

EFA Alignment Meeting with the Maltese Asthma Society

September 28th 2013
St Julian's, Malta



EFA Priorities and Recent Events

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EFA's Vision

EFA is...

- The leading reference point for people with allergy, asthma and COPD
- Dedicated to making Europe a place where people with allergy, asthma and COPD:
 - Have the right to the best quality of care and safe environment
 - Live uncompromised lives
 - Are actively involved in all decisions involving their health

EFA's Mission

EFA is aiming to be a powerful network that...

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

EFA's Objectives

For Members

- Actively communicates with members identifying their needs
- Develops Projects to meet these needs

For Patients

- Transparent access to information and educational tools in patient-friendly language

For Healthcare Professionals/Scientists

- Facilitates communication in patient-friendly language focusing on patient needs



EFA's Objectives

For Policymakers

- Acts as a liaison between people with allergy, asthma and COPD & EU Policymakers

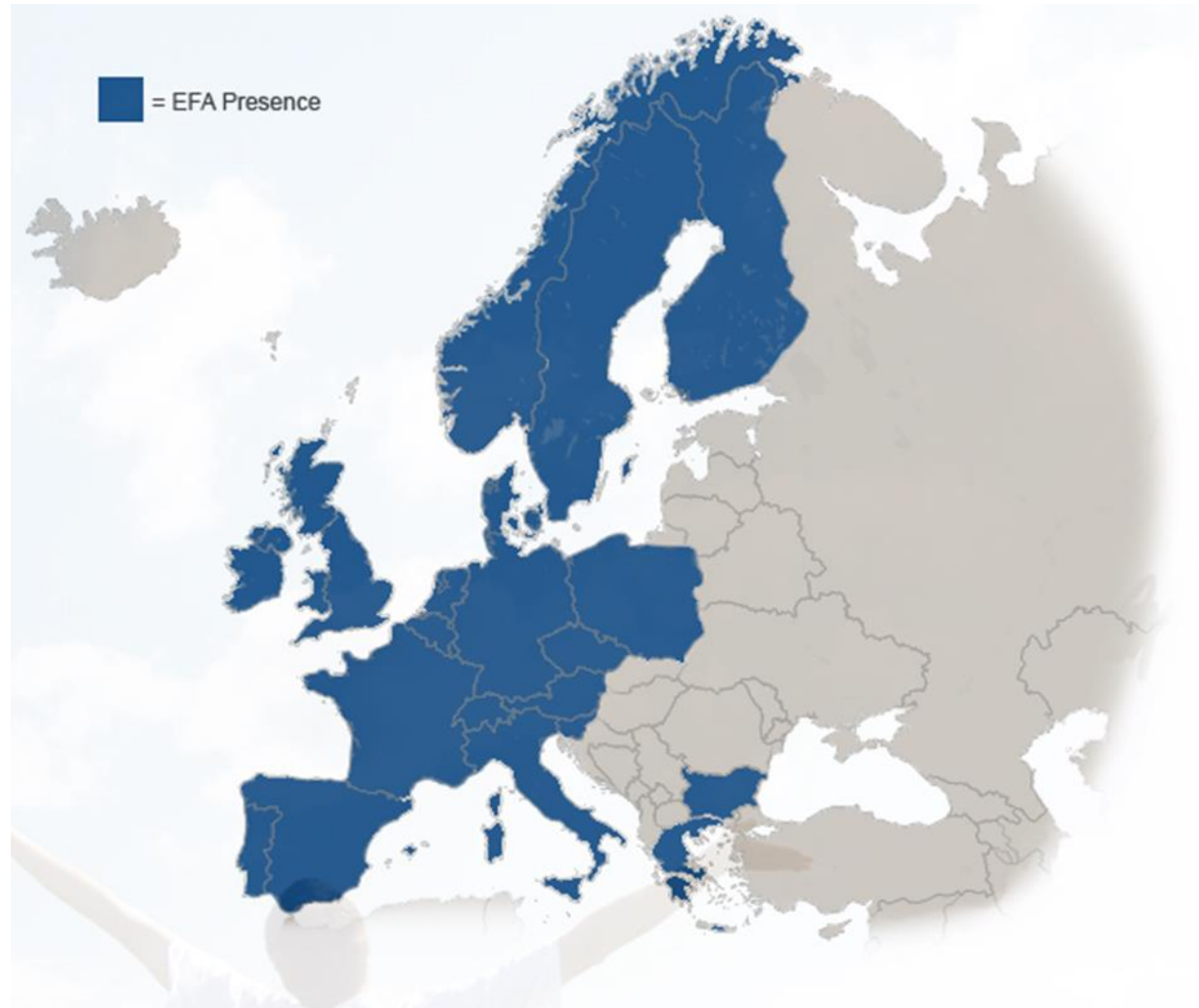
For Industry and NGOs

- Develops long term partnerships
- Ensures well defined conditions of partnership



