MEDIA KIT

EFA LAUNCH OF A CALL TO ACTION ON COPD

Contents

The European Federation of Allergy and Airways Diseases Patients' Associations

EFA is an independent non-profit organization and its central office is located in Brussels, Belgium.

EFA is a European alliance of 35 allergy, asthma and chronic obstructive pulmonary disease (COPD) patient associations in 21 countries, founded in 1991 in Stockholm, Sweden.

Over 500,000 patients and care givers are members in EFA member organisations.

EFA is the only patient organization working with the World Health Organization (WHO) as part of the Global Alliance Against Respiratory Diseases (GARD) Planning Committee and co-operates with other relevant NGOs: European Patients' Forum (EPF), Health and Environment Alliance (HEAL), European Network for Smoking Prevention (ENSP), European Respiratory Society (ERS) and European Lung Foundation (ELF).

EFA's mission statement

EFA´s mission is to draw together a European community of patient organisations which share responsibility for substantially reducing the frequency and severity of allergies, asthma and COPD, minimising their societal implications, improving health-related quality of life and ensuring full citizenship of people with these conditions, as well as pursuing equal health opportunities in the field of allergy and airways in Europe.

Objectives

To accomplish its mission, EFA focuses on the following strategies:

1. To influence European Union policymaking in such a way that it will result in:
    - Appropriate regulations for healthy (indoor and outdoor) air in Europe;
    - Appropriate regulations on the quality (including accessibility) of healthcare for people with allergy, asthma and COPD;
    - Appropriate regulations on societal participation of people with allergies, asthma and COPD;
    - Adequate funding of demand-driven research on allergies, asthma and COPD.

2. To support the creation of a Europe network of strong and professional national organizations of people with allergies, asthma and COPD and a strong and professional EFA.

3. To empower member organizations to achieve equality in the way patients' interests are served, by exchanging experiences of:
    - Influencing national policymaking on public health, societal participation and research in relation to allergies, asthma and COPD;
    - Products and services for people with allergies, asthma and COPD;
    - Increasing awareness.

Central values

In accomplishing EFA's mission, the central values are:

- The patient's perspective;
- Involvement;
- Sharing knowledge and experience;
- Partnership and co-operation;
- Visibility and presence.

Fields of activity

EFA represents its' members at European level and represents the view of people with allergy, asthma and COPD as a member of the EU Health Policy Forum, EU Consultative Forum on Environment and Health, EU Expert Group on Indoor air Quality and recently applied and was accepted to start to interact with the European Medicines Agency EMA.

Asthma

EFA is a partner in a new European collaborative project on 'understanding severe asthma' within the Innovative Medicines Initiative (IMI), the **U-BIOPRED** (Unbiased Biomarkers for the Prediction of Respiratory Disease Outcomes). U-BIOPRED aims to develop a greater understanding of severe asthma in order to increase the speedy development of new and better tailored treatments. Currently many people with severe asthma have even life-threatening symptoms despite using existing treatment. EFA's role is in ethics, patient friendly dissemination of research and patient input throughout the project.

EFA has campaigned for a better deal for people with severe asthma, based on EFA's Pan-European survey **Fighting for Breath** – A European Patient Perspective on Severe Asthma.

Allergy

EFA is a partner, representing the European Patient in two major European wide projects related to allergy: **EuroPrevall** (Prevalence, Cost and Basis of Food Allergy Across Europe) and **GA²LEN** (Global Allergy and Asthma European Network of Excellence) and took part in running a public campaign on 'Does Rhinitis Lead to Asthma?'.

Chronic Obstructive Pulmonary Disease (COPD)

COPD was added to EFA's mandate in 2002. EFA has been strongly involved since then in trying to raise awareness of the disease at the European level, through notably the EFA COPD Patient Manifesto, advocating that EU policies recognise COPD as a major public health issue. EFA, together with the ERS and ELF campaigned in favour of the Written Declaration (102/2007) on combating COPD at the European Parliament. 226 MEPs signed by February 2008.

Healthy Environment – cross cutting issues

Over the years EFA has conducted two European Commission funded projects on indoor air quality; Healthy Indoor Air in Schools in Europe and the THADE (Towards Healthy Indoor Air in Dwellings in Europe).
In 2008 EFA and Health and Environment Alliance launched a website with targeted information for people with respiratory diseases on air pollution in the EU www.knowyourairforhealth.eu
EFA has also campaigned for abolishing second-hand smoke in Europe through consultations in connection of the European Commission Green Paper on Europe free of tobacco smoke.

EFA has an annual conference which 2009 had the theme of 'Future of Patient Organisations' with focus on successful projects on allergy, asthma and COPD with patient perspective and EFA participation. It was held at the Italian Ministry of Health in conjunction with the WHO GARD Assembly.

