

## Welcome to EU-IPFF's Newsletter June 2021



EU-IPFF is pleased to publish the June 2021 issue of the Newsletter, which inter alia features the successful #PF2021Summit, our latest webinar - and upcoming AGM, presentation of the latest new member organisation and the awareness month in September.

Enjoy your reading

### Editorial by President of EU-IPFF Steve Jones



Welcome to the summer edition of the EU-IPFF's quarterly newsletter. Summer brings positivity with the long summer evenings and never more so than now as we emerge slowly from the grip of the Covid-19 pandemic.

As life slowly goes back to normal for the many, I look back at what has been an extraordinary time for our federation with some major projects completed amid the difficulties of the past year and a half. We like our national members have worked closely with clinicians to provide support & advice to our patient communities during Covid-19 ensuring that pulmonary fibrosis patients were highlighted as priorities for vaccination and changing our organisations to reflect the new virtual needs of patients & their loved ones.

In this edition of our newsletter, we reflect on some of what our federation achieved in the year to date such as successfully hosting the 1<sup>st</sup> ever European Pulmonary Fibrosis Patient Summit but looking forward there is always more to be done and in July our membership will join together virtually for two days of meetings at our 7<sup>th</sup> Annual General Assembly. At this meeting we will discuss the many unmet needs of pulmonary fibrosis patients across Europe and no doubt as always, the lack of awareness by both the public and some professionals & policy makers around the disease will be a common theme.

So, I invite you all now, ready for this September to join with us, our members and patient groups around the world in making a special effort to raise awareness during Global Pulmonary Fibrosis Awareness Month, so please follow our social media channels for more details of our 2021 campaign. Full details of what we have done and what we hope to do this year which can also be found on our website [www.eu-ipff.org](http://www.eu-ipff.org)

I take this opportunity to thank all those involved in our patient summit, our webinar series, patient advocate training and the numerous committees, advisory boards, research projects & funding submissions that the federation has been involved in and look forward to everyone's continued support as we continue our advocacy, awareness, and policy work for the rest of 2021.

Happy summer to all.

Steve Jones

### Brilliant, excellent, inspiring and marvellous



Late April 2021 the three-day #PFSUMMIT21 took place. It was a success reflected by the feedback from the attendees (to the left).

The Summit included 15 Sessions and 52 speakers, covering a wide range of topics including clinical, treatment, self-management and research. 335 people actively participated in the Summit via the online platform.

Please find the recordings of the presentations at the Summit here as well as link to the report of the summit below.

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### 7th Annual General Assembly in July



EU-IPFF will host its 7<sup>th</sup> Annual General Assembly on 16<sup>th</sup> and 17<sup>th</sup> July - since it was officially founded in July of 2016.

It will be held virtually for the 2<sup>nd</sup> year running due to the Covid-19 pandemic.

Growing from a small informal group, the federation now has members in fifteen European countries, who will come together again this year to decide the 2022 workplan including goals and strategies to best support the Pulmonary Fibrosis patient community.

More details on the EU-IPFF can be found on our website [www.eu-ipff.org](http://www.eu-ipff.org) and a summary of the 7th General Assembly will feature on the website after the event.

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### Last webinar before summer – IPF and Cancer



On 1st June 2021 the EU-IPFF had the honor of having Dr Francesco Bonello presenting the most recent research into links between Cancer & IPF.

The recording of this webinar can be found at this [link](#).

Dr Bonello is an associate professor at the ILD unit of the University of Essen, Germany and was the founding chair of the EU-IPFF Scientific Advisory Board.

More webinars to come - keep an eye on our website!

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### EU-IPFF & the IPF & Me Exercise Programme

Stay active with an online Adapted Physical Activity programme. Designed for patients with Idiopathic Pulmonary Fibrosis.

Register for free on:  
[www.getphy.com/ipf-and-me](http://www.getphy.com/ipf-and-me)

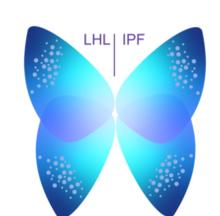
Supported by:

The federation has joined forces with the Siel Bleu Association to provide a free online Adapted Physical Exercise programme to patients with Pulmonary Fibrosis in the UK and Italy.

The IPF & Me programme was previously piloted by our Spanish & French organisations and was especially designed for IPF patients with the assistance of patients - patients in the UK or Italy can register through the link.

[READ MORE AND REGISTER](#)

### Introduction of the Norwegian Association of Heart and Lung Patients



The Norwegian Association has as the first Scandinavian lung association been a test member of the EU-IPFF for a year.

At the upcoming AGM the Board will make a final decision on their membership. Please find an introduction of IPF in Norway.

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### Global Pulmonary Fibrosis Month in September

Every September the Federation joins with its members and other groups around the world to raise awareness of Pulmonary Fibrosis, its signs and symptoms and its impact on patients and their loved ones.

Despite its severe nature and relatively collective high incidence the various diseases that make up Pulmonary Fibrosis remain virtually unknown to the general population.

Since 2017 the EU-IPFF has sought to provide a unifying message to its members to use on top of their own events and activities

This year we will continue to use the successful #MyPFstory & #CurePF branding. As an example, please see a video from the previous campaign: Alice's story. We are currently working on this year's campaign and will communicate about it when we get closer to September. So please keep an eye of our website ([EU-IPFF.org](http://EU-IPFF.org)) and follow our social media (find the icons at the bottom of this newsletter) for more details to support us this September.

**Global Pulmonary Fibrosis Month runs for the entire month of September whilst the 18<sup>th</sup> to the 25<sup>th</sup> of September has been specifically designated IPF Awareness Week.**

[WATCH ALICE'S STORY](#)



From Alice's story

### A news story from Ireland



RETIRED nurse Una McMillan's dearest wish is to see her grandchildren grow up, go to university and get married. But the 69-year-old Ballycastle woman and her family are painfully aware that she might not be able to enjoy these and other precious milestones.

A support group which has been recognised for its fundraising says sufferers of Idiopathic Pulmonary Fibrosis are being overlooked when it comes to timely treatment and financial assistance

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### Check the validity of social media content on IPF



Photo: Unsplash

EU-IPFF and its members provide trusted online resources for patients and their loved ones. A recent study shows that there are many social media pages around IPF but few check the validity of their content. Please be careful and use only trusted sites & talk with your doctor before following online advice.

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