Members of EFA

**22 countries
35 member
organisations
representing
over 400,000
patients
& carers**



Members of EFA

- Each EFA member has one vote for elections at the Annual General Meetings
- Each full member pays an annual fee of €500, which guarantees reimbursement of expenses when invited for EFA activities



- Current EFA member coalitions may continue as coalitions if need be

Membership Criteria

- Applicant patient associations must fulfill specific criterion:
 - Be a patient/carer organisation
 - Be accountable and transparent
 - Working towards EFA's aims and objectives
 - Legitimacy
 - Independence
 - Democracy



EFA Activities

EFA Board Meetings

- Board members convene to discuss and decide upon administrative matters, implement annual plans and continue planning ahead



President

Breda Flood, Ireland

Vice President

Christine Rolland, France

Board Secretary

Per-Åke Wecksell, Sweden

Treasurer

Ondrej Rybnicek, Czech Republic

Board Member

Lina Buzermaniene

EFA Activities

EFA Working Group Meetings

- EFA members convene in four distinct groups for different disease areas through the internet, teleconference or face-to-face meetings. These meetings can result in the brainstorming for and planning of future EFA projects and events.

Working Groups

Joint Severe Asthma & Allergy
Food Allergy
COPD



Annual EFA Events

Annual General Meetings (AGMs)

- All EFA members meet annually to elect board members, approve applications of new members, review activities of the past year and discuss strategic objectives for an annual plan

Last AGM: Rome, Italy (2013)

Next AGM: **Brussels, Belgium (2014)**

Networking Meetings

- Usually occurs the day after the AGMs as a means for EFA members to convene working groups and share best practices while creating work plans for the upcoming year

Annual EFA Events

Meet & Greet the EU Institutions Training

- EFA members are invited to Brussels each year for an opportunity to overview:
 - how the EU works
 - further understanding of EU policies in their fields of interest
 - have meetings with Members of European Parliament (MEPs)
 - Meet other EU policymakers

Next Meet & Greet:

October 14th – 16th 2013



Partner Organisations

EFA is a member of and collaborates with various partner organisations and:

- European Patients Forum (EPF)
- Health and Environment Alliance (HEAL)
- International Coalition of COPD Organisations (ICC)
- European Networking for Smoking Prevention (ENSP)
- International Primary Care Respiratory Group (IPCRG)
- Global Asthma and Allergy Patient Platform (GAAPP)
- European Respiratory Society (ERS)



EFA is a member of and collaborates with various partner organisations and:

The European Medicines Agency (EMA) is a **EU regulatory agency** located in London responsible for the scientific evaluation of pharmaceutical medicines for use in the EU



- I. Input for the implementation of new pharmacovigilance legislation
- II. Document review
- III. Involvement in providing patient perspective on medicines

EFA and EU Policy

- **Health and research programmes** - to be adopted in 2013, will enter into force during 2014
- **Horizon 2020** – first calls expected in December 2013
- **Medical devices and clinical trials legislation** – currently under ordinary legislative procedure and hopefully will be adopted before next EP elections in 2014
- **Tobacco products directive** – recast of the current text to be presented by the Commission and hopefully adopted before next EP elections
- **Revision of the EU air legislation** – to be reviewed in fall 2013
- **Seventh Environmental Action Programme** – Under ordinary legislative procedure at the EP and Council, expected to be adopted by the EP plenary in October and then finally adopted before end of 2013

EFA Public Events

EFA “Contains/May Contain” Food Allergen Labeling Event

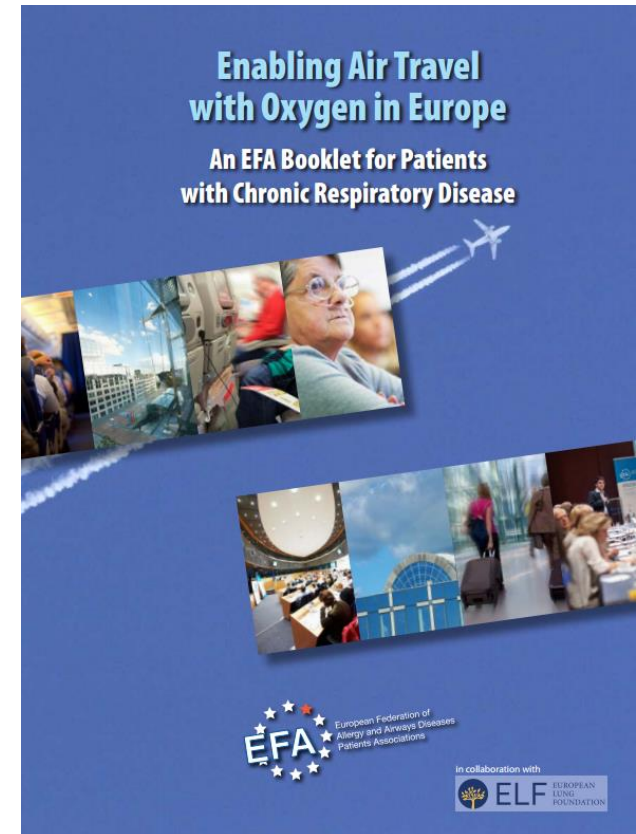
- EFA’s last event at the European Parliament took place on the 19th of September 2012 to discuss EU legislation on food allergen labeling
- 80 participants attended the event which was made possible through the persistence and support of EFA members in the food allergy working group



