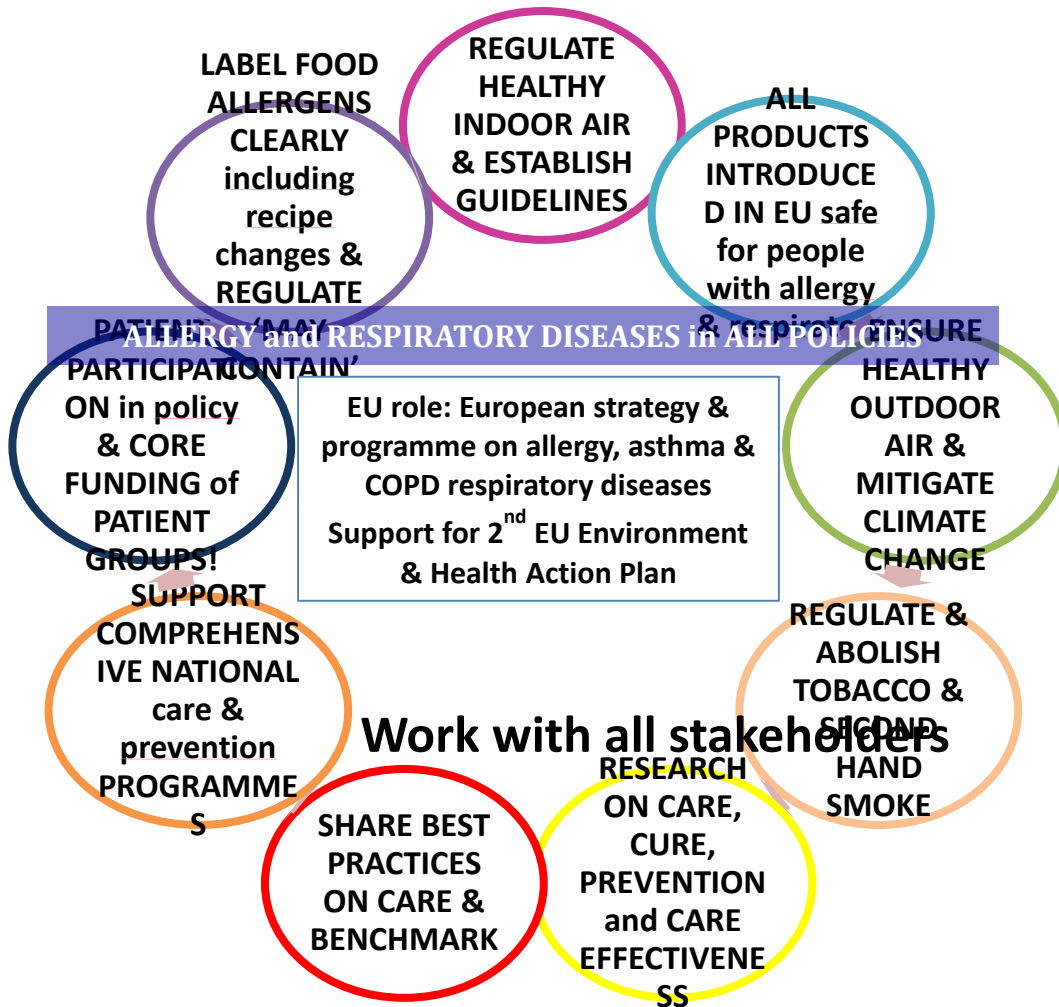
<sup>18</sup> [http://www.worldallergy.org/publications/wao\\_white\\_book.pdf](http://www.worldallergy.org/publications/wao_white_book.pdf)  
EFA Annual Report 2010



## ADVOCATING AT EU LEVEL FOR THE NEEDS OF PEOPLE WITH ALLERGY, ASTHMA AND COPD

All our work contribute to our advocacy role as the representative and voice of people with allergy, asthma and COPD at EU level. What we are striving for is comprehensive EU programmes with strategic view on our disease areas as already exist in rare diseases, alzheimers and cancer. This may be best achieved through programme on ‘Allergic and respiratory diseases either jointly, or separately that would support national programmes, implement health in all policies and share best practices in care and prevention.

Our two key advocacy campaigns 2010 were the launch of the Call to Action on COPD, see page 16 and food allergen labeling campaign presented in this chapter. Another key priority was our involvement in the European Medicines Agency.



EFA EU Policy goal

On the 7th of December, the Employment, Social Policy, Health and Consumer Affairs Council of the Council of the European Union adopted conclusions on [“Innovative approaches for chronic diseases in public health and healthcare systems”](#). The conclusions – which are policy statements that are non-binding but which

enable and legitimize common measures to be taken by one or more or all 27 EU Member States – followed a Ministerial level conference held in Brussels on the 20th of October. The EU Member States and the European Commission are recommended to work together to promote healthier choices for citizens, reduce inequalities in care, ensure integrated patient-centred care, and stimulate research into prevention, diagnosis and treatment of chronic disease. They are also recommended to exchange good practices in the area of chronic disease policy, and to cooperate with relevant stakeholders, especially patients’ organisations.

The Commission was invited to initiate a reflection process aiming to identify options to optimize the response to chronic diseases in Member States, and to summarize this in a ‘reflection paper’ to be published in 2012. It should also include good practices regarding ways to enable patients with chronic diseases to maximize their autonomy and quality of life. According to the Council, chronic diseases and the findings of the reflection paper should be integrated by the Commission as a priority in current and future European research and action programmes in the implementation of the [EU 2020 initiative](#). EFA welcomes the increasing collaboration at EU level on care, prevention and focus on patients, which is exactly what is our goal on our disease areas.

Prior to the Belgium Presidency Conference, the ERS organised one day conference focusing on respiratory diseases. EFA helped organise patient speaker and two patient representatives to speak at the event.

## **Medicines – Working with the European Medicines Agency**

In March 2010 EFA became full member of the Patients and Consumers Working Party (PCWP) at the European Medicines Agency (EMA). The purpose of the PCWP is to provide recommendations to the EMA on all matters of interest to patients in relation to medicinal products and to have a permanent dialogue with the EMA on their policies and activities and adapting information on medicines to the needs of patients. EFA has 4 patient experts nominated to review [Patient Information Leaflets of medicines](#) (PILs), [European Public Assessment reports](#) (EPAR) on medicines on our disease areas that they will be understandable for patients. EFA experts were invited into Scientific Committee meetings when specific medicines in our disease areas were evaluated.<sup>19</sup>

In January 2010 the European Medicine Agency (EMA) made available the draft of its road map “The Agency’s Contribution to Science, Medicines and Health”<sup>20</sup> for a public consultation. EFA developed on briefing on the Road Map and responded to the consultation. The three strategic priority areas proposed

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<sup>19</sup> [http://www.ema.europa.eu/htms/general/contacts/CHMP/CHMP\\_PCWP.html](http://www.ema.europa.eu/htms/general/contacts/CHMP/CHMP_PCWP.html)

<sup>20</sup>

[http://www.ema.europa.eu/ema/index.jsp?curl=pages/about\\_us/general/general\\_content\\_000292.jsp&murl=menus/about\\_us/about\\_us.jsp&mid=WC0b01ac05800293a4](http://www.ema.europa.eu/ema/index.jsp?curl=pages/about_us/general/general_content_000292.jsp&murl=menus/about_us/about_us.jsp&mid=WC0b01ac05800293a4)

are: addressing public health needs, facilitating access to medicines, and optimising the safe use of medicines. It sets objectives for future action, taking into account patient experience to improve decision-making through and the safe use of medicines involving patient organisations. The EMA also intend to take into account the demands for more transparency through giving more information targeted for users such as patients.

EMA also announced the consultation on their [Draft guideline on clinical investigation of medicinal products in the treatment of Chronic Obstructive Pulmonary Disease \(COPD\)](#). EFA will respond to the consultation in 2011.

In December, EFA attended EMA conference entitled "Regulatory Science: Are regulators leaders or followers?" held at the European Medicines Agency.

