#EPAllergyAsthma



For an EU NCD Initiative that prevents and cares:

Connecting the dots for better allergy and asthma health in Europe









Summary report

On the hybrid event of the

European Parliament Interest Group on Allergy and Asthma

29th September 2022, 14.00-15.30 CEST

On 29 September 2022, the European Parliament Interest Group on Allergy & Asthma held a policy event "For an EU NCD Initiative that prevents and cares — Connecting the dots for better allergy & asthma health in Europe", co-hosted by the Chair of the Interest Group, MEP Sirpa Pietikäinen (EPP-Finland), Vice-Chair MEP Juozas Olekas (S&D-Lithuania), and the Group's newest member MEP Ladislav Ilčić (ECR-Croatia).

The event took place in the European Parliament in Brussels and was the first event conducted in a hybrid format since the setup of the Interest Group in 2015. On-site audience was mostly composed by members of the European Allergy and Asthma Youth Parliament, a group that advocates change for all young allergy and asthma patients across Europe. These participants were aged 18-30 years old and came from EU and non-EU countries: Germany, Italy, Ireland, Serbia, Sweden, Spain, and Poland.

Introduction



(left to right) Isabel Proaño, MEP Sirpa Pietikäinen, Marcia Podestà, Professor Ibon Eguiluz-Gracia

The event examined the <u>Healthier Together</u> <u>– EU NCD Initiative</u>, an action orientated framework conceived to pull resources and

knowledge to help EU Member States reduce the burden of non-communicable diseases (NCDs) including, among others, chronic respiratory diseases. The meeting aimed to shed light on the place given to allergy and asthma health within the initiative, and trigger a debate among patients, healthcare professionals, researchers and policymakers on steps Member States can take to allergy and asthma prevention, management, and care.

In her opening remarks, MEP Sirpa Pietikäinen noted that the goal of the Interest Group and the event itself was to identify existing gaps in relation to allergy and asthma. She stressed that one in three people live with allergy and asthma, having to bear a huge health burden as well as economic costs.

On behalf of the European Federation of Allergy and Airway Diseases Patients' Association (EFA), which co-facilitates the work of the Interest Group, Marcia Podestà highlighted the EU NCD initiative both as an opportunity and a challenge for the allergy and asthma patient community. opportunity, because it marks the first time in more than a decade that the EU outlines plans to tackle chronic respiratory diseases and address determinants of health such as air pollution and tobacco smoke. However, she cautioned against the narrow scope of the initiative, given the secondary focus it grants to allergic diseases and its neglection of key health risks such as those arising from climate change.

Ms Podestà underlined the need to include in the EU NCD Initiative a holistic framework addressing the whole cycle of the diseases, from prevention to research, treatment, management, and cure.

Professor Ibon Eguiluz-Gracia, representative of the European Academy of Allergy and Clinical Immunology (EAACI), which co-runs the Secretariat of the Interest Group, highlighted the need for patients, healthcare professionals and researchers to work together. While the EU NCD Initiative is a milestone, he acknowledged that there is room for improvement, as various types of allergies need to be acknowledged in their own right, not solely as risk factors for other diseases.

Keynote address: Chronic respiratory diseases in the EU NCD Initiative



Audience at the Interest Group event

Dr Marianne Takki of DG SANTE welcomed the views of MEPs, patients and doctors. She outlined the main goal of the EU NCD initiative was to look at the burden of major NCDs and identify successful interventions in the field that could be transferred across Member States.

Dr Takki explained that the EU NCD initiative serves as a toolkit of policies and actions in the form of best practices, best buys from WHO, research results, and innovative ideas and approaches in the areas of prevention and promotion. The initiative has also served to earmark legal and financial tools to be used for public health interventions within the EU budget.

Referring to the scope of the NCD initiative, Ms Takki singled out five main areas of work:

- Promotion and prevention, making up for 20% of the budget;
- Knowledge and data, which unfortunately lacks on diseasespecific areas;
- Screening and early detection, to help Member States find useful best practices;
- Diagnosis, treatment and management, on which the EU can provide guidance;
- Quality of life, which is key in ensuring a good balance of treatment for a liveable life

Dr Takki noted that a joint action in the health determinants strand will be announced soon, relevant for chronic respiratory disease patients, and will focus on air pollutants and prevention of smoking among others. She then identified the three main areas that the Member States found as priority for actions on the chronic respiratory strand:

- prevention of onset and progress of the disease
- early detection
- and ensuring high-quality chronic respiratory diseases care and selfmanagement support.

Specifically on allergy, Dr Takki highlighted that the Finnish Asthma and Allergy Programme was recently presented as a best practice. It is now up to Member States to select their preferred best practices.

Keynote address: European Youth Parliament on Allergy & Asthma



Youth Parliament members Dunja Stojanović (Serbia) and Eimear O'Rourke (Ireland)

Speaking on behalf of the European Youth Parliament on Allergy & Asthma, Eimear O'Rourke referred to her near-death experiences as a result of allergic reactions. Living with food allergy is extremely mainly due to challenging, existing misconceptions about its importance. Ms O'Rourke highlighted the need for research in collaboration with patients, the health sector, food industry, and the public to better protect people with allergies. The youth advocate underlined the role of young patients in shaping EU policies, with a 'youth-in-all policies' approach. Young patients strongly suggest making use of digital and social media tools to allow for fresh feedback, but also measures to support awareness-raising at local level.