EFA's Founding Countries

Finland, Germany, Iceland, the Netherlands, Norway, Poland, Sweden and the United Kingdom founded EFA in 1991. Since then, EFA membership has grown rapidly and now covers most of the European Union countries: Austria, Belgium, Bulgaria, Czech Republic, Denmark, Finland, France, Germany, Greece, Ireland, Italy, Lithuania, Luxembourg, Netherlands, Norway, Poland, Portugal, Slovenia, Sweden, Switzerland and the UK.

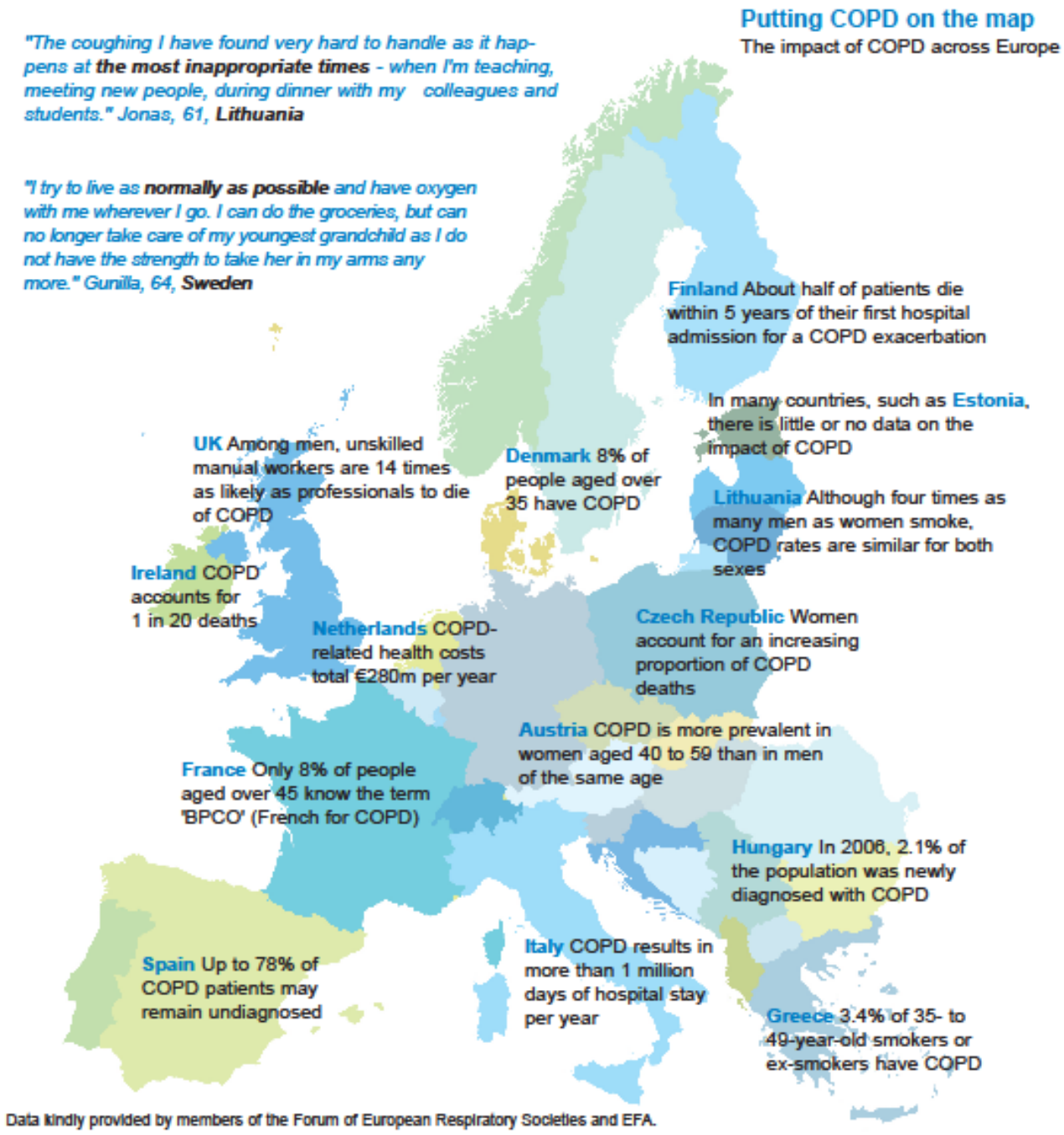
Facts and figures on COPD

- The World Health Organisation estimates 210 million people (2007) worldwide have COPD[1] and according to the ERS and ELF 4-10% of European adults have COPD[2]
- COPD is ranked as the fourth leading cause of death in Europe, exceeded only by heart disease, stroke, lung cancer and lower respiratory tract infections[3]
- The total financial burden of COPD in Europe amounts to nearly €102 billion and it is expected to increase. The social burden of COPD is also increasing, in particular, 21% of COPD patients are severely disabled.
- According to WHO, COPD is the fastest growing cause of death in the world's advanced economies and is projected to rank third by 2030.[1]
- Up to almost three out of four patients with COPD have difficulty in the simplest of everyday activities, being out of breath after simply walking upstairs[4]
- Lost productivity due to COPD has a particularly high impact on the economy, accounting for 67% of overall costs in France, 50% in the Netherlands and 41% in the UK[5]
- COPD severely affects Quality of Life (QoL). 80% of patients hospitalised following an exacerbation describing their health status being 'worse than death' [6]
- Patients who survive their first COPD related hospitalisation, up to 50% are readmitted within 6 months of discharge [7]

[1] World Health Organization Evidence for Health Policy Department http://www.who.int/respiratory/copd/burden/en/
[2] European Lung White Book. European Respiratory Society and European Lung Foundation. 2003.
[3] Murray CJL, Lopez AD. eds. The Global Burden of Disease: *a comprehensive assessment of mortality and disability from diseases, injures, and risk factors in1990 and projected to 2002*. Cambridge; Harvard University Press; 1996
[4] Vermeire P. The burden of chronic obstructive pulmonary disease. Respir Med 2002: 96(Suppl C): S3S10.
[5] Wouters EFM. The societal impact of COPD in North America and Europe: an economic analysis of the Confronting COPD survey. Respir Med 2003: 97(Suppl C): S3S14.
[8] O'Reilly J, Williams AE, Ledger G et al. Health utility burden for exacerbation of COPD requiring admission into hospital as measured by the EQ5D.Abstract presented at the American Thoracic Society Conference 2003, Seattle.
[9] Stoller JK. Acute exacerbations of chronic obstructive pulmonary disease. N Engl J Med 2002; 346(13): 988994.

European Federation of Allergy and Airways Diseases Patients Associations

