The role of patient organisations in fighting chronic respiratory diseases

Watching out for patient interest.

Otto Spranger, EFA Treasurer, GARD 31 May 2008
Patients are experts in their disease and living with it everyday and night – all the time, while medical professionals are experts in the disease.
20 countries
33 member organisations in which over 500,000 patients & carers
Speaking on behalf of over 30,000,000 patients

European Federation of Allergy and Airways Diseases Patients’ Associations

Highest governing body: the Annual General Meeting of Members
• About EFA
• Fighting CRD from patient perspective
• The role of patient organisations
• Example from EFA “Fighting for Breath Campaign”
• A successful CRD programme from patient perspective is…
• Patient organisations & GARD country
About EFA: MISSION

• Reducing the *frequency and severity* of allergies, asthma and COPD;

• Minimize their *societal implications*;

• Improve *health-related quality of life* of patients;

• and pursue *equal health opportunities* in the field of allergy and airways diseases in Europe.

**Central Values**

Patient perspective – Involvement - Sharing knowledge and experience - Partnership and cooperation - Visibility and presence
• **Advocacy**: Influencing European policy making on indoor & outdoor air quality, quality & accessibility of healthcare, patient participation and research

• **Capacity building**: strong and professional EFA and members

• **Empowerment**: Empowering member organizations to realize a comparable level of serving of patients interest by exchanging experiences on national level (policymaking, awareness and services)
Fighting CRD from patient perspective:

- Prevention
- Smoking cessation
- Early diagnosis
- Health care
- Social support
- Food labelling

- Medicines
- Rehabilitation
- Reimbursement
- Information
- Education
- Adherence, concordance

- Indoor Air
- Outdoor Air
- Chemicals

- Treatment
- Society
- Health, Env & Research Policy

- Prevention
- Care
- Medicines

- Quality of Life
- Finding the cure
For ALL patients with allergy, asthma & COPD

Comprehensive European and national programmes on

- Access to good, equal standards of care, no matter where you live in Europe
- High standards of and access to patient & professional education, information and new knowledge
- Healthy, unpolluted air to breathe indoors and out
### ALLERGY – first priorities
*European and national level*
- Allergology recognised as a medical speciality across Europe
- Safe food: clear and understandable food labelling

### ASTHMA – first priorities
*European level*
- High standards of regulation for indoor and outdoor air pollution
- Funding for research

*National level*
- Reimbursement of medication

### COPD – first priorities
*European level*
- Total ban of smoking in all public and workplaces
- Access to and awareness and understanding of early diagnosis

*National level*
- Access to and awareness and understanding of early diagnosis
- Access to rehabilitation
ROLE OF PATIENT ORGANISATIONS

- Patient information & education
- Peer support
- Participation in policy making on care, environment & research
- Advocacy on good quality patient centred care, healthy environment and patient-oriented research
- Partnership with other stakeholders
ROLE OF PATIENT ORGANISATIONS

Asthma Manifesto  COPD Manifesto  Allergy Manifesto
ROLE OF PATIENT ORGANISATIONS: EFA

- Coordinated advocacy action with members
- Multidisciplinary & global partnerships ie GARD, GA²LEN
- Projects to address a specific issue
- Campaigns to create awareness
- Surveys to produce patient centred intelligence to back our advocacy
- Communication through eZine, media releases, press events
- Events: conference, workshops
- Membership in EU committees & working groups
- Membership in other organisations: HEAL, ENSP
Example from EFA: Survey and Campaign on severe asthma Fighting for Breath

Fighting for breath

A European patient perspective on severe asthma

One person every hour dies from asthma in Western Europe
One in four people consider their asthma life-threatening
One in five experience attacks so severe that they limit their speech
at least once a week - imagine having a terrifying attack and being
unable to ask for help

90% of asthma deaths could be prevented by
- Increased public awareness
- Improved access to appropriate healthcare provision
- Improvements in environmental and healthcare policy
- Advances in research and the availability and accessibility
  of effective treatments

"I would like the air to be cleaner, to make breathing easier, and I would like children with asthma to
grow up to have a future without the problem of environmental pollution."
Soleida Alonso

"People with asthma merit significant attention from health services, we live with the
dread of social health and political violence."
Jesus Baglietto

"On a bad day I feel like I’m drowning and I can’t reach the surface of the water and I am
going to burst, yet a tiny, tiny bit of air keeps me alive. It’s
OBJECTIVES

- **Provide patients with a voice** - reported the reality of patient experiences, identifies current unmet needs and articulates patient wishes for the future

- **Raise awareness and educate** - insights provide effective platform to communicate seriousness of severe asthma

- **Support greater prioritisation of asthma** – addresses need to improve outcomes such as quality of life, hospitalisation and death rates

- **Influence policy**
Reflecting and reporting people’s experience
Our SAMPLE

- UK, France, Germany, Spain & Sweden
- Repeated in Italy, France, Austria, Norway and more
- “Severe asthma symptoms”
  - Disturbed sleep on a weekly basis
  - Attacks of wheeze
  - Speech limiting attacks in the last year
Quantitative survey generated and supported with qualitative group interviews

• Your experience of asthma
• Your experience of asthma care
• Your hopes for the future
“I would like the air to be cleaner, to make breathing easier, and I would like children with asthma to grow up to have a future without the problem of environmental pollution.”

