



## Report on the EFA Respiratory Allergy Book Launch Event



The European Federation of Allergy and Airways Diseases Patients' Associations (EFA) successfully held its launch event on November 22, 2011 at the European Parliament in Brussels, BE for the release of its new Respiratory Allergy Book. The publication provides new data on respiratory allergies, which are currently Europe's most common and underestimated chronic disease. Data was collected from across Europe, through the cooperation and participation of 18 EFA member organizations, which presented loopholes and challenges in the diagnosis and management of respiratory allergies, confirming the worrying estimation that 1 in 2 Europeans may suffer from an allergy by 2015. The event was co-hosted by Members of European Parliament (MEPs) Miss Elisabetta Gardini (EPP, Italy) and Miss Nessa Childers (S&D, Ireland). Mr. Michael Hübel from the European Commission as well as the representatives from the Polish Presidency participated along with patients and other relevant representatives of NGOs and the medical community.

EFA European Federation of Allergy and Airways Diseases Patients' Associations

# A Breath of Fresh Air

## ***Call to Action: Raise Awareness, Relieve the Burden***

The event began with an introduction of **EFA President Breda Flood**, who overviewed EFA initiatives for addressing respiratory allergies in Europe. The publication of the new book represents a milestone which marks the commencement of a four year allergy awareness project.

The launch event for the book at hand, represented a vital opportunity for bringing together policymakers, patients, medical experts and other stakeholders to address their concerns for respiratory allergies. The book itself seeks to bring better awareness on the burden of respiratory allergies and to grant greater access to quality care and prevention for patients.



Mrs. Flood underscored the importance of the “Call to Action” contained in the book, which outlines six clear objectives for ‘relieving the burden’ of respiratory allergies on societies.

The speakers throughout the event added value to the Call to Action by offering recommendations on one or more of the following objectives:

- “1) Increase the political recognition of respiratory allergies as a real and serious disease;*
- 2) Promote national programmes on respiratory allergies;*
- 3) Prioritize the management and control of respiratory allergies;*
- 4) Promote training in allergy for healthcare professionals to improve accurate and early diagnosis;*
- 5) Align healthcare and reimbursement policies to support appropriate disease management;*
- 6) Improve indoor air quality”*



## ***An Unsettling Trend: the Increasing Prevalence of Respiratory Allergies across European Countries***

The editor and former **EFA President Dr. Erkkä Valovirta** presented the key findings contained within EFA’s book on respiratory allergies. The rationale behind the EFA Allergy Awareness Project is to address the growing likelihood that over half of European citizens could have chronic allergic symptoms by 2015. Dr. Valovirta reaffirmed book findings that there is low awareness at all levels, including among the patients themselves, and a general deficiency for understanding both allergies and asthma as serious public health problems. Information in the book was collected from EFA members (i.e. patients’ associations) representing 18 European countries and 414 million people in Europe.

Dr. Valovirta emphasized the “One Airway-One Disease” premise, which acknowledges rhinitis to precede the subsequent development of asthma in a patient. As a result, there are high costs to the prevalence of respiratory allergies throughout Europe, as “every fourth working patient took time off due to allergic rhinitis” and “every third studying patient took time off school” as the result of the same chronic condition. Dr. Valovirta emphasized inflammation as the key mechanism behind symptoms for chronic respiratory allergies. He noted that while there is no primary means for the prevention of respiratory allergies, plenty of steps can be taken to successfully reduce the number and frequency of severe exacerbations among patients.

**MEP Elisabetta Gardini** expressed concern over how “respiratory allergies remain a neglected disease.” She explicitly endorsed EFA’s campaign for awareness-raising with the support of the European Parliament while encouraging others present to “ensure allergies have a place in the 2014-2020 Health programme.” Together such measures could provide a means for countering the most recent trend and permit the treatment of respiratory allergies as a legitimate public health concern across EU member states.

In addressing the priority on respiratory allergies on behalf of the Polish Presidency, Professor Bolesław Samoliński presented the Polish Presidency prioritization on chronic respiratory diseases, which will lead to the adoption of Council Conclusions on 2 December. He expressed concern for increases in the frequency of allergy prevalence across Poland and other neighboring countries of Central Europe. Additionally, he shared alarming statistics confirming a 14% increase in the number of children (6-7 years old) with asthma in Poland, the highest increase in Europe. The Polish Presidency’s presentation specifically described the necessity to focus upon the prevention and management of allergies and asthma among children because their health is one of the risk factors in the unhealthy ageing across societies.





