



European Federation of
Allergy and Airways Diseases
Patients Associations



Final Programme

13th European Federation of Allergy and Airways Diseases
Patients' Associations EFA Conference

The Future of Patient Organisations

12-13 June 2009 Rome, Italy

Venue: 12 June [Sheraton Rome Hotel & Conference Center](#), Viale del
Pattinaggio, 100, 00144 Rome, Italy

13 June [Ministero del Lavoro, della Salute e delle Politiche Sociali](#),
Sala Turina, Viale Giorgio Ribotta 5, 00144, Rome

Programme



Thursday, 11 June 2009

- 12:00 Press Conference with the Global Alliance Against Respiratory Diseases (GARD):
We work for and with respiratory patients for a world where everyone breathes freely – Venue: Ministero del Lavoro, della Salute e delle Politiche Sociali, Sala Turina

Friday, 12 June 2009

- 13:30 -16:00 EFA Annual General Meeting (Agenda sent separately)
- 16:00 -16:30 Coffee/Tea Break
- 16:30 -17:30 Opening Ceremony
- 16:30 -16:35
- Welcome by Giorgio Salerni, FEDERASMA
- 16:35 -16:40
- Greetings by Professor Ferruccio Fazio, Under Secretary of State, Ministry of Labour, Health and Social Politics
- 16:40 -16:45
- Welcome by Marianella Salapatas, Acting President, EFA
- 16:45 -16:50
- Greetings by Michael Hübel, Director of the DG SANCO Unit C4 Health Determinants, European Commission
- 16:50 -16:55
- Welcome by On. Cristina Muscardini, Member of European Parliament
- 16:55 -17:10
- Keynote Speech: "The Future of Patient Organisations", Nicola Bedlington, Director, European Patients' Forum (EPF)
- 17:10 -17:30
- Music and Poetry by Enzo Samaritani, Teatro Arciliuto

Short technical break

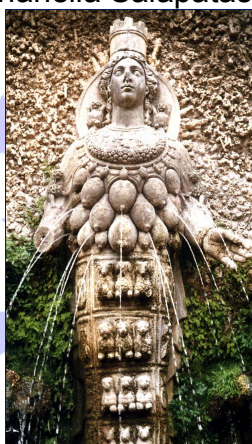
- 17:40 -18:00 Industry information session:
How to prepare for winter as person with lung or heart disease should do?
Speaker: Kjetil Herland, Nigaard
- 18:00-19:00 The Remeo Concept: Facility and Home Based Long-Term Care
Speaker: Konrad Bengler, Linde Healthcare
- 19:10 Transfer by bus from Sheraton Rome Hotel, Viale del Pattinaggio, 100, 00144 Rome, Main entrance for Welcome Dinner
- 19:30-22:30 Welcome Dinner at downtown restaurant
22:40 Bus departure from restaurant back to hotel



Saturday, 13 June 2009

08:00 Transfer from Sheraton Rome Hotel, Viale del Pattinaggio, 100, 00144 Rome, Main entrance

EFA Presentation to Global Alliance Against Respiratory Diseases (GARD) Leaders and Project Proposal
Speaker: Marianella Salapatas, Acting President, EFA



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- 10:00-13:20 **Session 1**
Asthma is still challenging!
Chair: Jenny Versnel, Board Member, EFA
- 10:00-10:15 What constitutes a successful patient organisation?
Speaker: Jenny Versnel, Board Member, EFA
- 10:15-10:30 News from the Global Allergy and Asthma European
Network of Excellence GA²LEN
Speaker: Torsten Zuberbier, Secretary General, GA²LEN
- 10:30-10:45 The Brussels Declaration: Change is needed in asthma
management
Speaker: Rob Horne, Centre for Behavioural Medicine, School of
Pharmacy, University of London, Member, Brussels Declaration
Steering Group