Soledad Alonso

“The severity of my asthma means I don’t have much of a social life and so I feel very isolated. It’s also embarrassing to have to [use] your nebuliser in public. I’ve lost a lot of friends because of my illness. My relationship with my partner broke down because of my asthma.”

Wendy Williams
Inadequate communication and partnership
Insufficient research
Unsatisfactory health care
Involuntary exposure to pollutants
The CONSEQUENCES

- Compromised lives
- Unnecessary illness
- Social isolation
- Preventable deaths
The SOLUTION

- Expert care where I live
- Sustainable research
- Clean Air (indoor and outdoor)
The CARE

- Access to specialist care
- Patient centred care
- Access to modern treatments
- Patient-physician partnership
- Freedom of choice
The RESEARCH

✓ Independent funding
✓ Innovative treatments
✓ Prevention programmes
✓ Finding the cure
Banning smoking
Reducing exposure to pollutants
LIZ LYNNE MEP IN COLLABORATION WITH THE EUROPEAN FEDERATION FOR ALLERGIES AND AIRWAYS DISEASES PATIENTS’ ASSOCIATION (EFA)

are delighted to invite you to the launch of ‘Fighting for Breath: a European patient perspective’ - a major European survey investigating the impact and burden on people living with severe asthma.

3RD MAY 2005 - WORLD ASTHMA DAY

A lunchtime reception will be held from 12.30-14.30 at The Renaissance Brussels Hotel, Rue du Parnasse, 19, B-1050 Brussels.

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Launch of the preliminary results in Brussels for EU Policy makers and media

Launch of survey results at ERS Conference for medical press
The limitations of severe asthma: the results of a European survey

Background: Asthma has a major impact on patients' lives, and severe asthma is a serious health problem. The European Federation of Allergy and Airways Diseases Patients' Associations (EFA) commissioned a telephonic survey to capture the views of people who are living with severe asthma in Europe.

Methods: A total of 1300 patients from the UK, France, Germany, Spain, and Sweden who reported a previous diagnosis of asthma and reported receiving asthma medication took part in the survey.

Results: Most patients reported having limitations to their lifestyles as a consequence of the symptoms of severe asthma. Almost 30% of patients reported that physical activity was restricted, 50% were restricted from having pets, 90% from taking holidays, and many felt their job prospects were limited. In addition, 50% of this population of patients were not convinced that guideline goals were being achieved, although it is not clear as to the cause of this failing. Patients indicated that they want treatments that are fast-acting, long-lasting and have minimal side effects, and they were optimistic for the development of effective therapies over the next 5 years.

Conclusions: The results of this study provide insight into how greatly patients' lives are affected by severe asthma.

Fighting for Breath evidence in EFA EU policy influencing and responses:
- Green Paper Towards a Europe Free of Tobacco Smoke
- Thematic Strategy and Directive on Ambient Air Pollution
- FP7 respiratory diseases & allergies as priorities
Total media impressions:

- 59 pieces of print coverage
- 35 pieces of online coverage
- 21 pieces of radio coverage
- 11 pieces of television coverage
- 7 pieces of newswire coverage
- Full oral presentation of data to ERS scientific session
- Final results and full EU report launched to media at press briefing attended by 29 international journalists
- Final report presented to over 600 EU policy makers, NGOs, WHO and MEPs by EFA
Thus far EFA members in Czech Republic, Finland, Lithuania, Italy – role:

- Providing patient perspective
- Patient education and information
- Communication and awareness
- Partnership every step of the way
From patient perspective a successful CRD programme is

- **Patient centred** – based on needs expressed by patients themselves
- **Comprehensive**; prevention, care, education, information, research, environment, patient participation..
- **In partnership & multidisciplinary**; policy makers, all patient and health professional organisations etc involved
- **Evaluated** – lessons learned
"The most exciting thing that allergy, asthma and COPD Patient associations have done for patients is to change their public image.

It used to be that they were sufferers – borers – asking for attention to their attacks. Now they have changed into fighters for the freedom to breathe."
Watching out for patient interest.

With You.

Thank You.

www.efanet.org