## ***Addressing the Challenges of Respiratory Allergies at the European Union***

The EU policymakers at the event collectively provided for a strong presence, representing the European Parliament, European Commission and Polish Presidency. **Mr. Michael Hübel, Head of Unit SANCO (C4)**, articulated that a challenge for the effective raising of awareness throughout Europe will be the ability of various respondents to contribute towards forming a cohesive response. In this way, the campaign to promote chronic respiratory diseases, including respiratory allergies, can be far more effective across all levels. However, such a process could begin through sharing consistent information across countries.

Mr. Hübel acknowledged the significance of the data collected by EFA in 18 Member States and the Call to Action points as they are “particularly relevant” in addressing socio-economic inequalities in healthcare. However, he also noted that the Call to Action points for respiratory allergies are “Member States responsibility, but the Commission has a role to play in addressing the risk factors, such as tobacco control and indoor/outdoor air quality.” Of particular relevance is the work performed between different Commission sectors and the World Health Organization (WHO) to mitigate tobacco smoke and support living healthy lifestyles.

During the event, the representatives from the Commission and Polish Presidency both highlighted the importance of the adoption of the Presidency Conclusions on 2 December, which will bring a political recognition on the burden of chronic respiratory diseases. By addressing the rising trend of chronic respiratory diseases, and respiratory allergies in particular, the much anticipated Presidency Conclusions will provide a crucial step towards promoting awareness in the both EU institutions and among European countries. In this way, political support can be generated to coincide with ongoing efforts at the national and local levels by governments, patient associations and other actors.

The importance of strengthening both European and national awareness promotion for improving indoor air quality was addressed specifically by **MEP Nessa Childers**. She attributes the decision of Ireland to be the first nation in Europe to ban tobacco smoking indoors as being “an absolute liberation” to her personal life. She confessed “it would have not been possible for me to become a politician without this ban. A smoke free environment is a huge issue every country should be dealing with.”

According to Ms. Childers, even within the European Parliament, MEPs often struggle with a lack of awareness of rhinitis, as they often overlook their conditions, which tend to worsen with air travel. To her surprise, indoor air quality in the Parliament buildings in Brussels and Strasbourg remains inadequately poor.



## ***Life with Respiratory Allergies: the Patient's Perspective***

In addition to remarks from MEP Childers of her own personal experience with poor indoor air quality and its effects upon respiratory allergies, two additional patient testimonies provided significant insight into life coping with respiratory allergies for all attendees.

**Joanna Bottema** agreed to travel from the Netherlands to participate in the event and share lessons learned from her personal experiences. As an active member of her local community, she expressed concerns with the deterioration of indoor air quality. The combined forces of inadequate climate control and increasing levels of fragrance use generate indoor environments of low compatibility with patients who have respiratory allergies.

Although the ban of smoking indoors in some European countries shows a positive trend, the patients still are at a disadvantage as they must be very attentive towards ingredients of almost all purchases on a daily basis. According to Mrs. Bottema, there are two ways to address allergies and asthma in public places. First, it is to improve indoor air quality through European level regulations on retail items, such as household products, with a greater potential to cause allergic exacerbations.



The other way is to improve healthcare for airways diseases, assuring early diagnosis and unified treatment processes, which are currently fragmented.

The second patient testimony came from **Sanna Kuuka** on the behalf of her son Alex. Her experience in seeking the right diagnosis and treatment for her young son within the Belgian healthcare system clearly demonstrates a greater necessity for respiratory allergy awareness even among primary care physicians. When Alex first began to experience severe allergic symptoms, Mrs. Kuuka was told Alex was allergic to milk and should avoid it at all costs. However, his symptoms never disappeared or showed any signs of improvement following treatments.

After being re-evaluated to possess a respiratory allergy and the prescription of appropriate medications, Mrs. Kuuka has witnessed a huge change with Alex's life. Thanks to correct medications and an accurate diagnosis, Alex is able to live a much more normal life as a small child. The story of Alex provides an inspirational message, which appropriately highlights the importance and relevance of the numerous recommendations the panel of respiratory allergy experts presented at the event.



**Dr. Jean Bousquet, representing ARIA**, described the Call to Action as “completely in line” with the World Health Organization objectives established for 2011, the Year of Respiratory and Allergy Diseases. With over 1 billion patients globally, the audience was reminded that task of raising awareness of these underdiagnosed and undertreated chronic diseases and conditions are not confined to continental Europe.



## Sharing Expertise

### *Partners of the Respiratory Allergies Project*

In order to contribute additional expertise to the event, the EFA partners of the respiratory allergies project were invited to make presentations to show solidarity on the subject. Participating organizations included representatives from ARIA, ERS, EAACI, GAL<sup>2</sup>EN and IPCRG.<sup>1</sup>

**Professor Torsten Zuberbier, the Secretary General of GAL<sup>2</sup>EN**, presented its project of a ‘pan-European surveillance system of allergy and asthma,’ which can track increasing intensities of allergy triggers, such as Ambrosia pollen, across Europe. Such a system is vital to identify trends and addressing their potential impact upon public health before they become serious problems. GAL<sup>2</sup>EN calculated the estimated costs of untreated patients amounted to a reduction in performance at work by 10-30%, which is a monetary loss of €24-72 per day. This is quite a contrast compared to the cost of treatment, which amounts to €1 per day. This evidence highlights the high burden of allergies on economies.

