

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

**12-13 June 2009**  
**Rome, Italy**



*pro  
gramme  
&  
abstract  
book*

**The Future  
of Patient  
Organisations**





## Conference Venues

### 12 June 2009

Sheraton Roma Hotel  
Viale del Pattinaggio 100, Rome

### 13 June 2009

Ministero del Lavoro, della Salute e delle Politiche Sociali  
Sala Turina, Viale Giorgio Ribotta 5, Rome

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*13th Conference*

*of the European Federation of Allergy and Airways Diseases Patients' Associations - EFA*

## The Future of Patient Organisations

*12-13 June 2009*

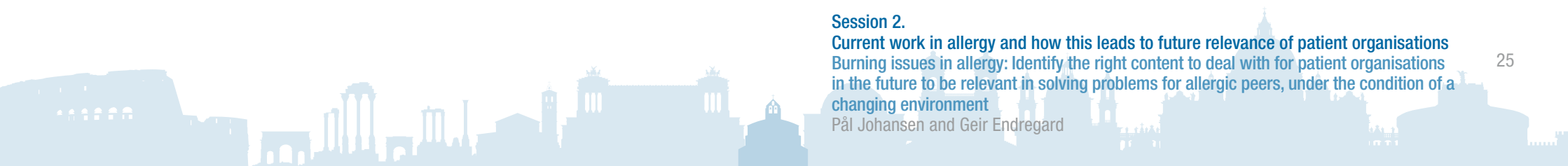
*Rome, Italy*

*programme & abstract book*



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## Welcome to Rome!

In tune with its policy of alternating venues in a north/south/east/west pattern, following the meeting in Warsaw, EFA has selected the unique city of Rome for its 13th Conference. Rome was also chosen in order to link with this year's GARD Assembly meeting. The topic of this year's conference, "The Future of Patient Organisations", is particularly timely because of the rapid changes that have occurred over recent years in communication, the economic climate, the environment and awareness of the importance of education in the patient/doctor dialogue.

One of the aims of the conference is to define what makes a successful allergy, asthma and COPD patient organisation. To help us do this, speakers will describe successful examples of activities by EFA member organisations. The conference is also an opportunity to inform members about the ongoing project in which EFA is involved and discuss unusual ways to obtain funding and of building sustainable partnerships. It is also the occasion to report on how the different projects are managed, and how to deal with the current challenges facing patient organisations. At a practical level and as a new venture, the EFA Food Allergy Working Group will be presented as a model for more active involvement of EFA members and as a model to achieve a good outcome for a specific patient group. Last but not least, the annual conference is an opportunity of contributing actively to EFA policy, and of letting EFA know what you want from the Federation.

EFA is also proud to be one of the organisers of the 1st World COPD Patient Conference, which takes place in Rome straight after the EFA Conference.

The Eternal City has long been an international meeting place given its climate, friendly hospitality and unparalleled monuments, fountains, buildings etc. We have done our best to make your stay in Rome a fruitful and enjoyable experience.

With all good wishes,



Marianella Salapatas  
Acting President, EFA



Sandra Frateiacci  
President, Federasma

## Goals of the Conference

- Demonstrate the power of patients and patient organisations
- Demonstrate the vital role of EFA in helping to improve 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
- 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 a variety of sources
- Spotlight what activities of patient organisations will help patients best deal with their disease
- Motivate patient organisations to work on long-lasting partnerships with all parties involved in the management of respiratory diseases to ensure that the other parties will accept patient organisations as an equal partner
- Motivate EFA members to participate in EFA's new project and send one delegate to the World Allergy Organisation (WAO)-EFA meeting in December 2009
- Motivate EFA members to participate actively in EFA projects

*Programme*

## 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 - Giorgio Salerni, FEDERASMA**16:35 - 16:40** Greetings - Professor Ferruccio Fazio, Vice-Minister,  
Ministry of Labour, Health and Social Politics**16:40 - 16:45** Welcome - Marianella Salapatas, Acting President, EFA**16:45 - 16:50** Greetings - Giulio Gallo, DG SANCO Unit C4-Health Determinants,  
European Commission**16:50 - 16:55** Welcome - Hon. Cristina Muscardini, Member of European Parliament**16:55 - 17:10 Keynote Speech: The future of patient organisations**

Nicola Bedlington, Director of European Patients' Forum

**17:10 - 17:30** Music and Poetry by Enzo Samaritani, Director of the Teatro L'Arciliuto  
Technical break**17:40 - 19:00 Industry Information Session****17:40 - 18:00 How to prepare for the winter?**

Kjetil Herland, Nigaard Pharma

**18:00 - 19:00 The Remeo® concept: Facility and home-based long-term care**

Konrad Bengler, Linde Healthcare

**19:10** Bus transfer for Welcome Dinner

Meeting point: Main entrance, Sheraton Roma Hotel, Viale del Pattinaggio, 100

**19:30 - 22:30 Welcome Dinner at downtown restaurant****22:40** Bus transfer to the Sheraton Roma Hotel

## Saturday, 13 June 2009

**08:00** Transfer from Sheraton Roma Hotel to Ministero del Lavoro, della Salute e delle Politiche Sociali  
Meeting point: Main entrance, Sheraton Roma Hotel, Viale del Pattinaggio 100

**08:30 - 10:00** **Patients' needs: GARD and patients' organizations (GARD Meeting)**  
Chair: Mariadelaide Franchi, International Coalition for Chronic Obstructive Pulmonary Disease - ICC

**08:45 - 09:15** **European Federation of Allergy and Airways Diseases Patients' Associations (EFA): Initiatives in European countries**  
Marianella Salapatras, Acting President, EFA

**09:15 - 09:45** **The International COPD Coalition (ICC): Initiatives in developing countries**  
Youssef Mohammad, ICC Co-Chair

**09:45 - 10:00** **General discussion**

**10:00 - 13:05** **Session 1 of the EFA Conference  
Asthma is still challenging!**  
Chair: Jenny Versnel, EFA Board Member