### **Environment: Air pollution – Workshop on environment and health**

EFA is a member of the EU Health Policy Forum, a consultation and dialogue forum of the Directorate General Public Health (SANCO), which organises every year a so-called Open Forum conference in Brussels to wider stakeholder community. The theme this year was 'health in all policies' - "Together for Health – a Strategy for the EU 2020"<sup>21 22</sup>, which is key for people with allergy, asthma and COPD because of the role environment can play in either exacerbating or even causing disease or when healthy, enabling for healthier life. EFA was the patient representative, alongside with the European Patients' Forum in the Steering Committee of the Open Forum and was invited to organise on voluntary basis, a workshop in the Forum on 'environment and health' and invited HEAL to co-organise.



On the 29<sup>th</sup> of June, first day of the Forum, the workshop on environment and health "Integrating environment and health policy towards better health"<sup>23</sup>, chaired by EFA and HEAL presidents, attracted 70 participants and finalised recommendations<sup>24</sup> arising from the workshop, see appendix 2. The objective of the workshop was to

discuss how the Commission should integrate health in EU environmental policies, and how the stakeholders can participate, as well as why it makes sense to "marry" environment and health.

The key recommendation was that the EU Environment and Health Action plan will come to end during this year and it is fundamental that a new plan, that integrates all EU actions and policies that have impact on

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<sup>21</sup> [http://ec.europa.eu/health/interest\\_groups/eu\\_health\\_forum/open\\_forum/2010/index\\_en.htm](http://ec.europa.eu/health/interest_groups/eu_health_forum/open_forum/2010/index_en.htm)

<sup>22</sup> [http://ec.europa.eu/health/interest\\_groups/docs/open2010\\_wg1.pdf](http://ec.europa.eu/health/interest_groups/docs/open2010_wg1.pdf)

<sup>23</sup> [http://ec.europa.eu/health/interest\\_groups/docs/open2010\\_progwg1.pdf](http://ec.europa.eu/health/interest_groups/docs/open2010_progwg1.pdf)

<sup>24</sup> [http://ec.europa.eu/health/interest\\_groups/docs/ohf2010-wg1-recommendations.pdf](http://ec.europa.eu/health/interest_groups/docs/ohf2010-wg1-recommendations.pdf)

environment from health perspective under one umbrella is established, in collaboration with stakeholders, including patient groups. EFA President presented the recommendations together with the Rapporteur from ERS on the final day plenary of the Forum.

DG Health video on health in all policies featuring EFA and HEAL project [www.knowyourairforhealth.eu: http://ec.europa.eu/commission\\_2010-2014/dalli/multimedia/videos/index\\_en.htm](http://ec.europa.eu/commission_2010-2014/dalli/multimedia/videos/index_en.htm)

## Food allergen labelling - Campaign at the European Parliament

In its proposal for regulation on "[provision of food information to consumers](#)", the European Commission had proposed that all food containing allergenic substances must be labelled, whereas in the current legislation only pre-packaged food is covered.

This is great news for people with food allergy and hypersensitivity, and means that restaurants and catering establishments would have to indicate the presence of allergenic substances and therefore more informed and safe choice for people with food allergies.

Unfortunately the Environment and Health Committee of the European Parliament (ENVI) in their [report](#) recommended giving up the 3mm minimum font size that EFA supports. For non prepacked food, an amendment proposed that a sign will be place in



### Position Paper European Federation of Allergy and Airways Diseases Patients' Associations<sup>1</sup>

#### [Proposal for regulation of the European Parliament and of the Council on the provision of food information to consumers 2008/0028 \(COD\)](#)

For the attention of the European Parliament, Council, the Commission, responsible authorities in the member states and European Food Safety Authority EFSA

04-05-2010

**The only way to manage a food allergy or intolerance is to avoid the allergen to which one reacts. Food Allergy is a Food Safety issue, and must be considered with other Food Safety risks (eg microbiological, physical and chemical). Food sold without accurate labeling and clear identification of all ingredients should be considered 'unsafe'.**

<sup>1</sup> EFA represents through its' [member associations](#) the people with food allergy in Europe. EFA is a non-profit network of allergy, asthma and COPD patient organisations representing 32 member organizations in 20 countries, and over 400.000 patients. EFA aims to substantially reduce the frequency and severity of allergies, asthma and COPD, minimize their societal implications; improve health-related quality of life of patients; and ensure full citizenship of people with these conditions.

the sale area to indicate that food allergen information is available on demand but unfortunately also warning that cross contamination cannot be avoided. However another amendment proposed to make it compulsory to indicate food allergen on the package for food chains serving standardized food.

EFA together with our Food Allergy Working Group of Members prepared campaign documents: a policy brief on the proposal for members, an explanatory document on the issues for people with food allergy and hypersensitivity, a summary document on precautionary labelling (“may contain”) and cross contamination, with best practice examples from European countries on how to manage allergens, to show that establishing a safety chain for people with food allergies is possible, [testimony of a patient with severe food allergy](#), Position Paper<sup>25</sup>, see annex 3 and template [letter to Members of the European Parliament](#), Ministries of health and governments health attachés in Brussels. Our objective was

- ✓ to raise awareness about food allergies
- ✓ to express concern about the risk of watering down the Commission proposal, especially the proposal that companies selling food (such as bakeries, restaurants, and caterers) should have a sign stating “cross-contamination cannot be avoided which would cancel responsibility of the enterprises for any good practice in managing food allergens and give legal backing to current wild and misleading precautionary labelling practices
- ✓ to advocate for a regulation of precautionary “may contain” labelling and
- ✓ for the necessity of putting in place a safety chain for food allergens, just as is currently in place for hygiene.
- ✓ To ask for clear labelling of non pre-packed food and of changes of recipe in case of allergens.
- ✓ To express our view that this regulation is an opportunity to seize in order to take into account the daily needs of all European consumers regarding food information, including people with food allergy.

EFA food allergy working group also advised of the draft proposals for amendments prepared by EFA, to try to introduce these issues in the regulation. The Green political group did propose an amendment in order to ask for European guidelines on allergen management, to regulate precautionary labelling.

The European Parliament (EP) debated on the 15th of June, and adopted amendments on the 16th of June.. Just before the vote, EFA sent out a [press release](#) together with the European Academy of Allergy and Clinical Immunology (EAACI) highlighted that this vote was a major opportunity to improve daily life of people with food allergy. Unfortunately the amendment on regulating precautionary labelling was not adopted. However the adopted text states that common rules should be drawn up for the purpose of indicating traces of allergenic substances, so that people with food allergy can make safer choice

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<sup>25</sup> <http://www.efanet.org/activities/documents/EFAPositionPaperonEUFoodLabellingFinal.doc>  
EFA Annual Report 2010



(amendment 18). This leaves the door open for regulation of precautionary labelling of allergens, which are currently misleading and undefined.

The vote resulted in many [amendments](#) to the original draft, including the rejection of a system of 'traffic light' labelling to alert consumers to health hazards and benefits of food products.

The EP adopted an amendment to ask for definition of a binding clear legibility concept for information on the labels after a consultation of stakeholders, instead of the mandatory 3mm font size proposed by the Commission. For non pre-packed food, information, including allergen information will have to be available on demand. There will also be a statement "cross-contamination cannot be avoided" on sign or menus.

On the 7<sup>th</sup> of December, the Council of the European Union (which represents the governments of the EU's 27 Member States) reached a political agreement on the draft Commission proposal. While the Parliament agreed that allergen information in pre-packed food must be available, they rejected the amendment proposed by the Green group to set up guidelines for allergen management as a first step for rules for precautionary labelling. EFA welcomes the [Council's opinion](#) that providing allergen information on non-pre-packed food should be 'mandatory', but objects to their proposal for minimum font size of 1,2 mm for labelling, compared to the Commission proposal of 3mm and Parliament's to consult stakeholders on the minimum size needed. Because the opinions of the Parliament and Council differ considerably on certain issues, the Regulation will very likely now undergo a second vote in the Parliament. This is expected to take place in 2011 and EFA will follow up.

A final agreement may still be quite some time off however, owing to the controversial nature of the legislation, and the differing opinions of the EU bodies. EFA intends to keep working so that people with food allergy may benefit from clearer rules and access to information that they should be entitled to in order to manage their condition.

