



European Federation of Allergy and Airways  
Diseases Patients' Associations

# Activity Report 2015

**Roberta Savli**

EFA AGM, London, 23 May 2016

## GOAL 1



**Improving timely and  
equal access to quality  
care for patients with  
allergy, asthma and COPD**

# Influencing Policies Affecting Care

- Launch of the **European Parliament Interest Group on Allergy and Asthma** with EAACI
  - 2 main events at the European Parliament (March and July)
  - Meetings with 8 Members of the European Parliament for World Asthma Day, total of 11 committed MEPs
- Call for a Commission **strategy on chronic diseases + personalised care** for allergy and airways diseases patients
  - Relaunching GARD, Global Alliance against Respiratory Diseases (July)
  - Participation as a Young Gasteiner in the European Health Forum Gasteiner, meeting with Commissioner (October)
  - World Health Organisation strategic technical meeting on management of chronic respiratory diseases (November)
- Patients' contributions in the implementation of the EU **clinical trials** regulation and discussions on **medical devices** legislation
  - EFA position on medical devices presented to national Ministers of Health (December)
  - Empowering patients through participation in EPF (Vice-President, consultations on adherence and concordance, and on continuous healthcare professionals development)

“The decisions taken by the European Parliament can make a difference in the life of European patients, and it is a pleasure to work with EFA within the Interest Group on Allergy and Asthma to push for decisions aiming at improving of health and quality of life of Europeans.”

Sirpa Pietikäinen, Member of the European Parliament (Finland, EPP), and Chair of the EP Interest Group on Allergy and Asthma





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# EFA Promoting disease self-management

- Towards a better understanding of **adherence of young people with asthma**
  - In collaboration with Maastricht University, survey in France, Germany, Spain and the United Kingdom
- Sharing best practices in **patient education**
  - New EFA Patients Education Working Group (May)
  - Collection of patient education materials from patients to patients in different languages



Pharmacist: "and which medication reminder device would you like to use with this prescription?"

## GOAL 2



**Ensuring people with  
asthma, allergy  
and COPD live in a  
healthier environment**



# Patient-centred preventative tobacco control

- Contributing to the implementation of the **tobacco products directive**
  - Contribution to DG SANTE Scoping Study on Communication to address Chronic Diseases, focus group on smoking-related harm (February)
  - Through ENSP, response to the European Commission consultation on tobacco traceability and illicit trade (July)
- Better care for **smokers willing to quit** + renewed attention on **smoke-free environments**
  - Representing patients at 16th World Conference on Tobacco or Health (March)
  - Patients' views included in the fifth edition of the Tobacco Atlas (March)



- Press release on World No Tobacco Day on smoking cessation programme in Europe (May)

# Improve air quality

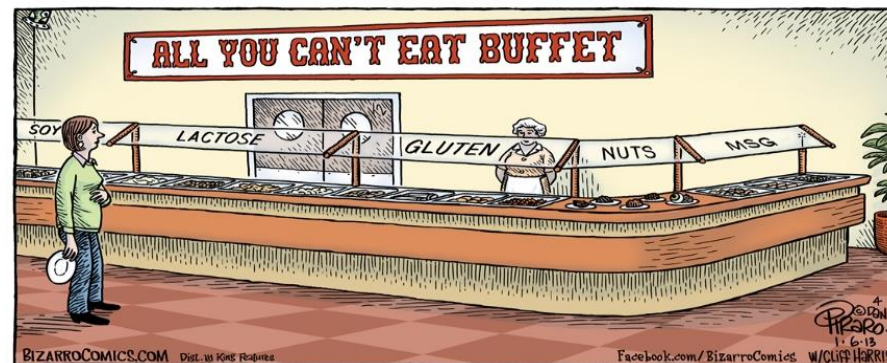
- Reducing current **air pollution** levels
  - Contribution to decision process of the EU national emissions ceiling directive, social media campaigns, event at the Parliament + 5 joint advocacy documents
  - Contribution to HEAL (Treasurer, dangerous effects of climate change on human health presented to Health Commissioner, video on need to act against climate change)
- Calling for **pollen monitoring** in Europe
  - Press release on International Ragweed Day (June)
  - Presenting patients' unmet needs on pollen at WHO European Task Force on Health Effects of Long-range Transboundary Air Pollution (April)





