



European Federation of  
Allergy and Airways Diseases  
Patients Associations



European Federation of Allergy and Airways Diseases Patients' Associations

# EFA Food Allergy Working Group

New way of working with diverse membership effectively

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



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## OBJECTIVE

Improve the management of food allergy through setting up a working group of members working on food allergy

- to plan, lead and engage in European patient collaboration and
- to provide a working mechanism for patient leaders to share best practices and collaborate in support of national efforts



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## SPECIFIC OBJECTIVES

- Practical flexible transparent and cost-effective way of working with members
- Improve input of members in EFA activities
- Improving access to member expertise
- Engaging more people with diverse skills and expertise at member associations in EFA activities (not only one contact person)
- Improve the ownership of members on EFA products, and thus their use at national level and making sure they correspond to real needs of patients



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## SPECIFIC OBJECTIVES

- Networking and improving colleague peer contact
- Sharing tools, actions, experience & information
- Support in developing new interesting EFA projects
- Provide a patient collaboration mechanism and sounding board for European projects EFA is partnering in
- Ensure and provide patient expertise
- Campaign on EU policy
- Patient consensus building on a specific topic
- Ensure, provide and mobilise patient experts support and expertise on a national or European issue
- Attract new members



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## WORKING METHODS

- Voluntary
- Coordinator to lead the group
- ‘*ad hoc*’ leaders on a specific topic/project/campaign
- email – list server, skype and/or telephone call and other means enabled by the internet
- Monitoring service on EU policy on food labeling
- Face-to-face meetings
- Work plan proposal for short and long term to the Board
- Flexible and adjustable
- Reports to the Board quarterly
- First tel meeting 28 May



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## MEASURING OUTCOME & EVALUATION

- Expectations of participants mapped in the starting phase
- Questionnaire to WG members at the end of running year mapping 1. Whether expectations were fulfilled 2. Advancing in specific objectives
- Number of participants involved
- Number of countries involved
- Conclusions for continuation/amendment
- Criteria for closing a working group: no regular reports, less than 3 active participants, no joint actions



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## MEMBERS

- Giorgio Salerni, FEDERASMA, Italy
- Marianne Jarl, Swedish Asthma&Allergy Association
- Emilia Vassilopoulou, ANIKSI, Greece
- Erna Botjes, the Netherlands
- Suzanne van Rokeghem, Prevention des Allergies absl, Belgium
- Betina Hjort, Astma-Allergi Forbundet, Denmark
- Georg Shäppi, aha!, Switzerland



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## EXPECTATIONS

- Sharing expertise
- Valuable contacts
- Access to funds
- Improve at European level the knowledge of food allergy
- Inform and train people with food allergy to cope with their disease
- Inform public
- Encourage food industry and restaurants on allergen free products/dishes and proper labels
- Joint venture for better regulations concerning labeling of foodstuffs



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## IDEAS - DRAFT WORKPLAN

1. Sharing best and bad practice and information
  1. To start with a survey and a list of what has been done in each country
2. Joint actions
  1. Influence European food labeling legislation & practice
    - o Organize a special information session on food allergy at the Eu Parliament
    - o Food labeling directive advocacy and campaign work with the new European Parliament elected 7 June 2009
    - o Work with food industry and restaurants on labeling & allergen free
    - o New strategies based on QoL & best practice
    - o Labeling and (tolerable) risk
    - o Joint letter to IATA to replace nuts on flights
    - o List of the 14 allergens in each language & put it on the website for the students going on Erasmus
    - o EuroPrevall – project outcomes sharing and dissemination



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## IDEAS - DRAFT WORKPLAN

2. **Training and education**
  - o Inform and train people with food allergy to cope with their disease;
  - o Training of professionals (restaurant) – conference
3. **Awareness raising:** Inform public, Early diagnosis



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THANK YOU

- Do not work in isolation for the future.
- Share your knowledge.

Sign up for EFA working groups:

- Food allergy
- Severe Asthma
- COPD

