

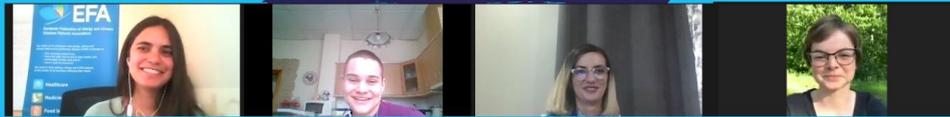


**Event Report:**  
**European Parliament Interest Group on Allergy  
and Asthma**  
**10<sup>th</sup> December 2020**

**The Youth Parliament of the Allergy & Asthma Interest  
Group**



**invites you to our digital launch**



**of our recommendations to the EU on health**



#EPAllergyAsthma

**10 December 15:15 CET**



**European Allergy and Asthma Youth Parliament**

*Growing up with Allergy and Asthma –*

*How EU policymakers can support young allergy and asthma  
patients to live better lives*

#EPAllergyAsthma

#EA2Youth

## Introduction

On Thursday 10 December, the European Parliament Interest Group on Allergy & Asthma hosted a digital launch of the policy recommendations *“Growing up with Allergy and Asthma – How EU policymakers can support young allergy and asthma patients to live better lives”*.

Developed by the European Allergy & Asthma Youth Parliament, the guidelines call for a “youth-in-all-policies” approach in EU decision making and a greater involvement of the youth in the policy discussions.

The launch was organised by the European Parliament Interest Group on Allergy & Asthma. It was co-hosted by the Interest Group’s Chair MEP Sirpa Pietikäinen (Finland/EPP), and its Vice-Chair MEP Tilly Metz (Luxembourg/Greens), while another of its Vice-Chairs, MEP Juozas Olekas (Lithuania/S&D) also participated in the discussions.

MEP Tilly Metz opened the event with a video, where she spoke about her personal experience and work in the European Parliament to address the challenges allergy and asthma patients face. Metz brought to attention the increasing impact asthma and allergies has on Europeans, and that young people bear a disproportionate burden as allergy and asthma are much more prevalent in younger age groups.

Following Tilly Metz, EFA President Mikaela Odemyr gave her opening remarks. She praised the initiative of the Youth Parliament, drawing from her own experience raising three children who suffer from allergies and asthma, and witnessing the challenges of growing up with a chronic disease. She expressed her pleasure that the young generation is engaging with EFA to promote their key priorities today: digitalisation, independence, and affordability.

Mikaela presented the work of EFA on allergy and asthma through its three pillars of work: to inform decision-makers and patients, prevent the risks of becoming a patient and to achieve equal access to high-quality care for everyone.

She reflected on EFA’s previous engagement with young people, who campaigned on topics such as indoor smoking and allergen labelling. Mikaela then highlighted the current challenges facing young people with chronic disease such as stigmatisation, improving allergen labelling, and opening up digital solutions. She iterated that these topics should be high on health policy agenda, with public information campaigns to help raise awareness and reduce ignorance surrounding allergies and asthma.

*“It is clear that young patients’ needs, concerns and capabilities are distinct from older patients. Different ways of life, qualities, and capacities call for different solutions... We as politicians need to reach out to the youth, engage with them, discuss their problems and, importantly, involve them in the decisions affecting their life. This is key for building good, active citizens.” – MEP Tilly Metz*



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### INTRODUCTION

The journey of European Allergy & Asthma Youth Parliament: Building the next generation of allergy and asthma patient leaders in the EU

