



# COPD in Europe, past, present & future

## The future of COPD patient associations: Patient Group Advocacy Global Lessons: **EUROPE**

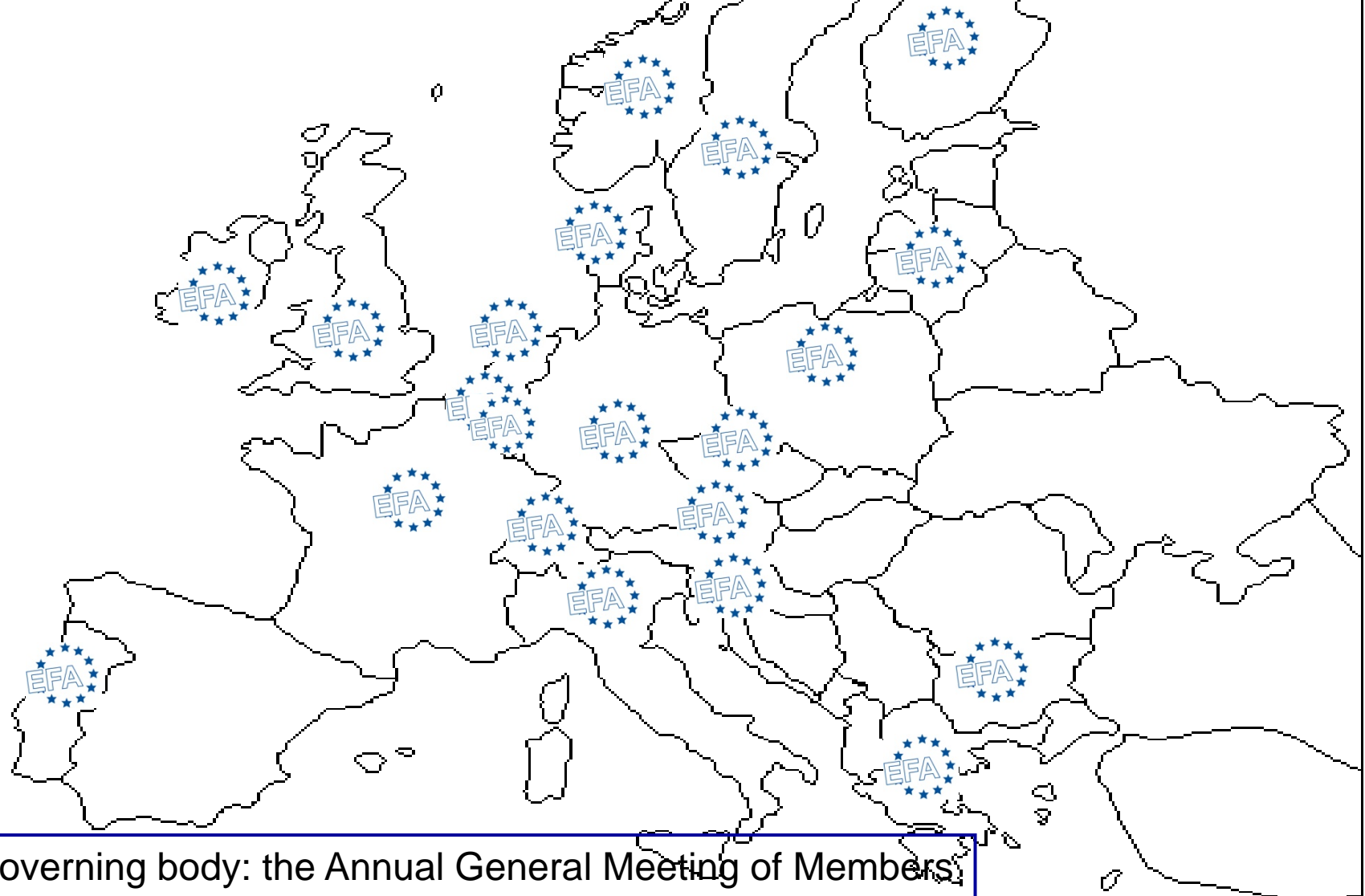
Marianella Salapatas

EFA Past President

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6-7 November 2011 2<sup>nd</sup> COPD Patient World Conference, Shanghai