**10:00 - 10:15** **What constitutes a successful patient organisation?**  
Jenny Versnel, EFA Board Member

**10:15 - 10:30** **News from the Global Allergy and Asthma European Network of Excellence, GA<sup>2</sup>LEN**  
Torsten Zuberbier, Secretary General, GA<sup>2</sup>LEN

**10:30 - 10:45** **The Brussels Declaration: Change is needed in asthma management**  
Rob Horne, University of London, and Member of the Brussels Declaration Steering Group

**10:45 - 11:00** **Helping Asthma Real Patients: The HARP Project**  
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**  
Matti Jantunen, EnVIE Partner

**11:15 - 11:30** **Definition and validation of the "Minimal written information programme". A requirement for asthma patient education to improve asthma management in Italy**  
Giorgio Salerni, EFA delegate, FEDERASMA

**11:30 - 12:00** **Coffee/Tea Break  
Special Interest Areas**

- Reimbursement of Medication, moderated by Manfred Caeser, 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: Phenotype "handprints" to identify severe asthma conditions**  
Peter Sterk, Coordinator, U-BIOPRED

**12:15 - 12:30** **Health & Environment Alliance HEAL & EFA Joint Project: [www.knowyourairforhealth.eu](http://www.knowyourairforhealth.eu)**  
Gill Erskine, Information and Policy Officer, HEAL

**12:30 - 13:00** **Discussion** - All participants

**13:00 - 13:05** **Key Messages**  
Jenny Versnel, EFA Board Member

**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: Geir Endregard, Secretary-General, The Norwegian Asthma and Allergy Association (NAAF)  
 Co-chair: Helle Grøttum, NAAF
- 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**  
 Geir Endregard, NAAF
- 14:20 - 14:35 Report of the EFA working group on food allergy**  
 Susanna Palkonen, EFA Executive Officer
- 14:35 - 14:50 Prevalence, Cost and Basis of Food Allergy in Europe (EuroPrevall)**  
 Ronald van Ree, Chairman, WHO/IUIS Allergen Standardization Committee, Executive Committee Member, EuroPrevall
- 14:50 - 15:05 EU Food Labelling Directive Proposal and Allergy**  
 Suzanne van Rokeghem, President, Prévention des Allergies absl
- 15:05 - 15:20 The voice of the patients: Allergic rhinitis is not a trivial disease**  
 Susanna Palkonen, EFA Executive Officer,  
 and Erkkä Valovirta, EFA Medical Advisor
- 15:20 - 15:50 Coffee/Tea Break**  
**Special Interest Areas**
- 15:50 - 16:05 Allergology recognized as a medical speciality across Europe: Current status**  
 Roy Gerth van Wijk, President, European Academy of Allergology and Clinical Immunology (EAACI)
- 16:05 - 16:20 Finnish Allergy Programme 2008-2018: Current status and patient involvement**  
 Tari Haahtela, Co-ordinator, Finnish Allergy Programme
- 16:20 - 16:50 Discussion - All participants**
- 16:50 - 16:55 Key Messages**  
 Geir Endregard, NAAF
- 16:55 - 18:10 Session 3**
- 16:55 - 17:15 Strategic alliances and value of partnerships with health care professionals, policy makers, other NGOs and industry for modern patient organisations**  
 Otto Spranger, EFA Treasurer
- 17:15 - 17:30 The new EFA Project: EFA beyond the borders of Europe**  
 Marianella Salapatas, Acting President, EFA
- 17:30 - 17:50 Discussion - All participants**
- 17:50 - 18:05 Winding-up of the Conference: Description of a modern patient organisation**  
 Ondrej Rybníček, EFA Board Member
- 18:05 - 18:10 Invitation to the 14th EFA Conference 2010**  
 Lina Buzermaniene, Lithuanian Council of Asthma Clubs
- 18:10 Transfer to Reception**
- 18:30 - 21:30 Welcome Reception, First World Conference of COPD Patients**

## Take Home Messages

- EFA is an established patient voice on global and EU level, and enjoys trustful co-operation with health care professionals as well as with policy makers, industry partners, patient organisations and other non-governmental organisations
- The EFA network is unique and participates in activities that help to improve the care, participation, preventive measures and the environment of people with allergy, asthma and COPD
- To achieve optimal outcomes, all health care partners must co-operate; the combined efforts of health care professionals, patients, care givers, policy makers and industry make the difference!
- EFA is active in 21 European countries
- EFA is proud to enjoy trustful co-operation with policy makers on EU level and to use the related opportunities to achieve better outcomes for people with allergy, asthma and COPD
- EFA's new project will foster discussions with health care professionals on eye-level and may become a relevant tool to enable patients to partner with GARD on a global level
- Involvement of patient organisations in research and providing 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 the patient's own disease are crucial if patients are to become accepted on eye-level for meaningful discussions
- Active involvement of all partners dealing with specific diseases like allergy, asthma or COPD will increase positive outcomes of projects
- Timelines and control mechanisms help to achieve better outcomes for projects
- Each health care system must focus on the patient's needs since patients are the customers of all health care work and therefore should be included in all decisions not as emotional petitioners, but as the objective voice of customers who know what is needed for patients
- Become an active member of EFA's new project
- The conference presented more than one dozen projects; the innovative aspects of these projects will ensure that patient organisations will be more effective

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>

*Conference  
Abstracts*

### Keynote Speech

## The Future of Patient Organisations

Nicola Bedlington  
European Patients' Forum, Brussels, Belgium. Email: nicola.bedlington@eu-patient.eu  
Website: www.eu-patient.eu

In recent years, the influence and impact of patient organisations throughout the European Union have increased dramatically, both in terms of their strong advocacy role, and in terms of capacity and knowledge building among their membership. Is this trend likely to continue? If so, what are the critical success factors that will make this happen, and what are the key challenges confronting patient organisations in the short and long term?

