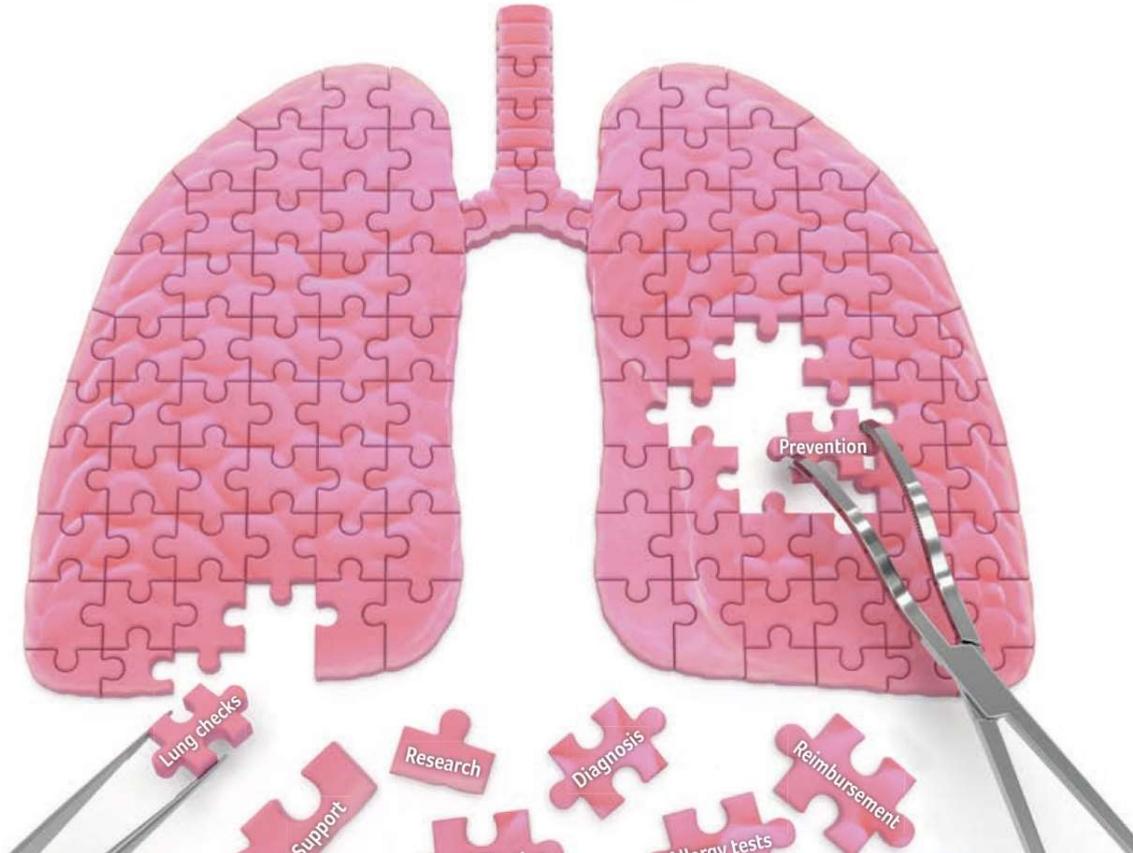


Act. Believe. Care.

The ABC to taking action on chronic respiratory diseases



11th January 2017, European Parliament, Brussels

EVENT REPORT

Co-hosted by:

MEP Karin Kadenbach, S&D, Austria

MEP Sirpa Pietikainen, EPP, Finland

Organised by:

The European Federation of Allergy and
Airways Diseases Patients' Association (EFA)

In collaboration with:

European Academy of Allergy and Clinical
Immunology (EAACI)

European Network for Smoking and Tobacco
Prevention (ENSP)

European Respiratory Society (ERS)

Act. Believe. Care.

Sign the Written Declaration on Chronic Respiratory Diseases
to make a difference in people's lives!

"I thank all stakeholders involved in our campaign: it is beautiful and inspiring to believe, act, and care altogether for social and economic improvement of our public policy, national health systems, and quality of life of EU citizens"

MEP Karin Kadenbach

The conference was opened by MEP Karin Kadenbach (Socialists & Democrats, Austria), a Member of the European Parliament (MEP) actively engaged in tabling and promoting the Written Declaration 115/2016 on Chronic Respiratory Diseases together with other ten Members of the European Parliament.



