

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^{1,2} 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. Treatments including lung transplantation and medication are available, but there is still no cure. IPF can worsen rapidly and the survival time ranges in average 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. [Read more](#)
2. **Equal access to care, including medication and transplantation irrespective of age**, by coordinating timely and efficient drug approvals at a national level and revising the eligibility criteria for lung transplantation. [Read more](#)
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. [Read more](#)
4. **Comprehensive and high quality information about the condition**, including its treatment, transplant information and emotional care for both patients and families. [Read more](#)
5. **Better access to palliative care and end-of-life care**, with support for both patients and families. [Read more](#)

The Charter has been endorsed by experts physicians and nurse 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.ipfcharter.org/the-charter/

European Idiopathic Pulmonary Fibrosis (IPF) Patient Charter

Call to Action

IPF Patient Organisations have identified concrete recommendations and urge European institutions, national governments, funders/payers and healthcare organisations to take the following actions:

1. Ensure early and accurate diagnosis

- Raise awareness of IPF amongst healthcare professionals by
 - Including IPF training in healthcare professionals' curricula and accreditation systems, so that also general practice physicians become familiar with the early signs and symptoms of IPF
 - Promoting and financing the development of specialist multidisciplinary teams throughout each country in Europe
 - Promoting standardised protocols and gold standard diagnostic methods that facilitate rapid and accurate diagnosis. This will help encourage non-specialist healthcare professionals to refer patients to established [multidisciplinary teams](#)
- Recognise IPF as a rare, rapidly lethal, chronic disease at a regional, national and European level

[back](#)

2. Irrespective of age, provide equal access to care, including medication and lung transplantation

- Coordinate timely and efficient drug approvals at national level and set up a European solidarity fund to allow access to drugs that have received [European Medicines Agency \(EMA\)](#) approval but are not marketed yet in some Member States as a result of delays in approval by national regulators
- Include the patient perspective in medical decision-making related to medical product approval and regulation.
- Revise the eligibility criteria for lung transplantation so that IPF patients have a realistic opportunity to undergo lung transplant irrespective of any age limitations

[back](#)

3. Promote a holistic approach to standardise IPF management

- Build and resource clinical networks at national level as well as [European IPF Reference Networks](#) (ERN) to serve as research and knowledge centres and ensure the availability of treatment facilities

- Encourage the establishment of IPF specialist [multidisciplinary](#) teams, including IPF nurses, emotional support experts to ensure early diagnosis and improved referral, appropriate treatment, rehabilitation, and access to ambulatory and domiciliary oxygen services
- Promote standardised protocols that determine care standards for patients and IPF nurses including guidance for reimbursement
- Encourage the development of local support groups given their role in providing information and peer support for patients, reducing feelings of loneliness and isolation
- Develop and finance specialist centres of care throughout Europe that can provide tailored clinical and emotional support for patients and families
- Provide more services in order to recognise the burden of this chronic disease including insurance, travel, financial, etc. for people living with IPF

[back](#)

4. **Ensure that comprehensive and high quality information about the condition is available**

- Develop high profile online information and promote public awareness and information campaigns on IPF at a national level
- Develop strategies and activities to empower patients by improving health literacy and the use of digital tools in health decision-making at both national and European level
- Set up and maintain national IPF registries and aggregate data into the European IPF registry developed by the [European IPF Network](#) to closely monitor IPF prevalence, detection, treatment outcomes and research development
- Create and implement fiscal incentives to foster research into fatal rare diseases including IPF
- Provide more funding and opportunities for patients to participate in IPF research by mainstreaming it into national agendas and the calls for European-funded projects under the European research framework [Horizon 2020](#)

[back](#)

5. **Increase access to palliative care and end-of-life care, with support for both patients and families**

- Ensure IPF patients have equal access to palliative care, such as access to hospice nurse, home care, etc. across the EU for both symptom management as well as end of life care, recognising that IPF deterioration can be unpredictable and sudden
- Acknowledge the psychological and emotional impact of IPF by providing access to the appropriate support services for patients with IPF and their families

The European IPF Patient Charter is supported by IPF healthcare experts and patient organisations, along with industry, united in an unprecedented European-wide call to action to address this under-recognised fatal chronic disease and to ensure consistent and fair access to quality care across European countries.

Glossary:

Multidisciplinary: composed of or combining several usually separate branches of learning or fields of expertise

Horizon 2020: The European Union Research Framework for the period 2014-2020 which received an endowment of €80 billion for the entire timeframe that can be allocated to research projects in a variety of areas, including health.

EMA: The European Medicines Agency, based in London, is the decentralised entity in charge of the scientific evaluation of medicines developed by pharmaceutical companies. The EMA is also responsible for the coordination of safety-monitoring of pharmaceutical products.

European IPF Network: The network was created in 2008 and received EU funding between 2008 and 2011. The Network created the EU IPF Registry in 2009 to collect longitudinal data from IPF patients.

European IPF Reference Network (ERN): As part of the Directive on patients' rights in cross-border healthcare, the Commission fosters the creation of reference networks amongst centres of reference across Europe. These networks should be knowledge and research centres, promoting research in particular in rare diseases but also treating patients. The importance of ERNs is particularly recognised in the area of rare diseases where available expertise and resources are scarce.

References

¹ Meltzer EB and Noble PW. Orphanet J Rare Dis 2008;3:822.

² Hodgson U et al. Thorax 2002;57:338342