Similarly, on behalf of the European Youth Parliament on Allergy & Asthma, **Dunja Stojanović** shared her experience with atopic eczema. Like her, today there are more than 13.5 million people under 25 in Europe living with asthma, allergies, and atopic eczema. The views of young advocates and patients must be reflected in the EU NCD initiative and the policy actions

in this area, as they have the best understanding of the physical and emotional burden of dealing with these diseases throughout childhood and during adolescence, as well as in transition to adulthood. Involving the youth is a great health prevention and protection strategy.

Panel discussion: Recommendations for an EU NCD Initiative that improves prevention, management and care for all

The panel discussion addressed issues around the EU NCD initiative from various stakeholders. **MEP Juozas Olekas** welcomed the Commission initiative, yet regretted the limited role of the European Parliament in shaping it. He stressed that research for allergy treatments needs to be supported and advanced, while the access to innovative treatments and medicines must remain accessible and affordable to patients. MEP Olekas added that countries must be supported in delivering better healthcare for patients, while involving young people in discussions co-shaping relevant policies.

Dr Marianne Takki explained that the Commission is currently shaping its 2023 work plan in the context of the EU4Health funding programme. The programme will feature a joint action, and a call for proposals for stakeholders.

Ms Mikaela Odemyr, President of the Swedish Asthma and Allergy Association and EFA member, underlined the main aspects that need to improve for allergy and asthma in Europe, namely prevention, diagnosis and disease management. She described allergy as a disease suffering from underinvestment, attracting limited research

interest, and often trivialised as a 'soft'. Ms Odemyr asked for an EU NCD initiative with a clear mission to improve life of allergy and asthma patients, with patients in every decision. This can be achieved by encouraging structural changes at national level, investing in access and promote personalised approaches and making sure treatments are fit-for-purpose.



MEP Juozas Olekas and Mikaela Odemyr

Prof. Ibon Eguiluz-Gracia explained that the lack of a strong medical community within allergy contributes to the limited focus on allergy in frameworks such as the EU NCDs Today, allergology is initiative. recognised as a specialty in all EU countries, and therefore there is little pressure on policymakers to act on allergy. Prof. Eguiluz-Gracia added that quality of life aspects are extremely important: for example, allergy patients' quality of life is much more impaired on average than suffering from other NCDs e.g. diabetes. A strong medical community and stakeholders is crucial to make this disease more visible.

Dr Arzu Yorgancioğlu, Chair of European Respiratory Society (ERS) Advocacy Council, drew attention to the importance of diagnosis and asthma treatment. Access to good spirometry needs to be improved, to reduce misdiagnosis. Moreover, asthma

patients deal with various misconceptions, and it is imperative to tackle stigmatisation. Moreover, Dr Yorgancioğlu highlighted the importance of health literacy at all levels, and particularly of providing patients with education and skills to manage their disease. To this end, the partnership between patients and healthcare providers is essential.

Prof. Tuomas Jartti briefly presented the Finnish experience with the decade-long national Allergy and Asthma Programme, emphasising its priority to improve prevention and patient care, but also address the disease burden, and avoid unnecessary treatment. Prof. Jartti shared some of the outstanding results, including curbing the disease prevalence, improving diagnosis and tolerance, and reducing allergy and asthma costs by 30%.



Professor Tuomas Jartti

Prof. Tari Haahtela, who recently presented the Finnish Allergy Programme as a best practice to the EU Member States, stressed that programmes similar to the Finnish one can be successfully developed as long as there are concrete goals and tasks outlined. He added that by addressing allergy and asthma, other NCDs are also prevented, as they all share the same underlying factors. Moreover, by preventing NCDs, big global

challenges, such as climate change, will be tackled, as they are testing it in the Lathi regional programme on climate change and health.

Closing remarks



(left to right) Dunja Stojanović, Eimear O'Rourke, Prof. Tuomas Jartti, Jennifer Baker, MEP Juozas Olekas, Mikeala Odemyr, Prof. Ibon Equiluz-Gracia, MEP Ladislav Ilčić

To conclude the event, **MEP Ladislav Ilčić** reiterated the need for allergies and asthma to be addressed in the EU NCD Initiative, highlighting their increasing prevalence in both adults and young people. This needs to be done by addressing the key elements for a better and healthier environment for patients across various policy files that deal with concepts such as air quality. Finally, he

stressed the importance of focusing on the common views and cooperation between all stakeholders in order to have better results for patients.

In his concluding remarks, MEP Olekas reflected on the long journey ahead of the EU to tackle the burden of NCDs, among which allergy and asthma hold a prominent position. He reinforced the need for a patient-centred approach in policies which should be developed jointly by policymakers and stakeholders, in order to ensure high-quality care for patients. At the end of the day, only with a healthy population can a true European Health Union be achieved.

After the event, MEP Sirpa Pietikäinen and members of the European Youth Parliament on Allergy & Asthma engaged in an informal yet lively Q&A discussion, where young patients had the opportunity to share their experiences and concerns living with allergy and asthma, and the MEP to share insights from her work at the European Parliament.

The European Parliament Interest Group on Allergy and Asthma was launched on 25 March 2015 as a result of a long-standing collaboration between the European Academy of Allergy and Clinical Immunology (EAACI), the European Federation of Allergy and Airways Diseases Patients' Associations (EFA), and a group of forward-thinking Members of the European Parliament (MEPs), who are committed to fight against allergy and asthma in Europe.

The European Allergy and Asthma Youth Parliament brings together young allergy and asthma patients and medical professionals between 16-26 years from across Europe. The Youth Parliament is a forum to share experiences and knowledge, to raise awareness for the pressing issues for young patients, and to inform European policymakers on how their work can support young people living with asthma and allergies.

To find out more about the Youth Parliament, contact youthparliament@efanet.org



European Parliament Interest Group



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