***The battle goes on!***

## **WORKING MORE AND EQUALLY WITH MEMBERS**

Throughout this year, each member association, but one was one way or other involved in EFA activities, whether as a speaker in our conference, in food allergy working group, at members steering group, in our projects, advocacy or partnership projects. Each of the disease areas EFA represents was visible this year.

### **Increasing member engagement and improve outcomes at European level**

The AGM 2009 decided based on a motion from members that EFA needs to find ways to improve the motivation and number of members to be involved in order to have better joint outcomes at the European level and it was decided to set up an interactive discussion group of members lead by EFA board member to take this forward. He conducted a small survey asking basic issues about each organisation and their

willingness to take part in the work. 68% of members responded and 12 organisations from 9 countries agreed to take part. Their membership varies from up to 44.000 members to 200 members, and some are not membership based organisations. 7 had more than 10.000, 9 between 10.000-1000 and 4 less than 1000 members. The number of employees varies from 1100 to 0, totally voluntary based.

The group held skype meetings 2009-2010 and their work was presented at the AGM 2010. The barriers for involvement are language, resources, sometimes policy, cultural differences, differences in diseases represented. Meeting on Skype every month for member organisations was proposed, sharing best practice on EFA website, EFA fundraising for member organizations, working groups on COPD and asthma, facebook group and joint EU projects. The AGM agreed to creating a group to work for a proposal/final outcome to be presented at the AGM 2011.

### **Working groups**

EFA's food allergy working group was active in our food labelling campaign, but there is also need for members to be able to just discuss about ongoing issues in their countries with colleagues.

### **Meet and Greet EU Institutions Training**

This year's meet and greet training was postponed to 2011. Based on the feedback from 2010, there could be two different level trainings/year or indeed one combined one run simultaneously. The purpose of the basic training is to introduce the main EU institutions: Parliament, Council and the Commission by going to meet and discuss with them in person. Advanced one could work on specific issues 'hands on' how to do EU advocacy.

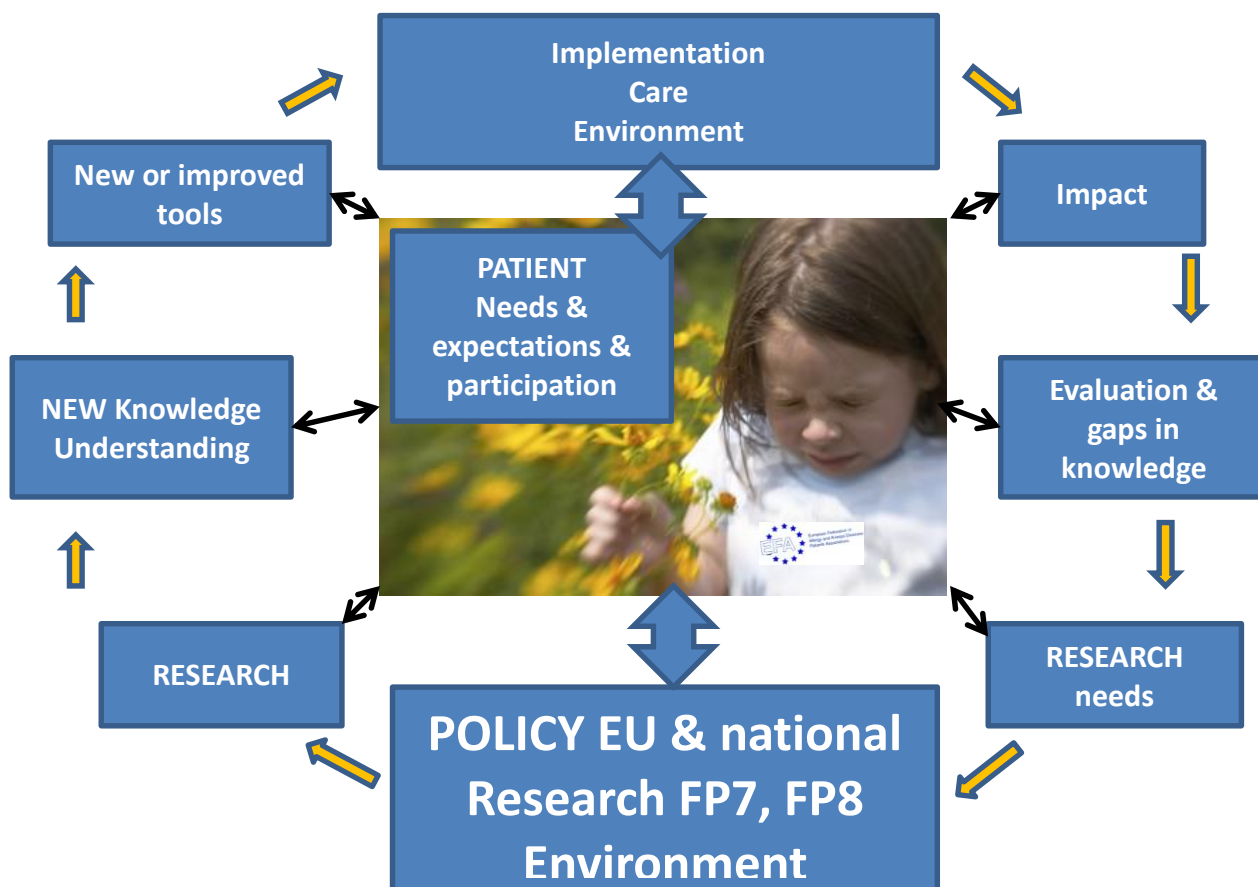
## **IMPLEMENTING BEST PRACTICE**

The EFA COPD Book, our conference and our policy work ultimately aim at best practice of care, environment and research to be shared and implemented where it matters, in national and local level, in the lives of patients themselves. By building our own projects and advocacy campaigns and also collaborating in others where the potential impact in patients lives is the ultimate goal and improving the way we work with our members implementing best practice has been a newly highlighted focus.

## **CO-OPERATING WITH HEALTHCARE PROFESSIONALS, SCIENTISTS AND OTHER NGOS**

### **Partnering in EU research projects**

EFA partners in EU funded research projects that have important contribution to our mission, lead to significant new knowledge or tools that can help patients with allergy, asthma and COPD and future generations and in which we can have a meaningful role and contribute from patients perspective.



EFA Strategy on research

### Severe asthma – the Unbiased BIOMarkers for the PREdICTing disease progression and medication efficacy U-BIOPRED project



The U-BIOPRED project which started in 2009, is all about understanding severe asthma better and will address the issue that new treatments are needed for severe asthma but limitations exist in identifying those patients who will benefit from a particular drug and identifying sufficient numbers of patients to participate in clinical

trials. The five year project, coordinated by professor Peter Sterk, the Netherlands is part of the so-called Innovative Medicines Initiative (IMI), a public-private partnership between the European Commission and the European Federation of Pharmaceutical Industries and Associations (EFPIA), which funds projects with the aim of combating causes of delay in development of medicines. U-BIOPRED brings together patients organisations, bio-pharmaceuticals enterprises, small and medium enterprises, the European Medicine Agency, and academic institutions.

EFA is contributing to U-BIOPRED and representing patients within this project together with Asthma UK and Netherlands Asthma Fonds through involvement in consensus, ethics and dissemination and training work packages and by giving opportunities for members involvement in providing patient perspective. theme of WAD: launch of a campaign by Global Initiative of Asthma to reduce asthma hospitalizations by 50%.

## Asthma art contest



U-BIOPRED (Unbiased BIOmarkers in PREdiction of respiratory disease outcomes) is a research project to understand more about severe asthma.

To bridge the gap between doctors' and patients' perception of asthma, U-BIOPRED have opened an art contest to the public.

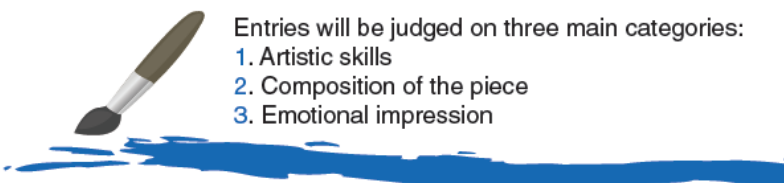
This is your chance to express your experiences of asthma through art.