Oxygen Harmonisation Project

Focuses on the inequalities which exist in relation to the availability of oxygen during travel on European airlines

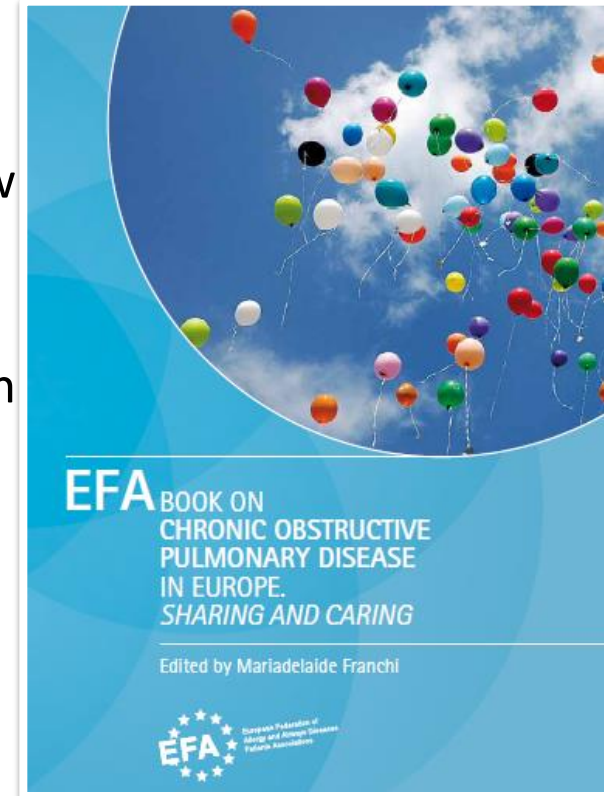
- EFA released Enabling Air Travel with Oxygen in Europe at ERS Congress 2013
- Follow-up actions:
 - Meet with MEP Taylor at EP
 - Meet with DG MOVE at the European Commission to try and push for meaningful change on air travel legislation
- Overarching objective to harmonise the conditions for patients with respiratory illness and a need for oxygen during travel, making oxygen available at all times and free of charge to all those patients in need



COPD Project

New Publication in 2013 on COPD in Europe

- EFA is currently working on it's follow up to the *EFA Book on COPD in Europe* from 2009 with a new publication focusing on *Minimum Standards of Care for COPD Patients in Europe*
- A public event will be co-hosted with the European COPD Coalition in Brussels on November 28th to commemorate World COPD Day
- Workshops in the European Parliament in 2012 helped raise awareness to policymakers



COPD Project

EFA identified allergies as requiring a four year project with three key objectives:

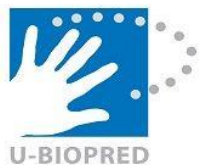
1. To raise awareness of allergies as chronic diseases and major issue areas;
2. To increase the ability of identifying early symptoms and diagnosis;
3. To encourage European level guidance on appropriate management and control of exacerbations for both patients and medical professionals

- The EFA Book on Respiratory Allergy launch event at the European Parliament (22 November 2011) joined EU policymakers and the European allergy community
- EFA's educational meeting to introduce the Finnish Allergy Programme (8-9 November 2012) in Helsinki, Finland with delegations, including EFA members and key stakeholders, from Bulgaria, Italy and Norway met Finnish Allergy Programme representatives and discussed potential for future national allergy programmes in other European Countries

Current Trend: 1 in 2 Europeans may suffer from an allergy by 2015



Involvement in EU Projects



U-BIOPRED - Research project to understand more about severe asthma and create a handprint for the different ways severe asthma affects each patient

AIRPROM - Research project with objective of modeling the human lung and generating its potential reactions to asthma and COPD medications



MeDALL - Aims at improving the health of European citizens by investigating the causes of allergy

EARIP – Newest project, which began in September attempting to promote best practices for Europe through national asthma programmes, identifying research gaps and establishing strong stakeholder networks for research and healthcare systems change

Thank you for your attention!

European Federation of Allergy and Airways Diseases Patients'
Associations (EFA)

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