

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: [Patients in the USA are also urged to sign the Patient Charter. Celebrate IPF World Week 2014, September 28 – October 5, by joining European Pulmonary Fibrosis patients in signing the Patient Charter!]

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

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

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

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

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



SIGN UP!

SIGN THE CHARTER

<http://www.ipfcharter.org/the-charter/>

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.



AMA Fuori dal Buio

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Belgische vereniging voor longfibrose

[\[visit website \]](#)



British Lung Foundation

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Association pour la fibrose pulmonaire idiomatique

[\[send an email \]](#)



Irish Lung Fibrosis Association

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Action for Pulmonary Fibrosis

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**Action for
Pulmonary
Fibrosis**



**Asociación de Familiares y Enfermos de Fibrosis
Pulmonar Idiopática**

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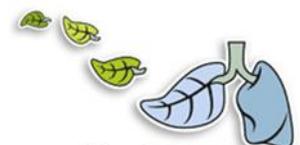
Longfibrose Patiëntenvereniging

[\[visit website \]](#)



Long Fonds

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LOT Austria

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And, in the USA ... the

European Idiopathic Pulmonary Fibrosis (IPF) Patient Charter

is endorsed by



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SIGN THE CHARTER NOW!

<http://www.ipfcharter.org>

IT: <http://www.ipfcharter.org/the-charter-ita/>

FR: <http://www.ipfcharter.org/la-charte-fra/>

ES: <http://www.ipfcharter.org/la-carta-esp/>

DE: <http://www.ipfcharter.org/die-charta-ger/>

NL: <http://www.ipfcharter.org/handvest/>

Post url: <https://www.rareconnect.org/en/community/fibrosi-polmonare-idiopatica-ipf/forum/topic/sign-up-the-ipf-patient-charter?from=modlink>



EUROPEAN IPF
Patient Charter

Support equal access to IPF treatment and care standards in Europe.
This initiative is supported by an educational grant from [InterMune](#)

Email: info@ipfworld.org

Web: ipfworld.org



September 28th through October 5th, 2014

RALLY FOR **MEDICAL RESEARCH**

CAPITOL HILL DAY

SEPTEMBER 18, 2014 • WASHINGTON, DC

September 18, 2014

Can't attend the Rally in Washington DC? No problem. You can still participate and make a difference by visiting with your US Senators & US Representative (or their Health Care staffers) in their offices near your home. Make a positive advocacy difference for pulmonary fibrosis! Need help? Call or write the [Pulmonary Fibrosis Advocates](#). 952.933.9990 paul@pfadvocates.org