



EU-IPFF

Breathing Hope



What is IPF?

Idiopathic Pulmonary Fibrosis (IPF) is a progressive, irreversible, chronic disease of the lungs, which currently affects between 80,000 and 111,000 people in Europe. Every year, 30,000-35,000 new patients will be diagnosed with IPF.

In people suffering from this condition, the normally thin and pliable lung tissue becomes increasingly thick and scarred over time. As the scar tissue prevents oxygen from moving properly into the bloodstream, the disease leads to a progressive decline in lung function. As a result, the brain and other organs do not receive enough oxygen, which initially leads to symptoms such as shortness of breath and chronic cough and eventually to respiratory failure and death. IPF has no cure yet and is difficult to diagnose. Rapid deterioration in some patients means that many people only live 2 to 5 years after diagnosis.



80,000 – 111,000
people living in Europe
have IPF



IPF is categorized as
“idiopathic”, meaning that
the cause of this rare disease
is unknown



After diagnosis,
people only live
2-5 years



With some younger cases having
been recorded, IPF generally
occurs in adults
aged 50 – 80



Fewer than **5%**
of IPF patients receive
lung transplants



Approximately
30,000 – 35,000
new patients will be diagnosed
with IPF each year

EU-IPFF – Who we are

We are a group of 18 patient organisations from 13 European countries committed to changing the IPF landscape in Europe. We believe that everyone, regardless of geography, socio-economic status or age deserves equal access to treatment and care. Our common view has framed the past years and has led us to achieve a key milestone within the IPF community by establishing the first European IPF and other related disorders federation in July 2016.

Our commitment and ambition are grounded in one of our key achievements: the development of the European IPF Charter which was launched in the European Parliament in September 2014. The Charter lays down the rights of IPF patients and concrete policy recommendations that, if adopted, would ensure improvements in patients' quality of life whilst supporting efforts to find a cure. Together with a group of healthcare professionals, the founding members of EU-IPFF developed five key policy goals that we would like to see transformed into reality over the next years.

Our aim

EU-IPFF defends the rights of IPF patients at European level by supporting an immediate and sustainable improvement of the quality of life and survival time of IPF patients, and of patients suffering from other interstitial lung diseases.

We have established the following priorities for the years to come:

- To secure the adoption of the EU IPF Patient Charter across European States
- To support and represent European IPF patient groups and patients
- To encourage future research into treatments and care pathways
- To provide validated and accurate information to IPF patients and their families via online and offline channels

EU-IPFF members

Currently, the federation includes 18 patient organisations from 13 European countries:

<p>PRESIDENT (ES)</p>  <p>AFEFPI Asociación de Familiares y Enfermos de Fibrosis Pulmonar Idiopática</p>	<p>SECRETARY (IE)</p>  <p>Irish Lung Fibrosis Association www.ilfa.ie</p>	<p>TREASURER (BE)</p>  <p>Belgische Vereniging Longfibrose vzw</p>	<p>BOARD MEMBER (FR)</p>  <p>APEFPI Fibrose Pulmonaire Idiopathique L'olivier arbre de vie Le poumon source de vie</p>
<p>BOARD MEMBER (DE)</p>  <p>LUNGENFIBRO2E</p>	<p>BOARD MEMBER (IT)</p>  <p>fuori dal buio informazione studio ricerca tutela malattie orfane e rare</p>	<p>MEMBER (AT)</p>  <p>Lungenfibrose Forum Austria</p>	<p>MEMBER (AT)</p>  <p>LOT Austria</p>
<p>MEMBER (BE)</p>  <p>AB FPI vivre avec la fibrose</p>	<p>MEMBER (BG)</p>  <p>IDIOPATHIC PULMONARY FIBROSIS ASSOCIATION BULGARIA</p>	<p>MEMBER (GR)</p>  <p>HELLENIC PULMONARY FIBROSIS ASSOCIATION</p>	<p>MEMBER (HU)</p>  <p>MAGYAR TÜDŐFIBRÓZIS EGYESÜLET</p>
<p>MEMBER (IT)</p>  <p>FIMARP ONLUS</p>	<p>MEMBER (NL)</p>  <p>Longfibrose patiëntenvereniging</p>	<p>MEMBER (PL)</p>  <p>IPF</p>	<p>MEMBER (UK)</p>  <p>Action for Pulmonary Fibrosis</p>
<p>MEMBER (UK)</p>  <p>British Lung Foundation</p>	<p>MEMBER (UK)</p> 		

Why we need you to join EU-IPFF

As the first European IPF patient federation we require your support to meet our policy goals, increase funding for research and hopefully one day be able to find a cure for IPF. We ask patient organisations in countries all over Europe to join our efforts in fighting for our goals at the European and national level. We can only overcome local barriers, push local policy makers for change and eliminate treatment obstacles if we speak with a common voice.

If currently no IPF or other related disorders patient group exists in your country, please reach out to us and we will be more than happy to help you set up a support system. Our member organisations are equipped with many years of experience and ready to share with you our learnings and best practices and mentor you throughout the process.

If you are a member of a patient support group that already exists in your country, we urge you to get in touch with us and join our European efforts. The more organisations from different countries work together under the umbrella of EU-IPFF, the stronger we will be in fighting for our common cause.

How to join EU-IPFF

If you are interested in joining us as a patient group, healthcare professional or individual then please do not hesitate to contact us.

The annual membership fee for the EU-IPFF full members is 100 EUR.

Please note that there is the possibility to waive fees for socially vulnerable patients or organisations. A waiver is subject to the revision of your case by the EU-IPFF board.

Sponsorship

As a young patient organization, we rely on the support of our generous sponsors. Our sponsors (three industry sponsors – Roche, Boehringer Ingelheim and Galapagos) have continuously backed our activities, making it possible for us to create this federation and they continue to support us in our ongoing activities. We are also supported by Three Lakes Partners, a venture philanthropy organization created specifically to support the fight against IPF. If you and your company are interested in supporting EU-IPFF please contact us to discuss possible opportunities.

Contact details

If you are interested in joining EU-IPFF, need assistance in setting up a local patient group, would like to provide donations or sponsorship, please contact:

secretariat@eu-ipff.org