

Appropriateness of severe asthma management – national and European experiences

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On behalf of EFA

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About EFA



- EFA has its Central Office in Brussels, Belgium

www.efanet.org

- The **European Federation of Allergy and Airways Diseases Patients Associations (EFA)** was founded in 1991
- EFA unites **35** allergy, asthma and COPD patient organisations in **22** countries at the European level
- EFA seeks to improve the health and quality of life for patients and their families by facilitating collaboration and sharing knowledge and experiences

What is EFA doing?

EFA promotes national and participates in European collaboration through the following actions:



1. EFA's Allergy Awareness Project
2. European Asthma Research and Innovation Partnership (EARIP)
3. Unbiased Biomarkers for the Prediction of Respiratory Disease Outcomes (U-BIOPRED)

EFA's Allergy Awareness Project Objectives

- **Raise awareness** of Respiratory allergies (Rhinoconjunctivitis and Allergic Asthma Rhinitis, Asthma) as a **serious chronic disease**
- EFA calls for:
 - **Early identification** of symptoms by target audience
 - **Early diagnosis**
 - Appropriate **strategies** including life style changes and physical activities to **manage** and **control** allergy
 - **Avoid exacerbations** of severe allergies
 - **Prevention** of allergies for all including a smoking control strategy

EFA's Allergy Awareness Project Activities to Date

- Developed, disseminated and evaluated **survey** (Benchmark) amongst EFA members
- Members from 18 countries answered survey with more than 50 questions regarding access, quality to care, best practices
- Survey Results published in **EFA Book on Respiratory Allergies**
- **Luncheon Debate** on Respiratory Allergies including « Call to Action » at EU Parliament in November 2011
- **Educational meeting** in Helsinki with EFA members to promote best practice example of **Finnish Allergy Programme**
 - 7-8 November 2012
 - NAAF, FEDERASMA & ABBA



Allergy's Impact

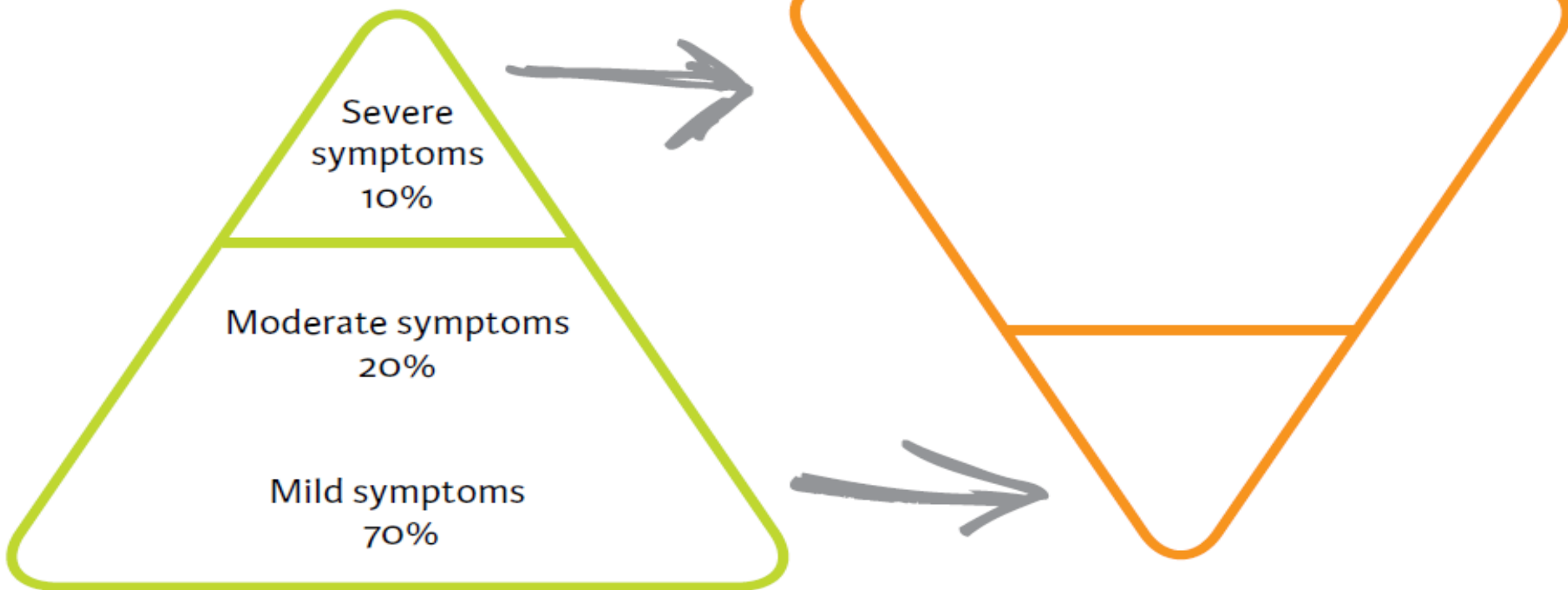
- **15 to 20%** of allergy patients suffer from a severe form of disease, potentially with considerable impact and several possible co-morbidities
- Severely affects the **Quality of Life (QoL)** of sufferers, care-givers and families
- Severe asthma and allergy has major impacts on both **work and school performance, productivity, and economic burden**