The European Patients' Forum, of which EFA is a founding member, is an example of a developing and growing European level patient organisation and with some key-milestones since its conception in 2003. Several external and internal political and cultural developments will influence the future of patient organisations. Recognising the role of partnership with other stakeholders is one key success factors in shaping the future of patient organisations and their drive towards high quality, patient-centred, equitable healthcare across the European Union and solidarity of the patient movement across disease areas and countries.

## What Constitutes a Successful Patient Organisation?

Jenny Versnel  
Asthma UK, London, UK. Email: jversnel@asthma.org.uk

The success and survival of patient organisations has never been a more relevant topic given the challenging financial environment we currently find ourselves in.

Long-term stability is influenced by:

- Ability to generate income from a range of sources, thereby reducing risk if one revenue stream is affected.
- A powerful mission and/or vision statement which drives stakeholders to you.
- Accountability, the ability to measure and demonstrate the impact of your work/funding.
- It is important for stakeholders to see evidence of the benefits of your work and the progress you are making towards achieving your vision.
- Credibility and professionalism so that you are recognised externally as an authoritative voice and provider of high quality information, advice and support.
- Partnership working to increase your profile, strengthen your voice and increase funding opportunities.
- Innovative projects and products.
- A strong volunteering programme.

A key element for long-term success is partnership working, with your stakeholders to support their needs, with Governments to raise the profile of respiratory conditions and influence the direction of health policy and with supporters and funders to raise the money needed to achieve one's mission. Each of these provide a platform in their own right and whatever the size of your organisation you need to maximise the opportunities that come from working together. EFA is an important forum to share expertise, ensure respiratory conditions are prioritised at EU level and provide opportunities for partnership working.

## News from the Global Allergy and Asthma European Network of Excellence, GA<sup>2</sup>LEN

Torsten Zuberbier

GA<sup>2</sup>LEN Secretary-General, Dept. of Dermatology and Allergy, Allergy Centre Charité Universitätsmedizin Berlin, Germany. Email: torsten.zuberbier@charite.de

GA<sup>2</sup>LEN<sup>1</sup>, the Global Allergy and Asthma European Network, is a “Network of Excellence” funded by the European Union 6th Framework Programme for Research. GA<sup>2</sup>LEN multidisciplinary research teams address all aspects of allergic diseases, from basic research to clinical practice, with a view to improving understanding of common risk factors and mechanisms and harmonizing European research in allergy and asthma.

GA<sup>2</sup>LEN has developed into a flexible, sustainable research network with expertise in pan-European research studies, education and dissemination. Several achievements of the network in the last five years will contribute to the success the ‘new’ GA<sup>2</sup>LEN structure, including the landmark 20-Centre GA<sup>2</sup>LEN Survey, the Pan-European Prick Test Study, numerous birth cohort studies, and countless GA<sup>2</sup>LEN papers and guidelines.

1. www.ga2len.net

## The Brussels Declaration: Change is Needed in Asthma Management<sup>1</sup>

Rob Horne

Department of Practice & Policy, The School of Pharmacy, University of London, UK  
Email: rob.horne@pharmacy.ac.uk

Clinical trials show that we have effective treatments for asthma and that it should be possible to achieve good control for most people with asthma. Unfortunately, the picture is very different in the real world where it is estimated that less than a third of patients are well controlled and asthma remains a significant burden for individuals and society. In 2006, a Summit for Change in Asthma at the European Parliament brought together patient representatives, policy makers and leading clinicians and researchers in asthma. The resulting Brussels Declaration set out a ten-point plan to revolutionise asthma management in Europe.

Having correct treatments on the shelf and issuing guidelines for how they should be prescribed is clearly not enough. The real challenge is to create the environment and support to enable people to manage their asthma to best effect. A key priority for health care professionals is to translate best evidence in clinical practice, take account of the patient’s perspective of asthma and its treatment, and to tailor treatment and support to meet their needs to enhance the motivation and ability to manage asthma. The key priority for patients is to become more involved in policy making and taking control of their own daily care. The policy makers’ challenge is to set the framework to enable this. Reducing the burden of asthma requires innovation in research, clinical practice and health and environment policy.

1. Holgate S, Bisgaard H, Bjermer L et al. The Brussels Declaration: The need for change in asthma management Eur Respir J. 2008;32:1433-42.

## Helping Asthma in Real Patients: The HARP Project

David Price and John Haughney

International Primary Care Respiratory Group, Department of General Practice and Primary Care, Foresterhill Health Centre, Aberdeen, Scotland, UK. Email: david@respiratoryresearch.org

The International Primary Care Respiratory Group (IPCRG) working with representatives from EFA has committed to helping physicians and patients to identify reasons for poor asthma control in individuals and has published tools suitable for this purpose.

The Helping Asthma in Real People (HARP) initiative is a pilot project which seeks to start to address some of these issues in real-life clinical practice by developing a system that supports the assessment of asthma control by collecting and linking data routinely recorded by the practitioner coupled with data from the patient, in the form of written or web-based questionnaires ([www.asthmatrak.org](http://www.asthmatrak.org)). The factors assessed include: current asthma control; current management; adherence to prescribed treatment; and possible reasons for poor adherence, and identifies other remediable factors that may be responsible for poor asthma control, such as poor inhaler technique, smoking or untreated or undertreated rhinitis.

Feedback is provided for patients and clinicians as summarised questionnaire and electronic data on current asthma control and recommendations based on the IPCRG rule set.<sup>1</sup>

### HARP in Ireland

With an extremely active national asthma patient group (the Asthma Society of Ireland), interested clinicians and the prospect of institutional and political support, together with a shared language, Ireland was chosen as IPCRG's pilot centre for the HARP project.

From 15 initial practices, 3593 people with asthma were identified and sent questionnaires. 62% of patients who responded had uncontrolled asthma according to the measures used and had considerably more reliever medication use, days lost from work, rhinitis, and need for oral corticosteroid courses. Interestingly, a high percentage of respondents cited concerns about the long-term use of inhaled corticosteroids as a reason for poor compliance. Both individual patients and practices (in terms of individual and aggregated data) received feedback reports.