**Mikaela Odemyr – EFA President**

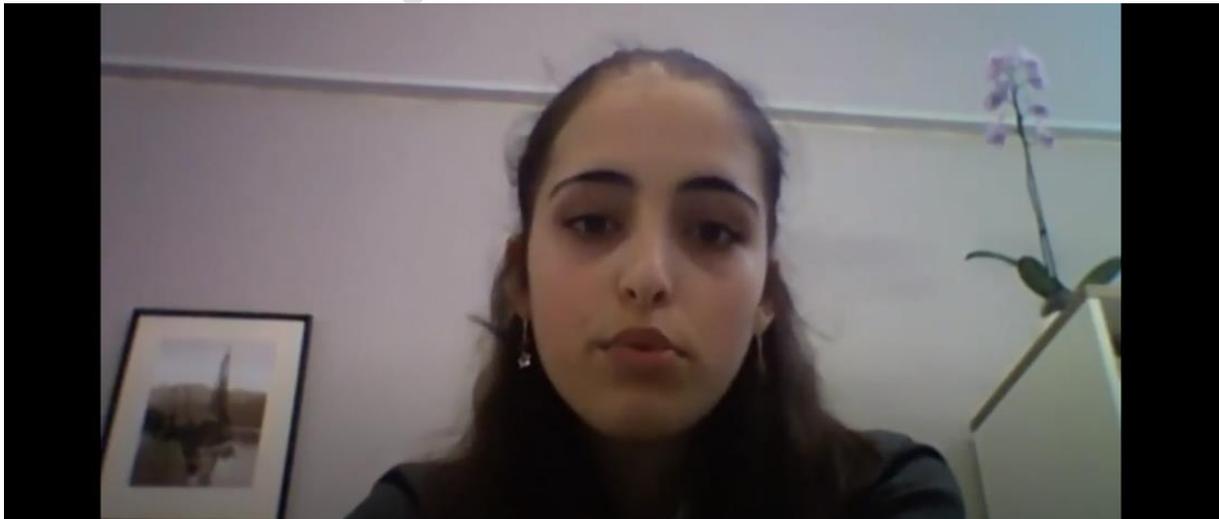
**Monica Volini - Member of the EA<sup>2</sup> Youth Parliament**

Mikaela Odemyr (EFA President)

Youth Parliament member Monica Volini (17) introduced the ongoing work of the Youth Parliament since its beginnings in early 2020. She spoke of the reasons the Youth Parliament came together, to use their personal experiences to influence European policymaking and healthcare.

With an average age of 21, the Youth Parliament members have experienced growing up with allergies or asthma. Monica explained how young people with these health conditions are facing challenges to travel freely for work or university whilst having to balance these huge life experiences with their long-term treatment and care, or in environments that are not equipped to accommodate their needs.

Monica highlighted the differences in needs and priorities that young patients have compared to adult patients, and she called for EU policy and healthcare treatments to reflect this and take into consideration. She gave examples of personal independence, affordability and flexibility of medicines and treatment, as well as technology's role in these areas. She also emphasised that young people's opinions need to be heard much more, both by the broader public and policymakers, something the Youth Parliament sets out to achieve.



## Inform, prevent, care: how to involve young patients in their healthcare

Advocating for a ‘youth-in-all-policies’ approach in EU policies, members of the Youth Parliament presented the guidelines and recommendations to EU policymakers along its thematic topics of Inform, Prevent, and Care, to benefit the young patients living with allergy and asthma in Europe.

### Inform

Youth Parliament member Francesco Aldo Russo (19) focused on how to raise awareness and increase knowledge around asthma and allergies and young people. Francesco spoke about the exclusion young people with chronic disease feel in their everyday lives, often being unable to participate in activities alongside their peers. He raised the need for information to normalise the experiences of young people growing up with allergies and asthma to accommodate their needs better. This is especially apparent as they enter the world of work.

Francesco presented the opportunities created by digital tools such as social media to support young people with allergies and asthma, mentioning Instagram and YouTube as two platforms that can establish contact between young patients and doctors or policymakers. He also flagged the dangers of such platforms in that they can also serve to increase discrimination.

For the Youth Parliament, educational settings such as schools are a crucial mechanism to disseminate information. Teachers could be ambassadors for allergy and asthma to help raise awareness on the diseases at an early stage.

He spoke about the importance of valid statistics about allergic and asthmatic people, for example new diagnoses, or the status of air pollution, to help others recognise the gravity of allergies and asthma.

Through informing, young patients can be better involved in decision-making while helping others understand the daily and lifelong challenges they face.

### Prevent

Another member of the Youth Parliament, Laura Stenz (26), presented to participants the prevention measures which can better protect the health of young people living with allergies and asthma.

First, Laura spoke about the environmental factors which impact people living with asthma and allergies. Air pollution is the single deadliest environmental health risk and causes 400,000 annual premature deaths in the EU. Both indoor and outdoor air pollution can aggravate symptoms, while the transport, industrial and building sectors are each major emitters of pollution. Laura also discussed the impact of climate change on young people with allergies and asthma, for example pollen numbers increasing in recent years. She mentioned that Eurobarometer research places climate change, air pollution, and waste as the three most important environmental issues for young Europeans.

She urged policymakers to commit to fighting climate change and air pollution, such as through mobility improvements, investment in rail, and regulation against vehicles such as SUVs. To this end, Laura encouraged policymakers to support the EU zero pollution ambition through the EU Renovation Wave Strategy and with at least a 60% reduction target in emissions by 2030. Supporting research in digital tools for handling environmental risk factors, for example pollen monitoring, is also key.

