



## Dear members of the EU-PFF community,

**a lot has happened in the field of Pulmonary Fibrosis in the time since our last newsletter in September 2022** – please find the most important news, information and updates from the Federation together with an editorial from our President Steve Jones in the first newsletter of 2023.

### Editorial by EU-PFF President Steve Jones

**We held the Federation’s Annual General Meeting in April at Castelldefels, Spain.** Over three intense days, representatives of our member organisations, experts from our Scientific Advisory Board, guest speakers and industry representatives gathered to reflect on 2022 and look forward to 2023 and beyond



We welcomed new member organisations from Hungary and Turkey, took stock of achievements and decided together on future projects and discussed the overall mission and direction of the Federation. As a membership organisation we took the opportunity of the to strengthen our commitment to working together. We also forged new partnerships with our advisors, sponsors and other networks across Europe.

It was a joyous and productive reunion after such a long time of virtual meetings – with an abundance of new ideas, fresh perspectives, and new faces. **As the voice of pulmonary fibrosis patients in Europe, we are excited about the challenges ahead!**

## Latest news from EU-PFF

[View all](#)



### The EU-PFF Awareness Campaign 2023 is around the corner

Every year, **PF Awareness Month** takes place in September with patients, carers, health care professionals and organisations like the EU-PFF joining together from across the globe to raise awareness of PF – find out more about our campaign and how to support it [here](#).



26-28 April 2024, Castelldefels, Spain

### Save the date!

We are very happy to announce that the **3rd European PF Patient Summit will take place in April 2024**. This time, the event will be hybrid and we will have the opportunity to enjoy it face-to-face and learn together. For those who cannot attend on-site, the sessions will be streamed live.



### New EU-PFF website

New name, new website: As we changed our name, we took the opportunity to rebuild our website to make it more accessible and user friendly. Among other things, it now offers trusted information, recordings of our webinars, and an easy-to-use PF Clinical Trial Finder. [Please have a look.](#)



### New webinar series in 2023

On April 24th the EU-PFF launched its new **2023 series of free webinars for the PF community**. The first two sessions, including summaries with subtitles in 11 different languages, are now available on the [EU-PFF website](#).

### EU-PFF welcomes two new members

We welcome two new members which have been accepted as full members at the Annual General Meeting 2023 in April: [Tüdőfibrozis Egyesület](#), a pulmonary fibrosis patient organisation from Budapest, Hungary; and [PAHSSc](#), a pulmonary hypertension and scleroderma patient association based in Izmir, Turkey. Both were accepted by unanimous vote. **Thank you both for joining our cause and the Federation!**



### Summit Sessions with subtitles

The most popular sessions of the **2nd PF Patient Summit 2022** are now available with subtitles in German, Greek, Spanish, French, Bulgarian, Italian, Dutch, Polish, Romanian & Norwegian. Find them [here](#).

- *Pulmonary Fibrosis & Covid-19*
- *Latest research in PF*
- *Caregivers – the unrecognised patients*
- *Oxygen use*

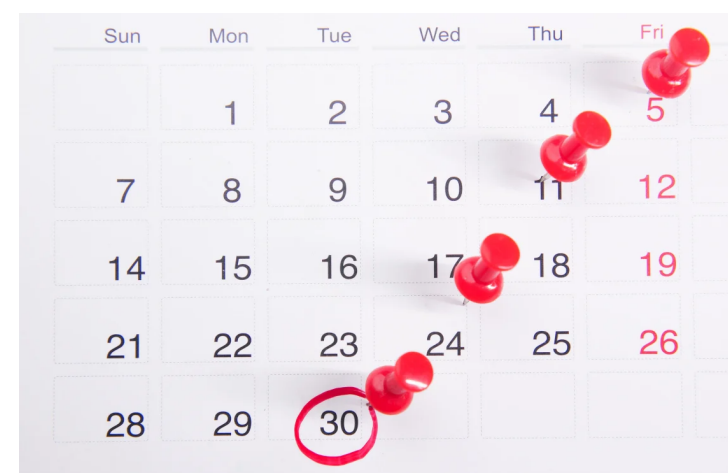


September 9 – 13, Milan

### ERS 2023: reduced tickets for patients

The European Respiratory Society International Congress 2023 will take place at MiCo in Milan, Italy from 9 – 13 September and bring together the world’s respiratory experts to showcase all the latest advances in respiratory medicine and science.

Attendance at the conference, where EU-PFF will also be represented, is open to patients and patient representatives at reduced fees. Find out more [here](#).



### The EU-PFF Adherence Project

In 2022, EU-PFF started to work on a Europe-wide survey on treatment adherence in PF patients. Its primary objective is to assess the extent to which people adhere to their medications and to investigate motivations and patterns of adherence. Learn more about the project [here](#).



### The 2022 PF Patient Summit Report is now available

From November 3rd-5th 2022, the second virtual European Pulmonary Fibrosis Patient Summit brought together patients and caregivers, healthcare professionals, policy makers and industry representatives, with 12 Sessions and 37 speakers covering a wide range of topics including clinical, treatment, patient involvement and research. You can find the report [here](#).



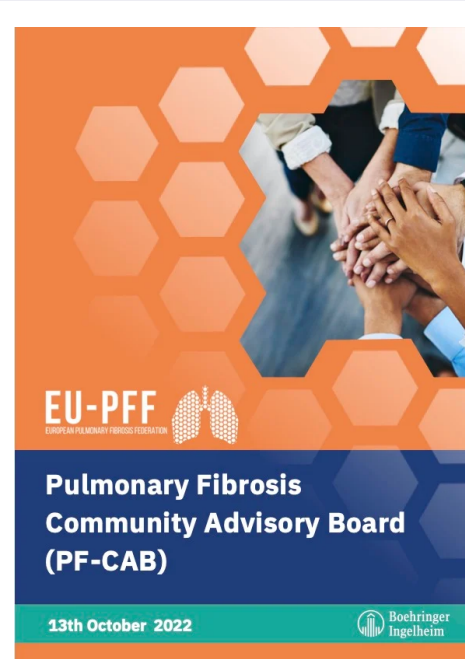
### EU-PFF Annual Report

The EU-PFF Annual Report 2022 has been published. It contains news, information and updates about the Federation, its members and staff as well as activities and projects carried out in 2022. You can find it [here](#).

### Pulmonary Fibrosis CAB – Report on first meeting available

EU-PFF has set up a Pulmonary Fibrosis Community Advisory Board (PF-CAB) as a working group of the EU-PFF. It comprises a panel of leading European patient advocates who can also call on other international experts. PF-CAB members work together to address issues of strategic importance to the PF community.

The report covers the first PF-CAB meeting, which was organised with Boehringer-Ingelheim. You can find it [here](#).



**If you have any questions, suggestions, comments or criticism, please email [secretariat@eu-pff.org](mailto:secretariat@eu-pff.org). Thank you!**

Kind regards,

The EU-PFF Secretariat

on behalf of the European Pulmonary Fibrosis Federation

## About the European Pulmonary Fibrosis Federation

- [Who we are](#)
- [What we do](#)
- [Get involved!](#)



### EU-PFF

Abstratt 127, 3090 Overijse Belgium

email: [secretariat@eu-pff.org](mailto:secretariat@eu-pff.org)

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