- 10:45-11:00 Helping Asthma Real Patients Project HARP
Speaker: David Price, Chair of Research Committee, IPCRG,
Project leader, HARP
- 11:00-11:15 Co-ordination Action on Indoor Air Quality and Health
Effects project EnVie
Speaker: Matti Jantunen, EnVie Partner
- 11:15-11:30 Definition and validation of 'Minimal written information
programme', a requirement for asthma patient education,
to improve asthma management in Italy
Speaker: Giorgio Salerni, EFA delegate, FEDERASMA
- 11:30-12:00 Coffee/ Tea Break
Special Interest Areas
- Reimbursement of Medication, moderated by Manfred Caesar,
Reimbursement Specialist
 - Patient Information Tools. Examples from all EFA members
and exchange of interest desk
 - EFA Working Group Nomination desk, moderated by Antje
Fink-Wagner, Project building and Fundraising, EFA
- 12:00-12:15 U-BIOPRED project: Phenotype "handprints" to identify
severe asthma condition
Speaker: Peter Sterk, Coordinator, U-BIOPRED
- 12:15-12:30 Health & Environment Alliance HEAL & EFA joint
Project: www.knowyourairforhealth.eu
Speaker: Gill Erskine, Information and Policy Officer, HEAL
- 12:30-13:00 Discussion -All
- 13:00-13:05 Key messages
Speaker: Jenny Versnel, Board Member, EFA
- 13:05-14:05 Lunch at Special Interest Areas



- 14:05-16:50 **Session 2**
Current work in Allergy and how this leads to future relevance of Patient Organisations
 Chair: Pål Johansen, Board Member, EFA
- 14:05-14:20 **Burning issues in Allergy:**
 Identify the right content to deal with for patient organisations in the future to be relevant in solving problems for allergic peers, under the condition of a changing environment
 Speaker: Pål Johansen, Board Member, EFA
- 14:20-14:35 **Report of EFA working group in food allergy**
 Speaker: Susanna Palkonen, Executive Officer, EFA
- 14:35-14:50 **Prevalence, Cost and Basis of Food Allergy in Europe (EuroPrevall) project**
 Speaker: Ronald van Ree, Chairman, WHO/IUIS Allergen Standardization Committee, Executive Committee Member, EuroPrevall
- 14:50-15:05 **EU Food Labelling Directive Proposal and Allergy**
 Speaker: Suzanne van Rokeghem, President, Prevention des Allergies abs
- 15:05-15:20 **Voice of the Patients: Allergic Rhinitis is not a trivial disease**
 Speaker: Susanna Palkonen, EFA and Erkka Valovirta, Medical Advisor, EFA
- 15:20-15:50 **Coffee/ Tea Break**
Special Interest Areas
- 15:50-16:05 **Allergology recognized as a medical speciality across Europe: Current status**
 Speaker: Roy Gerth van Wijk, President, European Academy of Allergology and Clinical Immunology (EAACI)
- 16:05-16:20 **Finnish Allergy Programme – Current Status and Patient Involvement**
 Speaker: Tari Haahtela, Co-ordinator, Finnish Allergy Programme
- 16:20-16:50 **Discussion - All**
- 16:50-16:55 **Key Messages**
 Speaker: Pål Johansen, Board Member, EFA



- 16:55-17:15 **Session 3**
Strategic Alliances and Value of Partnerships with Health Care Professionals, policy makers, other NGOs and industry for modern Patient Organisations
Speaker: Otto Spranger, Treasurer, EFA
- 17:15-17:30 **The new EFA Project**
Speaker: Marianella Salapatas, Acting President, EFA
- 17:30-17:50 **Discussion**
All
- 17:50-18:05 **Winding-up of Conference:**
Description of a modern Patient Organisation
Speaker: Ondrej Rybniceck, Board Member, EFA
- 18:05-18:10 **Invitation to 14th EFA Conference 2010**
Speaker: Lina Buzermaniene, Lithuanian Council of Asthma Clubs
- 18:10 **Transfer by bus to the Reception to welcome participants of the 1st World COPD Patient Conference**
- 18:30-21:30 **Reception**