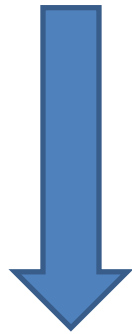
# European Federation of Allergy and Airways Diseases Patients' Associations



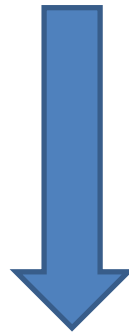
Highest governing body: the Annual General Meeting of Members

# 1st ICC Conference Rome

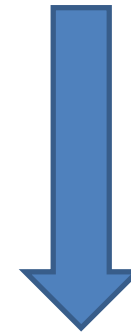
## JOINT FORCES



**EFA**



**GARD**



**ICC**



# BILL OF RIGHTS

## The right

- to receive early and accurate diagnosis
- for information and education about COPD
- for support and understanding
- to receive care and treatment that will benefit them
- to their fair share of society's involvement and investment in their welfare and care
- to advocate with other COPD patients and supporters for improved COPD care and COPD prevention
- to safe air and environment



# EFA Book on COPD in Europe

## ***“Sharing and Caring”***

- ✓ Launched on World COPD Day 2009
- ✓ EFA Book presentation & COPD launch of “COPD Call to action” for Europe at the European Parliament



Unprecedented collection  
of information  
from patients to policy  
makers



**EFA** BOOK ON  
CHRONIC OBSTRUCTIVE  
PULMONARY DISEASE  
IN EUROPE.  
*SHARING AND CARING*

Edited by Mariadelaide Franchi



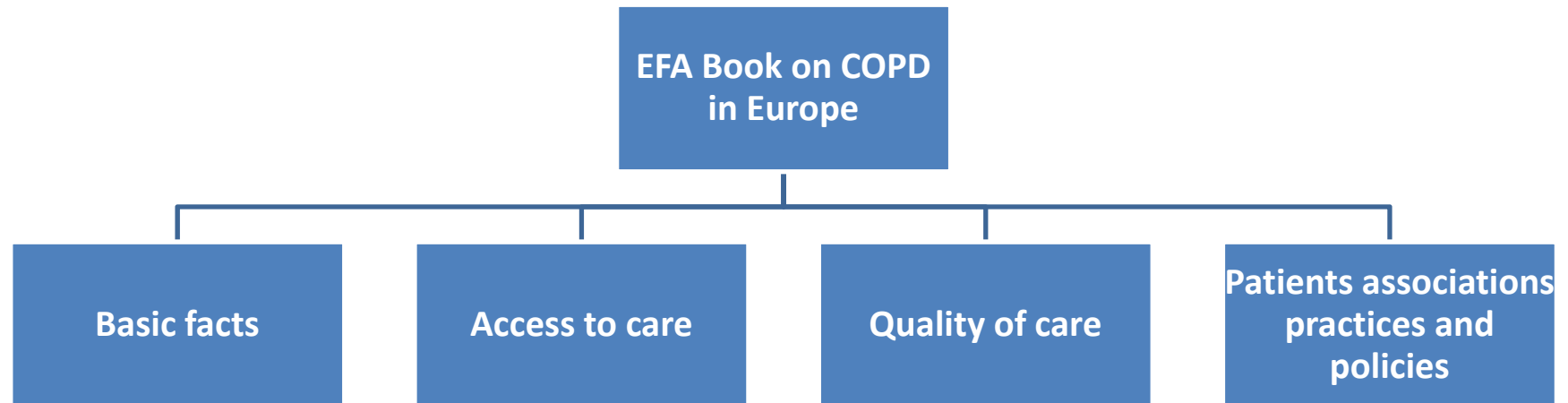
<http://www.efanet.org/documents/EFACOPDBook.pdf>