### How to Enter

Anyone can enter this competition, just log on to [www.ubiopred.eu](http://www.ubiopred.eu) and upload your artwork.

Winners will be invited to a multimedia science/art show in Brussels.

The deadline for entries is 01/05/2011.



Entries will be judged on three main categories:

1. Artistic skills
2. Composition of the piece
3. Emotional impression

This is an IMI funded project



Disclaimer: The content on this Flyer reflects only the author's views and neither the IMI JU nor the Commission is liable for any use that may be made of the information contained herein.

For more information, please go to: [www.ubiopred.european-lung-foundation.org](http://www.ubiopred.european-lung-foundation.org)

In September the U-BIOPRED, launched an art competition<sup>26</sup> to help bridge the gap between patients' and doctors' perceptions of asthma and raise awareness of the disease. EFA members in Denmark, Italy, Norway, Poland and Sweden volunteered to translate to their language and promote the competition in their country. Translations are planned in all 'U-BIOPRED languages' including also Dutch, French, Hungarian and German. Our Belgium Flemish member will promote the contest in Belgium. The competition is open to anyone who wishes to enter, and who would like to express their experience of living with asthma through art and will be judged on the basis of artistic skill, composition and emotional impression.

The U-BIOPRED public website was launched featuring lay-friendly information about the project, severe

asthma and how people with severe asthma and can take part. The Ethics and Safety boards were formed, including patient representatives, Lina Buzermaniene and Per-Ake Wecksell and led by the Astmafonds, the U-BIOPRED Patient Input Platform formed. The PIPs task is to advice on all aspects of the project from patient

<sup>26</sup> <http://www.ubiopred.european-lung-foundation.org/index.php?id=16279>

and carer perspective. The PIP is composed of patients and carers from the Netherlands, UK, Italy and Ireland and more nationalities are welcome through EFA member associations. The consortium prepared for the research to start in 2011.

On World Asthma Day, with the theme of reducing hospitalisations due to asthma, EFA distributed the U-BIOPRED press release<sup>27</sup>. [www.ubiopred.european-lung-foundation.org](http://www.ubiopred.european-lung-foundation.org)

### **Indoor air quality – Health Based Ventilation Guidelines for Europe the HealthVent project**



Health Vent project started in July 2010. The purpose of the project, funded by the EU Public Health Programme, is to develop health based ventilation guidelines for Europe that can be used as a policy making and practise tool by the EU member states. The guidelines, which will be produced lead by professor Pawel Wargogi, Denmark, in collaboration with the multidisciplinary project partners in 10 countries, the Federation for European Heating Ventilation Air Conditioning Associations (REHVA), EFA,

the WHO European Centre for Environment and Health and the EC Joint Research Centre (JRC) are to form the basis for the revision of relevant building codes and standards, and take into consideration health, energy efficiency, different building types and climate conditions in Europe. Indoor air quality is a key priority for people with allergy, asthma and COPD, and EFA therefore welcomes this partnership and project with practical results, and hopes that it will help to stimulate a strategic approach to IAQ by the EU. EFA's role in the project, in collaboration with interested EFA members, is to review the evidence, collect relevant information from patients' perspectives, review the guidelines and disseminate project information to our members and partners. [www.healthvent.eu](http://www.healthvent.eu)

### **Allergy - Mechanisms in the development of allergy the MedALL project**



In December the MeDALL project – a large new research project that will investigate the causes of allergy. MeDALL is funded by the EU Research Programme, the FP7. The project results should help to provide better answers as to why and how allergy develops, and to design, clarify and target prevention opportunities and innovation in treatment – why, how and what can we do?

Allergy often starts in childhood and it is children who are the focus of MeDALL. Information from previous birth cohorts, including 42,000 children in Europe, will be looked at, and 18,000 re-examined using similar methods.

<sup>27</sup> <http://www.efanet.org/enews/documents/U-BIOPREDPressreleaseWorldasthmaday2010FINAL.doc>

EFA's role in the project will be communication, dissemination and offering a patient perspective. There will be a fact sheet summary on any significant scientific paper drawn up by MeDALL, directed to lay-audiences. EFA will keep its members informed throughout the project and it is foreseen that training for patient representatives will be organized during it. EFA will also help MeDALL to contribute to EU policy. The coordinator of the project is professor Jean Bousquet, France and it involves 16 of academic centres in Europe and one in the US and 4 small and medium size companies. <http://medall-fp7.eu/>

## COMMUNICATIONS

EFA published eight electronic newsletters 'EFA ezine' to promote our work, digest and keep up to date on EU policy developments that are relevant for people with allergy, asthma and COPD and offer opportunity for members to promote their work at the European level. In total 15 articles from members in 9 countries were published.

EFA published and distributed in total eight press releases<sup>28</sup> in connection of our project work and EU advocacy.

EFA was in 2010 more visible both at EU level and in the media than ever before. We were invited to write to the European Parliament Magazine two articles on allergy and respiratory diseases, and one article on COPD:

- COPD Part of the solution <http://www.theparliament.com/digimag/issue310>
- A role for Europe, EU needs to take a strategic approach on allergy and respiratory diseases, Parliament Magazine January 2010: <http://viewer.zmags.com/publication/8119c6af#/8119c6af/60>
- Where is the vision? EU must develop patient centred action plan on allergy and respiratory diseases: Parliament Magazine <http://viewer.zmags.com/publication/357a4a63#/357a4a63/10>

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

In connection of the EU Health Policy Open Forum conference in June, EFA was featured in the video by the European Commission Directorate General for Health video on health in all policies featuring EFA and HEAL project [www.knowyourairforhealth.eu](http://www.knowyourairforhealth.eu): [http://ec.europa.eu/commission\\_2010-2014/dalli/multimedia/videos/index\\_en.htm](http://ec.europa.eu/commission_2010-2014/dalli/multimedia/videos/index_en.htm)

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<sup>28</sup> <http://www.efanet.org/enews/press.html>  
EFA Annual Report 2010

On World COPD Day in November, EFA published our video from the COPD event at the European Parliament<sup>29</sup> in June: Raising Awareness of COPD <http://www.efanet.org/video.html>

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<sup>29</sup> <http://www.efanet.org/enews/documents/EFAMediaAlertCOPDVideoClipavailablenow.docx>  
EFA Annual Report 2010

## ANNUAL ACCOUNTS

### FINANCIAL REPORT

#### Financial report 2010

##### 1. The Financial Report is in Euro.

##### 2. Bank Accounts

EFA has four Bank Accounts:-

- a. A current (sight) account in Luxembourg in Euro. The balance at 31:12:10 was 119.940,30 Euro.
- b. A deposit (term) account also in Luxembourg. The balance at 31:12:10 was 57.674,89 Euro.
- c. A Visa account in Luxembourg in Euro. The balance at 31:12:10 was 0,00 Euro.
- d. A Swedish Currency Account in Euro. The balance at 31:12:10 was 50.356,74 Euro.

The total balance in the four Bank Accounts and Petty Cash at 31:12:10 was 227.971,93 Euro.

