

#EPAllergyAsthma



Addressing patient unmet needs in allergy and asthma care



Summary report

On the policy meeting of the

**European Parliament Interest
Group on Allergy and Asthma**

13th January 2022, 13.00-14.15 CET

On 13 January, the European Parliament Interest Group on Allergy & Asthma held its annual policy event **“Addressing patient unmet needs in allergy and asthma care”**, co-hosted by two of the Group’s Vice-Chairs, MEPs Juozas Olekas (Socialists & Democrats – Lithuania) and Tilly Metz (The Greens/EFA – Luxembourg). The event took place in a fully virtual format.

Introduction

In view of the new Pharmaceutical Strategy for Europe and the revision of the relevant legal framework, the event served to bring to light the unmet needs that patients with allergy and asthma face today to foster a patient-centred EU pharmaceutical policy. Speakers and the audience focused on key challenges linked with patient unmet needs in allergy and asthma care, such as access to medicines, patient involvement in pharmaceutical strategies and research, improved treatment methodologies, and the opportunities offered by digital health.



MEP Tilly Metz, The Greens/EFA

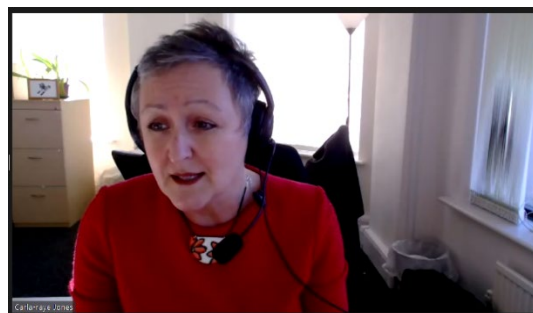
In her opening remarks, **MEP Tilly Metz** acknowledged the burden that allergy and asthma incurs to health, but to the social, economic, and emotional dimensions of patients and society.

Unfortunately, these challenges are linked to persistent unmet needs, including high levels of asthma mis- and underdiagnosis, lack of access to high-quality treatment, innovative development of solutions for low-prevalent

allergies and paediatric asthma, and limited patient access to medical trials. MEP Metz remarked that these challenges have been even more pressing in the context of the COVID-19 pandemic. A point that has not been missed by policymakers who have finally placed health centre stage in EU discussions.

Many legislative initiatives are currently on the table with the new Pharmaceutical Strategy for Europe, the revision of legislation on medicines for children and rare diseases, and the proposal on a European Health Data Space. She believes that as policymakers working on health, it is imperative to listen to patients and build collaboration between patients and other stakeholders.

Patient unmet needs in times of change



Carla Jones, EFA President

In the introduction of the event **Carla Jones**, President of the Board at European Federation of Allergy and Airways Diseases Patients’ Associations (EFA) and **Freja Anckers** of the European Allergy and Asthma Youth Parliament spoke up from the patient perspective on patient unmet needs in Allergy and Asthma.

Carla Jones highlighted the importance of the European Health Union ambition, and the revisions of the pharmaceutical legislation arising from it, as a unique opportunity to change the lives of patients and their carers in the coming decades.

Ms Jones described the key unmet needs that patient communities have to face today:

- unequal access to medicines, old and new, and across Europe, which is due to many factors such as differing national regulations, pricing, shortages, or reimbursement systems. Yet the main victims are patients, many of whom are prevented from getting the treatment they need;
- persistent low patient adherence to medicines, mainly due to lack of support in disease management. An alarming fact illustrating this point is that 1 in 4 asthma patients have to visit the emergency room on average once a year.
- limited interest towards allergy needs, reflected by the under-prioritisation of allergy in public policies, plans and budgets.

In this light, Carla stressed that the opportunity presented by the European Pharmaceutical Strategy should not be wasted in addressing these gaps and looking beyond the medicines to work at improving patient quality of life.



Freja Ankers, EFA Allergy and Asthma Youth Parliament

Freja Ankers spoke on behalf of the EFA Allergy & Asthma Youth Parliament. She noted that young patients living with asthma and allergies need different resources and capacities than adults to cope with their diseases. She expressed the need for young patients to be considered as a category rather than a subcategory, to better understand the needs of a young patient in dosages, care pathways but also how their

treatment fits in their lives to improve quality of life and treatment adherence.

Finally, Ms Ankers also welcomed research initiatives, as young patients should not be forgotten in medical research to create personalised treatment approaches and to help push forward the opportunities provided by digital healthcare.

Panel discussion: Championing EU policy solutions to address unmet needs in allergy and asthma care



Isabel Proaño, Director of Policy and Communications at EFA, moderated the panel discussion on championing EU policy solutions to address unmet needs including those put forward in the introduction. She took the panellists through various questions to explore the subject fully.

Prof. Jürgen Schwarze, Secretary General at the European Academy of Allergy and Clinical Immunology (EAACI) and paediatrician expert on immune mechanisms, gave his perspective on patient unmet needs and potential solutions. For one, Prof. Schwarze referred to the need for easy access to appropriate, safe, and effective medicines and management options. This would

be possible through better alignment of reimbursement policies across Europe, universal access to non-specialist treatment, the use of precision medicine, and higher digitalisation to aid with adherence and improved diagnosis.

