EFA Manifesto for 2014 European Parliament Elections

Three priority areas and fourteen actions to improve the health and quality of life of people with asthma, allergy and chronic obstructive pulmonary disease in Europe

“From 2014, help to improve health among people with allergy and airways diseases”
Asthma, allergy and chronic obstructive pulmonary disease (COPD) are among the most common chronic diseases in Europe, affecting millions of EU citizens and imposing significant burdens on European healthcare, social systems and the patients themselves.

**Asthma and allergy** are the most common chronic diseases in children and the leading cause of school absences, emergency department visits and hospitalisations. 30 million people in Europe are affected by asthma, with six million of these people suffering from severe symptoms of the disease. When it comes to allergy, it is estimated that 1 in every 2 Europeans will suffer from an allergy by 2015. While the main cause of COPD is tobacco smoke, we do not yet know the very origins of allergy and asthma. COPD remains largely unknown: it affects 44 million people in Europe and is expected by the World Health Organisation (WHO) to become the third leading cause of death by 2030. Despite this, COPD is vastly underreported in the mass media and very few people have heard about it, placing early diagnosis, which is key for successful management of COPD, at risk.

The Members of the European Parliament, as the only democratically elected representatives of more than 500 million Europeans, should act in the interest of EU citizens and public health. You have already contributed in many ways to improve the quality of our lives and our well-being. Nevertheless, many challenges still remain. It is up to you now to rise to these challenges, tackle the most pressing issues, help patients with asthma, allergy and COPD to live uncompromised lives and help prevent these diseases.
Develop an EU strategy on chronic diseases with disease specific chapters

As an outcome of the EU reflection process on chronic diseases, dating back to 2010, an EU strategy with disease specific chapters should be developed. The strategy would enable us to effectively tackle incidence and risk factors, while helping us deal with negative consequences for the health of affected people, their families and the economies of the EU and its Member States.

“We are calling on you to commit yourselves to the following priorities in the area of health:

1

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“This year, I have planned a trip to Martinique where my son lives currently. My calculation is once again quickly realised: I cannot pay for the trip AND an oxygen tank… So, my decision in the end was that I could not go on the trip. Currently, as I am truly dependent upon my oxygen for physical activities, I wish for a life as normal as possible during my retirement.”

Betty Moureaux, patient requiring oxygen therapy, France

“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.”

Betty Sutton, patient requiring oxygen therapy, Ireland

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“Allergy is far more than huffing and sneezing for a couple of weeks during the pollen season. The quality of life of patients suffering from allergic rhinitis and allergic asthma is often severely impaired as is their social life, their career and even their school performance.”

Breda Flood, EFA President

“I wouldn’t have thought that my daughter would die of an asthma attack in a million years. I’m paying a very high price for something I didn’t know. I’m living without her and that’s just a nightmare.”

Mother of a 14-year old girl that died of asthma, Ireland

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“[COPD] makes everyday social life and arranging journeys difficult for me, my family, and others.”

COPD patient, France

“Parenting a child with asthma can be a scary experience.”

Nuria Martín, parent of an asthma patient, Spain

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Asthma patient, Sweden
Invest in prevention – tackle health determinants

2.1. Reduce tobacco consumption through a stricter tobacco products directive

2.2. Implement the smoke free Europe recommendations

2.3. Introduce a better strategy on outdoor air pollution with limit values in line with WHO recommended levels

2.4. Adopt a strategy on indoor air quality that includes the home and the workplace

2.5. Include pollen monitoring under the Clean Air Programme for Europe

2.6. Reduce exposure to chemicals in everyday life

2.7. Introduce labelling of all ingredients in the ingredients list of food products and in the long-term perspective, abolish the “may contain” labelling for allergens

Bearing in mind the principle of health in all policies, all EU activities should take into account their impact on public health. The objective of improving the health of European citizens should be overarching all EU decisions.

“I felt that I only really had the choice between giving up smoking and giving up breathing.”