Putting COPD on the map – Highlights of the impact of COPD in Europe



The map is from a leaflet by ERS, ELF and EFA 2008.

Q&As on COPD

What is COPD?
COPD (Chronic Obstructive Pulmonary Disease) is a progressive, debilitating and often life-threatening disease that affects the patient's ability to breathe, gradually making breathing increasingly difficult. COPD is a preventable and treatable disease that mainly affects smokers and ex-smokers aged over 40.

Chronic means it is persistent – the disease won't go away
Obstructive means the airways are partly blocked
Pulmonary means in the lungs
Disease means sickness

What is the Difference between COPD and Asthma?
COPD and Asthma are only similar in that they affect breathing, but they are not the same disease. Medicines can usually reverse the effects of asthma, but COPD is progressive disease, and medicines cannot fully reverse the effects of COPD.

One way to be sure you have COPD rather than asthma is to have a breathing test called a spirometry test.

What are the Symptoms?

- Breathlessness
- An increased effort to breathe
- Excessive mucus
- Chronic cough.

These symptoms get worse when exercising, in the case of a respiratory infection or during an exacerbation – periods of time when there is a sudden increase in symptoms and the disease gets worse**.**

Who is Affected?
COPD is more common in men over 40 years old, mainly smokers, but the prevalence of the disease is greatly increasing among women and amongst the younger population.

What are the Causes?

- Smoking (including second hand smoke)
- High levels of pollution (indoor and outdoor) and exposure to a variety of airborne particles such as occupational dusts and chemicals;
- Genetic factors may also be associated with a risk of developing COPD because not all smokers develop COPD and a rare known risk factor is hereditary deficiency of protein called alpha-1 antitrypsin.

Is it Treatable?
The earlier the disease is detected, the more effective the treatments will be to treat the symptoms and delay progression.

Stopping smoking is the single most effective intervention to reduce the risk of developing COPD and stop its progression.

Therapeutic interventions include the following:

- Inhaled bronchodilators, which are the main medicines used to treat breathlessness
- In particular in severe COPD, inhaled corticosteroids (ICS) to help reducing exacerbations and symptoms
- Oxygen therapy is needed in severe COPD, and in very advanced disease most or all the time

A balanced diet, regular exercise and flu vaccination (the flu can lead to exacerbation of the disease) are also recommended.

The Personal Burden of COPD

The most significant burden is carried by people with COPD themselves – impacting considerably on their quality of life. Fatigue, complicated by sleep disturbance, and breathlessness severely limit physical activity and impact ability to work and therefore finances, as well as limiting social life and daily routines.