In her opening speech, Ms. Kadenbach expressed her pleasure in seeing that 1 out of 5 Members of the European Parliament had already signed the Written Declaration on Chronic Respiratory Diseases. "Today we have 161 MEPs committed to respiratory chronic diseases and this is fantastic! I am happy and honoured to be one of MEPs that launched one of the last WDs in such an important topic as chronic respiratory diseases".

Ms. Kadenbach stressed that the European Parliament effort to improve chronic respiratory diseases policy will not stop when the Written Declaration closes on January 24th, but it will be carried on because, as part of the United Nations targets on non-communicable diseases, the EU is committed to:

- Reduce premature death from chronic respiratory diseases by 25% by 2025
- Decrease tobacco use by 30% by 2025
- Prevent diseases through improved outdoor and indoor air quality

For MEP Kadenbach, the Written Declaration on Chronic Respiratory Diseases is a sign that the European Parliament is:

- Acting to implement concrete actions about prevention, health determinants such as smoking and air quality, and diagnosis
- Believing that inequalities in Europe can be reduced and public health policy should be harmonised within the Member States
- Caring to ensure that the political actions asked by Written Declaration 115/2016 will not stop with the ending of the campaign, but policy makers will engage to continue achieving its objectives in line with UN targets on non-communicable diseases

“As EFA President, I am here today to voice people (and EU citizens!) with allergy, asthma, and COPD in Europe. Chronic respiratory diseases are amongst the most relevant chronic diseases, and we, together with our fellow doctors, patients and health organisations are asking for your cooperation”

Mikaela Odemyr, EFA President

Chronic respiratory diseases impact on peoples’ lives causing serious health problems to the patients and their families, and they also represent a societal challenge and an economic burden. Ms. Odemyr explained how good care systems can improve patients’ lives. In her life, she has experienced the vulnerability, fear and hope brought by illness, and how difficult it is to live with chronic diseases when healthcare and social systems are not conceived and prepared to fully embrace patients’ and their families’ needs.

Ms. Odemyr underlined how respiratory chronic diseases can have a negative impact on employment, education, consumption and quality of life (both of the affected and their families). Chronic diseases result in less people within the workforce, early retirement and sometimes barriers to enter the labour market and stigmatisation from employers. They affect educational performance, both in the case of a pupil/student and/or when a family member is affected by at least one chronic disease. From the economic perspective, chronic respiratory diseases are linked to high indirect costs, mainly due to the working days/school days lost and disability.



Chronic respiratory diseases’ public policy can be improved from the patient perspectives with several public reforms:

- Disease prevention: primary, secondary, and tertiary prevention are all crucial to reduce the economic burden of chronic respiratory diseases. In Europe, more than 97% of health expenses are spent on treatment and care, less than 3% is dedicated to prevention. This percentage needs to be increased as prevention is not just awareness, but also action.
- Actions on health determinants causing or exacerbating respiratory diseases, such as EU tobacco control measures and an EU efficient strategy on indoor and outdoor air quality.
- Improve access to health care and reduce inequalities between and within Member States of the European Union.

As a mother, EU citizen, and President of the patient community, Ms. Odemyr concluded that a more comprehensive approach to tackle chronic diseases is needed. “They are becoming the epidemics of the new century and you, me, people far and near, everyone is concerned”.

“In the next 10 years, there will be a larger collaboration.”