# Better quality of life with food allergy & less chemicals' exposure

- Towards accurate **food labelling**
  - EFA Food Allergy Working Group working on adequate and patient-centred national transposition of allergen labelling regulation
  - Patients' perspective presented at the Universal Exposition in Milan



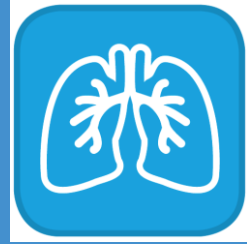
Chemicals in beauty products go more than skin deep, they seep; Buyer beware, if hazardous chemicals are listed in your skin care!



someecards  
user card

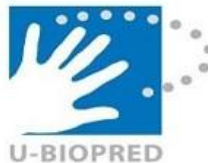
- **“Suitable for” labelling**
  - New EFA Working Group on Environmental Determinants (May)
  - Collection of best examples of existing “suitable for” allergy and respiratory disease patients' labels developed for cosmetics, cleaning or other products

## GOAL 3



**Ensuring patient  
involvement  
in European projects,  
initiatives  
and decisions impacting  
their health**

- Making **research meet patients'** needs
  - Through EFA working groups, mapping research gaps from patient's perspective
  - Organising MeDALL final event at the European Parliament (May)
  - Disseminating patients' friendly materials within AirPROM
  - Developing guide Successful patient involvement in EU-funded research projects with U-BIOPRED Patients Input Platform
  - Publication of manuscript National and regional asthma programmes in Europe: a systematic review in European Respiratory Review + 2 events proposing recommendations for healthcare systems changes, including at the European Parliament (September, October) within EARIP
  - New MyAirCoach project: coordinating the Advisory Patient Forum + leading communication and dissemination (brochure + World Asthma Day press release)
  - Member of the Scientific Advisory Board of ERACoSysMed

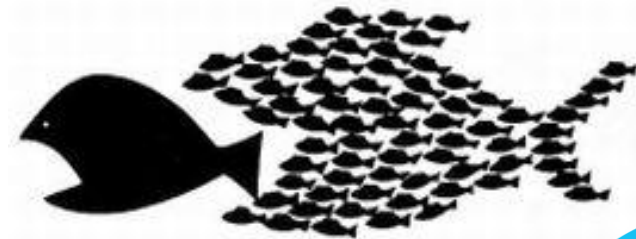
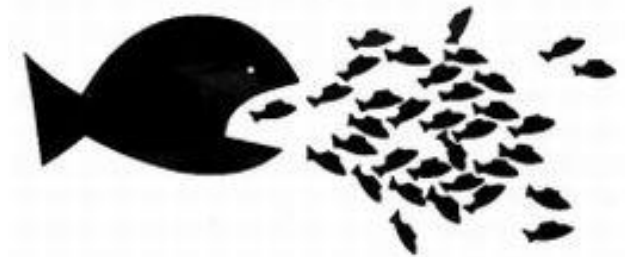


# People with asthma, allergy and COPD in EU health policies

- **Harmonising COPD care** in Europe
  - Launch of the report Harmonizing prevention and other measures for COPD patients across Europe (March) + poster presentation at ERS congress (September)
  - Organisation of 3 meetings to facilitate members' advocacy in Belgium, France and Spain
- Facilitating our members health **policy and advocacy** initiatives
  - Organisation of sixth EFA Meet and Greet the EU Institutions training with 8 members and 1 candidate member (October)
  - Visit to the Council of the EU + role play + meetings with 6 Members of the European Parliament
- Advocating for the rights of passengers requiring **oxygen for air travels**
  - Presentation at ERS congress of leaflet Steps for passengers flying with medical oxygen (September)
  - Marking World COPD Day with booklet Enabling air travel with oxygen in Europe (November)