It is hoped and expected that this will lead to better appreciation of the issues, the reality an individual patient's status, mutual understanding of the problems and thus to dialogue, revision of the management plan and ultimately better outcomes.

It is hoped HARP can be further rolled out in Ireland and beyond that to other European countries and in collaboration with interested EFA members. Led by the Asthma Society of Ireland, clinical colleagues, and galvanized to some extent by the success of the HARP pilot, the Irish Government are now looking at the Finnish asthma programme with a view to adopting some of the Finnish strategies in Ireland.

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1. Haughney J, Price D, Kaplan A et al. Achieving asthma control in practice: Understanding the reasons for poor control. *Respir Med.* 2008;102:1681-93.

## Coordination Action on Indoor Air Quality and Health: EnVIE

Matti Jantunen  
National Institute of Health and Welfare, Department of Environmental Health, Kuopio, Finland,  
Email: Matti.jantunen@thl.fi

EnVIE (<http://www.envie-iaq.eu/>) was the first European indoor air project with public health, more specifically the burden of disease (BoD), as its starting point and assessment criterion and with intentional focus on only the most important diseases and their causes at European level. In the process, EnVIE involved a wide range of stakeholders, including patient organizations to contribute to a new comprehensive EU policy on indoor air quality (IAQ).

The role of environmental tobacco smoke as indoor air pollutant and cause of disease is already well established, and environmental tobacco smoke was therefore excluded from the following analyses.

Disability adjusted life year (DALY), promoted by the WHO, was chosen as the common unit for the burden of the different diseases/symptoms (BoD). One DALY is the equivalent of one year reduction of life expectancy.

A short list of the most important IAQ-related health effects was created. These should be relevant for all Europe and represent the bulk of the BoD attributable to IAQ. For each of the health effects, the total national BoDs were first obtained from WHO and national statistics, and the fractions attributable to IAQ were estimated to compute the respective indoor air burdens of disease (IABoD). The final list consists of cardiovascular diseases, asthma, sensory irritation (including sick building syndrome), lung cancer, carbon monoxide poisoning, COPD, and respiratory infections. The estimated total EU-27-wide IABoD was 2.2 million DALY/year. The most significant causal pollutants for the IABoD were combustion products, bioaerosols, VOCs, CO, pathogens and radon. The contributions of the sources of indoor air pollution were outdoor air, dampness and mould, heating and combustion, furnishings, interior materials and electric appliances, building site, household chemicals, ventilation and air conditioning systems and building materials.

EnVIE also evaluated the public health gain potentials of IAQ policy options.

Acknowledgement. EnVIE project funding by EC, 6th Framework Programme, Priority 8.1, Policy oriented research (SSP), 2004.

## Definition and Validation of the “Minimal Written Information Programme”. A Requirement for Asthmatic Patient Education to increase Asthma Management in Italy

Giorgio Salerni and Sandra Frateiacchi

FEDERASMA, Prato, Italy. Email: salernigenoa@tin.it, Website: www.federasma.org

The guidelines of the Global Initiative for Asthma (GINA) suggests clear communication between health care professionals and patients with asthma, to meet patients' information needs, which is key to enhance compliance in asthma management. A recent study demonstrated non optimal asthma control in Italy.<sup>1</sup> A high percentage of asthmatic patients in Italy still have unscheduled visits as well as emergency room and hospital admissions. Furthermore, only 5% of Italian asthma patients are well controlled as defined by GINA guidelines.<sup>2</sup> The “Insight Asthma Research”<sup>3</sup> survey documented poor communication between physician and patient as a result of lack of information and education on the part of patients.

The aim of this project is to define and validate the quality and quantity of minimal information required by people with asthma in order to comply with asthma management recommendations in daily life in Italy.

Three working groups with appropriate skills have been identified:

- (1) asthma physician experts;
- (2) patients associations;
- (3) experts in validation methodology.

The task of the asthma physician expert group is to define patient information needs regarding the diagnosis, secondary prevention measures, types of available treatment, the rationale for specific therapeutic interventions, and the written asthma action plan.

Patients associations have to identify what patients wish to know starting from the perception of the disease in their daily life, i.e. increase of understanding, skills, satisfaction, confidence and thereby compliance, and hopefully self management. Lastly, the methodology expert team has to ensure the correct validation of the developed documentation.

The project is planned to start in the second quarter of 2009 and to be completed by the end of 2009; this will be followed by dissemination of the minimal written information.

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1. Caramori G, Bettoncelli G, Carone M et al. Degree of control of physician-diagnosed asthma and COPD in Italy. *Monaldi Arch Chest Dis.* 2007;67:15-22.

2. Vermeire PA, Rabe KF, Soriano JB et al. Asthma control and differences in management practices across seven European countries. *Resp Med.* 2002;93:142-9.

3. Abacam, November-December 2005



## U-BIOPRED: Phenotype “Handprints” to Identify Severe Asthma Conditions

Peter J. Sterk

Dept. Respiratory Medicine, Academic Medical Centre, University of Amsterdam, The Netherlands  
Email: p.j.sterk@amc.nl

There is increasing evidence that severe asthma is a heterogeneous condition that requires individualized therapeutic approaches. The new European consortium “Unbiased Biomarkers for the Prediction of Respiratory Disease Outcome” (U-BIOPRED) has brought together academic centres, biopharma industry, patient organisations, care organisations, small-medium enterprises and multinational industry to overcome the current bottlenecks in the development and targeting of new therapeutics in severe asthma, as recently defined by the Innovative Medicines Initiative of the European Union (IMI: [www.imi-europe.org](http://www.imi-europe.org)).

The aim of U-BIOPRED is to combine the clinical profiles of patients with modern molecular biomarker profiles into so-called “handprints” of severe asthma. These “handprints” are meant to characterize individual patients, and should enable better prediction of therapeutic interventions and disease management.