For the benefit of patients, Dr. Bousquet argued, an appropriate diagnosis is the first step to control and effective management afterwards allows patients to keep control. **Dr. Dermot Ryan, from IPCRG**, reiterated the necessity of ensuring treatment does not harm patients and stressed they must receive proper instructions for effective treatments. Personalized ‘action plans’ were also highly recommended to allow patients to reduce medication intake when necessary and keep control of the disease. Collective agreement among the experts present indicated all doctors and patients must increase cohesive awareness.



<sup>1</sup>See Acknowledgements on Page 8 for clarifications of acronyms

The trend of increasing prevalence for respiratory allergies and chronic diseases was a universal cause for concern among the experts as well.

**Professor Francesco Blasi, the President elect of ERS**, outlined the potential factors driving this trend. The list was extensive, ranging from gene-environment interactions to second hand smoke and occupational exposure for adults.

An increase in allergic rhinitis of greater than 5% has been observed in the last 5 years and such a trend continuing is particularly concerning as can result in 50% of children having the condition by 2020. Additionally, the influx of migrants from afar in many European countries can continue to increase the population of patients sensitive to respiratory allergies. Their new homes, neighborhoods and workplaces can trigger respiratory allergies as their bodies are exposed to a new environment.

**Pascal Demoly and Moises Calderon from the EAACI** contributed to the panel discussion by re-emphasizing the direct impacts upon quality of life associated with allergic diseases among European patients. These included decreasing efficiency at work for adults, decreasing performance, and increasing absenteeism at school for children. The failure to address allergic diseases clearly points to both a rise in healthcare costs while patients continue to experience more health-related impairments. The EAACI representatives pointed towards varying reimbursement policies across Europe as a worrisome representation of the costs associated with maintaining the status quo.



## Discussion and Conclusion

Following the speakers, time was given to discussions, providing an opportunity for Ms. **Agnieszka Czupryniak**, who is the **Chair of the Working Party on Public Health of the Council of the EU** to outline the Polish Presidency's work on respiratory diseases over the previous month while encouraging MEPs to continue raising awareness. She provided encouraging news by confirming the recommendations of the EFA Call of Action had been addressed in the Presidency draft Conclusions on chronic respiratory conditions to be adopted at the EPSCO Council on 2 December. As an additional insight, **Olli Seppänen of the Federation of European Heating, Ventilation and Air Conditioning** called for attention upon the need to promote a balanced approach on energy efficiency which also includes space for a debate on the importance of preserving personal health and indoor air quality.

The EFA Respiratory Allergies book launch event brought together a diverse group of stakeholders, sharing different experiences and expertise. A consensus was tangible among event speakers that the recognition of respiratory allergies is presently insufficient. The Call to Action and data from the book were well received and although the alarming rise in respiratory allergies presents a major health challenge for societies across Europe, the recommendations of experts and encouragement from policymakers can contribute towards enhancing progress and reducing the burden of these diseases

## Policy recommendations

- Actively promotes the six recommendations of the EFA Call to Action, which are in line with the draft Presidency Conclusions as an opportunity to encourage Member States to adopt national plans on rare diseases and therefore reduce costs to society and increase quality of life among patients. EFA recommendations are:
  - Respiratory allergies must be taken seriously as a public health problem;
  - National health programs for respiratory diseases must be adopted;
  - Respiratory disease management and control must be prioritized;
  - Healthcare professionals must receive adequate training for proper diagnosis and treatments to benefit patients;
  - Healthcare and reimbursement policies must be aligned to support appropriate disease management;
  - Indoor air quality must be improved
- Acknowledging Trends: Throughout the EU, the rising prevalence of respiratory allergies, especially amongst children, will be directly linked to the unhealthy ageing of European populations;

## Acknowledgement

The event was endorsed by Allergic Rhinitis and its Impact on Asthma (ARIA), the European Academy of Allergy and Clinical Immunology (EAACI), European Respiratory Society (ERS), the Global Allergy and Asthma European Network (GA<sup>2</sup>LEN), the International Primary Care Respiratory Group (IPCRG), and the World Health Organization's Global Alliance for Respiratory Diseases (WHO GARD) and supported by unrestricted educational grants from EFA sustainable funding partners ALK Abelló and Stallergenes.

To access the book online:

<http://www.efanet.org/documents/EFABookonRespiratoryAllergiesFINAL.pdf>

