

Press Release

Frankfurt, 9 May 2017

European reference network for rare lung diseases established

New hope for improved quality of care and measurable patient outcomes for patients with rare lung diseases across Europe

On March 1, 2017, the European Reference Network for rare respiratory disorders (ERN-LUNG) was launched, to advance and improve treatment and management of children and adults with rare and complex lung diseases.

Rare diseases are those that affect no more than 5 in 10,000 people. Taken together, between 6,000 and 8,000 rare diseases affect the daily lives of around 30 million people in the EU - many of whom are children. Rare and complex diseases of the respiratory system can cause chronic severe health problems and many of them are life-threatening.

The ERNs aim to bring together specialised research centres to combine expertise in the field. The EU's cross-border healthcare directive recognised the strength of this concept and officially recommended the creation of the reference networks in 2011.

ERN-Lung is currently made up of 60 centres in 12 countries and is organised into nine core networks representing the diversity of diseases and conditions affecting the respiratory system.

"ERN-LUNG is a network of European healthcare providers dedicated to ensuring and promoting excellence in care and research for the benefit of patients affected by rare respiratory diseases", states Prof. TOF Wagner from the Frankfurt University Hospital, coordinator of the Network.

Prof. Marc Humbert, vice coordinator from Hôpital Bicêtre, Paris, adds "ERN-LUNG's vision is to be a European knowledge hub for such diseases and to decrease morbidity and mortality from them in people of all ages".

The network is a non-profit, international, professional, patient-centric, and scientific network, which is committed Europe-wide and globally to the prevention, diagnosis, and treatment of rare respiratory diseases through patient care and advocacy, education and research. "Current systems aren't working properly and it is costly for patients to access treatment. Through the ERN-Lung, patients will have better access not only to treatment, but also expertise in their disease. This is really important", said Gergely Meszaros, European Pulmonary Hypertension Association and ePAG member.

ERNs create a clear structure for knowledge sharing and care coordination across the EU to improve access to diagnosis and treatment, as well as the provision of high-quality healthcare for patients and the training of professionals.

They are networks of centres of expertise and healthcare providers that are organised across borders. The first 24 ERNs were launched in 2017, involving more than 900 highly-specialised healthcare units from over 300 hospitals in 26 Member States. "ERN-Lung will allow us to build collaborative networks to drive future research into new and emerging therapies, and allow more

patients to access clinical trials. Through the network, we can build research capacity, which is especially important for the rare disease community”, said Kate Hill, June Hancock Mesothelioma Research Fund and ePAG member.

In practice, ERNs will develop new innovative care models, eHealth tools, medical solutions and devices. They will boost research through large clinical studies and contribute to the development of new pharmaceuticals, and they will ensure a more efficient use of costly resources, which will have a positive impact on the sustainability of specialised rare disease services by national healthcare systems.

ERN-LUNG will therefore improve the situation for tens of thousands of patients in the EU suffering from rare and/or complex lung diseases and conditions.

For more information, please contact: t.wagner@em.uni-frankfurt.de