Laura then presented information about indoor triggers of symptoms, connected to indoor air pollution. Examples include mouldy, damp, badly ventilated buildings; tobacco smoke and the furniture fabric in schools or on public transport that can attract dust mites, pollen, and pet hair.

Finally, she brought attention to necessary prevention measures around allergies and food and consumer products. She spoke about the need for a standardised Precautionary Allergen Labelling (PAL) scheme across Europe to help people with allergies avoid potentially fatal triggers. Accordingly, workplaces where food is served need to integrate mandatory training in allergy management, as currently there is a lack of awareness which can lead to social isolation from people with allergies.

## Care

To offer insight into what care-related measures can be done, Youth Parliament member Julijana Asllani (29) presented the group's recommendations. Julijana began by speaking about the rising prevalence of allergies and their impact, highlighting the need for new health policies that include young patients as a priority.

Julijana also spoke about the rising importance of digital tools in healthcare, especially for young patients. Examples that already exist are mobile apps that can be used to monitor allergic diseases, however only a few have been evaluated. It is necessary to create a standardisation of apps in Europe to offer improved healthcare services for patients. Julijana then called for the need to involve young patients and allergists in the designing of apps, in every step of the way to create beneficial digital tools.

The Youth Parliament stresses the indirect high costs for patients that come with healthcare. Reimbursement policies differ across Europe with many areas to improve. The EU has a role in the future to improve reimbursement across its Member States, as well as supporting research into new devices and medications.

Julijana concluded by emphasising the importance of implementing a new personalised and multidisciplinary approach for young patients. To ensure that new approaches benefit young patients, Julijana called for research to focus on young patients.

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## INFORM

Involve young allergy and asthma patients in policy decisions affecting their health.

### General discomfort: young and adult patients.

Young patients are often discriminated due to their diseases and experience limitations.

### Social media, a wrong used vehicle.

For young people, social media has a big impact on social life. Yet it evolved as an easy way to discriminate people. Let's use it in the right way!

### Putting young patients at the center of discussions

Young patients should be at the centre of discussions affecting their health. Including them is key for establishing effective and future-oriented health policy frameworks.



## Panel discussion: How to bring these recommendations into reality?

Following the presentations from the Youth Parliament, panel speakers were invited to share their thoughts on the recommendations and how to support young patients. The speaker included:

- Nikos Papadopoulos, professor of Allergology and Paediatric Allergy in Greece and the UK;
- Ioana Agache, past president of the European Academy of Allergy and Immunology (EAACI);
- Carmen Riggioni, Assembly Chair of EAACI Junior Members;
- Mikaela Odemyr, EFA president

In his role as the Senior Scientific Advisor of the project, Professor Nikos Papadopoulos congratulated the Youth Parliament on what he called “ambitious but realistic guidelines”. Prof. Papadopoulos noted that 20% of people who move around Europe have an allergy or asthma. Therefore, as the recommendations address that young people are likely to move for studies or work, they can have a direct impact for these people. He spoke about how the Youth Parliament has an important role to play in getting their voices heard in EU policy and transporting the messages from the recommendations to the European Parliament, and that it was welcome that MEPs attended the launch. Prof. Papadopoulos concluded by stating that more investment in research is essential for all three pillars of the recommendations: Inform, Prevent, and Care. People have seen what greater resources in research can do due for COVID-19, and that increased research must be problem-oriented to find solutions.

Immediate past president of EAACI, Professor Ioana Agache, took the floor. She reiterated Prof. Papadopoulos’s praise of the Youth Parliament’s recommendations, and the importance of investing in research to achieve its priorities. Commenting on the EU’s Pharmaceutical Strategy, Prof. Agache spoke of how it can lead to innovative medicine, and the importance that it covers from research to what is delivered to the patient. The many new developments in healthcare including precision medicine, applied research, and the development of new vaccines offer new opportunities. However, Prof. Agache pointed out that many new products are unavailable or unaffordable to the wider public who require them. There is also currently a lack of investment in allergy and asthma in comparison to other chronic diseases. This is where the Youth Parliament can make their voice heard.

In terms of other priorities, Prof. Agache agreed that digital health should be prioritised, alongside a global multi-discipline partnership, a patient-first approach, and the establishment of a European Council for Health Research.