	<u>31-12-08</u>	<u>31-12-09</u>	<u>31-12-10</u>
Luxembourg 1	478,13	13.519,51	119.940,30
Luxembourg 2	20.155,44	0,00	57.674,89
Luxembourg 3	8.367,57	18.738,80	0,00
Sweden	50.302,63	50.356,74	50.356,74
<b>TOTAL</b>	<b>79.335,06</b>	<b>83.562,26</b>	<b>227.971,93</b>



Breda Flood  
EFA Treasurer



Marianella Salapatas  
EFA President



**BALANCE SHEET**

IN EURO

	31-déc-10	31-déc-09	31-déc-08
<b>ASSETS</b>			
<b>VII. DEBTORS</b>	<b>0,00</b>	<b>61.975,33</b>	<b>70.090,71</b>
Debtors <sup>(1)</sup>		61.975,33	70.090,71
<b>IX. LIQUIDITIES</b>	<b>227.971,93</b>	<b>83.562,26</b>	<b>79.335,06</b>
Bank Account 0038/4174-7	119.940,30	13.519,51	478,13
Handelsbanken 41 402 669	50.356,74	50.356,74	50.302,63
Bank Account 0038/8721-9	-	-	20.155,44
Bank Account 5912/7917-1	57.674,89	18.738,80	8.367,57
Petty Cash Account		947,21	31,29
<b>X. DEFERRED CHARGES AND ACRUED INCOME</b>	<b>0,00</b>	<b>0,00</b>	<b>0,00</b>
Deferred Charges	0,00	0,00	0,00
<b>TOTAL ASSETS</b>	<b>227.971,93</b>	<b>145.537,59</b>	<b>149.425,77</b>
<b>LIABILITIES</b>			
<b>IV. RESERVE</b>	<b>209.546,14</b>	<b>107.701,71</b>	<b>96.465,57</b>
Reserve last year	107.701,71	96.465,57	155.292,77
Excess of income over expenditure from current year	101.844,43	11.236,14	(58.827,20)
<b>IX. DEBTS</b>	<b>18.425,79</b>	<b>37.835,88</b>	<b>52.960,20</b>
Creditors <sup>(2)</sup>	18.425,79	37.835,88	52.960,20
Received grants for next year <sup>(3)</sup>			
<b>TOTAAL DER PASSIVA</b>	<b>227.971,93</b>	<b>145.537,59</b>	<b>149.425,77</b>
	0,00	0,00	0,00

INCOME AND EXPENDITURE ACCOUNT  
IN EURO

**31-déc-10**

<b>Income</b>	<b>361.093,29</b>
Fees	26.250,00
EFA Conferences	4.540,00
Grants <sup>(4)</sup>	330.122,59
Bank Interests	136,09
Difference	44,61
<b>Expenditure</b>	<b>259.248,86</b>
Board Meetings	12.876,44
Partnerships and representation	4.359,52
Fundraising	79.912,95
EFA Conferences	26.169,00
COPD Project	56.384,32
U-BIO	551,78
Medall Project	242,00
Health Vent Project	1.160,61
Meet and Greet Project	595,32
EFA Net	2.972,49
Secretariat	34.229,05
Exec. Officer	39.600,00
Bank Charges	174,55
Difference	20,83
<b>Result of the Year</b>	<b>101.844,43</b>

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

(1)

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Total Debtors	0,00
---------------	------

(2) Susana Palkonen : advance petty cash	889,35
Spranger	900,00
Burotel	1.667,44
Hotel du Congres	- 432,55
Hotel Charlemagne (COPD Project)	- 110,00
Allan Stone (COPD Project)	149,00
Hotel Royal Centre	436,00
Ogilvy Group (COPD Project)	5.000,01
Wagner Henriettefink Antje	9.688,60
Breda Flood	237,94

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Total Creditors	18.425,79
-----------------	-----------

(3)

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Total Received for next year	0,00
------------------------------	------

(4) Smithkline Beecham	15.000,00
AMC Medical Research (U-BIOPRED)	19.878,60
Chiesi Farmaceutici Spa	30.000,00
Pfizer	30.000,00
Novartis Pharma	73.000,00
Smithkline Beecham	55.000,00
Inserm (MeDALL)	27.243,99
Schering Corporation	45.000,00
BI International	35.000,00

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Total Grants	330.122,59
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**AUDITING OF WORKING-ACCOUNTS AND BALANCE  
FOR THE FINANCIAL YEAR 2010  
OF THE EUROPEAN FEDERATION OF  
ALLERGY AND AIRWAYS DISEASES PATIENTS ASSOCIATIONS**

As appointed EFA Auditor by the Assembly General Meeting, I checked the annual accounts of the year 2010 of the European Federation of Allergy and Airways Diseases Patients Associations.

The financial statements for the year 2010 are established in Euro.

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

The financial year closes at a profit brought forward of 210.034,08 Euro. The net result of the year 2010 amounts to 102.332,37 Euro and the balance-total to 227.971,93 Euro.

It is my opinion that the balance sheet and the profit and loss account as at 31 December 2010 gives a fair view of the financial situation of the organisation.

Brussels 29 April 2011  
Sara CEUSTERS  
Accountant

<b>BUDGET</b>
---------------

**BUDGET FRAMEWORK 2011****INCOME**

<b>MEMBERSHIP</b>	36000		
			36000
<b>CORPORATE</b>			
ALK Abelló	30000		
AirLiquide	30000		
BoehringerIngelheim	30000		
Chiesi	30000		
GSK	55000		
Novartis	55000		
Nycomed	30000		
Pfizer	30000		
Stallergens	30000		
			320000
<b>PROJECTS</b>			
<b>Allergy</b>			
ALK Abelló	25000		
Stallergens	25000		
		50000	
<b>COPD</b>			
AirLiquide	20000		
BoehringerIngelheim	20000		
GSK	20000		
Novartis	20000		
Nycomed	20000		
Pfizer	20000		
		120000	
<b>GA<sup>2</sup>P</b>			
GSK	15000		
		15000	
			185000
<b>EU/Commission</b>			
<b>MEDALL</b>	13200		
<b>U-BIOPRED</b>	24000		
<b>HealthVent</b>	5000		
<b>AIRProm</b>	25000		
			67200
<b>TOTAL</b>			608200
			<b>608200</b>

**BUDGET FRAMEWORK 2011****EXPENDITURE****STAFF**

Executive Officer	42000
Project Manager**	-35000
Fundraising*	40000
EU Policy&Project Officer	45000
IT	1500
Communications***	6000
Accounts	7500
Intern	7500
OFFICE	25000
BOARD	10000
PARTNESHIPS/Representation	5000
WORKING GROUPS	5000
MEMBERSHIP FEES	5000
WEBSITE	15000
AGM & NETWORK Meet	27000
PUBLICATIONS	7500
MEET & GREET TRAINING	18000
ALLERGY	80000
GA <sup>2</sup> P	15000
COPD	120000
HealthVent	5000
AIRProm	25000
MeDALL	13200
U-BIOPRED	24000
Other	5000

**TOTAL****554200****Balance****54000**

\*12 hours/month keeping sustainable partners, 70 hours/year scoping new partners,  
5 hours/partner contract finishing, 7000 travel+accommodation

\*\* This cost AF working hours is calculated in the project spending already

\*\*\*Ezine 500/issue by PM

**EFA thanks our sustainable funding partners and project supporters who have made our work possible:**

5 star  
GSK  
Novartis

3 star  
Boehringer Ingelheim  
Chiesi  
Merck  
Pfizer

Project funding:  
U-BIOPRED and MeDALL projects  
the European Commission DG Research

EFA COPD Project  
Boehringer Ingelheim and GSK

To support EFA participation in AIRE survey  
Merck

In kind support  
EFA COPD video  
Boehringer Ingelheim and GSK

Primary Care education project  
Chiesi

Detailed information on the EFA funding and our Framework for Sustainable Corporate Partnership is available at: [www.efanet.org/about](http://www.efanet.org/about)

## Annex 1



## Will Europe suffocate or breathe? A CALL TO ACTION TO COMBAT COPD IN EUROPE

***Chronic Obstructive Pulmonary Disease (COPD) is a leading cause of death, and affects approximately 210 million people. Despite this, COPD remains insufficiently recognised, diagnosed, prevented and treated in Europe. We, the undersigned, call upon the European Union (EU) to take the necessary steps to develop a strategic, comprehensive and integrated European approach to respiratory diseases with a focus on COPD which brings all initiatives and actions under one umbrella, and supports the launch and implementation of national plans on COPD.***

***We assert that the following actions should be supported by the European Parliament, European Commission and European Council:***

1. **Make COPD a political priority**
2. **Increase awareness of COPD**
3. **Prioritize the early diagnosis of COPD**
4. **Support an integrated and multidisciplinary patient-centered approach to the treatment of COPD to improve the care and management of COPD**
5. **Prevent COPD**
6. **Improve Air Quality**
7. **Support better understanding and management of COPD through research**

