

The Role of EFA in GA²LEN

Erkka Valovirta, M.D., Ph.D.

EFA Medical Committee Coordinator

EFA GA²LEN Project Member

Topics

- EFA Mission & objectives
- Patient education & information
- GA²LEN objectives & activities
- EFA Allergy Manifesto
- EFA role in GA²LEN

What is allergy?

”They got stuff called allergy.

Used to call it hay fever - made you sneeze.

Guy that figured out allergy should of got a patent.

An allergy is, you get sick when there’s something you don’t want to do.”

Sweet Thurday, J Steinbeck 1954

EFA Central Values

- Patient perspective, patient in the focus (including patient education)
- Involvement
- Sharing knowledge and experience
- Partnership and co-operation
- Visibility and presence
- Health equity in Europe
- Production and dissemination of highly scientific information



European Federation of
Allergy and Airways Disease
Patients Associations

EFA Mission Statement

- EFA is a European community of patient organisations that share the responsibilities for
 - Substantially reducing the frequency and severity of allergies, asthma and COPD
 - Minimizing their societal implications
 - Improving health-related QoL
 - Ensuring full citizenship of people with these conditions
 - Pursuing equal health opportunities in the field of allergy and airways in Europe



Network of Excellence



European Federation of
Allergy and Airway Disease
Patients Associations

EFA Objectives

1. To influence European Union policy making

- Healthy indoor and outdoor air in Europe
- High quality (including easy accessibility) of healthacare for people with allergies, asthma and COPD
- Unlimited societal participatiton of people with allergies, asthma and COPD
- Adequate funding of research



Network of Excellence



European Federation of
Allergy and Airway Disease
Patients Associations

EFA Objectives

2. To support the realization of a European network of

- Strong and professional national organisations of people with allergies, asthma and COPD
- A strong and professional EFA



Network of Excellence

EFA Objectives

3. To empower member organisations to reach comparable level of serving the interests of patients by exchanging experiences on
- Influencing national policymaking on public health, healthcare, societal participation and research in relation to allergies, asthma and COPD
 - Product and services for people with these diseases
 - Increasing awareness



European Federation of
Allergy and Airway Disease
Patients Associations

Patient Education

- ” A systematic learning experience in which a combination of methods is generally used, such as provision of information and advice and behaviour modification techniques, which influence the way the patient experiences his illness and/or his knowledge and health behaviour, aimed at improving or maintaining health or learning to cope with a condition, usually a chronic one”.

The patient from receiver of information to informed decision-maker.

Van den Borne HW. Patient Educ Counsel 1998; 34:89-102



Network of Excellence



European Federation of
Allergy and Airways Disease
Patients Associations

Patient Education

- Patient education is based on
 - Correct and precise information
 - Continuous research
 - Implementation of the latest scientific information from reliable sources (nationally and locally)



Network of Excellence

GA²LEN Activities

- 1-7 activity points
- 5. Incorporation of patient's needs and policy makers' views into the formulation of research and public health policy
- 6. Assistance with the development of evidence-based policies for the prevention and management of allergy and asthma
- 7. Research on all issues in order to develop new ways preventing or managing allergies and asthma



European Federation of
Allergy and Airways Disease
Patients Associations

GA²LEN Objectives

- Address all aspects of allergy and asthma
 - By tackling the fragmentation of European research
 - By interacting EU research centres on a long term basis
- Spread excellence and knowledge to interested targets
- In long term, decrease the burden of allergy and asthma in Europe



Network of Excellence



European Federation of
Allergy and Airway Disease
Patients Associations

EFA Allergy Manifesto: The Key Goals

1. Change the cultural attitudes of society
2. Adapt healthcare systems and resources
3. Understand the nature of allergy
4. Establish programmes for training, education, empowerment and rehabilitation
5. Establish research programmes



Network of Excellence

Establish Research Programmes

- Epidemiology
- Genetics
- Pathophysiology
- Pharmacology
- Socio-economy
- Psychology
- Environment



European Federation of
Allergy and Airways Disease
Patients Associations

GA²LEN Research Programme

- Nutrition
- Infection
- Environment, indoor and outdoor pollution
- Occupation and pollution
- Gender
- IgE sensitization and allergic diseases
- Early events in airway remodelling
- Genetics and genomics



Network of Excellence



European Federation of
Allergy and Airway Disease
Patients Associations

EFA Role in GA²LEN

- **INDEPENDENT ROLE**

- Dissemination and translation of information to EFA members and to patients as well as public at large
- Proposals for activities in Workpackages (including budget) in spreading information from different GA²LEN WPs
- EFA SubWebsite in the GA²LEN Website
- EFA member GA²LEN Contact Person: access to the Partners Only GA²LEN Website



