EU-IPPF and European Parliament celebrate achievements on rare disease policies

The EU-IPFF and MEP Elena Gentile (S&D, IT) hosted an event to discuss the health-related achievements of the current legislative term and look ahead to future political agendas.

Brussels – 20 November 2018. The S&D Group and the European Idiopathic Pulmonary Fibrosis Federation (EU-IPFF) today hosted an event at the European Parliament to review what has been achieved on the topic of rare diseases in the past four years and what remains to be done.

Against the backdrop of the current mandate of the European Parliament and European Commission drawing to a close, the event brought together stakeholders from across the health sector, as well as EU policymakers – notably MEP Elena Gentile (S&D Group, IT) and Annika Novak from the Cabinet of Commissioner Andriukaitis (DG SANTE) – to discuss how to ensure rare diseases remain a political priority for the new legislature.

Attendees at the event celebrated the achievements of the past few years, made possible by joining forces at a European level. These include the establishment of the European Reference Networks (ERNs) connecting highly-specialized European healthcare professionals working on rare diseases.

However, it was also acknowledged that gaps remain within and across EU countries when it comes to delivering care and treatment for complex, chronic conditions such as Idiopathic Pulmonary Fibrosis (IPF). These have been identified within a new Benchmarking Report which was presented by the EU-IPFF during today's event.

The Report outlines the current state of IPF care and management in Europe, identifying best-performing countries along with challenges that demand greater political attention and an immediate response. It showed an alarming variation in access to specialised care across countries and it called for the implementation of existing guidelines to help standardise processes and address health inequalities. The Report also showed that greater awareness of IPF signs and symptoms among general practitioners is needed to address delays in diagnosis, to increase referral to specialist care and to improve timely access to treatment, which can slow disease progression. It also highlights that too many barriers exist in access to non-pharmacological treatment including lung transplantation, supplemental oxygen, pulmonary rehabilitation, and palliative care.

Speaking about the importance of EU support for rare disease patients, EU-IPFF President, Carlos Lines Millán, said "The involvement of the European institutions fostered the hope of many patients, doctors and researchers. This institutional support has been translated into recommendations to member countries, into research aid and into better policies."

However he also noted the need for future leaders to continue with the work and ensure rare diseases remain a political priority, adding "Current decision-makers can still have a word to say on rare diseases, and notably by securing sufficient funding for scientific research in the negotiations of the Multiannual Financial Framework (2021-2027)".

While healthcare delivery remains a Member State competence, there is a role for the EU to play in sharing best practices and pooling resources, to benefit of all European IPF patients. The upcoming 2019-2024 European parliamentary term represents an opportunity for future EU leaders to promote radical policy change that can improve healthcare services and outcomes.

To receive more information on the EU-IPFF activities, and notably on the Benchmarking Report, do not hesitate to contact the EU-IPFF Secretariat at secretariat@eu-ipff.org.

ENDS

About the European Idiopathic Pulmonary Fibrosis & Related Disorders Federation (EU-IPFF)

The European Idiopathic Pulmonary Fibrosis and Related Disorders Federation (EU-IPFF) brings together 17 European national patient associations from twelve European countries. Its mission is to serve as the trusted resource for the IPF community by raising awareness, providing disease education, advancing care, and funding research. EU-IPFF collaborates with physicians, medical organisations, people with IPF, caregivers and policy-makers throughout Europe. For further information, please visit www.eu-ipff.org.

About Idiopathic Pulmonary Fibrosis

IPF is a rare, long-term, progressive disease that affects the fragile tissue in the lungs. It leads to a gradual, persistent decline in lung function. IPF typically occurs in people over 45 years of age, and is more common in men than women. About 110,000 people in Europe live with IPF, and 35,000 new patients are diagnosed every year. The disease is irreversible and, without treatment, half of all patients will die within 2-5 years of diagnosis.