

World COPD Day 2013

**What role for diseases and patients in
shaping Horizon 2020? A COPD case
study of patient involvement**



**World COPD Day: it's not too late....
Or is it?**



28th November, 2013
Residence Palace , Brussels



A conference organised by ECC and EFA under the auspices of the
Lithuanian Presidency of the Council of the European Union



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Conference Programme

8.30 -10.00

Welcome coffee, registration and spirometry

Join us before the start of the conference for a **free spirometry test**: get your lung capacity assessed with a simple test. It does not take more than 10 minutes.

10.00 – 11.00

Is Horizon 2020 fit to accommodate disease specific research? Is it too late to make it fit for disease purpose?

Introduction:

Breda Flood, EFA President

Sylvia Hartl, Senior Physician, Otto Wagner hospital in Vienna

Welcome address by the Lithuanian Presidency of the Council of the European Union:

Giedrė Medžiaušaitė, Deputy Health Attaché

Chair: Catherine Hartmann, Secretary General, ECC

What does Horizon 2020 mean for public health and quality of care? The European Commission's point of view

Mr. Kogan will present the health part of the EU research funding programme and its importance. The difference between FP7 and Horizon2020 will be highlighted with the goal to inform the audience that, despite the changes, seeking funds for a single disease, taking COPD as an example, is not impossible.

Another goal of this part of the programme is to raise awareness on the added value of patient involvement in research projects.

Speaker: Grigorij Kogan, Research Programme Officer, Medical research, DG Research and Innovation, European Commission

The role of European Parliament and Member States: how they could influence the content of Horizon 2020 - The political point of view

This part of the session will address what is at stake for Health in Horizon 2020 from a more political point of view: how the political leaders changed the original drafts, what is their role to make Horizon 2020 fit for purpose and address patients, and citizens in general, needs.

Speaker: Monika Kosińska, Secretary General, European Public Health Alliance

How concretely will Horizon 2020 work for health research?

In this last part of the session, the audience will learn how Horizon 2020 will work for academic and clinical researchers seeking funds to support their work, by taking COPD as an example. The speaker will, in a pragmatic manner, answer the questions: is Horizon 2020 fit for purpose – when the purpose is to find funds to support research in a single disease? If not, what are the concrete ways to deal with this problem?

Speaker: Mike Galsworthy, Department of Applied Health Research, University College London

Discussion

11.00 – 11.30 Coffee break and free lung testing

Respiratory healthcare professionals will be on-site to offer you a free lung test

11.30 – 12.30 What is the best care for COPD and how can research improve standards of care for COPD?

Chair: Isabel Saraiva, COPD patient, RESPIRA

This session seeks to identify and share best practices, raise awareness of current deficiencies in care, inform stakeholders (such as policymakers and healthcare professionals) of patient needs and encourage prompt actions for changes in COPD care and research.

State of play in COPD care in Europe, an EFA survey

The key outputs of the EFA COPD Survey 2013 will be presented and the major differences in prevention, diagnosis and rehabilitation between 16 European countries that participated to the survey to inform care and research agenda will be outlined.

Dr. Hartl will also present the European Respiratory Society COPD Audit, which surveyed the state of secondary care in Europe for COPD, linking EFA's booklet findings to those of the Audit. Discussions from the perspectives of patients, primary care and research will together highlight the importance of national standards for COPD care.

Speaker: Sylvia Hartl, Senior Physician, Otto Wagner hospital in Vienna

Patient driven minimum standards of COPD care for Europe

Building upon the discussion following Dr Sylvia Hartl's presentation, this part of the session will showcase the patients' perspective, in particular on the inequalities that COPD patients are facing in Europe and they will present COPD patient-driven minimum standards of prevention, diagnosis, care and rehabilitation and patient perspective on need for research. In addition, EFA's booklet 'Enabling Air Travel with Oxygen in Europe' will be presented as a case study for ongoing discrimination against patients with chronic respiratory diseases.

Speakers: Isabel Saraiva, COPD Patient, RESPIRA & Michael Wilken, COPD patient, Patientenliga Atemwegserkrankungen e.V.

COPD standards of care recommended by physicians and the role of research in improving them

Often, the first person to diagnose an abnormal breathing pattern is the general practitioner, who may then refer the person to a specialist. Both clinical and organizational standards of care must help ensure that patients are provided equity in healthcare delivery and access, at primary and secondary care levels. What do healthcare primary care professionals recommend as standards of care for people suffering from COPD and how would further research in the subject matter improve the life of patients? Do they work with patients and other healthcare professionals to foster an integrated, coordinated approach? Which type of research is needed to improve these standards?

Speaker: Rupert Jones, General Practitioner, International Primary Care Respiratory Group

Discussion

The conference is organised by ECC and EFA.

ECC receives unrestricted funding from pharmaceutical companies http://www.copdcoalition.eu/who_we_are/membership and EFA's funding for this event is through our sustainable funding partners Air Liquide, Almirall, Boehringer Ingelheim, Chiesi and Novartis www.efanet.org/funding-partners.

12:30 – 13:30 **Lunch break and free lung testing**

13.30 – 14.30 **Patients working with academia and policy makers to inform Research**

Chair: Nicola Bedlington, Executive Director, European Patients' Forum

The final session of the day will be focusing on the issue of how patient involvement has occurred in EU research and research policymaking as well as how it can improve in the future so patients can influence topics which may directly affect their quality of life thus enabling research based on needs. Each of the speakers will present a unique approach of current patient involvement and will discuss how to ensure the patient's voice will be integrated in Horizon 2020.

The Patient Input Platform (PIP) for PROactive (physical activity in COPD) & U-BIOPRED (severe asthma) projects

The Patient Input Platform (PIP) is an advisory platform consisting of patients and patient representatives in two IMI projects. Dr. Pim de Boer will be talking about PIP involvement in both projects, including the process of recruitment of study participants, the achievements of the PIP until now and many more aspects of patient involvement to put the patient topic in the context of benefit and best practice in patient involvement in EU research projects.

Speaker: Pim de Boer, PIP coordinator, Longfonds

Innovative Medicines Initiative (IMI) as a public-private partnership moving COPD research forward

In this session, you will learn how the biggest private-public partnership operates to uphold and advance health research in real cooperation with corporations. Should then, IMI be the funding model for future health research? Does this mean the end of public funds? If this should be the case, what are the potential impacts on the quality and the quantity of health research?

Speaker: Nathalie Seigneuret, Senior Scientific Project Manager, IMI

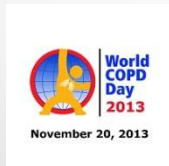
Real world burden of COPD

This session will present EFA's article in collaboration with academia and policy makers "Real world burden of COPD: A cross-sectional retrospective analysis focusing on employed and 'not in paid employment' patients in Europe." Using conclusions from this article, real and perceived burden of COPD regarding quality of life, exacerbations, use of health care resources, and loss of work productivity will be overviewed. MEP Kadenbach will focus on needed political consequences to minimize the impact on COPD and to help COPD Patients to stay employed.

Speaker: Karin Kadenbach, Member of European Parliament

Discussion

14.30 – 15.30 **Free lung testing**



The event is to mark World COPD Day, which is an annual awareness-raising event organized and sponsored by the Global Initiative for Chronic Obstructive Lung Disease (GOLD). For more information please visit www.goldcopd.org/wcd-home.html