U-BIOPRED includes 6 patient and care organisations. During the early phases of writing the project, a national patient’s platform was consulted to assist in developing and checking its aims from the patient’s perspective. In addition, there is strong representation of patient organisations in the U-BIOPRED Workpackages: (a) consensus generation, (b) ethics and safety monitoring (Ethics Board and Safety Board), and (c) dissemination. The project will run between 2009 and 2014 and provides a pan-European opportunity to link patient organisations with academia and industry in the field of (severe) asthma.

## Know Your Air for Health: EU Air Pollution Forecasting Offered to Those with Breathing Problems

Genon K. Jensen

Health & Environment Alliance, Brussels, Belgium, Email: [genon@env-health.org](mailto:genon@env-health.org)  
Websites: [www.env-health.org](http://www.env-health.org); [www.knowyourairforhealth.eu](http://www.knowyourairforhealth.eu)

European citizens, and in particular people with respiratory diseases, are increasingly concerned about the effects of air pollution on their health. Under European law on ambient air quality adopted in 2008,<sup>1</sup> special provisions should be made to protect the health of and provide information to “susceptible populations” such as patient organisations. The 2008 Brussels Declaration on the need for change in asthma management clearly highlights in its 10 recommendations the need to “understand and reduce the impact of environmental factors”<sup>2</sup>.

Within this context, the European Federation of Allergy and Airways Diseases Patients Associations (EFA), EFA members and the Health and Environment Alliance (HEAL) launched the joint project *Know your air for health*. This collaboration illustrates the importance of patient group involvement in using EU legislation to the fullest to contribute to prevention goals such as creating healthier outdoor environments.

*Know your air for health.eu* provides a starting point for people with respiratory diseases and others to find information about:

- forecasts and levels of air pollution across Europe;
- the health effects associated with various air pollutants;
- individual rights to breathe clean air;
- simple ways of avoiding and reducing air pollution;
- useful links to information on air pollution and health

The project has also been used by EFA and HEAL to build relationships to advocate for clean indoor and outdoor air. It is an innovative and excellent illustration of just how vital patient organizations are in the creation of sustainable and healthy environments and could provide a model for future patient activities. The site this year will be expanded into more languages and will start to include more action-oriented and children-focused information and tools.

*Continued overleaf*



This is both in preparation for the 2010 Pan-European Ministerial Conference on Health and Environment and to encourage the EU to produce a policy for greater levels of health protection in a 2013 review of EU laws on ambient air quality.

**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**

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Allergies are increasing worldwide. The official estimate from the World Health Organization (WHO) is that in year 2030, 50% of the world's population will have one or more allergies. Not all are severe of course and many without medication needs, but nevertheless, half of the world's population!

The actual facts are scary as we know them. The growth in allergic reactions is not particularly due to new substances we are exposed to through our changes in lifestyles and societies with many more products around us, but to traditional allergic reactions.

More people, both children and adults, develop allergy to proteins in milk, egg, birch, fruits etc. Proteins that are usually harmless for human beings. The concern is that healthy people with healthy bodies get ill because of common foods, plants and other natural materials. The human race becomes incompatible with the natural environment we are born in – our own planet! This raises some important issues for patient organisations. How to balance the work between preventing the increase in allergies and helping those affected? Do we help more people in practice by addressing the causes of the increases in allergies and thereby prevent people from developing allergies? Or do we plan for substantial growth in our services to meet the needs of the increasing numbers of people who must manage their lives with allergies?

Many EFA members work on both paths. At present, we must recognise that despite much work by many EFA member organizations and by the EFA Board, the trends are very negative in too many countries. How do we help all those who need us for their daily life? At the same time our goal must be to overturn the WHO prognoses. The prevalence of allergy must stop increasing. In 2030, not 50% of the world's population will be allergic, but 40, 30 or 20%.

1. <http://eurlex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:32008L0050:EN:NOT>

2. Holgate S, Bisgaard H, Bjermer L et al. The Brussels Declaration: the need for change in asthma management. Eur Respir J. 2008;32:1-10.

## Report of the EFA Working Group on Food Allergy

Susanna Palkonen

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In May 2009, EFA set up its first working group of members – on food allergy. The aims are to provide a practical, flexible, transparent and cost-effective way of working with more members on a specific disease, to improve the engagement and input of members in EFA activities as well as EFA's access to the input and expertise of members, and lastly to foster direct collaboration and exchange of best practice by members rather than working in isolation. The group is open to anyone working in EFA member associations, whether volunteer or staff member, interested in networking with colleagues and joint projects to improve the care and participation of people with food allergy in Europe and on voluntary basis.

The working method is mostly electronic. The group set up a plan on immediate actions for 2009 to submit to the EFA Board for approval. These actions include collaborative actions to agree and communicate a joint position on the European Commission proposal for a regulation of the European Parliament and of the Council on the provision of food information to consumers.<sup>1</sup>

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1. [http://ec.europa.eu/food/food/labellingnutrition/foodlabelling/proposed\\_legislation\\_en.htm](http://ec.europa.eu/food/food/labellingnutrition/foodlabelling/proposed_legislation_en.htm)

## Prevalence, Cost and Basis of Food Allergy in Europe (EuroPrevall)

Ronald van Ree

Department of Experimental Immunology and Department of Otorhinolaryngology,  
Academic Medical Center, University of Amsterdam, The Netherlands

EuroPrevall is a large EU-funded multicenter project focusing on the epidemiology of food allergy (what is the prevalence, which foods are involved, what are risk and protective factors, what is the social and economic impact?) and its diagnosis (how can we improve diagnostic protocols?). Studies are performed across Europe, in Australia and in some countries in Africa and Asia. They include general population surveys amongst newborns (prospective birth cohorts), school children and adults (cross sectional) and outpatient clinic studies amongst food allergic patients. Standardized questionnaires have been developed aimed at establishing prevalence and risk and protective factors, and at determining quality of life and economic costs. A central role is played by the double-blind placebo-controlled food challenge to which patients are subjected to confirm their food allergy. A standardized protocol has been developed. Biological samples are taken from patients and healthy controls for serologic testing, gene-expression profiling and DNA-analysis. The project will deliver a better insight into the prevalence and impact of food allergy, and will provide improved tools for diagnostic testing.