Dr. Carmen Riggioni, Chair of the EAACI Assembly of Junior Members, presented ways in which allergist knowledge can be equalised across Europe. Dr. Riggioni highlighted current issues in achieving this, mostly that there is currently a low number of healthcare workers with allergist knowledge and the need for all healthcare workers to be trained in allergy specialist information, and to harmonise the distribution of allergists across Europe. While the transition from primary to secondary care can be complicated, Dr. Riggioni spoke of how people contact their primary care providers first, therefore knowledge and awareness around allergies needs to be present in all healthcare physicians, and better equipped with tools for managing treatments.

EFA President Mikaela Odemyr brought the panel to a close, and spoke about the EU Green Deal and its potential for young patients with allergy and asthma. Mikaela named the EU Green Deal as the last opportunity to protect both peoples’ health and the planet simultaneously, as the environment is essential for health, especially for allergies and asthma. Mikaela highlighted that environment issues is something that young people in particular see very clearly and advocate for. EFA is also dedicated to this issue, covering environmental topics such as air quality, circular food systems, and reducing chemical exposure through EU legislation including the Farm-to-Fork strategy and the Zero Air Pollution Action Plan. Mikaela called for the urgent need for concrete policies with prompt implementation that consider the Youth Parliament’s recommendations.

## Roundtable discussion

The last session of the programme consisted of an open roundtable discussion with MEP Juozas Olekas, Vice-Chair of the Interest Group on Allergy and Asthma, the Youth Parliament members, and the participants to the event.

Mr Olekas opened the discussion by thanking the Youth Parliament for its work, stating that the involvement of all generations in EU policy, especially health policy, is vital. He spoke of the importance of creating a standardised quality of European healthcare that covers day-to-day care of patients and the quality of healthcare services. He mentioned the growing increase in chronic disease patients, especially in young people, and the need for the EU to act.

*“We are fighting in the European Parliament for health to be seen as holistic for all patients. We need equal possibilities for all patients in all Member States. Young people will benefit from a health union that guarantees regular healthcare everywhere in Europe no matter where they live or which healthcare system they belong to.”*

– MEP Juozas Olekas

The Youth Parliament asked Mr. Olekas how a stronger EU role in health policy could be implemented in a manner that is fit for young people and their access to care. The MEP responded that young people will be able to benefit from a European Health Union that guarantees regular quality healthcare access across member states, and regardless of the healthcare system each person belongs to. With better research and resources available, a standardisation of healthcare could be implemented across Europe, including latest technology and methods to increase access.

When asked how the EU can make sure that young patients can take Erasmus opportunities without interrupting their care and treatment, Mr. Olekas emphasised the importance of healthcare without borders to enable the same quality of healthcare across EU member states through a standardised approach.

A question was posed to Prof. Papadopoulos whether he could provide possible reasons for the increasing number of children with allergies in the last decade. Prof. Papadopoulos explained that this has in fact been an occurrence over the past century rather than decade. He attributed this to disturbed interaction within the environment, in particular with microbes.

As the recommendations shed light on the importance of digital healthcare, the Youth Parliament were asked which of their demands around digital care they would want to see addressed first.

Julijana Asllani answered that they see digital apps as a priority to be implemented. If developed well, they can help young people to assess their symptoms and manage their treatments.

Considering joint work between the EU and patient groups, Mikaela Odemyr was asked if she saw it possible for EFA to work with the European Commission and Parliament to add allergenic pollen in list of pollutant regulated parameters to increase efficiency of national networks. Mikaela empathised as this is a big topic in Sweden. She stated that EFA should investigate working and advocating on this, as when people travel abroad for a variety of reasons those affected by pollen counts should be able to know the pollen count of their travel destinations.

The Youth Parliament asked MEP Olekas how the EU could take advantage of the digital transformation to involve young patients in healthcare and policy. He referred to the recommendations of the Youth Parliament as outlining key aims for the EU to consider, and the need to involve more patients and healthcare workers for a holistic approach. Mr Olekas called for political unity in achieving this.

The EAACI Primary Care Working Group asked the Youth Parliament how they want primary care to be involved. They provided a wide range of answers including recognising primary care as frontline, and the creation and implementation of digital apps across Europe should involve primary care workers as well as young patients. It was also emphasised that more education through trainings for all healthcare workers, especially primary care workers, should be implemented for increased knowledge and awareness. Young people, especially those taking part in exchanges such as Erasmus, face perceived barriers in accessing primary care. One solution could be to include English language content to make primary care more easily accessible for young people.

