

Report of the launch event:

Towards a European Health Union: BREATHE vision for the future

A BREATHE Vision for 2030.

European Parliament Lung Health Group January 27 2021, 10h00-11h15 CET Hosted byMEP István **Ujhelyi** (S&D, Hungary) and MEP Željana **Zovko** (EPP, Croatia)

#BreatheVision



Introduction

On 27th January 2021 the European Parliament Lung Health Group hosted the *'Towards a European Health Union: BREATHE vision for the future'*, the digital launch of the <u>Breathe Vision</u> for 2030. We were pleased to welcome over 200 participants to this event.

The Breathe Vision for 2030 reflects changes that lung patients want to see in their lives in the coming years. This initiative is led by a number of leading European-level patient and healthcare professionals' organisations, who have come together for the first time to focus on a vision for lung health. These organisations combined give a voice to half a million lung patients and 40,000 health professionals in Europe.

The Breathe Vision sets out to provide clear goals for lung health towards 2030, linking also to the UN Sustainable Development Goals (SDGs), such as SDG 3 on good health and well-being and SDG 10 on reduced inequality. The full range of opportunities in the vision provides a **positive approach to how lung health** can be significantly and realistically improved by 2030 and offer synergies in working towards a **European Health Union**.

The launch event discussed the current context of health in Europe and the five themes in the Breathe Vision for 2030: Awareness, Prevention, Access, Research, and the impact of COVID-19. Through these key themes, the participants reflected on how we can move forward to achieve healthier lungs for all in Europe by 2030.

The event was moderated by Tamsin Rose, Director at Tamarack.

Welcome

István Ujhelyi MEP: S&D, MEP Lung Health Group (Hungary)

MEP Ujhelyi remarked on the synergies between the Breathe Vision for 2030 and the call for a European Health Union, supported by the MEP Lung Health group alongside all of the large pro-European groups. MEP Ujhelyi highlighted the challenges and opportunities that the Breathe Vision provides, drawing on his own interest in health. For instance, the **need for better health** care, prevention and more patient-centred services were clear from the Hungarian consultation around creating a European Health Union. The EU4health programme has created a step towards this Union, as it was approved at the end of 2020 with the historical result of securing a budget 12 times larger than the previous mandate.

MEP Ujhelyi pointed to the importance of the Breathe Vision, with the collaboration representing 197 member associations to provide weight to the clear and realistic goals defined in the vision. The potential to work together to reduce the burden on national health systems by producing disease guidelines, prevention campaigns and education is significant and is supported by the EU.

197 member associations provide weight to clear and realistic goals defined in the Breathe Vision for 2030

Željana Zovko MEP: European People's Party, MEP Lung Health Group (Croatia)

MEP Zovko brought out the importance of moving the lung health agenda forward during this pandemic, highlighting that the Breathe Vision proposes to make EU healthier and more patient-friendly. With 600,000 deaths a year from lung disease prior to COVID-19, the need to promote lung health for both humanitarian and economic reasons is seen to be clear. MEP Zovko pointed to the need for a better understanding of risk factors and to translate dialogue into action. This is where the Breathe Vision can have an important contribution to prevention policies.



Pierre Delsaux: European Commission DG SANTE Deputy Director-General

Mr Delsaux noted that the Breathe Vision comes at a time of increased focus on health, due to the COVID-19 crisis. Simultaneously, a dialogue has started over a European Health Union with the European Commission and the European Parliament, with potential to exploit the increased funding that the €5.1bn EU4health programme will offer. Mr Delsaux pointed out that the medium-term targets and objectives in the Breathe Vision for 2030 can help improve our handling of crises in the future.



Mr Delsaux regards the European Health Union as providing the framework to allow all stakeholders to move in the same direction, working beyond nations as we have seen with the COVID-19 pandemic. This means more equity in terms of the strength of health systems across Europe with a new authority preparing us better for the future. All citizens should fight for this to happen.

A European Health Union can better prepare us for future crises

The Breathe Vision for 2030 demands, according to Mr Delsaux, are valuable input to the EU Health strategy. Policy change requires a wide range of input, including that from initiatives such as the European Health Emergency Preparedness and Response Authority (HERA) which will aim to help us better prepare for future crises, the EU pharmaceutical strategy, as well as existing agencies such as the European Centre for Disease Prevention and Control (ECDC) and the European Medicines Agency (EMA).