The Pyramid of Costs

Disease severity

Cost



The allergy pyramid. Most allergy symptoms are mild and intermittent, but due to the high prevalence of allergy, severe symptoms are also common and account for most of the costs. From: The Finnish Asthma Programme [25].

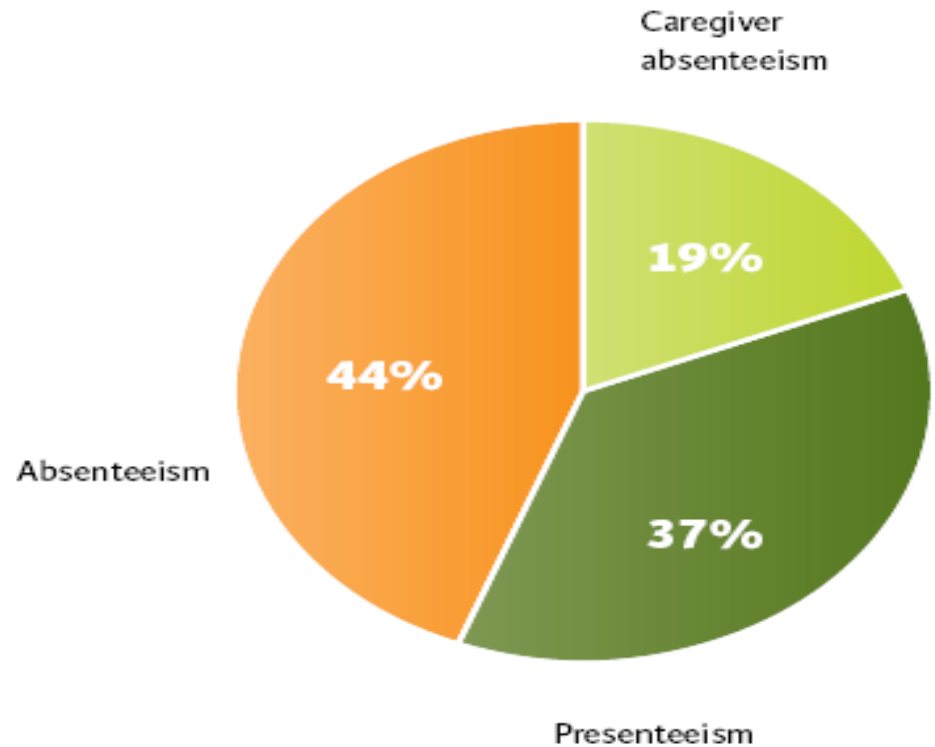
Productivity Loss in Allergy Rhinitis

“My son doesn’t sleep well because of his rhinitis, so he gets sleepy during the day. Although he is still young, I’m beginning to worry about his school work.”

