

## COPD - the epidemic of the working population workshop 2

*Care and research for a growing disease undermining Europe's economy*

Following the successful workshop on the prevention and diagnosis of chronic obstructive pulmonary disease (COPD) on 29 June 2011, the European Federation of Allergy and Airways Diseases Patients' Associations (EFA) held its second workshop in the European Parliament on 9 November. This time focusing on COPD care and research needs, the workshop was co-hosted by Sean Kelly MEP and Karin Kadenbach MEP. Representatives of the current Polish Presidency of the European Council and of the European Commission Services "Public Health" and "Employment, Social Affairs and Inclusion", as well as representatives of partnering health NGOs, participated in the debate.

### COPD CARE

**Lively life and work with COPD are possible the patient and the employer perspective**

Mrs. Elizabeth Sutton, 69, from Bray, Ireland goes line dancing three times a week. On her back, as always, is a portable oxygen apparatus. As uncomfortable as this device is, it allows Ms. Sutton to enjoy a reasonable quality of life despite COPD. Like the vast majority of COPD patients, she was diagnosed late, despite several symptoms pointing in the direction of COPD for quite some time. Surprisingly, many primary care professionals, who are in fact the first contact point for patients, fail to take the COPD symptoms - shortness of breath, wheeze, phlegm and/or recurrent respiratory infections - as a reason to test their patients for COPD. However, Mrs. Sutton was lucky in the sense that once she was diagnosed correctly, she received all the necessary therapy, including free access to an oxygen apparatus

and the reimbursement of a rehabilitation programme. Even within Ireland, which is rightly considered as advanced in COPD care, such adequate access to therapy is not a given for all COPD patients, and health inequalities with regard to COPD are even more pronounced across the EU. Today, when she is traveling, she has to roll a bigger and heavier oxygen condenser (which is not provided free of charge), and therefore needs someone to accompany her, as her strength does not allow her to lift it.



**Betty Sutton COPD patient on oxygen** *"Whilst COPD is a pain, I am lucky enough to enjoy a good quality of life, since I have a therapy and staying-active programme tailored to my own needs - unfortunately, my case is rare."*

Ms. Birgit van den Bos, former head of an agency which supports comparative clinical trials as part of the Comprehensive Cancer Centres in the Netherlands (IKNL), gave an employer's perspective. While Ms van den Bos was not able to attend this workshop in person, a staff member Ms. Juliëtte Kamphuis, data manager in oncology, with a chronic lung disease, joined



**Juliëtte Kamphuis, suffering from a chronic lung disease** *"Ms. Birgit van den Bos, my employer, has opted for a flexible approach with regards to the allocation of my working hours, since she does not want to lose her staff member to a chronic lung disease"*

the workshop and read the statement she co-wrote with Ms van den Bos. Together, they have found a solution where the employee works all the contractually agreed hours, but is flexible in their allocation throughout the week. Ms van den Bos also allows her staff to take holiday when the climate in the Netherlands is most problematic for her employees' condition. For Ms. van den Bos such an arrangement is natural, all the more since her staff are all highly qualified and trained on the job and finding a replacement is extremely costly. However, she also admitted to feeling let down on occasions by a health system which time and again fails to help manage and control chronic diseases and in particular chronic respiratory diseases. The employee pays for such failures with impaired personal health and quality of life and the employer with a loss in productivity at the workplace, Ms van den Bos concluded.

## Patient Focused Care can prevent Costly Exacerbations

Professor Jørgen Vestbo from the University of Manchester, UK, Chair of the scientific committee of the Global Initiative for Chronic Obstructive Lung Disease (GOLD), in charge of global COPD guidelines, shared the brand new revised GOLD Strategy Document, adopted on 7 November in Shanghai at the annual conference of the Asian Pacific Society of Respiriology. Professor Vestbo highlighted the high costs involved to inpatient care because of exacerbation, which costs an incredible 2.9 EUR billion annually.

It follows that individualised therapy strategies for patients are needed to avoid these exacerbations, involving the patient so that he or she can take an active role in intervening and setting goals for disease management. This way, costs will be saved and the patient can enjoy a higher quality of life. The revised GOLD strategy document can support doctors in developing such individualized therapy strategies, helping them to understand and treat COPD better and reduce the number and severity of exacerbations. They “only” need to be implemented.