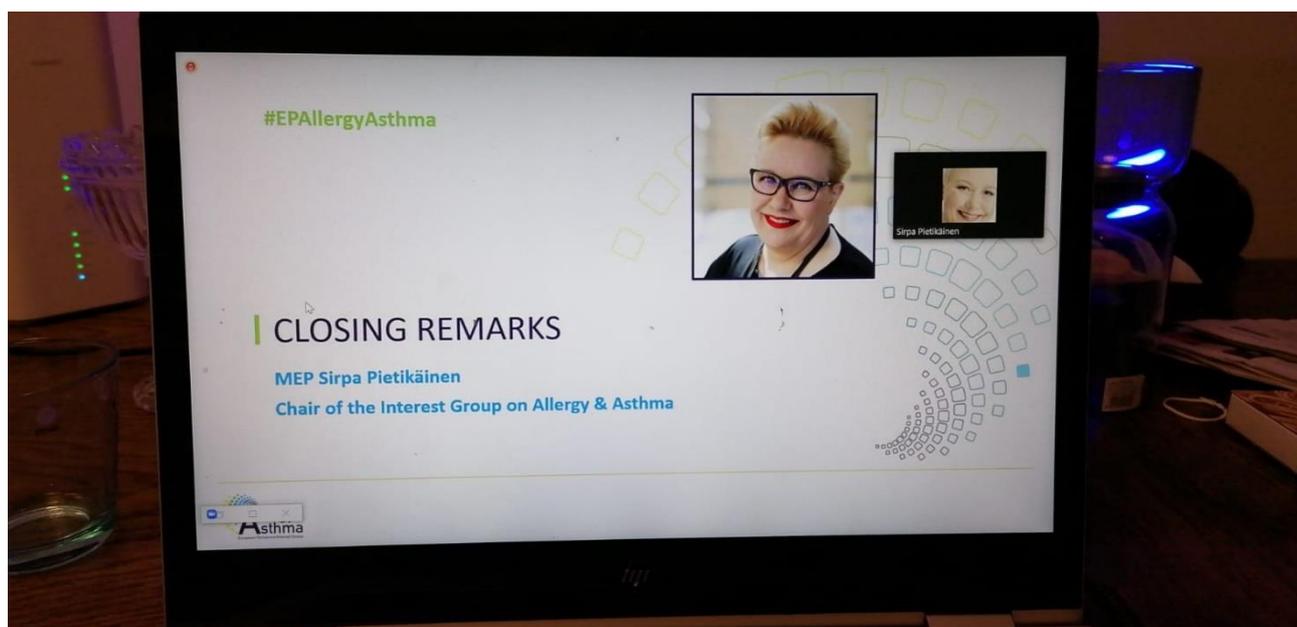
The final question asked Ioana Agache her opinion around the latest challenge of vaccinated people with allergies. Prof. Agache responded that while there currently is not enough data to comment concretely, she agreed that there is the need to fight for the full rights of allergic people to be treated, and to integrate this into all healthcare aspects.

## Closing remarks

As the roundtable closed, the Chair of the Interest Group on Allergy and Asthma MEP Sirpa Pietikäinen brought the event to an end with her final remarks. She spoke of her personal experience living with asthma, and the need to reduce stigma and raise awareness around the severity of asthma. MEP Pietikäinen also shed light on the key environmental factors affecting people living with allergies and asthma, mentioning air quality, damaged biodiversity, and chemicals as issues that exacerbate symptoms, and she highlighted that there are many ways for the EU to act to address this issue. She also spoke of how asthma and allergic diseases are key in broadening Europe's approach to health policy to address common diseases as well as rare ones to create good quality treatment and best practices. She further noted that healthcare costs are too high for young people across Europe, an issue that the European Parliament could work on.

To conclude, MEP Pietikäinen spoke of how the Youth Parliament is a key platform to build the voices of young patients for the European Parliament to listen. She said she hopes to see the recommendations as just the start of good dialogue between policymakers and the Youth Parliament, as well as to see this occurring at the national level in Member States also. Ms Pietikäinen described her hopes to see young patients coming together through the Youth Parliament to send a strong signal to the European Parliament and said that she is looking forward to cooperating in the future with the Youth Parliament to build a new generation. She thanked the Youth Parliament on behalf of whole interest group with the hope to see them in the future.

*“Building a new generation shows how much we need a European approach and competencies in healthcare. Allergy and asthma are a good candidate to expand the competency from rare diseases to common diseases so we can level the quality of treatment in Europe, set the standard and create the possibility of treatment in other member states.” - MEP Sirpa Pietikäinen*



## **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 tackle allergy and asthma in Europe.

### **CONTACT US**

For more information on the Interest Group on Allergy and Asthma please contact the Secretariat.

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