# EFA Book on COPD in Europe

- Raise awareness & highlight the gaps and positive highlights
- Inform & encourage into collaboration with patient organisations
- Share best practices on care & provide a tool for advocacy, internal & external work
- **Prompt into action!**



# Contents



# Patient perspective

- **'The term COPD [BPCO] remains unknown to most people and is difficult to explain'. *France and Italy***
- **'Diagnosis is generally made too late.' *Germany***
- **'When I heard I had COPD in 2002, I had no clue what it was.' *European patient with COPD***
- **'It's frustrating – you don't look sick, I can get up and put make-up on but I can't walk 10 yards without being out of breath.'" *Patient from Ireland***
- **I still remember the day: 2nd of June 1995, and I was diagnosed with COPD. It was at that very moment that I understood the disease and the implications for my daily life. *Patient from Portugal***



# 7 point Call-To-Action, Event at European Parliament

1. Make COPD a political priority
2. Increase awareness of COPD
3. Prioritize the early diagnosis of COPD
4. Support an integrated and multidisciplinary patient-centered approach to the treatment to improve the care and management of COPD
5. Prevent COPD
6. Improve indoor and outdoor Air Quality
7. Support better understanding and management of COPD through research



# Call to Action for Europe – Partnerships

- European Respiratory Society ERS
- European Lung Foundation ELF
- International Primary Care Respiratory Group IPCRG
- International COPD Coalition ICC
- Health and Environment Alliance HEAL
- European Network for Smoking Prevention ENSP



# Continuously raising awareness on COPD

- 2 Workshops at European Parliament in 2011
- Discussion Groups
  - ✓ leading experts & national patient representatives
  - ✓ European policymakers from Parliament and Commission

**AIM** : How to curb the disease burden for the benefits of patients and society at large; described as “own initiative report” of the European Parliament or similar “official” EU policy document



# 1st Workshop

- ✓ 29<sup>th</sup> June 2011
- ✓ Prevention and Diagnosis
- ✓ Hosted by MEP Sean Kelly
- ✓ Supported by MEPs from major political groups:
  - ✓ Eva-Britt Svensson
  - ✓ Catherine Stihler
  - ✓ Francoise Grossetete



# Policy Recommendations of 1st WS

- Prevention; **role of employers**
- Smoking cessation
- Tobacco labelling
- Education of health care professional
- Access to spirometry testing
- Registration for COPD patients



# 2<sup>nd</sup> Workshop

- ✓ 9<sup>th</sup> November 2011
- ✓ Care and Research
- ✓ Hosted by MEP Sean Kelly
- ✓ Partners & experts:
  - ✓ ELF
  - ✓ ERS
  - ✓ GOLD
  - ✓ IPCRG



# European Parliament Magazine

*My lungs work at 30 percent of that of a healthy person.*

Michael Wilken, COPD patient, Germany



*It is difficult to say when exactly I developed COPD: coughs, phlegm and acute breathing problems becoming heavier and heavier throughout the 1990s without a diagnosis being made. Having been a heavy smoker, both the healthcare professionals and I seemed to consider my condition as "normal".*

*On 3 January 2004 I felt extremely ill. It seemed I only had the choice between giving up smoking and giving up breathing. I chose the former, and since then have invested all the energy that had previously gone into denying my addiction, into coping with the consequences.*

*I managed to find a competent pulmonologist and finally obtained the diagnosis COPD. Together with him and my GP we coordinate the necessary therapeutic measures. I only have to see the specialist once a year.*

*There is no easy answer to "what if? However, having actually been aware of the disease COPD and being diagnosed earlier would have probably helped me to change my life much sooner."*

The vast majority of patients have never heard of COPD. Better diagnosis and therapy add to the patient's quality of life and save costs. Emergency hospital visits due to badly managed COPD are immensely expensive, aside from the working days lost. 16 November is World COPD Day. Spread the word!