### 1. Make COPD a political priority

- COPD affects approximately 210 million people worldwide, and according to WHO estimates COPD will become the third leading cause of death by 2030. In Europe 4-10% of adults have COPD. The total financial burden of COPD in Europe amounts to nearly €102 billion and it is expected to increase. Moreover, the social burden of COPD is also increasing; in particular, 21% of COPD patients are severely disabled. COPD is implicated in about 5% of deaths. Despite disabling symptoms (especially breathlessness), complex co-morbidities, and social isolation, the needs of people with very severe COPD are rarely adequately addressed.
  - The prevalence of tobacco smoking, which is the most important risk factor for COPD, is still high. Outdoor and indoor air quality remains poor in many urban areas. At the WHO 5th Ministerial Conference on Environment and Health, the Commission rightly highlighted the negative impact of bad air quality on children which can lead to chronic respiratory conditions.
- ***We call upon the European Commission to recognise COPD as an urgent, preventable and real public health problem and to adopt a comprehensive and integrated approach to address these problems in order to improve the quality of life of patients, decrease the social and economic burden of the disease and stop the COPD epidemic.***

### 2. Increase awareness of COPD

- COPD is a chronic common lung disease that obstructs the airways making breathing difficult. The worse COPD is, the more difficult it is to breathe, with those at the end stage of the disease on permanent mechanical ventilation. Unfortunately, COPD is vastly underrepresented in the mass media and very few people have heard about it. It is crucial that people in every Member State know about COPD but also that patients and their families have easy to understand information on the disease, prevention, and treatment.
- ***We call upon the EU/National Ministries of Health to implement large-scale public health campaigns to increase awareness of COPD amongst the general public, General Practitioners and patients about the symptoms and risk***



**factors (especially smoking) associated with COPD in order to prevent the disease and to encourage an early diagnosis.**

### 3. Prioritize the early diagnosis of COPD

- The later the diagnosis, the more severe the disease. An early and accurate diagnosis of COPD allows for timely treatment and lifestyle changes that can prevent the progression of the disease and its associated premature morbidity and mortality. Despite this, access to early diagnosis of COPD remains difficult in many countries across the EU. This is in-part due to the lack of necessary COPD screening equipment.
  - Spirometry is the equipment which tests the lung function, and is a cost-effective, easy to use and non-invasive test which can be performed routinely by General Practitioners. Spirometry should be made available across health services in all EU Member States and should become a normal part of regular health checks.
- ***We call on the EU to promote and share best practices on early diagnosis and the national authorities to take their responsibilities and ensure that early diagnosis of COPD is undertaken, and General Practitioners are willing and able to perform the appropriate diagnostic tests.***

### 4. Support an integrated and multidisciplinary patient-centered approach to the treatment of COPD to improve the care and management of COPD

- COPD is preventable and treatable, but is in most countries the treatment is only partly reimbursed. COPD places a considerable social and economic burden on patients, their families and the whole society. Access to treatment, continuity of care, and rehabilitation, effective self-management programmes are essential for the optimal management of chronic respiratory diseases.
- Patients with advanced COPD have worse quality of life, greater limitation of activity, more anxiety and depression than patients with lung cancer, yet access to palliative care services is rare.
- Many COPD patients die during an exacerbation, and it is important to develop management strategies before a crisis occurs.

***We call upon the EU to adopt measures in support of ensuring and sharing best practices on the best standards of care for COPD patients at every level, from primary care to specialist healthcare. This includes equal access to treatment, palliative care, patient information and education and rehabilitation programmes for all COPD patients and treating patients and patient representatives as equal partners in their care and health policy.***

### 5. Prevent COPD

- Early COPD symptoms are often mistaken by people as ‘just a normal part of ageing’, or ‘just a smokers cough’, without recognizing that these are early stages of COPD. Diagnosing COPD early would greatly lessen the economic and social burden of the disease on already-stretched health systems.
  - Smoking is the main cause of COPD and passive smoking can cause and severely aggravate the condition of people with COPD, yet very few people who start or continue smoking know about COPD, like they do about lung cancer – both having devastating impact.
- ***We call upon the EU and Member States to put in place prevention campaigns and initiatives, in order to reduce the risk of COPD.***

### 6. Improve Air Quality

- 19 000 European non-smokers die every year from exposure to second-hand smoke either at home or at the workplace. According to recent Eurobarometer survey a quarter of non-smokers are exposed to tobacco smoke at home and a quarter of EU citizens are exposed to tobacco smoke at work.
- Poor indoor air quality (such as damp or mouldy buildings) is particularly harmful for people with COPD. Air pollutants like dust, or fumes can also irritate the lungs and cause exacerbations.

In the WHO European Region, “70% of the population lives in urban areas, and over 92% of city dwellers are exposed to levels of particulate matter that exceed the WHO air quality guideline value<sup>30</sup>”. The peaks of pollution can be devastating for people with COPD.

➤ **We call on the EU and the Member States to ensure improved outdoor and indoor air quality, including binding measures to abolish smoking in both the work place and public places across Europe and a joint framework on healthy air indoors.**

#### 7. Support better understanding and management of COPD through research

- There are a number of research questions that need to be addressed before care for people with COPD can be at the same level as other chronic diseases. These include questions about prevention, diagnosis, case-finding and spirometric assessment in primary care, management and organization of care, and support and palliative care for patients with severe COPD.
  - COPD together with asthma is the most common lung disease, yet mechanisms behind the development of COPD are poorly understood and there is no cure. EU research must focus on understanding the mechanisms in the development of this major disease.
  - Availability and comparability of COPD prevalence data in Europe is poor leaving important gaps of knowledge.
  - Research makes a direct contribution to the prevention and treatment of COPD and can lead to increases in the quality of life of European citizens.
- **We call on the EU and Member States to prioritize investment in real life, basic and prevalence research in respiratory diseases and prevention, to ensure that effective treatments and cures can be developed.**

SIGNED by  
EFA PARTNERS:



<sup>30</sup> Source: WHO Europe: [http://www.euro.who.int/mediacentre/PR/2010/20100406\\_1](http://www.euro.who.int/mediacentre/PR/2010/20100406_1)

## Annex 2

**EU Health Forum Workshop:  
Policy Recommendations**

**Integrating Environment and Health policy towards better health outcomes:**

EU environment policies can contribute to improving people's overall health status, and address a number of public health concerns, ranging from obesity, nutrition and food safety to reduction of environment contaminants related to chronic diseases such as respiratory and cardiovascular diseases, cancer or developmental problems. The mounting body of environment and health information and research provides the evidence basis for understanding environment's impact on these diseases, and identifies significant opportunities for prevention policies and activities given that the majority of environmental policies are set by EU environmental laws. An integrated EU approach on environment and health could also strengthen member states implementation work by providing coherent and coordinated action on environmental determinants of health.

The first Community Strategy on Environment and Health SCALE and the EU Action Plan EHAP aimed to develop a more integrated approach to tackling the environmental burden of disease. It has also highlighted the overarching objective of better health protection of vulnerable groups such as children, pregnant women and health affected groups who are more biologically susceptible to environment contaminants (e.g EU Air quality legislation recognizes that vulnerable populations includes people with respiratory disease who need a higher level of protection from pollution).

To continue integrating health concerns in environment policies as part of the wider health in all policies approach, the EU Health Forum workshop has discussed and agreed on the following recommendations.

**1. Support for a second EU Action Plan on Environment and Health.** The EU Action Plan on Environment and Health 2004-2010 has provided added-value and provides a foundation to bring together information, research, and best practice, and to translate it into policy to reduce the environmental burden of disease. It can also serve to highlight the positive benefits to health from a more sustainable and cleaner environment. The workshop welcomes the Commission's Progress Report (March 2010) to continue to consolidate this work and continue discussions with member states and stakeholders to develop a new Action Plan in 2011.

**2. Greater synergies with the 2010 WHO Parma Ministerial Declaration and implementation:**

Future environment and health work should ensure synergies and support to EU member states in fulfilling their WHO commitments, such as the time bound targets on improving children's environmental health, related to unclean water and sanitation, poor air quality and tobacco smoke, exposure to hazardous chemicals and accident prevention. This should also include action on the priorities identified by health and environment ministers in the Parma Declaration as the key environment and health challenges of our time: health and environmental impacts of climate change; health risks to vulnerable groups from environment working and living conditions; socioeconomic and gender inequalities; reducing the burden of non-communicable diseases from policies such as environment, transport, urban development; and emerging issues such as persistent, endocrine-disrupting chemicals and nanoparticles.