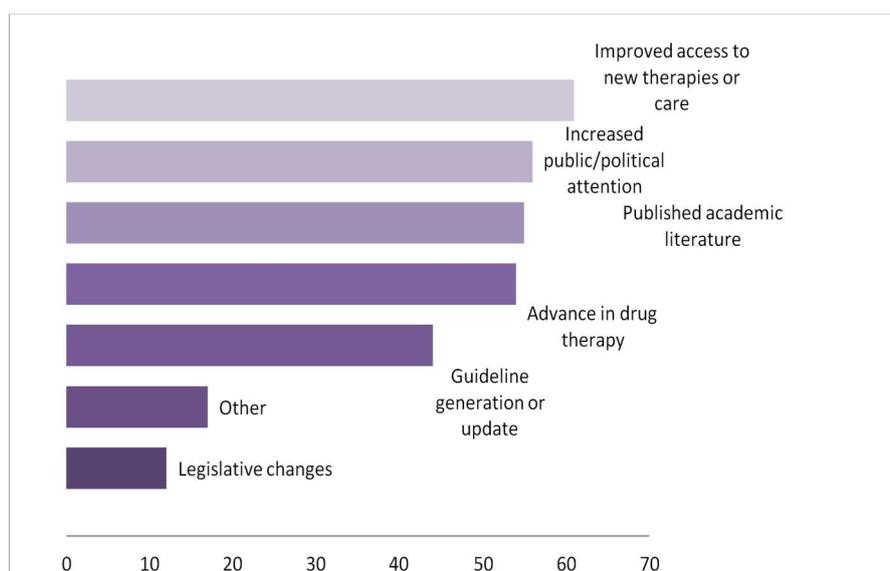
John Wright, London School of Economics and Political Science

Associate Professor John Wright presented a study on the impact of the investments in major chronic respiratory diseases for a sustainable healthcare. According to his research, the two major and most common chronic respiratory diseases leading to the highest percentage of healthy life years (DALYs) lost are asthma and COPD.

Asthma and COPD are also the two main disease areas where EU research funds are invested, asthma accounting for 33% and COPD for 24% of the total EU28 projects. The highest amount of funding come by public national authorities, in particular in the Southern Europe region. The Netherlands is the country with the highest level of investments in Europe, followed by Germany.

According to the enquiry, the expected impacts of the research funding organisations can be classified as follows:

Figure 1: CRDs RFO Expected Impacts (n=82)



**The RFOs provided more than one answer. The point number is 299. In addition, website enquires uncovered a range of expected impacts within single RFOs. Results combine data combine from Survey and online sources.*

The future strategies implemented by the research funding organisations will focus on development and evaluation of treatment, detection, screening, and diagnosis, as well as prevention.

Prof. Wright underlined that to enhance COPD and asthma, smoking cessation, health service delivery and treatment, and innovative and game-changing pharmaceuticals are key factors. He concluded that stratified medicine, new broad collaboration between patients, industry, scientific, and policy makers, and a broad portfolio of research investments are needed.



Welcoming the presentations, MEP Kadenbach stated that we usually talk about legislation, but we do not mention why we need to have these laws: *“in Austria, 25,000 children under 6 have asthma and we will work hard to get the momentum and try to reach the goals previously mentioned”*.

Mr. Gregorij Kogan from DG Research of the European Commission stated that chronic respiratory diseases is one the most important area of research, and the programme FP7 invested 400 million Euros in this policy area, of which 142 million Euros in COPD. New calls in 2017 will focus on this areas and so will do the work programme 2018/19.



“The Written Declaration on Chronic Respiratory Diseases including respiratory allergies and asthma is an important advocacy action that EAACI is glad to support”

Prof. Peter Hellings, EAACI Secretary General

EAACI is the European association, which includes over 50 national allergy societies, and it represents more than 9,500 academicians, research investigators and clinicians, from 121 different countries. For EAACI General Secretary, Prof. Peter Hellings, the European Commission has to boost research in the field of chronic respiratory diseases including respiratory allergies and allergic rhinitis, and to work with Member States to help identify, promote and share best practices in prevention, management and care.



In Europe, 30 million of citizens are affected by asthma, 15,000 die every year from an asthma attack. More than 20% of Europeans suffer from respiratory allergy, and half of them have never received a proper diagnosis, and thus are inappropriately managed. Prof. Hellings stressed that improving public policy has social and economic benefits, and it is a win-win situation for both economic and social actors. Only in Europe, respiratory allergy annual cost is estimated to be over 100 billion Euro, and both asthma and respiratory allergy result in more than 100 million lost work days and missed school days every year.

Prof. Hellings underlined the importance of the Interest Group on Asthma and Allergy, jointly coordinated by EFA and EAACI, as a good decision making tool to raise awareness and drive policy changes in Europe. He stressed the value of multi-stakeholder’s initiatives to articulate common unmet needs towards EU decision makers, and his engagement to continue a strong collaboration.

