What we do
EU-IPFF in action: promoting awareness and defending interests of PF patients across Europe through a united patient voice

**European Pulmonary Fibrosis Virtual Summit**
The first virtual PF Summit took place from 23-25 April 2021 bringing together patients, healthcare professionals, policy makers and industry representatives.

**Organisation of monthly webinars**
A series of EU-IPFF webinars. Everybody can join to meet professionals presenting and discussing the most relevant topics.

**Awareness Campaigns**
Annual Campaigns since 2017 to raise awareness during September as Pulmonary Fibrosis Month and IPF Awareness Week #MyPFStory

**Advocate Development Programme**
A one-year training programme for patient advocates active in member /associate organisations which aims to increase the members’ capacity as leading patient advocates in IPF/PF and enable them to become an influential expert patient advocate.

**Consultation Guide**
A guide to IPF and Pulmonary Fibrosis with patient testimonies and input from our experts. The guide is currently undergoing review and update including creation of two booklets for patients / caregivers and HCPs.

**Member training: access and policy**
To ensure that members of EU-IPFF through their respective country organisations, understand and can deploy the Benchmarking Report and the respective Country Reports in their local policy work.

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EU-IPFF in action: The EU-IPFF Charter

A patient-physician initiative aimed at gathering perceptions from European patient advocacy groups regarding inequalities and unmet needs in IPF care

https://www.eu-ipff.org/library/item/the-ipf-charter

• 11 European patient advocacy groups were interviewed regarding the care of patients with IPF in their countries

• Interview feedback was presented to a Working Group including patient advocacy group representatives and IPF specialists; key areas of agreement were developed into the European IPF Patient Charter

• The interviews identified five key themes that fed into the final Charter: the need for improved diagnosis, treatment access, holistic care, disease awareness and palliative care

• This patient–physician initiative highlights the inequalities and unmet needs in IPF care across Europe, and demonstrates how this insight can inform the development of a Patient Charter, designed as a call to action for healthcare policymakers to drive improvement in European IPF care.

Endorsed by patient advocacy groups and presented to 26 Members of the European Parliament in September 2014. It has received more than 8900 signatures to date
With a view to driving evidence-based policies, EU-IPF commissioned the first Benchmarking Report in 2018. Its goal was to measure how European countries, where EU-IPFF members are based, were performing against a number of criteria related to IPF care and management. A new edition of the report (2020) is now available and includes four additional countries. In 2022 the report will be extended to include a further 2 countries and a deep-dive of at least 3 indicators identified as of utmost importance to the patient community.

The Benchmarking Report aims to:
• Collect qualitative information about IPF patient care in Europe in order to compare the situation of patients between countries
• Identify gaps in IPF care in Europe
• Identify best practices in IPF care across Europe
• Make recommendations for solutions that could improve IPF care and the overall quality of life of people living with IPF
In April 2016, a written declaration on IPF was launched with the support of 16 Members of the European Parliament (MEPs). The declaration aims to promote better cooperation between EU Member States to address existing health inequalities and promote research activities to find its cause and a cure.

It encourages the European Commission and EU Member States to work together to…

...support timely access to treatment

...limit the delays in approval by national regulators of authorised medication

...address the existing inequalities in access to lung transplantation

https://www.eu-ipff.org/library/item/declaration-on-ipf