**3. Increasing health community and youth participation** (public health institutes, patient and disease prevention groups, medical professionals, NGOs) in EU, national and local policy making and implementation would provide additional public health lever for environmental

policies. Short and medium-term policy opportunities include:

Discussion on a second EU Action Plan on Environment and Health and topics identified as providing added-value such as indoor air quality, human biomonitoring, and environment and health information systems.

Ensuring health benefits and cost savings are integrated in the wider EU climate discussions on the greenhouse gas emission reduction target and greening health care systems.

Ongoing revisions and implementation of key EU environmental legislation and strategies such as the Air Quality, Biocides Directive, Mercury Strategy, REACH, Pesticides, GMOs as well as other environment and health related forthcoming EU initiatives, for example in transport. Particular attention should be paid to prenatal exposure.

Implementation of the European Partnership for Action against Cancer to integrate environmental factors within the prevention working group, and beginning discussions on identifying a second priority disease such as respiratory diseases, and neurodevelopmental diseases for a future EU strategy. Promotion of population-based disease registries should also be encouraged. The EU Health Strategy should include prevention policies which incorporate environmental factors, and care policies should incorporate prevention. Ensuring that the health stakeholder community and citizens have accessible information on EU policy in the field of environment and health and how it can impact their lives – the EU added value.

Facilitating greater environment and health education and capacity, particularly for medical students and environmental and health professionals.

- 4. Translating research into ambitious action which addresses the urgency of environmental health impacts:** The 6 EU Research Framework programme has provided around 200 million Euros for 2002-2006 for environment and health projects, and the current FP7 continues to spark research projects, many of which will be producing policy relevant results in the next years. The current mechanisms and structures need to be strengthened to ensure research is translated into actions for implementation or further policy revisions on an ongoing basis.

**Links:**

*EU Commission Progress report on the implementation of the EU Action Plan on Environment and Health, March 2010:* <http://register.consilium.europa.eu/pdf/en/10/st08/st08201.en10.pdf>  
*Fifth Ministerial Conference on Environment and Health of the WHO European Region: Parma Declaration on Environment and Health, March 2010:*  
[http://www.euro.who.int/\\_data/assets/pdf\\_file/0011/78608/E93618.pdf](http://www.euro.who.int/_data/assets/pdf_file/0011/78608/E93618.pdf)

Annex 3



Position Paper  
European Federation of Allergy and Airways Diseases Patients'  
Associations<sup>31</sup>

[Proposal for regulation of the European Parliament and of the Council  
on the provision of food information to consumers 2008/0028 \(COD\)](#)

For the attention of the European Parliament, Council, the Commission,  
responsible authorities in the member states and European Food Safety Authority  
EFSA

04-05-2010

**The only way to manage a food allergy or intolerance is to avoid the allergen to which one reacts. Food Allergy is a Food Safety issue, and must be considered with other Food Safety risks (eg microbiological, physical and chemical). Food sold without accurate labeling and clear identification of all ingredients should be considered 'unsafe'.**

<sup>31</sup> EFA represents through its' [member associations](#) the people with food allergy in Europe. EFA is a non-profit network of allergy, asthma and COPD patient organisations representing 32 member organizations in 20 countries, and over 400.000 patients. EFA aims to substantially reduce the frequency and severity of allergies, asthma and COPD, minimize their societal implications; improve health-related quality of life of patients; and ensure full citizenship of people with these conditions.



Food Allergies are a lifestyle burden for people concerned as well as for their families and people who share their food, as it requires extreme vigilance. Allergic reactions to food can be life threatening. Eating out in particular poses dangerous risks. Therefore the list of contents on all labels of food products purchased for consumption must always be carefully checked to avoid introducing an allergen in the diet of persons at risk from allergic reactions.

### Background: the situation in Europe for people with food allergies

1-2% of adults and 5-8% of children live with IgE-mediated<sup>32</sup> food allergies.<sup>33</sup> In addition, at least 1% of the population has celiac disease and up to 20% of the population has non-IgE-mediated food intolerances<sup>34</sup> and need to avoid particular foods. The prevalence is an important gap in research.

The introduction of mandatory allergen labeling on pre-packed food has changed our lives. [The directive 2003/89/EC](#) was a step forward. The effect on public health has been immediate as can be seen in the statistics of anaphylactic shocks<sup>35</sup> caused by « hidden allergens ». However feedback from EFA members and associated help-centers and fatal cases indicate that there are still problems to be addressed.

As a result, EFA very much welcomes this proposal but notes that some issues related to food allergies are not sufficiently taken into account. This paper presents the EFA position. The patient groups who gave input are listed at the end.

## 1. Quality of labeling for pre-packed food

September 2008: Deja Hay, a seven-year-old boy who is allergic to cow's milk died after drinking a carton of pineapple and coconut juice. Skimmed milk was listed among the ingredients, but he didn't expect milk to be present in a fruit juice drink and nor did his mother. Neither of them noticed it in the ingredients list.

July 2008 : Dexter Skinner, 16 who suffered from a severe peanut allergy, died after biting into a chocolate bar. **Could you read this?**

**Legibility of the label:** Very often, the labeling is not easy to read. Nowadays, the letters of

the ingredients list are often smaller than 1 mm ... while there is no newspapers or book using font size under 2 mm!

December 2007 : Stephanie Faulkner, 14, was out for a meal with her best friend but suffered a severe anaphylactic shock and died after she ate a chicken tikka masala at a Bangladeshi restaurant. The menu did not mention nuts.

**EFA urges the European Parliament and the Council of the European Union to ensure that the 3mm font size and provisions on the contrast between writing and background as proposed by the Commission are kept.**

*"I take my glasses with me, because everything – all ingredients are written obviously in extremely tiny print, and my eyesight is such these days that I can't read it. "*

A person with food allergy

**Change in the recipe:** There is nothing in the Commission proposal on warnings of introduction of one of the 14 mandatory allergens in a new recipe of an existing product. It is of particular concern since it has led to serious accidents as consumers do not expect danger coming from a product that has been eaten without problems in the past. In this case, mentioning the allergen in the ingredient is not sufficient. Best practice

<sup>32</sup> IgE mediated means allergic

<sup>33</sup> The prevalence, cost and basis of food allergy across Europe. ENC Mills, AR Mackie, P Burney, K Beyer, L Frewer, C Madsen, E Botjes, RWR Creve, R van Ree. Allergy 2007; 62: 717–722

<sup>34</sup> Zopf Y, Baenkler HW, Silbermann A, Hahn EG, Raithe M. The differential diagnosis of food intolerance. *Dtsch Arztebl Int.* 2009;106:359–369.

<sup>35</sup>Anaphylactic shock is a life-threatening allergic reaction, i.e. to food.

guidance suggests the use of a 'New Recipe' flash on the front of the packet. This could be a legal requirement.

**EFA demands that changes in the recipe be clearly mentioned on the labeling by a "new recipe" statement or a notice "contains, in addition, the name of the allergens" on the main side of the package.**

## **2. Labelling for non pre-packed food – 7 out of 10 severe reactions happen when people eat out**

In most countries non-pre-packed food (sold in bakeries, butcher's shops, snack bars, restaurants and canteens) is not covered by regulation. There is no information available to protect people against an allergen they need to avoid.

Therefore we welcome new provisions included by the Commission concerning allergen information for non pre-packed food in its proposal, which acknowledge that 7 out of 10 severe allergic reactions happen when people eat out<sup>36</sup>. However there are shortcomings in this proposal concerning this issue.

The proposal states that information "should be provided" but doesn't indicate how. The Parliament Rapporteur Renate Sommer proposes that the information should be available by any means, not necessary a label.

**EFA demands that the labeling of allergens or availability of this information one way or the other but preferably in written form wherever food is sold (catering, sold loose) be mandatory in non pre-packed food.** It is essential to guarantee that people with food allergies have access to information that will protect them and may save their life.

## **3. "May contain" labeling - precautionary labeling (pre-packed or non-pre-packed!) - serious reactions, and even deaths, have been caused by foods with "may contain" labeling:**

This type of labeling has been introduced by the food industry on a voluntary basis. Some allergens are part of the recipe while others may be present in the prepared food by cross contamination. As this term "may contain" is not legally defined, each producer has his own interpretation. Therefore the food allergic consumers are not able to judge if there is a risk involved, especially if they find this mentioned on labels for products that have previously been consumed without problems.