Moreover, the European Commission will adopt its <u>Beating Cancer Plan</u> in February 2021, including targets for lung cancer. This plan will have a holistic approach including prevention, early detection, treatment and quality of life. Stakeholders will be included in forming an ambitious and timely implementation plan. The EC commitment to a **tobacco free generation** and to a **greener Europe** are also clear synergies with the Breathe Vision.

Dr. Jill Farrington: WHO Europe Division of noncommunicable diseases

Dr. Farrington linked the Breathe Vision to the many WHO Europe programmes on lung heath. In this context, significant progress, such as the expected achievement of SDG on reducing premortality by a third and the reduced incidence and mortality in tuberculosis sit alongside big differences between eastern and western Europe. Dr. Farrington gave the example that in Eastern Europe air pollution is higher, which is linked to over 500,000 deaths, and tobacco use is among the highest in the world.

The advances of recent years are equally threatened by the pandemic. Dr. Farrington cited a WHO survey in 2020 which showed that 59% of countries had partial or complete disruption of asthma services and 60% had reduced tuberculosis services.

Dr. Farrington stated that WHO Europe calls for a partnership approach to enable united action for better lung health. This approach aims for universal health protection, improved preparations for health emergencies, stronger health systems and immunisation initiatives. Lung health is seen in multiple WHO programmes including updating global air pollution guidelines, strengthening the tobacco control framework convention, implementing the tuberculosis action plan, improving Cystic Fibrosis services and strengthening palliative care. WHO also embraces the move to digitalisation, and accounts for climate and air quality concerns.

59% of countries had partial or complete disruption of asthma services due to the pandemic



A poll asked attendees what they want to see from a potential European Health Union. The most popular options were:

- Information and best practice across the EU – 62%
- Disease prevention and better healthcare outcomes – 54%
- Greater EU interest in research 48%
- Better response to health threats –
 54%

Towards a BREATHE Vision for 2030

Mikaela Odemyr, President, European Federation of Allergy and Airways Diseases Patients' Associations (EFA)

Ms Odemyr remarked on how COVID-19 has brought health systems to the brink of collapse and that it is time to take lung health seriously. The virus has shown how fragile our lungs are and what it means to be out of breath.

Ms Odemyr noted that the European Lung Health Group produced the Breathe Vision to help move lung health in Europe forward. With **1** in **8** deaths in the EU due to lung diseases and 30% of asthma and COPD patients visiting the emergency room each year this shows the severity and impact of lung disease.

The Breathe Vision provides a set of principles to guide future European policies affecting lung health with **clear**, **achievable goals** to be reached by 2030. This roadmap is for everyone to make it a reality and Ms Odemyr called on organisations to endorse the vision.

Breathe Vision for 2030 provides a set of principles to guide future European policies

Prof. Thierry Troosters, Past-President, European Respiratory Society (ERS)

Prof. Troosters highlighted that despite the issues in responding to COVID-19, it has shown that we are able to respond quickly to emergencies, scaling up the EU vaccines strategy,

ECDC and EMA operations and massive investment accelerating research. It is now time to translate what we have learned in the pandemic into principles to achieve the 2030 SDGs, such as ending infectious disease epidemics.

Prof. Troosters related the five Breathe Vision themes to existing EU policies and programmes. For instance, awareness links to the ECDC work on disease control, prevention to the EU Green Deal and EU4Health programme, care to the new EU pharmaceutical strategy and research to the Horizon Europe programme. This synergy shows how we can work together to make breakthroughs in lung health, and in related diseases, as lung patients often experience several diseases at the same time.

Coherent collaborations and networks were felt by Prof. Troosters to be important in helping to push forward research and understanding. This can build on achievements like the ERS White book, and the ERN Lung network can help dissemination efforts and in bringing patients into policy development. Our networks can also provide a European Health Union with stakeholders to build and create policy change.

It is now time to translate the lessons we have learned in the pandemic into principles

BREATHE Vision for 2030 – a path forward, Roundtable

Raising awareness on respiratory disease

Gergely Meszaros, Project Manager, Pulmonary

Hypertension Association Europe (PHA-Europe)

In the first of the thematic presentations, Mr Meszaros reflected on how shocking it is when we think about the number of people with lung disease and the resulting human and economic cost. Given this, it becomes obvious that **action needs to be taken**. The cause of Pulmonary Hypertension (PH), a rare and often misdiagnosed disease is still unknown. Patients live with a breathlessness similar to that experienced after hard exercise. Yet 1 in 5 patients wait over 2 years for a correct diagnosis.