**EFA's second COPD workshop**  
**COPD - the Epidemic of the Working Population**  
Care and research for a growing disease undermining Europe's economy

**9 November 2011**  
**15:00 – 18:00 Atilio Spinelli**  
**A7F387**

You can read the newsletter from EFA's first COPD workshop at [www.efanet.org/documents/newsletter.pdf](http://www.efanet.org/documents/newsletter.pdf)

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<http://www.efanet.org>



+ articles on COPD by the MEPs and EFA President

# Policy Recommendations of 2nd WS

- Care
  - Newest guidelines of GOLD
  - Best practice example from Finland
  - Focus on better communication between PCP and specialists
- Research needs to overcome knowledge gaps
  - As seen by specialists
  - As seen by PCP
  - As seen by patients



# Patient involvement in treatment policy

- EFA Conference: Vilnius, Lithuania: 28-29 May *Towards equal access to health care all over Europe for and with people with allergy, asthma and COPD: The Case of Reimbursement & health technology assessment HTA*
  - EFA members sharing their involvement in reimbursement decisions
  - Reimbursement agencies sharing reimbursement practise & patient involvement: NL, UK, G, IT, FR
  - Introduction to HTA & good practice in patient involvement
  - Patient involvement in HTA today and tomorrow



# COPD patient expertise at European Medicines Agency (EMA)

- EFA Experts take part in Scientific Advisory Groups (SAG) meetings when requested
- Review Patient information leaflets (PILs), European Public Assessment Reports (PAR's) of medicines approved by EMA
- Dissemination of information received from Agency: lay language
- Consultations for EMA work & strategy and information for the Public
- Involved in risk communication



# More about patients involvement in EMA work



**Further information**

**European Medicines Agency  
Patient Health Protection**

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Canary Wharf  
London E14 4HB  
United Kingdom  
Telephone +44 (0)20 7418 8400  
Facsimile +44 (0)20 7523 7129  
Website [www.ema.europa.eu](http://www.ema.europa.eu)

**Working with  
patients and  
consumers**



[http://www.ema.europa.eu/docs/en\\_GB/document\\_library/Other/2010/03/WC500075353.pdf](http://www.ema.europa.eu/docs/en_GB/document_library/Other/2010/03/WC500075353.pdf) leaflet in all 27 EU languages

# IAQ Health Based Ventilation Guidelines for Europe

- Project funded by the European Commission EU Public Health Programme
- Developing health based ventilation guidelines for Europe to complement the energy efficiency (climate change agenda)
- EFA role: patient input, patient needs, dissemination for members -> patients

[www.healthvent.eu](http://www.healthvent.eu)



# Meet & Greet EU Institutions Training for Members

- Improve knowledge on how EU institutions work and affect health of people with allergy, asthma and COPD
- Provide opportunity meet and greet in person relevant Commission services, Parliament, Council
- Build capacity, improve and motivate in taking part influencing EU policies



# Advocacy: Role of Patient Organisations

- Listen, collect & summarise **patient voices, experience, needs and expertise**, facilitate patient **participation**
- Represent these to **healthcare professionals & policy makers** – anyone having impact in care/prevention
- Facilitate **communication, partnership, collaboration and greater understanding** between them
- Take advantage of **unique position of patient organisations**: neutral, non profit-seeking, patient at the core – ideally placed to influence
- **ENSURE PATIENT VOICE IS HEARD** – in research, policy, funding and public arena
- Don't give up! Progress step by step...



# THANK YOU

EFA European Federation of Allergy and Airways  
Diseases Patients'

Remembering Mariadelaide Franchi



*“For every person diagnosed as having COPD, there are about 3 other people who have unrecognized COPD. Diagnosed COPD is only the very tip of the iceberg and is far from being an accurate measurement of the prevalence of this chronic disease”*

*T. McDonnell*





Prof Boleslaw Samolinski & the 'Patients' at the Polish EU Presidency Conference on Childrens Allergy and respiratory diseases 21-22 September 2011, Poland