A recent study has shown that parents of allergic children perceive risk and react differently depending on the wording used to warn that the product may contain allergen, despite the fact that there is may not be any difference between what is meant as they are not defined<sup>37</sup>. In other words, without a legal and common definition, people with food allergy are misled.

**80% of parents with food allergic children would not let their children eat a product where it reads:**

- 'Not suitable for nut allergy sufferers' or
- 'May contain nuts'

**Only 50% if it is mentioned:**

- 'This product does not contain any nuts but it is made in a factory that uses nuts'
- 'Cannot guarantee nut free'
- 'May contain traces of nuts'

According to feedback from people with food allergy in Belgium and France to our member associations, they think that it is a legal requirement to use precautionary labeling.

<sup>36</sup>[http://ec.europa.eu/food/food/labellingnutrition/foodlabelling/publications/labelling\\_citizens\\_summary\\_310108\\_final\\_cab.pdf](http://ec.europa.eu/food/food/labellingnutrition/foodlabelling/publications/labelling_citizens_summary_310108_final_cab.pdf)

<sup>37</sup> [Parents' attitudes when purchasing products for children with nut allergy: a UK perspective.](#) Noimark L; Gardner J; Warner JO. *Pediatr Allergy Immunol.* 2009 Aug;20(5):500-4. Epub 2009 Jun 17.



Our associations are aware and have examples that serious reactions, and even deaths, have been caused by “may contain” labels. These labels indicate a doubt or give the option for the reader to opt for the doubt factor. Young people (in particular) are tempted to ignore these messages. In cases where there is in fact a real cross contamination of the product, this can lead to a severe reaction or death.

Parliament Rapporteur Renate Sommer proposes in her draft report on the current Commission proposal a solution to indicate the risk for cross contamination in non pre-packed food: a legal sign, indicating that “*information on the ingredients is available, but that cross contamination cannot be avoided*”, and we are concerned that this would remove the food supplier’s obligation to comply with the law to supply ‘safe food’ and to alert customers to any risks associated with the food on sale. It would not resolve the current ‘may contain’ labelling dilemmas faced by high risk consumers. This later warning would also delete the responsibility of the enterprise for good practice and in fact confirm by law the current wild practice on the use of “may contain”.

**For cross contamination, and for may contain labelling, the Swiss legislation sets the following rule :**

“Unintentional impurities” can only be declared with a level more than 1g/kg of allergen (for all mandatory allergens except cereals and sulphites which have different thresholds)

This declaration should only be authorized if the company can prove that cross contamination cannot be avoided despite the respect of all rules of good practice in manufacture.

[http://www.admin.ch/ch/f/rs/c817\\_022\\_21.html](http://www.admin.ch/ch/f/rs/c817_022_21.html) (in de, fr or it)

*“I'm always scared to ask. I feel I'm a nuisance. It's a bit embarrassing.”*  
An English University student about restaurants and takeaways.

**Swedish food sector guidelines 2005** give the following definition and guidance on the use of **precautionary labelling**:

“May contain” labelling should only be used as a last resort when the risk for contamination by each allergen in a specific production-line is:

1. **Uncontrollable**, i.e. the ability to ensure the entire process is considered impossible, e.g. due to manufacturing in part occurring in systems that cannot be cleaned with water.
2. **Sporadic**, e.g. if the allergen is detected sporadically after product changes.
3. **Documented** through cleaning controls, test results, or substantiated consumer reaction

**EFA urges the European Commission to put in place a definition of “may contain” precautionary labeling for the European market, and ensure that it cannot be used unless:**

- All reasonable **precautions** have been taken in the production
- **Good practices** are in use
- The workers have received awareness and practical **workplace training** on food allergy, as they do for managing microbiological and other food safety risks

On the long term, **precautionary labeling should be abolished and threshold levels need to be defined** in order to have the lowest risk possible for people living with food allergies. As it is impossible to have a zero risk, this could be ‘95% of people who are most allergic do not react to this dose’. **When there is a realistic danger, and the allergen is always present in the product, it should be mentioned in the ingredients list.**

#### **4. Establishment of a safety chain for people with food allergies – people with food allergy need to be vigilant but industry must do their part**

In our developed society, we cannot accept that some people are faced with danger simply by eating everyday food. That is why each person working at every stage of the production, delivery, manufacture, sale and service of food should always be able to check the ingredients used, as well as any possible contaminants. Each “food business operator” must be aware of the risks involved by food allergy in the same way as they understand the risks involved in poor cleanliness.

It’s not our fault that the food industry is so complicated and even the simplest products have tens of ingredients. We have a right for information and to choose our food without risk of getting sick because of allergens.

**The responsibility for providing information – the right for information:** We agree with the principle that it is the food suppliers' responsibility to keep product information and be ready to inform their customers about allergens at each step in the distribution chain, as mentioned in the proposal. The labeling of and information on ingredients and possible allergen contaminants for non pre-packed food is essential information for people suffering from food allergies and intolerances. Some European countries have already made this information compulsory.

The full ingredient list including the 14 main allergens should be collected and managed at each stage of the food preparation process, where a product or a package is changed, either by packaging or addition of an ingredient so that people know what they eat and can choose the right product without the ingredients that they are allergic to. This means the producer of the raw material, the wholesaler who sells it to the shop or the catering establishment, the place where it is prepared, sold or served to the consumer.

**EFA demands that every food business operator must be required by law to provide a complete and accurate ingredients list to another food business operator customer (including catering establishments) at the time the food is delivered. Any subsequent changes in specification must be communicated to the catering establishment or final retailer.**

*"They don't know what's in it. A lot of them are youngsters. They are not taught about special diets as part of their catering course."*  
Parents of allergic child

The Swedish Asthma and Allergy Association has a **programme called Great, an Allergic Customer! for restaurants and catering**. As part of the programme, they receive training to manage and declare allergens. When they fulfill the criteria for best practice they can receive a certificate for good practice and 'endorsement' from the Association that people with food allergy are welcome! For example the MacDonaldis chain restaurants in Sweden are certified.  
<http://www.astmaoallergiforbundet.se/>

It is the responsibility of each producer, wholesaler, retailer or caterer to check the accuracy of what he or she receives and what sells, in order to be able to give the information requested by people with food allergies. **Training is the key as it is has been for the success of managing other food safety risks eg hygiene.**

**The wholesaler needs to be involved too:** All this should apply to the "convenience" or "ready-made" products and ingredients bought from a wholesaler such as spices mixtures, ready made bread mix, ready made cake or pastry mix...

At any given moment in the production/supply chain, if the producer or wholesaler decides to mix several different products in one package, for example sesame seeds rolls with plain unseeded rolls, it should be mandatory that a new label is developed and applied.

In case where the product delivered to the catering establishment is not exactly the one that has been ordered or usually bought, it should be clearly indicated (e.g. a danger signal if one of the 14 allergens is used).

In each of the above examples, our associations have been aware of serious and sometimes fatal reactions due to a lack of accuracy or information from the wholesaler.

The Swiss association for people with allergy aha! published a practical guide for managing allergens in food sold loose after a discussion with different stakeholders. It gives the following recommendations:  
1. **Principles that food sector personnel should follow to give reliable information** to the customers with food allergy  
2 **Good practices through best practise examples**  
3. **Check-list of actions** to be taken by food professionals.  
<http://www.ahaswiss.ch/>

*"We go to a holiday resort. They'll cook everything with separate utensils, and they'll even change the menu to accommodate us. So when places like that will accommodate our allergies, we tend to go with what we know, because we know we're going to be safe there."*  
A person with food allergy.

**Managing food allergens must become a key component of all Food Safety Manuals, Guides and Training. All wholesalers need to be aware of severe allergies and alerted to what is required by the new regulations.**

EFA asks for the establishment of European guidelines/legislation on the training of personnel in the food sector on managing food allergens.

*Read the attached testimony: the life of a patient with severe food allergy: Growing-up and living with severe food allergies – I don't want to be special, I just want to be safe*

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