**Jørgen Vestbo GOLD** *“The new GOLD strategy can help doctors better understand and treat COPD. This is why its dissemination and implementation is key.”*



**Anne Pietinalho FILHA** *“Thanks to our COPD programme, the societal costs of COPD in Finland have dropped by 88 percent over 10 years”*

## Finland – the EU’s best practice country for COPD

Dr. Anne Pietinalho, chief physician at Raasepori Health Care Centre and a specialist at the Finnish Lung Health Association (FILHA) outlined the cornerstones of the successful Finnish COPD programme, which reduced the societal costs of COPD by an enormous 88 percent in the course of ten years from 1998 to 2007, in particular bringing down the costs related to disability from more than 550 million EURs to less than 100 million.

This was achieved by a variety of complementary measures, such as general COPD awareness-raising campaign amongst all healthcare workers, as well as the public. Furthermore, multidisciplinary educational programmes were developed involving specialists, those working in primary and occupational care, as well as private doctors and nurses, and consisting of both seminars and online training tools. As a result, the attitude of healthcare professionals towards smokers and COPD patients improved, patients were empowered to self manage their disease and the general population has demonstrated a better understanding of COPD, primary care

has improved both in terms of resources (700 asthma nurses in primary care are also trained in smoking cessation support and in helping COPD patients) as well as tools (testing devices are available in all healthcare stations). Finally, there are 700 contact persons in pharmacies throughout Finland who not only take care of asthma patients, but advise also on COPD and smoking cessation.

## COPD Research Needs The specialist’s perspective

Concerning exacerbations in COPD which lead to irreversible damage, more research needs to be undertaken on how to prevent the risk of future exacerbations, irrespective of the immediate impact on symptoms, Professor Francesco Blasi, President elect of the European Respiratory Society (ERS), pointed out. Such approaches have been employed successfully for other conditions such as hypertension and it has been suggested that this might be beneficial for COPD as well. Furthermore, translational research needs to be undertaken addressing how to improve the cooperation between specialists and those working in primary healthcare to curb



**Francesco Blasi ERS** *“Biomedical and health research for COPD need to increase dramatically, if we want to avoid costly exacerbations. This also includes research on how improve the cooperation between specialists and General Practitioners”*





**Miguel Roman Rodriguez IPCRG**  
*“More real life studies are needed to develop therapies which are closer to patients’ needs”*

the high number of in-hospital deaths. Finally, biomedical research needs to be significantly promoted, since few effective pharmacological treatments of COPD are currently available.

### The primary care perspective: the need for studies on ‘real life’ effectiveness of COPD care

Dr. Miguel Román Rodríguez, President of the International Primary Care Respiratory Group (IPCRG) pointed out that in addition to Randomized Control Trials (RCTs) which measure the efficacy of a drug, there is need for more pragmatic studies, in order to assess the effectiveness of COPD care in real life. Since RCTs have been conducted in patient populations which are not representative for the specific patient characteristics, complementary real life studies can provide added value since they also take into account patients with co-morbidities, a very important aspect in COPD.

The growing use of informatics health registers in primary care makes it increasingly possible to access reliable clinical data collected in real time which can be

used for research purposes. This information, flowing from everyday consultations, could be used for specific research projects to address research questions in a pragmatic way which reflects the realities faced by COPD patients in different situations and contexts.

### The patient perspective: exploiting a patient’s potential for health –salutogenesis

A recent study from the United States estimates that 40 percent of COPD patients suffer from depression. Despite this shockingly high co-morbidity, the research in this field is in its infancy for COPD, compared to other chronic illnesses, such as cardiovascular disease, as Mr. Michael Wilken, Chair of EFA’s COPD working group, pointed out. This is not acceptable, since COPD patients suffering from a depression are less likely to adhere to the therapy prescribed for them. They are less capable of leading a healthier lifestyle and manage their disease pro-actively and independently. Furthermore, the interdependencies between depression and



**Michael Wilken EFA** *“For a patient to enjoy a continuous quality of life, we not only need a pathogenesis, but also a salutogenesis”*



**Breda Flood EFA** *“A European Parliament Own-initiative report will recognize the European importance of the fight against COPD and hence fuel the advocacy efforts of EFA members at national level .”*

exacerbations remain unexplored. The knowledge of a person’s mental state before an exacerbation, however, might well be essential when taking steps to avoid future exacerbations.