Another key unmet need is to ensure better prevention for allergy and asthma and long-term treatment, for which innovation and research need to be supported using Real-World Data for holistic treatments, and the development of stronger disease-modifying treatments.

Speaking from the industry perspective, **Tina Taube**, Director Market Access & Orphan Drug Policy Lead at the European Federation of Pharmaceutical Industries and Associations (EFPIA), discussed how patient unmet medical needs influence company decisions and the challenges faced. She explained that for the pharmaceutical industry patient unmet needs are a strong and constant factor in investment decisions, beyond scientific factors, commercial factors, and policy frameworks. In a preclinical stage, Ms Taube explained that the most important consideration are clinical and scientific factors. In the case of allergy and asthma this means bringing in patients and physicians early on to seek an understanding of the disease but also better know their needs and preferences.

She gave the example of severe asthma for which the main challenges stem from poorly understood physiology and the need for further research. Moreover, beyond the pre-clinical stage, patient involvement is crucial also to reimbursement decisions. While there is always room for improvement, Ms Taube stated that the pharmaceutical industry is working on tools and instruments on how to best engage with patients along the value chain.

Dr Stanimir Hasardzhiev, Secretary-General of Patient Access Partnership (PACT), representing the patient voice expressed the importance of defining patient unmet needs in a way that goes beyond mere treatment needs, but rather looks

at patient as a human being within their lifestyles, homes, families, and daily activities. Patient needs are much broader, and with this broader understanding he expressed that we will be able to encourage data collection from all aspects of a patient's life. A key example is adherence to medicines, which can be improved through proper information and tools.

Dr Hasardzhiev urged for a holistic approach not focusing solely on the disease, but based on people being able to lead healthy lives and detect diseases from early on. The COVID-19 crisis revealed huge disparities among wealthier and poorer countries in accessing medicines. No matter where they live in Europe, patients need timely diagnosis, equal access to high-quality treatments, as well as care services as a whole. Finally, Dr Hasardzhiev insisted that patients appreciate the opportunities offered by digital health and are willing to share their data, as long as this has tangible outcomes for their health.



From left to right: Isabel Proaño (EFA) | Prof. Jürgen Schwarze (EAACI) | Tina Taube (EFPIA) | Dr Stanimir Hasardzhiev (PACT) | MEP Tilly Metz (The Greens-EFA) | MEP Juozas Olekas (S&D)

In the ensuing Q&A session, the discussion pivoted around improving the situation for

patients. **MEP Juozas Olekas** started off by expressing the need to address allergy and asthma at a European level for better innovation, and to push for holistic treatments to which **MEP Tilly Metz** added the need to rethink healthcare to push for more personalised and targeted medicines.

Further ideas were brought forward by the panellists. **Prof. Schwarze** underlined the need for a holistic approach to patients in the daily clinical practice. Understanding broader aspects of patient's life with allergy and asthma, such as the fear, is key for healthcare professionals to be able to give proper advice.

Accordingly, the training of clinicians of all specialities on asthma but especially allergies which can touch all elements of medicines.

Dr Hasardzhiev elaborated on the challenges that many countries face in accessing medicines. These include long delays between EMA market authorisation and reimbursement decisions, as well as the lack of a common approach on the implementation of treatment guidelines. Both challenges may lead to lower-quality care for patients.

Finally, **Ms. Taube** stressed the industry's dedication to engage with patients along the whole lifecycle of medicines, getting their input at every step from R&D to reimbursement. Companies try to do so via the development of tools to enhance patient participation in processes such as research priority-setting and clinical trial design.

Commenting on the panel discussion and the questions from the audience, **MEP Juozas Olekas** stressed that allergy and asthma must get European-level solutions that are innovative and holistic. Regarding childhood asthma, he highlighted several existing barriers such as lack of information, misdiagnosis and insufficient adaptation between adult and paediatric

medicines. Crucially, it is imperative to develop treatments that serve everybody.

MEP Tilly Metz underlined the value of ensuring patient involvement in all medicine-related procedures, integrating more real-life data and evidence on quality of life. Further, she highlighted the need to guarantee a healthy environment as a powerful way to enhance quality of life, and keep this concern in mind when developing legislation. A holistic and patient-centred approach is essential in all decisions.

Concluding remarks and way forward



MEP Juozas Olekas, S&D

Closing the event, **MEP Juozas Olekas** referred to the unique opportunity to focus on health as allergy and asthma remain prevalent and critical. He iterated his support for the European Health Union that prioritizes patients and their needs, expressing that this will strengthen bridges between countries but also ensure that all patients in Europe will be treated equally with innovative and inclusive healthcare. It is through this union that patient unmet needs will be defined to be able to better overcome the challenges faced by patients, improve research, and assess how new technologies and digital solutions can play a role in improving patient care.



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This project is made possible thanks to unrestricted grants from EFA's Sustainable Funding Partners Chiesi, GSK, Sanofi/Regeneron