Goal of the Conference

- Demonstrate the power of patients and patient organisations
- Demonstrate the vital role of EFA to help improving the care, participation and environment of people with allergy, asthma and COPD and prevention
- Motivate participants to reach the next tier of awareness on national level of adherence to asthma treatment
- Request to build EFA working groups in asthma, allergy and COPD
- Update audience about current asthma and allergy projects with EFA involvement
- Motivate EFA members to ask potential partners for funding from variety of sources
- Spotlight those aspects of presented projects, which will lead to the most effective dealing and solution finding for patients
- Motivate EFA members to work as progressive but also objective and sustainable as possible on long-lasting partnerships with policy makers and health care professionals (HCP) organisations to further increase acceptance as patient voice and reliable partners
- Motivate EFA members to participate at EFA's new project and send one delegate to the World Allergy Organisation (WAO)-EFA meeting in Dec 2009
- Motivate EFA members to participate actively in EFA projects

Content of Conference

- Define attributes of successful allergy, asthma and COPD patient organisations in the future
- Give examples of other successful and modern patient organisations
- Present examples of activities by national EFA member organisations
- Emphasise the role of patients and patient organisations
- Present the role of EFA as umbrella organisation to create noise on EU level

- Present new project by EFA to GARD and EFA members and request support
- List unresolved and burning issues in asthma and allergy
- Present all ongoing projects with EFA involvement in a way showing key-learnings for future co-operation by highlighting what gave preference to the projects and mention the arguments to build the projects
- Discuss unusual ways to receive funding and build sustainable partnerships
- Present the work of the EFA Food Allergy Working Group as a model for more active involvement of EFA members and as model to achieve good outcome for a specific patient group
- Present the different partnerships under the perspective to achieve objective, sustainable, trustful and reliable relations at eye level and not as petitioners
- Detailed description of the new EFA project
- Highlight all modern aspects on how the different projects are managed as answer and to deal with current challenges of the patient organisations work
- Convince the delegates of the need of transparent networks as good way to increase the influence of patient organisations in the future
- Invite EFA members to provide key learnings of this years conference and consequences for the work of the national EFA members as well as ideas for next years conference content to EFA board
- Invite auditorium to participate on the 14th Annual EFA Conference at Vilnius from June 11-12, 2010

Take Home Messages

- EFA is an established patient voice on global and EU level enjoying trustful co-operation with HCPs as well as with policy makers, industry partners, patient organisations and other non-governmental organisations
- EFA network is unique and covers relevant ongoing activities to help to improve care, participation, prevention and environment of and for people with allergy, asthma and COPD
- For best outcomes ALL health care partners have to co-operate; combined efforts of HCPs, patients, care givers, policy makers and industry make the difference
- EFA is active currently in 21 European countries
- EFA is proud to enjoy trustful co-operation with policy makers on EU level and the related opportunities to achieve better outcomes for people with allergy, asthma and COPD
- EFA's new project will help to discuss with HCP's on eye-level and may become a relevant tool for patients to partner with GARD on global level in the future
- Involvement of patient organisations in research and to offer updated information and education in allergy, asthma and COPD management are key success factors

- Continue to work on better asthma management by trying more progressive learning styles
- Education and knowledge of patient's own disease are key for patients to become accepted on eye-level for meaningful discussion
- Active involvement of all partners dealing with specific diseases like allergy, asthma or COPD will increase positive outcomes of projects
- Timelines and control mechanisms to help to receive better outcomes for projects
- Each health care system has to focus on patient's needs since patients are THE customers of all health care work and therefore need to become included into all decisions not as emotional petitioners, but as objective voice of customers, who knows what is needed for patients
- Become an active member of EFA's new project
- The conference presents more than one dozen projects and reflects the modern aspects of these projects to achieve better outcome for patient organisations in the future

The funding for this non-profit conference is covered by participant fees and through core grants (non-project related) received by EFA from our sustainable industry funding partners GSK, Novartis, Linde Healthcare and Nigaard. For more information on our funding visit <http://www.efanet.org>

The logo for the European Federation of Allergy and Airways Diseases Patients Associations (EFA). It features the letters 'EFA' in a large, outlined, sans-serif font. To the right of the letters is a semi-circle of ten five-pointed stars, similar to the European Union flag.

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