– A mother from Italy



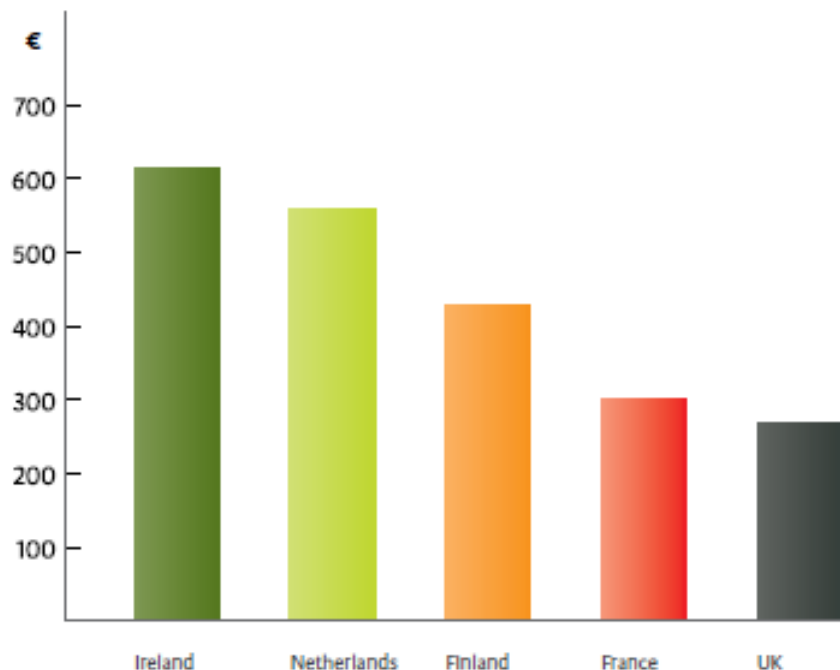
Factors of productivity loss for patients with allergic rhinitis



Source: Hellegren et al. 2010 [26].

Annual Costs of Childhood Asthma Per Child

Yearly direct and indirect costs of childhood asthma per child



“Economic support is provided for asthma patients only after a lengthy bureaucratic procedure and only under certain conditions.”

- FEDERASMA (Italy)

EFA's FAP Workshop in Helsinki (2012)

- Delegations from Bulgaria, Norway and Italy
 - Patient orgs, policymakers, healthcare representatives, etc.
- Detailed presentations from Finnish stakeholders and programme coordinators
- Opportunity for delegations to begin planning for their own programmes



EFA's FAP Workshop in Helsinki (2012)

Italian Delegation

- Filomena BUGLIARO – Federasma Onlus
- Rossana DI NATALE – FEDERSANITÀ – ANCI
- Lorenza MELOSINI – MD, GINA-LIBRA Project
- Giorgio SALERNI – Federasma Onlus
- Giulio TOCCAFONDI – PATIENT SAFETY Tuscany Region



Characteristics of the Finnish National Programmes

Asthma

Programme:

Focus on

- (1) inflammation,
- (2) early treatment,
- (3) guided self-management,
- (4) networking



Allergy Programme:

Focus on

- (1) prevention,
- (2) tolerance induction,
- (3) quality control of diagnostic work,
- (4) early treatment of exacerbations

Finnish Allergy Programme 2008 – 2018

- **STRUCTURE:**

- Medical Care and Key Messages
- Funding:
 1. Finnish Slot Machine Association (RAY)
 2. Finnish Government/Ministry of Social Affairs & Health

- **SUBSTANCE:**

- Focus is on two main target groups
 1. Education of healthcare professional personnel
 2. Education and awareness of the general public

The FAP Goals

▶ Prevent allergies

Indicator: prevalence of asthma, allergic rhinitis and atopic dermatitis reduces by **20 %**

▶ Increase tolerance to allergens in the population

Indicator: avoidance diets to foods decrease by **50 %**

▶ Improve allergy diagnostics

Indicator: all patients are tested in a quality certified allergy-testing centre

▶ Reduce work related allergies

Indicator: Their numbers reduce by **50 %**

▶ Focus to severe allergies and reduce attacks

Indicator: "Good Allergy Care" employed in the country, asthma attacks reduced by **40 %**

▶ Reduce costs caused by allergies

Indicator: total costs of allergic diseases reduced by **20 %** in 10 years



How should national programmes seek change?

A national disease programme is an Educational Action Plan. The aim is **not to increase work** but change **how work is done!** Target audiences:

- Healthcare personnel at all levels
- Pharmacy personnel
- Patient organisations (and relevant NGOs)
- Patients with asthma and allergy
- General public as a whole
- Authorities, politicians and the media

The European Asthma Research and Innovation Partnership (EARIP) - *coordinated by Asthma UK*

- The EARIP project is a support action from 7th Framework Programme (FP7) **which defines a roadmap for asthma research**
- EARIP seeks a pan-European approach to **reduce asthma attacks, emergency healthcare utilisation and asthma deaths** in adults and children
- The overarching objectives of EARIP are:
 - **Reduction of asthma deaths in Europe by 25% within 10 years and by 50% within 20 years**
 - **Reduction of hospital visits by 50%**
 - **Increase optimum asthma self-management by 20%**