Network of Excellence

- **COLLABORATIVE ROLE : Incorporating of patients view in research policy**
 - An EFA representative in the GA²LEN Assembly
 - An EFA representative in the Steering Committee of WP 2.8. Clinical Care and Quality of Life
 - Proposals for activities in GA²LEN Workpackages (including budget)
 - EFA SubWebsite in the GA²LEN Website
 - EFA member GA²LEN Contact Person: access to the Partners Only GA²LEN Website



European Federation of
Allergy and Airway Disease
Patients Associations

EFA Role in GA²LEN

- GA²LEN “Summer Courses”
 - Partners can apply for one day courses
- EFA Conference
 - A GA²LEN Symposium on the latest results and campaigns as well as key messages
- Co-operation with GA²LEN Management Office
- Co-operation with GA²LEN Communication Centre:



Network of Excellence



European Federation of
Allergy and Airways Disease
Patients Associations

EFA Role in GA²LEN

- Annual GA²LEN Congress 17-19 April 2005
 - 17 April: Meetings of WPs in Ghent
 - 18 April: Annual Conference for GA²LEN members
 - 19 April: Conference for Public and Press in Brussels
- Lobbying
- Campaigns and projects



Network of Excellence



European Federation of
Allergy and Airway Disease
Patients Associations

EFA Role in GA²LEN

- **COLLABORATIVE ROLE : Incorporating of patients view in research policy**
 - An EFA representative in the Steering Committee of **WP 2.8. Clinical Care and Quality of Life**
 - Sub-working groups:
 - Early diagnosis
 - Prevention and early intervention
 - Clinical care and follow-up
 - Structure of care and health economy
 - Clinical trials



Network of Excellence

Dissemination of Knowledge

- GA²LEN will establish information exchange
- NoE brings this knowledge to
 - Patients, general public and policy makers by increasing the awareness of allergy and asthma by providing evidence based advice to patients and parents
 - This process will also provide new diagnostic, prevention and therapeutic modalities for all interested partners

Dissemination of Knowledge

- GA²LEN scientific centres produce new scientific data
- Data collection by the GA²LEN Management Office
- EFA Central Office receives and collects data from the Management Office
- Data is adapted, translated and disseminated in co-op with EFA Central Office and GA²LEN Management Office to EFA members

Dissemination of Knowledge

- EFA members adapt, translate and disseminate new data nationally and locally
- >>> this ensures that patients receive the latest adequate information from the “ocean” of new information
- >>> this ensures also that patients can rely on the information they receive

Dissemination of Knowledge

- EFA members have a key role
- WS: practical everyday actions are planned
- Goal is to list key actions ("Tool Kit") in the dissemination of the information according to the resources
- Logbook in every EFA member ass and in EFA Central Office: actions, meetings, publications should be listed



European Federation of
Allergy and Airways Disease
Patients Associations

**incorporation of patients'
views into the formulation
of research policy**

**incorporation of policy
makers' views into
the formulation
of research policy**

**developm. of
mechanisms
to disseminate inform. to
policy makers, professions,
patients, private sector
and public**

GA²LEN

**development
of a pan-European
system of quality management
for allergy services based
on research findings**

**development
of evidence based
policies for prevention and
management of allergy
and asthma**



European Federation of
Allergy and Airways Disease
Patients Associations

Communicating Evidence for Participatory Decision Making

- Steps for discussing evidence with patients
- 1. Understand the patient's experience and expectations
- 2. Build partnership
- 3. Provide evidence, including uncertainties
- 4. Present recommendations based on scientific data
- 5. Check for understanding and agreement

Epstein RM et al. JAMA, 291;19:2359-2366,2004



Network of Excellence



European Federation of
Allergy and Airways Disease
Patients Associations

What is needed now?

- Key action points – “Tool Kit”
- EFA member GA²LEN Contact Person
- Continuous flow of new data from GA²LEN Management Office to EFA Central Office and to EFA members
- A system will be developed for the translation and delivery of scientific data in a structured form to EFA
- GA²LEN Website plays key role in the dissemination process



Network of Excellence



European Federation of
Allergy and Airways Disease
Patients Associations

EFA Mission Statement

- EFA is a European community of patient organisations that share the responsibilities for
 - Substantially reducing the frequency and severity of allergies, asthma and COPD
 - Minimizing their societal implications
 - Improving health-related QoL
 - Ensuring full citizenship of people with these conditions
 - Pursuing equal health opportunities in the field of allergy and airways in Europe



Network of Excellence



Network of Excellence