The symptoms and the limitations in daily life they cause can often have a psychological impact – people with COPD frequently experience feelings of anxiety, hopelessness and depression.

Because of the chronic nature of the disease and disabling symptoms, carers often have to take on considerable physical, social and emotional responsibilities when caring for relatives and friends.

About the Book on COPD in Europe "Sharing and Caring"

On World COPD Day 2009 which took place on 18 November, EFA launched its *Book on COPD in Europe 'Sharing and* Caring' which gives an unprecedented collection of data on the quality of care, disease management, and social and financial burden of COPD in Europe.

The book sheds light on the inequalities in the understanding, prevention and management of COPD in the various European countries and showcases the striking impact of COPD across Europe. For example, the number of people with COPD reaches as high as 13.2% in Germany. It accounts for 1 in 20 deaths in Ireland and 1 million hospital stays per year in Italy. Apart from the significant burden of the disease on patients, the total annual financial burden of lung disease in Europe already amounts to nearly €69 billion. COPD accounts for more than half of these costs.

Despite the differences in the various countries surveyed, all countries agree that the prospects are alarming. If no decisive and comprehensive action is taken, COPD is expected to grow further in the next decade and become the third leading cause of death worldwide and increasingly affect the younger population.

Despite these alarming figures, COPD is still largely unknown among the general public, which makes prevention difficult. The EFA book also highlights the fact that "COPD has been neglected by healthcare services, with no diagnosis or misdiagnosis being the unfortunate common themes. Patients and health services are already paying the price".

COPD can be treated, reducing symptoms and improving patients' quality of life. The EFA study showcases that the rapidity and ease of access to care varies greatly from one country to another with unacceptably long waiting times in some countries like France and Ireland.

This book is a first step towards a coordinated response to COPD. It will be presented to the Parliament and Commission together with a concrete call-to-action on 30June.

The book is available online: www.efanet.org/EFABookonCOPDinEUROPE.html

About the EFA Call to Action on COPD Launch

On 30 June EFA is organising an important event at the European Parliament in Brussels to mark the launch of a European Call to Action on COPD, to gather support on the need to adopt a comprehensive and integrated EU approach on COPD. The event will gather together patient and medical communities, and officials from the EU institutions to discuss the urgent need to reduce the suffering and mortality linked with COPD, and address the disease. The event is hosted by MEP Catherine Stihler (S&D), and will follow the EU Open Health Forum "Together for Health – a Strategy for the EU 2020" organized by the European Commission, in which EFA is involved in planning and running a strategic workshop on the environment and health. The Call to Action will be released during the event.

European Union Policies related to COPD

Article 3 of the EU Treaty as amended by the ratification of the Lisbon Treaty states that the EU aims to promote the 'wellbeing' of its people. Wellbeing relates directly to health.The Lisbon Treaty also allows the EU to adopt incentives to safeguard human health.

In relation to health, Article 168 of the Lisbon Treaty also states that the Commission may take initiative to promote Member States coordination, especially to establish guidelines and indicators, organise exchange of best practices, and prepare the necessary elements for periodic monitoring and evaluation.

The European **Council Conclusions on Common values and principles in European Union Health Systems** (2006/C 146/01) state that *universality, access to good quality care, equity, and solidarity are values shared by all 25 member states.*

However, these principles are still far from reality for people with COPD.

Some important EU policy areas that affect people with COPD include: public health, in particular health determinants, health systems and tobacco control; environmental legislation, in particular indoor and outdoor air quality and other policies affecting these, such as research, pharmaceuticals, product regulations and safety and health at work.

Acknowledgement

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Boehringer Ingelheim

The Boehringer Ingelheim group is one of the world's 20 leading pharmaceutical companies. Headquartered in Ingelheim, Germany, it operates globally with 142 affiliates in 50 countries and more than 41,500 employees. Since it was founded in 1885, the family-owned company has been committed to researching, developing, manufacturing and marketing novel products of high therapeutic value for human and veterinary medicine. In 2009, Boehringer Ingelheim posted net sales of 12.7 billion euro while spending 21% of net sales in its largest business segment Prescription Medicines on research and development.

For more information please visit www.boehringer-ingelheim.com

GlaxoSmithKline

GlaxoSmithKline one of the world's leading research-based pharmaceutical and healthcare companies – is committed to improving the quality of human life by enabling people to do more, feel better and live longer. With a strong heritage in discovering and developing respiratory products, today GSK continues to invest in widespread research designed to advance understanding of respiratory disease and facilitate the future development of innovative treatment strategies that meet patient needs.

For more information please visit www.gsk.com

This event is part of The Year of the Lung 2010 initiative, organised by the Forum of International Respiratory Societies (FIRS).

For more information please visit www.2010yearofthelung.org

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