Michael Wilken, COPD patient, Germany

“[There] is sometimes a temptation of food producers to play safe and place the ‘may contain…’ on everything to protect themselves. Whilst we are in our home country food labelling is a daily activity to keep our son alive, but when we go overseas things become a lot more difficult – I do wonder why there cannot be a pictorial or icon based system to get over the language barrier.”

David, dad of a 10-year old boy with food allergy, United Kingdom

“I would like the air to be cleaner, to make breathing easier, and I would like children with asthma to grow up to have a future without the problem of environmental pollution.”

Soledad Alonso Mostaza, asthma patient, Spain

“There is abundance of evidence that human activities are affecting pollen production and actually worsening the situation of people with allergy. The Commission should thus include real-time pollen monitoring in the Clear Air for Europe Programme and secure the funding of pollen monitoring activities, because it is a matter of public health.”

Joanna Bottema, allergy patient, The Netherlands

“Fragrances are increasingly being used in places frequented by the public, for instance in department stores, and in the rest rooms of hotels, restaurants and some companies. Another aspect of this trend is the habit of making the fragrance of detergents long-lasting – a disaster if you have asthma and someone near you is using such products! This pungent odour (and the additives) makes it hard for people with (allergic) asthma to remain in the vicinity. They are forced to leave or in the best case to take more medication to be able to stay.”

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Help ensuring equal access to care for each patient

3.1. Eliminate discrimination of patients based upon their disease or condition
3.2. Reduce health inequalities as regards access to care and quality of treatment within and between Member States
3.3. Initiate or boost patients’ participation in decision-making in all areas relating to their health and wellbeing, particularly concerning the placement of medicinal products and medical devices on the market and their reimbursement, priority setting for studies, trials and research, through promotion, facilitation and support of programmes in Member States, ensuring funding for patients’ organisations
3.4. Strengthen patients’ safety
3.5. Improve accuracy and quality of information to patients and boost health literacy
3.6. Ensure early and accurate diagnosis of allergies and chronic respiratory diseases, such as asthma and COPD, through increased training for healthcare professionals, development of national programmes, set up of registers and spirometry testing
3.7. Ensure that more funds are allocated for EU health policy and programmes and prioritise investments in research of allergic and respiratory diseases

Better treatment and healthcare contribute to the long-term objective of the EU to guarantee healthy ageing for all citizens and make the healthcare systems more sustainable.

“People with asthma merit significant attention from health services. We live with the heartache of social, health and political isolation.”

Jesús Baglietto, asthma patient, Spain

“Our life and our six-year old child’s life changed when my husband and I were trained about skills to manage the asthma of the child. Now we can sleep again.”

Elena Rubio, asthma patient, Spain

“In order to secure the participation of patients in the decision-making, funding for patients’ organisations must be secured.”

Ilkka Repo, patient leader, Finland

Ahead of the European Parliament elections in 2014, patients with allergy, asthma and COPD in Europe ask you to take these concerns into account and to make these actions a priority in your political agenda. Help us make Europe a place where patients have the right to best quality of care and safe environment, live uncompromised lives and are actively involved in all decisions influencing their health.
The European Federation of Allergy and Airways Diseases Patients’ Associations (EFA) is a non-profit network of allergy, asthma and COPD patients’ organisations, representing 35 national associations in 22 countries and over 400,000 patients. EFA is dedicated to making Europe a place where people with allergies, asthma and COPD have the right to best quality of care and safe environment, live uncompromised lives and are actively involved in all decisions influencing their health.

www.efanet.org

“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. No matter how slow people walk it’s never slow enough – I feel I have to walk faster to keep up but then I have to stop, gasping for breath. I’m not an old woman – no one expects you to be the way you are.”

COPD patient, Ireland

“I started smoking when I was a thirteen years old, and I was a heavy smoker for 39 years. Each day I smoked more and more. I was sinking in tobacco… I still remember the day [when] I was diagnosed with COPD… I quit smoking on that day and only three days after I was already feeling the difference. I couldn’t allow my smoking to kill me.”

COPD patient, Portugal

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

Michael Wilken, COPD patient, Germany

“Ahsta feels like a huge weight upon my chest. It is a very scary feeling.”

Asthma patient, Ireland

Commit to our manifesto here: manifesto.efanet.org

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