## EU Food Labelling Directive Proposal and Allergy

Suzanne van Rokeghem

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In our developed society, we cannot accept that some people face danger simply by eating an everyday meal. 1-2% of adults and 5-8% of children live with IgE-mediated food allergies.<sup>1</sup> The number of people suffering from an adverse reaction to food is growing. The only way to manage food allergy or intolerance is to avoid the allergen to which one reacts. It is not easy to do.

The number of meals taken outside the home and food bought “ready-to-eat” are increasing. Global changes have made the choice of food larger, complicated and also unsafe, as people are not used to new foods or recipes from other countries.

Directive 2003/89/EC<sup>2</sup> was a step in the right direction. The effect on public health has been immediate as can be seen in the statistics of anaphylactic shocks caused by what is called “hidden allergens”, allergen ingredients that were used in the product but not mentioned on the label. However feedback from EFA members and associated help-centers and fatal cases indicate that there are still problems to be addressed. A new regulation has been proposed by the European Commission.<sup>3</sup> It would expand mandatory labeling to catering and foods sold loose.

What do we need?

1. To establish a safety chain for people with food allergy: managing food allergens must become natural part of Safety Manuals and Guides regarding hygiene.
2. Mandatory labelling of allergens in non-packaged food – sold through retail and catering.
3. Readability of labels: font size needs to be readable by real people.
4. Clear marking on labels of any changes in recipes that include allergens.

5. Regulating ‘may contain’ – precautionary labelling. Clear distinctions between mandatory and voluntary labelling.

To obtain what we need, actions should be taken by EFA and all its members.

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1. Mills ENC, Mackie AR, Burney P et al. The prevalence, cost and basis of food allergy across Europe. *Allergy* 2007;62:717-722

2. Directive 2003/89/EC of the European Parliament and of the Council of 10 November 2003 amending Directive 2000/13/EC as regards indication of the ingredients present in foodstuffs  
<http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2003:308:0015:0018:EN:PDF>

3. Proposal for a Regulation of the European Parliament and of the Council on the provision of food information to consumers 2008/0028(COD) <http://www.europarl.europa.eu/oeil/file.jsp?id=5592852>

## The Voice of the Patients: Allergic Rhinitis is not a Trivial Disease<sup>1</sup>

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The perspectives of patients and physicians on the impact of allergic rhinitis have previously been studied in the general population. We evaluated the burden of allergic rhinitis among patients from the members of European allergy patient organizations. The Patient Voice Allergy Survey was a quantitative, self-completion survey of 3,562 patients with allergic rhinitis (16 years and older). Background information on allergic rhinitis, severity of allergic rhinitis symptoms and their impact on lives, non-medical measures for relieving of symptoms, types of medications, and concomitant conditions were evaluated.

Almost 50% of responders reported symptoms lasting for more than a season. Preventive household adjustments are expensive with little perceived benefit. Sleep and emotional life are affected by allergic rhinitis. Most patients are satisfied with the current allergic rhinitis medications; however, at least one fifth reports dissatisfaction. Patients perceive that allergic rhinitis worsens other concomitant allergic diseases.

Allergy patients in 11 European countries have voiced their experiences of a disease which is not always seen as serious enough to warrant attention from policy-makers, prescription medications, doctor's visits, and follow-up or patient education. Patients with allergic rhinitis revealed the emotional burden and restrictions to daily life. They shared satisfaction for the current treatment options, and dissatisfaction for most of the preventive measures.

While being satisfied with medical treatment, patients suffer a significant impact in daily life.

The results of this survey:

- should be taken into account in future guidelines on allergic rhinitis
- should promote relief of the emotional burden of allergic rhinitis
- should stimulate patient education
- should encourage relationship between allergic rhinitis patients and healthcare professionals
- should urge governments to abolish preventable triggers in public places, schools and work places.

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## Allergology Recognized as a Medical Specialty Across Europe: Current Status

R. Gerth van Wijk

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The specialty of allergology and clinical immunology (ACI) in Europe is characterized by a diversity in position, number of practitioners, organization and training schedule. Three organizations dominate the field of allergy professional education. The European Academy of Allergy and Clinical Immunology (EAACI), the Global Allergy and Asthma European Network (GA<sup>2</sup>LEN), and finally the European Union of Medical Specialists (UEMS) which addresses the recognition of the speciality and the registration of specialists. According to the UEMS (<http://www.uems.net/>), in 8 of 22 countries, ACI is a full speciality, in 3 countries both a speciality and a subspecialty exist, whereas in 5 countries ACI is a subspecialty embedded in another speciality. Six countries do not recognize ACI as a speciality.

Practice in allergology may be carried out in public hospitals or private practices. The distribution of hospital- and private-based practices varies among countries. The number of allergists per head of population may vary from 1:17,500 to 1:1,000,000. Also, training schedules are characterised by variation.

Thus, there is a need for harmonisation. Quite recently, the UEMS established a core curriculum, defining the requirements for a high standard programme for allergists in training. An EAACI task force defined the requirements for qualified medical centers. In 2008, EAACI in collaboration with UEMS started a pan-European knowledge examination in ACI to increase the level of knowledge and to promote harmonisation in knowledge. There is however much room for improvement in order to enable qualified care for people with allergy across Europe, and patient organisations can play a key role in supporting this.

## Finnish Allergy Programme 2008-2018 : Current Status and Patient Involvement

Tari Haahtela

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The Finnish initiative is the first nationwide, comprehensive plan to reduce burden of allergies. The prevalence of allergic diseases has grown in Finland, similarly to many other western countries. Although the origin of allergy remains unresolved, an increasing body of evidence indicates that modern man living in an urban environment is deprived of environmental protective factors (e.g. soil micro-organisms) that are fundamental for normal tolerance development. The current dogma of allergen avoidance has not proved effective in halting the “epidemic”, and it is the Finnish consensus that restoring and strengthening tolerance should be more focused. The Finnish Allergy Programme aims also to change attitudes to support health instead of medicalizing common and mild allergy symptoms.