Finally, the potentially protective impact of patient self-help groups is under-researched, as far as COPD is concerned. Having experienced the support of such a group himself, Mr. Wilken finds this research gap particularly regrettable, pointing also to the low costs of running such self-help groups, which is all the more relevant in times of tight budgets for public health. In conclusion, Michael Wilken calls for funding to help identify patients’ potential for health and to explore its utilization.

### Discussion

In the subsequent discussion, Mrs. Karin Kadenbach MEP, a former regional health minister in Austria, stated that public awareness of COPD was significantly lower than the other chronic diseases mentioned in the European Parliament’s resolution on non-communicable disease, such as diabetes, cardiovascular diseases or cancer.



**Sean Kelly MEP** *“We need to increase awareness of COPD amongst colleagues in the European Parliament”*

She hence advised the concerned stakeholders to build pressure in a grassroots campaign and make constructive suggestions on how to fight COPD. The recommendations of EFA’s workshops could be extremely helpful in this context.

Participants were extremely complimentary of the tireless efforts of the Polish Presidency to adopt meaningful Council Conclusions on chronic respiratory diseases in children. However the Council Conclusions will not mention COPD specifically. This is why Breda Flood, EFA President, reiterated EFA’s request of a European Parliament own-initiative report on COPD, to give much needed limelight to the disease, which has an average prevalence in Europe of 10 percent but is virtually unknown. With the help of such an own-initiative report,



**Prof. Radoslaw Gawlik and Ms Agnieszka Czupryniak, Polish Presidency** - *Participants applauded the Polish Presidency’s tireless efforts with regard to chronic respiratory disease under the motto “there is no life without breath”. However, disappointment was voiced in so far as the upcoming Council Conclusions are unlikely to mention COPD explicitly. Another lost opportunity to give much needed limelight to the disease.*

EFA members could fuel their own advocacy efforts at national level, proving to national decision-makers that COPD was an issue whose European wide importance had been recognized at EU level. She hence hoped that EFA’s policy recommendations formed during the course of the two workshops would provide the necessary proof points for such a report.

## Conclusion

Concluding the meeting, Mr. Sean Kelly MEP confirmed his support for an own-initiative report by the European Parliament. However, he believes that more awareness amongst his MEP colleagues is needed to adopt such a report. As politics is a reactive process, constructive proposals from this workshop can aid in increasing pressure at the European Parliament and the promotion of COPD awareness will be more likely to attract more importance and generate increased political backing. In addition, Mr. Kelly pointed to an initiative in the European Parliament to increase the number of physically active people by 100 million across Europe, thus complimenting vital components for COPD patient therapy.



**Karin Kadenbach MEP** *“COPD is significantly less known than the other big non-communicable diseases diabetes, cancer and cardiovascular disease. It is time to change that.”*

## Acknowledgement

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## Policy Recommendations

- Disease Management: With a view to preventing costly and irreversible exacerbations.
  - o COPD care needs to become tailored to each patient’s needs and support staying active, allowing patients to take ownership of the management of their disease;
  - o the cooperation between specialists, primary care workers as well as those disciplines taking care of potential co-morbidities needs to be optimized;
  - o healthcare workers need to adopt a more positive attitude towards smokers and COPD patients;
- Access: Throughout the EU, equal access needs to be given to oxygen and rehabilitation programmes. The formation of self-help groups needs to be promoted.
- Best practice: The EU needs to facilitate the dissemination of lessons learned from best practice programmes, such as the Finnish COPD programme.
- Employment: Employers need to be motivated to adopt flexible approaches to allow their staff with COPD to remain in the work force. Policymakers should promote such flexibility, as well.
- With a view to achieving a sustainable improvement in the quality of life for COPD patients and ensuring their contribution to society, biomedical and health research must increase for COPD in the following fields:
  - o How to reduce the risk of exacerbations;
  - o How to improve the cooperation within a multidisciplinary team;
  - o Real life studies to complement randomized controlled trials;
  - o Comorbidities, such as depression, and the interdependencies;
  - o The impact of patient self-help groups.