Mr Meszaros put forward that we need to better use resources and structures to improve lung health. This includes focusing on Health Technology Assessments (HTA) and incorporating patients fully into policy making decisions. Issues, such as a common lack of diagnosis or misdiagnosis, appropriate and comprehensive information is **needed** for both patients and healthcare professionals. This would allow better awareness of the guidelines.

Mr Meszaros highlighted that data needs to improve to better understand current prevalence rates, the impact and severity of disease and how it changes lives. Health literacy also needs to be improved at all levels, meaning identifying and exploring policy gaps and reaching people with lung health issues. Overcoming the negative perception or stigma over lung disease as something caused by patients is vital. World PH day has helped make a start in getting these messages out.

Stigma over lung health has to be overcome

Greater prevention of lung disease Anne-Marie Baird, President, Lung Cancer Europe (LuCE)

Ms Baird brought our attention to the fact that lung disease accounts for 1 in 8 of all deaths, yet only 3% of the EU health budget is spent on prevention. A multi-pronged risk reduction strategy and increased funding is needed.

Reducing the number of people developing diseases and improving the lives of those with disease can be achieved through prevention measures. Air pollution is the largest environmental health risk for lung disease. Ms Baird called for the **EU air quality framework to be implemented** and that continued tobacco use be met with stringent regulation, including for ecigarettes. Increased screening and specific lung health checks must be an EU priority. The WHO vaccination agenda should also be realised in the context of COVID-19.

Ms Baird believes that **Education around risk factors** is necessary to achieve these goals. People can have a **false sense of security if they are non-smokers**. For instance, COPD may be a risk for lung cancer, even in the absence of smoking. A focus on risk reduction for all air pollution and less known but widely prevalent causes like radon can better get the message across. The EU cancer plan needs to address these preventable risks.

Air pollution is the largest environmental health risk for lung disease, The EU Air quality framework must be implemented

Getting the right care Hilde De Keyser, Chief Executive Officer, Cystic Fibrosis Europe (CF-E)

Ms De Keyser captured the fact that before care can begin, timely and accurate diagnosis is needed for all lung diseases. To achieve this the major divide between the western and eastern European countries in access to healthcare needs to be addressed.

The EU Pharmaceutical Strategy promises to foster access to innovative and affordable medicines for patients. Within this Ms De Keyser believes that there is **ample space for the EU to act decisively for multi-disciplinary care** which enables active lives and ensures that innovative digital technology is available to all.

With Cystic Fibrosis (CF) the life expectancy of people has improved in many countries, resulting in most countries having more adult people with CF than children. However, countries remain with more people with CF under 18 due to lack of access to treatment and early diagnosis. The innovative drugs involved are very expensive and this has led to health driven emigration in recent years, affecting economies and patient lives.

Ill health costs the EU €380billon, yet access to healthcare remains inequal



Advancing Research into lung health
Liam Galvin, Secretary, European Idiopathic
Pulmonary Fibrosis and Related Disorder
Federation (EU-IPPF)

For Mr Galvin, Horizon 2030 itself is the main research priority. This programme provides the opportunity to contribute towards proven health models like the EU health network, and to act as a catalyst for best practice while eliminating duplication as far as possible.

A combination of pan-EU data collectives, registries and databanks enabling cross boarder research would address an unmet research need. Cooperation is vital for Mr Galvin in achieving this enabling infrastructure. Forming air quality initiatives and supporting innovation leading to better treatments is also required. 50,000 European lives are taken by lung scarring, with more cases expected following COVID-19. Therefore, a greater emphasis needs to be placed on a lung health research agenda driven by patient priorities.

COVID-19: Help or Hindrance for Other Lung Diseases

Paul Sommerfeld, Board Chair, Tuberculosis Europe Coalition (TBEC)

Mr Sommerfeld reported that he is fortunate to have received a first vaccination for COVID-19, which has been developed in just 9 months. Yet for tuberculosis (TB) we have to live with the weak vaccine developed over a 100 years ago.