# Patients' empowerment in disease management

- Even stricter collaboration with the **European Medicines Agency**
  - Since 2010, active member of EMA Patients' and Consumers' Working Party
  - Involvement in new 5 EMA topic groups dealing with acknowledgement and visibility of patient input (co-chair), patient involvement, training, social media and involvement of young people and children
  - 6 patient experts contributing to EMA activities
- Input in **patient advisory committees** of our scientific partners ERS, EAACI, ARIA and GARD
- **Patient-centred sessions** in major European scientific events, such as ERS and EAACI congresses





## GOAL 4



**Ensuring equitable  
representation of  
European  
patients with allergy,  
asthma and COPD**

# Solid allergy, asthma and COPD patients' network

- **AGM & networking meeting** in Malaga (Spain) hosted by FENAR
  - 3 new members + new Board: Christine Rolland (new President, French Asthma and Allergies Association), Erna Botjes (Vice-President, Dutch Food Allergies Foundation), Sharon Cosgrove (Treasurer, Asthma Society of Ireland), Dan Murphy (Secretary, Asthma UK), Mikaela Odemyr (Swedish Asthma and Allergy Association)
  - 5 working groups: Environmental Determinants, Patient Education, Allergy and Asthma, COPD and Food Allergy



- Updated **Framework for Sustainable Partnership** with our corporate supporters

# Expanding EFA's network towards underrepresented patients

- **3 more members** to our patient network
  - German Allergy and Asthma Association
  - Food Allergy Italia
  - Action against Allergy (United Kingdom)



- Mapping **candidate members**
  - Czech Civil Association against Lung Diseases
  - Potential members active in Balkan countries and Estonia



# Increasing asthma, allergy and COPD profile in Europe

## Our 2015 outreach in figures

**15,196**  
visits to efanet.org

**11**  
events  
organised

**2,500**  
subscribers to our  
monthly newsletter

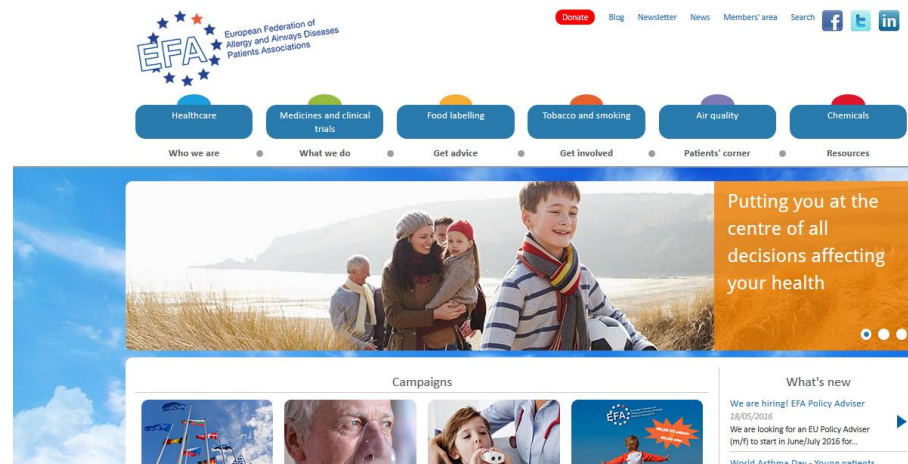
**56%**  
Twitter  
followers  
increase

**165 events**  
attended,  
32 as  
speaker

**8**  
testimonies  
in our new blog

**1380**  
Facebook followers

## • New website



## • New logo (!)



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# Patients' participation in European patient-centred research

- **Capacity building** for members
  - First training at Asthma Society of Ireland (October) & FENAER, Spain (November)
  - Follow-up session with 2014 participant FederASMA e ALLERGIE Onlus, Italy (December)





# Questions?

# THANK YOU!





**European Federation of Allergy and Airways Diseases Patients' Associations**  
**35 Rue du Congrès**  
**1000 Brussels**  
**Belgium**

**Website: [www.efanet.org](http://www.efanet.org)**  
**Tel.: +32 (0)2 227 2712**  
**Email: [info@efanet.org](mailto:info@efanet.org)**  
**Twitter: [@EFA\\_Patients](https://twitter.com/EFA_Patients)**