

Dear members of the EU-PFF community,

As the year draws to a close, you will find all the EU-PFF projects, events and news from the field of pulmonary fibrosis from the second half of the year in this newsletter - along with an editorial by our CEO Liam Galvin and a kind request to complete our <u>Adherence Survey</u> if you haven't had time to do so yet. Many thanks, Merry Christmas and a Happy New Year to you all!

Editorial by EU-PFF CEO Liam Galvin

Looking back on the past year, the federation has again devoted its focus on fulfilling its mission as the voice of pulmonary fibrosis patients in Europe. It has supported its members, welcomed new groups from Hungary and Turkey to join and expanded its advocacy team.



Dedicated to supporting the patients, carers and families impacted by pulmonary fibrosis, we work together in different ways to deliver our mission. Directly, during 2023 we have delivered our webinar series, various supportive guides, our Breathing Life Awareness Campaign, and also our international survey on treatment adherence in patients suffering from pulmonary fibrosis which is running until January 7th 2024. Indirectly, through our strategic partnerships such as with Eurordis, European Lung Foundation and the European Lung Health group among others, we have ensured that the voice of the pulmonary fibrosis community is heard by other stakeholders and policymakers.

numerous national and international projects, whilst the federation has been a successful partner in several EU-funded projects furthering the research around pulmonary fibrosis. Looking ahead, planning for our next big project is already in full swing: From 26 to 28 April 2024 we invite the patient community, researchers, healthcare professionals, representatives from industry and others to the <u>3rd European Pulmonary Fibrosis Patient Summit</u> in Castelldefels, Spain!

In addition, our members and the members of our SAB have been involved in

We would be delighted to welcome you there. You can find more information on the event in this newsletter.

Until then, all the best, happy holidays and a happy new year to you all!

EU-PFF Adherence Survey: We need your support!

Our Europe-wide survey on treatment adherence in patients suffering from pulmonary fibrosis is running until January 7th 2024. If you are a PF patient taking one of the two medications currently available, please help us by completing the survey. You can find it here.

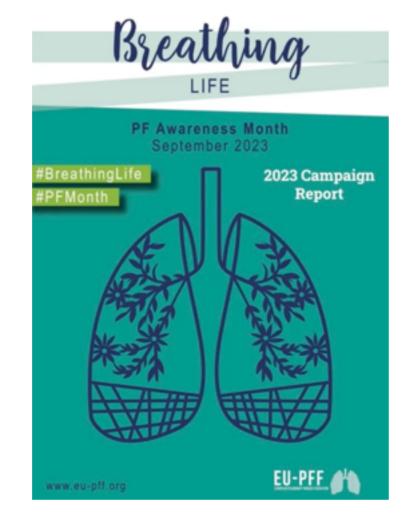
The survey is available in English,
French, German, Greek, Italian, Polish,
Romanian and Spanish languages.

Thank you very much for your time and support!



Latest news from EU-PFF

View all



The 2023 EU-PFF Breathing Life Campaign Report is now available

The report takes a detailed look at the background, rationale, design and execution of the campaign, and also includes a brief analysis of its social media performance. You can find the report here.

EU-PFF's delegation also played an



26-28 April 2024, Castelldefels, Spain

Save the date!

The 3rd European PF Patient Summit will take place in April 2024.

It will feature

- 6 plenary sessions,
- 2 recap sessions 6 parallel workshops

patients

2 industry symposiaand designated pulmonary rehabilitation sessions for

Registration for the hybrid event will open in January 2024 on the Summit platform. You can already find essential information on the event here

active role at this year's ERS **International Congress and gave** presentations on various topics: Chantal Vandendungen spoke together with her husband on the topic of palliative care, Jean-Michel Fourrier on the positive impact of exercising for patients with PF, John Solheim on symptom burden, and Stefano Pavanello on getting involved in international research networks. CEO Liam Galvin co-chaired the ELF Patient Organisation Networking day and spoke at the joint ERS/ERN-Lung Symposium. EU-PFF President Steve Jones also led our delegation in forging relationships via the many meetings we held with stakeholders including sponsors, industry, clinicians and researchers.



Pulmonary fibrosis: a supportive guide



"Pulmonary Fibrosis: a supportive guide" now available

Together with the European Lung Foundation, EU-PFF has developed a supportive guide for PF patients that covers essential aspects such as the disease itself, treatment, supportive care and living well. You can download "Pulmonary Fibrosis: a supportive guide", which will be available in other languages in the future, here.



Webinars #3 and #4 now available as recordings

On April 24th the EU-PFF launched its new 2023 series of free webinars for the PF community. **Webinars 3 and 4** are now available in full length on our website.

Summaries with subtitles in different languages will be available soon.

If you have any questions, suggestions, comments or criticism, please email secretariat@eu-pff.org. Thank you!

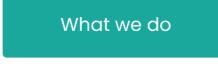
Merry Christmas and a Happy New Year to you all!

The EU-PFF Secretariat

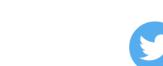
on behalf of the European Pulmonary Fibrosis Federation

About the European Pulmonary Fibrosis Federation

Who we are



Get involved!











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