Mr Sommerfeld has seen the impact of COVID-19 on TB services. PCR test machines have disappeared to be available for COVID-19 and staff have been switched to COVID-19 responses. The result is that 6 million more cases and 1.5 million more deaths from TB are expected in next 5 years.

Patient groups can play a significant role in health interventions.

While the overwhelming distraction of COVID-19 has harmed services of other diseases, it has given an impetus to digital technology. Mr Sommerfeld shares the belief that **research**

findings can advance treatment development and disease understanding in other areas. The pandemic has shown that that civil society and patient organisations are effective in reaching hard to access communities. For example, the Stop TB partnership in Tajikistan has trained 850 imams on COVID-19 and TB. After COVID-19 we will need to re-focus on research into TB and other lung diseases.



Audience questions and answers

Frank Willersinn of Alpha-1 Plus Belgium_asked how we can sensitise the general public about symptoms of rare conditions. While a difficult question, Mr Meszaros recalled the patient journey descriptions and the hurdles identified. The focus should be on professional education, with GP's, cardiologists and pulmonologists acting differently to **shorten time to diagnosis**.

Mr Meszaros noted that awareness measures are key to sensitisation, while patients can be empowered by HTA which give access to new information. Keeping pressure on patient involvement will help enable patient centred developments. Mr Troosters noted that medical societies can reach many health professionals through training in recognising the symptoms of lung diseases. ERS achieves this **ERN-LUNG** preparing materials by developed with patient input.

Krisnah Poinasamy from Asthma UK and the British Lung foundation asked how we can influence European research. Mr Troosters suggested using positive stories, such as using awareness of well-known outputs such as the COVID-19 vaccine to highlight the opportunity



and importance of research funding. Mr Troosters also called for **consistency in funding support,** as research evolves over many years. It is due to long term investment that COVID-19 vaccines have been able to be developed quickly.

Closing remarks

Kjeld Hansen, Chair, European Lung Foundation (ELF)

Mr Hansen closed the discussion by emphasising the efforts that have been made in creating the Breathe Vision, forming a great start to improving lung health in Europe. However, implementation is more important than planning. Now is the time to **build solutions to move forward**. The collaborative effort made developing the Breathe Vision and the European Lung health group show how this can be done. He emphasised that everyone should disseminate the Breathe Vision as far as possible.

Željana Zovko MEP thanked speakers and participants and committed to look at how to the contribution from the Breathe Vision for 2030 and discussion today can be incorporated into policy making. Over the last year the right will and means have been shown to achieve solutions. Building on the EU4Health programme is a first step in achieving change.

MEP Zovko noted that upgraded screening is recognised as vital in early diagnosis. Croatia has become the first EU country to deploy nationwide screening for early lung detection. It is hoped that other countries will follow this example. COVID-19 has been a **crisis but also a stimulus for progress**, for a European Health Union among things that can improve prevention, care and manage health supplies through the RISK EU programme. The Breathe Vision for 2030 provides focus and the MEP lung health group will act to move forward, aiming to finish the decade healthier with a common European approach that allows us to breathe easier.

Seán Kelly MEP: European People's Party (Ireland)

MEP Kelly noted that COVID-19 has highlighted health inequalities. In particular, those dealing with underlying conditions, such as COPD or asthma are at a higher risk. We have to address these health vulnerabilities in society, ensuring that all people living with lung conditions are prioritised for vaccines. MEP Kelly highlighted the impact of the backlog of lung disease cases due to COVID-19, and the danger to individuals health that this poses. A European Health Union would provide more co-ordinated efficient response to future crisis.

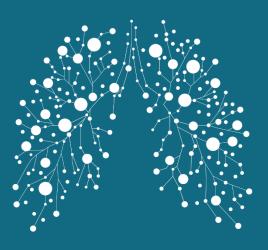
MEP Kelly closed by appealing to take advantage of the impetus that COVID-19 provides in order to improve lung health and research, to gain better treatment for infections and non-infectious chronic diseases at each stage of the disease.

We should finish the decade healthier with a common European approach that allows us to breathe easier



The moderator Ms Tamsin Rose thanked all participants and speakers. 47% of participants ranked the event as excellent and 40% as good. Questions can be posted through www.breathevision.eu/. You can endorse and disseminate the Breathe Vision for 2030 here: https://www.breathevision.eu/





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Watch the event recording

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