“This Declaration is important. Not only because written declarations will cease to exist, but also because it is a vehicle for civil society organisations such as ours to present the problems and the suffering brought by chronic respiratory diseases to patients across Europe”

Prof. Guy Joos, ERS President

ERS is the European association that represents the community of respiratory professionals, and they work to raise awareness on lung disease in Europe. Prof. Joos underlined the importance of the Written Declaration as a vehicle for the civil society organisations, a useful tool to raise awareness and to present health problems linked to chronic respiratory diseases in Europe. He encouraged the European Parliament to take concrete measures to ensure lung health in all policies, for example in term of air quality, such as:



- Call for stricter limits on pollutant levels in ambient air
- Keep your attention focused on the so called “dieselgate” scandal, and push for European level oversight on vehicle emissions
- Support the implementation of the Paris Agreement on Climate Change and also the phasing out of fossil fuels
- Engage with the “Winter Package” regarding clean energy, while keeping health considerations central to the discussions on energy efficiency and the move to renewables

Prof. Joos concluded stating that policy makers and stakeholders have to join forces in both proposing political positions as well as in supporting these changes in key areas for EU citizens health.

“Our goal is to reduce tobacco use in Europe to under 5% by 2040”

Cornel Radu-Loghin, ENSP Secretary General

ENSP is a European association with the mission of developing a strategy for co-ordinated action among organisations active in tobacco control in Europe by sharing information and through joint activities and projects.

ENSP Secretary General, Cornel Radu-Loghin, stated that tobacco is a legal product that kills 50% of its users, and ENSP aims to create coherence among smoking prevention activities and to promote comprehensive tobacco control policies at both national and European levels. Mr. Radu-Loghin expressed his happiness for the collaboration developed to raise awareness on the need for actions in chronic respiratory diseases.



Mr. Cornel Radu-Loghin declared that without the harms provoked by the large consumption of tobacco, actions needed on chronic respiratory diseases would be reduced, and ENSP goal is to reduce tobacco consumption in Europe under the 5% by 2040.

Act. Believe. Care. The ABC to lead actions on Chronic Respiratory Diseases: The interest Group on Allergy and Asthma will launch a call to action in the 2017

Susanna Palkonen, EFA Director

EFA Director Susanna Palkonen declared that EFA actions on chronic respiratory diseases will be continuing in 2017. She happily announced that the EP Interest Group on Allergy and Asthma is already planning to open a call to actions in collaboration with EU and national stakeholders, the European Commission, and healthcare professionals.

The policy actions will be in line with written declaration 115/2016, and we will focus on:



- Action on environmental factors with a focus on prevention and highlighting the link between non-communicable diseases, allergy, and asthma
 - Early diagnosis and evaluate the impact of an adequate medical response on productivity, quality of life, and health systems
- The call to action will have the objectives to:
- Inform about the burden of diseases such allergy and asthma on Europe’s economy and society
 - Encourage coordinated political actions in Europe
 - Raise awareness on best practices in prevention and management of these diseases

Warm thanks to all supporters MEPs and participants to this event!

Written declaration 115/2016 is an important policy tool to raise awareness about the burden chronic respiratory diseases are posing on patients, families and the economy. We wish to thank the 12 MEPs proposing the written declaration as well as the more than 160 MEPs that until now have committed to act, believe and care about chronic respiratory diseases with their signature. We also wish to thank our campaign partners and the participants that joined us in the European Parliament event The ABC to lead actions on Chronic Respiratory Diseases.

For more information related to this report, please visit www.efanet.org or contact info@efanet.org.

The European Federation of Allergy and Airways Diseases Patients' Associations (EFA) is an alliance of 42 allergy, asthma and COPD patients' organisations in 25 European countries. Our vision is that European patients with allergy, asthma and chronic obstructive pulmonary disease (COPD) live uncompromised lives, have the right and access to the best quality care and a safe environment. Our mission is to be their voice and to be actively involved in the decisions impacting their health.



**We are asking the Members
of the European Parliament
to take action on chronic
respiratory diseases now.**

Our health. Your mission.

Sign the written declaration 115/2016 on chronic respiratory diseases.



#BreatheMission