The aim of the national 10-year programme is to reduce the burden of allergies. The main goals are to 1) prevent the development of allergic symptoms, 2) increase tolerance against allergens, 3) improve the diagnostics, 4) decrease work-related allergies, 5) allocate resources to manage and prevent exacerbations of severe allergies, and 6) decrease costs due to allergic diseases. Three national non-governmental organisations (NGOs) are implementing the Programme at population and patient level. These NGOs include two patient organisations, The Finnish Allergy & Asthma Federation and the Pulmonary Association HELI that are directly involved in the educational process of both health care professionals and patients. The local bodies of these Associations work directly with patients and give “grass-root” guidance.

The time to act is now, when allergic individuals are becoming a majority of Western populations and their numbers are rapidly increasing worldwide. The Programme is associated with the Global Alliance of Chronic Respiratory Diseases (GARD), WHO.

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## Strategic Alliances and Value of Partnerships with Health Care Professionals, Policy Makers, Other NGOs and Industry for Modern Patient Organisations

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Alliances are cooperations or collaborations that aim for a synergy where each partner hopes that the benefits from the alliance will be greater than those from individual efforts. Although patients are THE reason and customers of all activities that we call “health system”, patients are just one part of the efforts to manage a disease. Therefore, it is necessary for patients and patient representatives to work as creatively as possible but also to be as objective and sustainable as possible in long-lasting partnerships on eye-level with policy makers, health care professional (HCP) organisations, other NGOs and industry to increase acceptance as the patient voice and reliable partner.

Particularly in these times, when there is an economic crisis of unknown dimensions, and all parties understand better than ever that all of us are in the same boat, it may be easier for patient organisations to become accepted as an equal partner of all involved in order to achieve optimal outcomes. Combined efforts to increase the situation for patients make the difference. Strategic alliances can help to reduce the often still existing fears of HCPs, can motivate politicians to give patient organisations the place as an integrated partner in the healthcare system, can show industry the value of respectful cooperation and help patients to reduce the burden of their disease.

Most of the presentations of EFA’s 13th conference demonstrate that EFA’s unique, transparent, trustful and reliable strategic alliances and partnerships are of vital value for patients.

This presentation will discuss where to look for potential sustainable partners, how to partner and how to define aims as well as outcomes.

## The New EFA Project: EFA Beyond the Borders of Europe

Marianella Salapatras

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It is in our history that patients from any disease area have always had the need to form groups with same needs, that strive for understanding of their disease, see an opportunity to exchange ideas and most of all to unite in order to change their quality of lives by influencing the society.

Many patient organizations have been formed upon exactly that need; to share information, fears and mainly to combine forces in order to change the quality of their lives. EFA was created to combine the forces of national patient associations on asthma and allergy in order to improve the health and quality of life of people in Europe with those diseases. EFA, since its foundation in Stockholm in 1991, is continuously growing to form one voice in Europe on allergy and airways diseases and has a vision and a mission to change society’s perception of these diseases and to concretely take part in the improvement of patient’s lives.

EFA also has another vision. A vision where all patient organizations combine globally to share experiences, ideas and to form one global voice. With EFA’s experience, all patient organizations or coalitions can come together and gradually build an International Patient Organization on Allergy and Asthma. This International Patient Organization will thrive beyond borders and fight above political ideas. We hope that one of our major alliances will be GARD and that through GARD’s power and global influence, we can be a strong united patients’ voice in all five continents.

## Invitation to the 14th EFA Conference in 2010

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EFA and the Lithuanian Council of Asthma Clubs welcomes everybody to the EFA conference 2010 and AGM that will be held in Vilnius, the capital of Lithuania, in conjunction with the XVI Vilnius International Paediatric Pulmonology and Allergology Conference – School.

Why Lithuania and why Vilnius? The Lithuanian Council of Asthma Clubs, founded in 2003, became an EFA member in 2006. The Asthma Patients' Club is a registered association with members throughout the country. All the work is based on volunteer services: no offices, no paid staff. The main goals are to establish educational and self-supporting programmes for asthma patients, increase awareness of asthma and allergic diseases, awareness and public control of patients' rights, building bridges between patients with chronic illnesses and the community and international co-operation. More information is available on [www.astmainfo.lt](http://www.astmainfo.lt)

Lithuania is on the eastern shore of the Baltic Sea. In 1989, the National Geographical Institute of France established the geographical centre of Europe 24 km northwest of Vilnius. Lithuania is a country of great cultural and science traditions and rich history. It has been occupied so many times but it has resisted all the occupations. Perhaps the most oppressive was the occupation by Soviets in 1944-1990. Since 2004 Lithuania is a member of the EU.

You will all like Vilnius. Its Old Town is one of the largest old town centres in Central and Eastern Europe, covering almost 360 hectares and including over 1,500 buildings. As one of the most authentic and best-preserved cities in Europe, Vilnius was included in the UNESCO World Heritage List in 1994. Vilnius has been declared the European Capital of Culture 2009. It is a modern city, the political, administrative and economic centre of the country and the heart of its education and culture.

*Industry  
Information*



## How to Prepare for the Winter?

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Acute or chronic cold exposure elicits several effects on the respiratory system. Pulmonary mechanics are compromised by bronchoconstriction, airway congestion, secretions and decreased mucociliary clearance. These responses are active in cold- or exercise-induced asthma. The primary ventilatory effect of cold air is to decrease baseline ventilation and respiratory chemosensitivity. Cold exposure also elicits an increase in pulmonary vascular resistance. This stimulus is synergistic with hypoxia and may mediate pulmonary hypertension and oedema at altitude. Chronic exposure to cold environments results in morphological changes such as increased numbers of goblet cells and mucous glands, hypertrophy of airway muscular fascicles and increased muscle layers of terminal arteries and arterioles. The latter two factors may play a role in the symptoms of chronic obstructive pulmonary disease and bronchitis, high altitude pulmonary hypertension and oedema, and right heart hypertrophy.<sup>1</sup>

Sudden submersion in cold water may provoke myocardial infarction in subjects with atherosclerotic coronary disease and people with angiographically normal coronary arteries. A report by Ragus and co-workers<sup>2</sup> indicates that sudden cold exposure and the resulting cold shock response may provoke acute myocardial infarction in young susceptible patients. In Finland, Näyhä<sup>3</sup> reported that mortality increases steeply in autumn, peaks during the Christmas holidays and declines slowly towards a trough in August. An estimated 2000-3000 extra deaths occur in Finland during the cold season, most of which are people aged  $\geq 65$  years but 20% are of working age. Exposure to cold air increases blood pressure and haemoconcentration which lead to increased tendency to vascular thromboses.