EFA's Role: Work Package 3a

WP3a: Health and Care System Change

- **Objectives:** to develop better and more efficient healthcare systems putting **individual patients at the heart of asthma management and treatment** and achieve much improved outcomes
 - **Verify status-quo** on patient-centred asthma care
 - **Provide a platform** for sharing **best practices** on asthma programmes for a wide stakeholder audience
 - **Foster consensus building** among stakeholders for **system change** and **providing guidance** for this to occur



Task 1: Literature Review

- Publication in a peer-reviewed journal of literature review
- Confirms the a status quo on healthcare system change in asthma and identifies current asthma programmes and existing gaps in research for evaluation and measurement of this change

Task 2.1: Stakeholders Workshop at the EP

- Stakeholders workshop “Towards European Innovation Partnership in Healthcare Change in Asthma”
- Based upon findings of the literature review and to include patient representatives, healthcare professionals, experts, policymakers and others with interest in establishing national programmes

Task 2.2: Consortium/Expert Workshop

- Follows up on the Stakeholder Workshop to review conclusions from the meeting
- Provides recommendations for stakeholders on implementing change and research needs
- Agrees on a structure for final event report

Task 3: External Stakeholder Collaboration

- Creation of a directory for local stakeholders to facilitate collaboration in different European national contexts:

Network for Healthcare Change

WP3a Timeline of Actions



Literature Review
M12
September 2014
Deliverable 1

Stakeholder
Workshop @ EP
M24
September 2015

Consortium/Expert
Workshop
M26
November 2015

Final Report of
Workshops
M27
December 2015
Deliverable 2

U-BIOPRED

- **Aim:** to better understand the different types of severe asthma.
- **Starting Date:** 01 October 2009 with duration of 60 months.

This will enable us to:

1. Better consider individual characteristics of patients their diagnosis and management
2. Make it easier to develop new and more effective medicines by overcoming the present bottlenecks to advancing new therapies

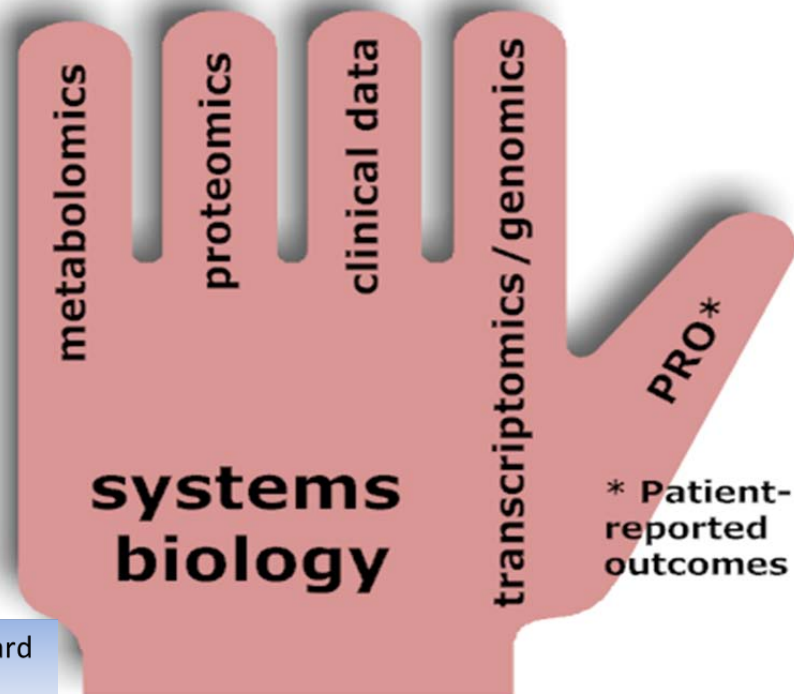


The role of EFA in U-BIOPRED

The resulting handprint will enable us to precisely characterise patients with different types of severe asthma = understanding different types of asthma better



Lina Buzermaniene, Lithuania, patient representative in the Ethics Board
Per-Ake Wecksell, Sweden, patient representative in the Safety Board



The role of participants in U-BIOPRED

- From the start patient organizations and patients themselves have been involved in U-BIOPRED.
- Not just as study participants, they helped in **designing the patient information sheets, the protocol, and the overall focus.** However, that is not their biggest input.

Patients give the project meaning !!!

Conclusion

- **EFA** strives to promote **best practices** (e.g. Finland) wherever possible in both its own and EU projects to improve care for asthma patients at the national and European levels
- **EFA** actively contributes to European projects on severe asthma to help **raise awareness** and assure research is focused upon **improving the quality of life** for asthma patients



Thank you for your attention!

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