

Welcome to EU-IPFF's Newsletter March 2021



**European PF
Patient Summit 2021**
Patients Driving Change

EU-IPFF is pleased to publish this new format of the EU-IPFF Newsletter, which is an integrated part of our new website.

The newsletter will from now on be published quarterly in March, June, September and December leaving space for special editions related to specific events.

This newsletter is dedicated to the first ever European Pulmonary Fibrosis Patient Summit, which will take place, virtually, from 23rd -25th April 2021.

It features

- Steve Jones, President of EU-IPFF giving his thoughts on the current status of Pulmonary Fibrosis seen through the light of the COVID-19 situation and previews the summit.
- Details and links on [Accreditation](#), Registration and the [Summit programme](#).

Enjoy your reading

Editorial by President of EU-IPFF Steve Jones



In 2020 EU-IPFF had planned to hold the 1st ever European Pulmonary Fibrosis Patients Summit in Warsaw, Poland. Unfortunately, we had to cancel the event at short notice due to the COVID-19 pandemic. Since then, we have monitored the COVID-19 situation carefully and have decided to hold the Summit as an on-line event in 2021.

We look forward to welcoming you in April

On 23rd-25th of April 2021 we will open the virtual doors to our Summit. We have many speakers confirmed and sessions covering three tracks on Research, Person-Centered Care and Policy and Advocacy. There will be presentations, panel discussions and roundtables and a special conference website, where all attendees can have an individual log-in and profile. Participants can choose which sessions to attend and which people to meet in the virtual conference room and registration is free to all.

In the lead-up to the Summit, we arranged four webinars covering the important topics of: [Optimising the quality of life for pulmonary fibrosis patients](#), [Genetics of ILD](#), [Progressive pulmonary fibrosis and co-morbidities](#), and [Pulmonary fibrosis and COVID-19](#). These were well attended with great Q&A sessions, which bodes well for the Summit.

The Summit takes place at a time when the pulmonary fibrosis community faces the difficult challenge of raising awareness of the disease with the public and health care professionals. The pandemic has made governments everywhere think more about respiratory disease and consult respiratory clinicians and patient organisations for advice, expertise, and support. While this overdue recognition of lung health is welcome, we need to focus policy makers' attention on the specific problems facing the 300,000 people across Europe living with pulmonary fibrosis. Our disease is not the same as asthma or COPD. Progressive pulmonary fibrosis has a worse prognosis than most common cancers, but we do not receive anything like the same level of support and care. While most cancer patients are diagnosed and start treatment in a few months, this is not the case for pulmonary fibrosis patients, who often must wait a year or more. Also, pulmonary fibrosis patients are especially at risk from COVID-19 and should be made a high priority for vaccination. There are many issues to discuss at the Summit!

We look forward to welcoming you from April 23rd to 25th together with the 300+ other people who are expected to attend.

I would like to take this opportunity to thank our many speakers and panelists for sharing their expertise and experience with us at the Summit and the many people who have submitted posters and abstracts. Finally, I would like to thank everyone involved in the organising this landmark Summit for their enthusiasm and help. I am sure it is going to be a great success!

Steve Jones

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Summit's conference page to open on 9th April 2021



The Virtual Pulmonary Fibrosis Patient Summit platform will be launched on 9th April 2021.

The Summit Platform will allow you to access the programme, visit the virtual exhibition and meet your fellow attendees.

Once you are logged in, set up your own profile and make the most of it in the two week run up to the Summit.

Everyone registered for the Summit will receive platform access alongside a user guide before the 9th so register now as registrations will close on **20th April**.

[GUIDE TO THE PLATFORM](#)

Calling all HCPS



European PF Patient Summit & EACCME Accreditation

Accreditation certificates will be issued upon request to Health care professionals who are registered and attend the live research sessions. The maximum award will be three points for those who attend all three of these educational sessions.

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Online translation in seven languages

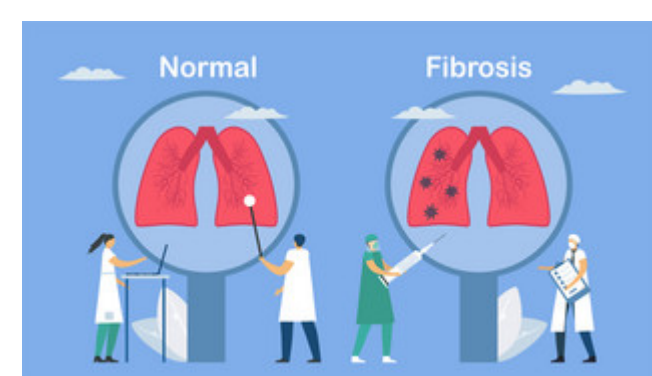


We are pleased to launch seven language options at the Virtual PF Patient Summit. Please tick your preferred language upon registration

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Abstracts and posters

We welcome abstracts and posters for three tracks - deadline 31 March 2021



EU-IPFF looks forward to receiving abstracts and posters covering the thematic sessions of three tracks - research, person-centred care and policy and advocacy.

Follow the link and find the guidelines

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Submitted abstracts and posters for the Virtual PF Patient Summit

Abstracts and posters for the summit are submitted on a continuous basis.

[ABSTRACTS AND POSTERS](#)

Three tracks at the Virtual PF Patient Summit

Person-centered care



An important part of the treatment and care of Pulmonary Fibrosis is the collaboration between the carer and the individual patient. Person-centered care, where the patient is encouraged to practice self-management of the disease plays an important part in living with Pulmonary Fibrosis.

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Get new insights on research and development at the Summit



There is no cure for pulmonary fibrosis and current treatments aim at slowing the course of the disease, relieving symptoms and helping people affected by PF stay active and healthy.

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The Policy and Patient advocacy track regards any activity which ultimately benefits a patient



Three Round Tables at the Summit will put focus on the support of newly diagnosed patients, how patient representatives may be involved in medical congresses and examining the status of new and ongoing EU policies impacting people with Pulmonary Fibrosis

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