Recently a new thermal mask is available for patients who are sensitive to breathing cold air. It contains an efficient, patented thermal exchange module that affects a heat exchange cycle by regulating air flow through its chambers and directing air over a low turbulence thermal medium. Heat and moisture from each exhaled breath is captured within the module and transferred into the next inhaled breath of fresh air, setting up a cycle of breathing warm, moist air.

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1. Giesbrecht GG. The respiratory system in a cold environment. *Aviat Space Environ Med.* 1995;66:890-902
  2. Ragus M, Bergovec M, Kranjcec D et al. A cold shock response triggering acute myocardial infarction. *Int J Cardiol.* 2008;128:e37-9.
  3. Näyhä S. Environmental temperature and mortality. *Int J Circumpolar Health.* 2005; 64:451-8.



## The REMEO® Concept: Facility and Home-Based Long-Term Care

Konrad Bengler  
Linde Healthcare

Until a few years ago, caring for ventilated patients at home was inconceivable. Today, thanks to new medical developments in ventilatory therapy, it is now possible.

The REMEO® programme has been created to support both patients and family caregivers by providing a calm and effective process that prepares them for the challenge of complex care in the patient's home. In many cases, there is no need for a patient with stable ventilation to stay in intensive care; however, direct discharge into an outpatient setting may not always be possible.

The inpatient REMEO® Ventilation & Weaning Center has been created to bridge this gap. Here, patients and relatives can find a comfortable, relaxed atmosphere, supported by state-of-the-art medical equipment. Patients receive in-depth competent care thanks to the wide-ranging experience of the REMEO® staff.

The team's aim is to gradually withdraw or 'wean' ventilatory support wherever possible. This allows patients to steadily increase their (respiratory) independence after a stay in intensive care. Our specialist staff is aware of relatives' worries and concerns, and they will look after you like a family member, with equal empathy. As the potential family caregiver, you will be supported in many ways – from comprehensive care training that allows you to manage the routine tasks, to individual visits by the REMEO® staff on request after the patient's return home.

REMEO®, Linde Healthcare's innovative care programme, specializes in the care of long-term ventilated patients. Derived from the Latin remeo ("I return home"), REMEO® combines the expertise, staff and equipment to help manage the often complex process from when a patient is discharged from hospital to their return home and subsequent ongoing support.

## The Need for a Patient-completed Assessment Test in COPD

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### Introduction

COPD is projected to become the world's third largest killer by 2020.<sup>1</sup> Despite increasing mortality and morbidity, people with COPD could remain under-recognised, under-acknowledged and under-treated.<sup>2</sup>

### The need for an assessment test in COPD

COPD is frequently sub-optimally managed in a significant proportion of people, who may suffer increased disability and reduced quality of life as a result. The need to improve the assessment of patients with COPD has long been recognised:

- Current guidelines determine treatment and management based on whether patients are "stable" and existing tools have struggled to describe and account for the subtle and progressive nature of COPD.
- Some patients and physicians have difficulty in recognising and communicating the symptoms of COPD
- Patients and physicians also often underestimate the severity of their disease during normal consultations.<sup>1</sup>

These patients may be experiencing a detrimental impact on their quality of life which could be improved through consistent, regular review and an appropriate change in management. Effective dialogue between physicians and patients in a consultation could address this situation, however, this can be complex and time-consuming in an open ended conversation, especially in primary care settings.

### Conclusion

A short, simple test to assess COPD patients' condition regularly is required to support this dialogue and enhance understanding of the impact of COPD between patients and physicians in order to manage the disease optimally.

*Continued overleaf*

GlaxoSmithKline is working with an independent expert steering committee and engaging with COPD patients and well-respected professional and patient groups (including EFA) in the development and validation of a short and simple assessment test for COPD, the COPD Assessment Test™ (CAT). It is hoped that this will be available in late 2009.

## Novartis Respiratory: Breathe It All In

Keith Allan  
Novartis Pharma AG, Basel, Switzerland

Novartis, a long-term Platinum partner of the European Federation of Allergy and Airways Diseases, is proud to support the 13th annual EFA Conference, Future of Patient Organizations, as part of its promise to help all patients breathe better.

As part of its commitment to EFA and this year's conference, Novartis supports the federation in raising the importance of chronic respiratory diseases to European policy makers and highlighting the conditions needed to manage future challenges of national and international allergy and asthma patient organizations.

Novartis is committed to discovering, developing and delivering innovative medicines to enhance quality of care, ease suffering and prevent and cure a broad range of respiratory diseases.

*Advancing patient care* - Novartis continues to leverage its understanding of patients who live with respiratory disease and is developing solutions that address their most important unmet needs. By performing studies in various patient populations, Novartis is poised to help treat a broad range of respiratory conditions.

*Building global partnerships* - Through its recruitment of clinical investigators and partners from regions around the globe, Novartis is developing integrated solutions that result in optimal therapeutic outcomes.

*Innovating Research and Development* - Novartis is focused on asthma, chronic obstructive pulmonary disease (COPD), cystic fibrosis, pulmonary arterial hypertension (PAH), idiopathic pulmonary fibrosis and smoking cessation. By targeting new pathways and developing novel therapies, Novartis is committed to addressing patients' individual needs.

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We are grateful to our sustainable partners  
for making this event possible through  
unrestricted educational grants.

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*Silver partner*



*Other partner*

