Breathing LIFE

THE EUROPEAN PULMONARY FIBROSIS FEDERATION

Through its 22 member organisations from all over Europe who unite their voices, share experience and knowledge and communicate about Pulmonary Fibrosis (PF) care and treatment on a national level, the European Pulmonary Fibrosis Federation (EU-IPFF) creates impact and exerts influence on how individual countries handle the disease.

We serve as the trusted resource for a united PF patient voice by raising awareness, providing disease education, advancing care, and promoting research.

CONTACT

EU-IPFF AISBL
Abstratt 127
3090 Overijse
Belgium
secretariat@eu-ipff.org
www.eu-ipff.org

#BreathingLife
#PFMonth

About EU-IPFF

PF Awareness Month
September 2021

Voices OF AWARENESS

Steve Jones
Patient & EU-IPFF President (UK)

"Progressive pulmonary fibrosis is a devastating disease with a life expectancy of only 3-5 years, no known cure and few treatments. More people die from pulmonary fibrosis than some well-known types of cancer, but few people have ever heard of the disease. Patients face tough challenges due to slow diagnosis and difficulties in accessing treatments and supportive care. They fight both the disease and the lack of understanding among policymakers, doctors, researchers and the public. It is vital we do all we can to raise awareness of this cruel disease affecting so many European families and to encourage people to go and see their doctor at the first symptoms since early diagnosis and early treatment lead to better outcomes."

"In the next 5 years we will see a dramatic change in how we treat patients with PF."

Helen Parfrey, Chest physician (UK)
#PFSUMMIT21
Patients already lose a lot of lung function during the process of diagnosis. Awareness campaigns play an important role in getting patients to see a general practitioner and avoid delayed diagnosis. My urgent appeal would be: Don’t underestimate PF! As a patient, see your GP at the first signs and symptoms; as a GP, refer to a specialist at early stages; to my colleagues, start treatment as soon as possible.

Liam Galvin
Former Carer & EU-IPFF CEO Secretariat (Ireland)

"To have my wife diagnosed with an unknown disease was a shock, especially when we found out it was so serious. Its symptoms impacted all our lives. She struggled for breath. But with support from a patient group we adjusted our lives and enjoyed the things we could do rather than focus on what we could not. Anxiety for patients & carers alike is a big issue and one made harder by people not knowing the disease. Cancers are well known and unquestioning sympathy and support is rightly given. But for us we had to explain each day how serious pulmonary fibrosis is. This needs to change."

Marlies Wijsenbeek
Lung Specialist (The Netherlands)

"Patients already lose a lot of lung function during the process of diagnosis. Awareness campaigns play an important role in getting patients to see a general practitioner and avoid delayed diagnosis. My urgent appeal would be: Don’t underestimate PF! As a patient, see your GP at the first signs and symptoms; as a GP, refer to a specialist at early stages; to my colleagues, start treatment as soon as possible."