

European Idiopathic Pulmonary Fibrosis (IPF) Patient Charter

Idiopathic Pulmonary Fibrosis (IPF) is a chronic and ultimately fatal lung disease, the cause of which is still unknown.

There are currently between 80,000 and 111,000 people living with IPF in Europe and each year at least 35,000 people are newly diagnosed. It is anticipated that this number will continue to increase. IPF affects more men than women and usually occurs between the ages of 50 and 70. This rare condition has been consistently misunderstood, and as a consequence there is still no cure. Although treatments including lung transplantation and medication are available, their efficacy is limited. IPF can worsen rapidly and the survival time ranges from two to five years. Diagnosis is often delayed because of the insidious nature of the condition's onset and a lack of awareness of it amongst healthcare professionals.

With this European Idiopathic Pulmonary Fibrosis (IPF) Patient Charter, IPF Patient Organisations across Europe call on policymakers, healthcare providers, funders/payers and national governments to take action to help campaign for greater awareness of IPF, establish equal and better standards of care and to improve the quality of and access to care in European countries. The Charter lays down recommendations for national governments, European institutions and healthcare organisations that, if adopted, would ensure improvements in IPF patients' quality of life, whilst supporting efforts to develop better long-term treatments and ultimately find a cure.

European IPF Patient Organisations call for patients and their families to have consistent and fair rights to:

1. **Early and accurate diagnosis**, by raising awareness of IPF and recognising IPF as a chronic condition.
2. **Equal access to care, including medication and transplantation**, by coordinating timely and efficient drug approvals at a national level and revising the eligibility criteria for lung transplantation.
3. **A holistic approach to standardise IPF management**, by involving all aspects of support from early diagnosis to treatment and rehabilitation including correct referral, access to multidisciplinary teams, lung transplantation, emotional support, ambulatory and domiciliary oxygen services.
4. **Comprehensive and high quality information about the condition**, including its treatment, transplant information and emotional care for both patients and families.
5. **Better access to palliative care and end-of-life care**, with support for both patients and families.

The Charter has been endorsed by expert physicians and nurses actively involved in the management and treatment of IPF.

Join us in making these recommendations become a reality. We are seeking **35,000 signatures** - equal to the number of people in Europe who are newly diagnosed with IPF each year.

Sign the Charter now! Check out www.lpfworld.org/Charter

[Handwritten signatures: Hope, J. Hauck, Mike, SN, Wms, J. van der, Mike Ba]