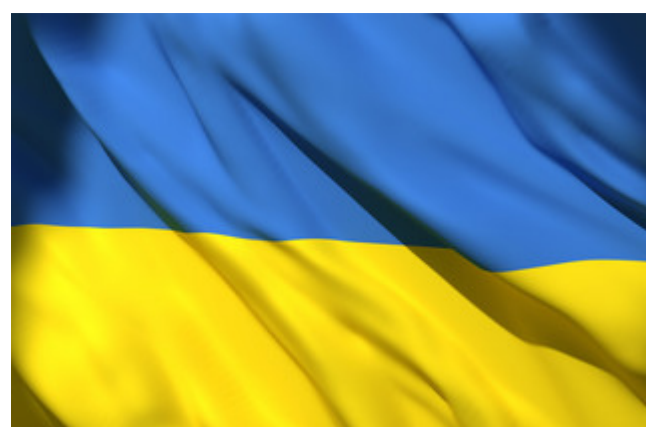


## Welcome to EU-IPFF's Newsletter August 2022



As a organisation dedicated to people, patients and health the EU-IPFF stands with the people of Ukraine, a innocent population suffering dire oppression and harm - we fully support the statement of [Eurordis](#) and join the many other organisations and governments across the world that condemn this unjustified war.

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



We held our EU-IPFF Annual General Meeting on 15-16 July 2022. At the meeting I was elected President of EU-IPFF for a second term of two years. I am delighted to be able to continue working with my amazing colleagues at EU-IPFF.

In just six years, EU-IPFF has become firmly established as the voice of Pulmonary Fibrosis Patients across Europe. Over this time, we have had many successes and have become recognised by official bodies across the continent. Most recently, I am pleased to report, we have become an eligible organisation of the European Medicines Agency (EMA), which means we can now nominate representatives to take part in EMA's scientific assessments, for example for new pulmonary fibrosis drugs and other treatments

Also, at the AGM, we agreed to change our name to the European Pulmonary Fibrosis Foundation. This change recognises our focus on patients living with all types of pulmonary fibrosis, not just IPF. The abbreviation will be the same "EU-IPFF" but with "European Pulmonary Fibrosis Foundation" as the tagline in the logo.

There is so much to do to tackle the challenges facing the pulmonary fibrosis community. In our 2023 -2025 strategy, we outline our future priorities. This was completed while implementing our 2022 work programme, which includes the annual Awareness Month Campaign in September, the second EU-IPFF Pulmonary Fibrosis Patient Summit in November and our webinar series. Additionally, the Board is busy working on advisory boards, committees and other activities to strengthen the patient voice in industry and among the researcher community

Despite the situation in Europe, with health care systems struggling due to COVID and under financial stress, we remain dedicated to creating awareness about pulmonary fibrosis, promoting research and development towards finding a cure for this dreadful disease, improving the treatment received by patients and improving access to lung transplantation for people living with pulmonary fibrosis.

We wish you a nice summer.

Steve Jones

### New elected Executive Board

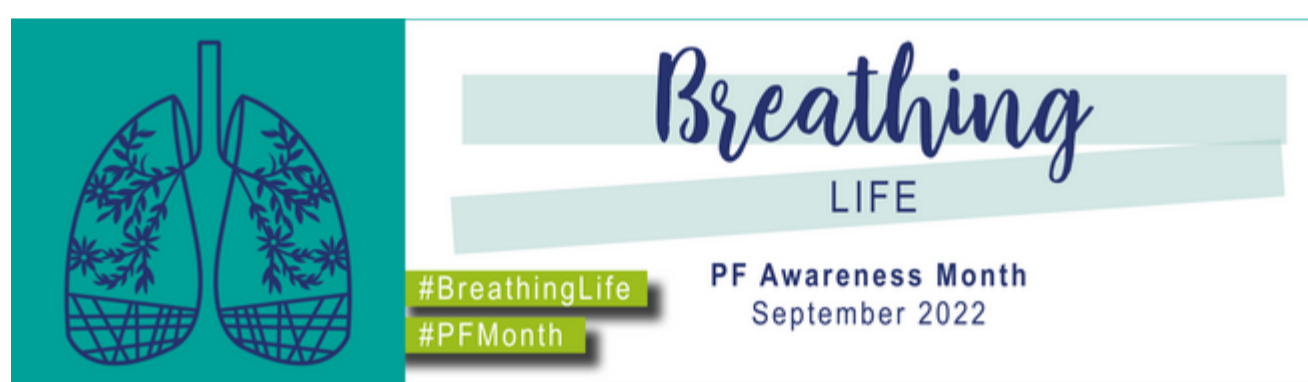


The EU-IPFF members re-elected Steve Jones, John Solheim and Stefano Pavanello to the Board of Directors at this year's Annual General Meeting whilst Steve Jones also kindly agreed to continue as President for the next two years. Chantal Vandendungen from Belgium, was elected as a new Board member

The Board and membership wishes to thank Ralph van Lysebeth from Belgium who stepped away from the Board for all his efforts and hard work over the years and we look forward to working closely with him as he continues to represent his Belgium Patient Organisation within the federation.

> WHO WE ARE

### Pulmonary Fibrosis Awareness Campaign in September



EU-IPFF's Annual PF Awareness Campaign will take place in September adding our voice to those of patients from across the globe during Pulmonary Fibrosis Awareness Month. During #PFMonth our community raises awareness of the disease, the many unmet needs of patients and the often long path they have towards diagnosis and treatment. With over 300000 Europeans and their families impacted each year by #pulmonaryfibrosis we not only focus on spreading public awareness of the disease but as well highlighting issues around early diagnosis and access to treatments.

Like many chronic conditions pulmonary fibrosis impacts not only the physical health of patients but also their mental health whilst their families are suddenly dealing with a disease many of them have never heard of. So during #PFMonth we highlight the need and benefits of not only of things like pulmonary rehabilitation, diet and exercise but self management ideas like mindfulness and yoga.

This September as we do throughout the year we are calling for resourcing of supports that we know make a difference - psychological services, specialised ILD nurses and dedicated social workers. This disease is hard for patients and hard for their loved ones and nationwide specialised supports should be there for them.

At national level our members and other patient organisations are calling and campaigning on behalf of patients as well as providing trusted information and whatever support they can. So please get involved this September, support #PFmonth and visit our campaign site where you can download materials for posting on your social media as well as ordering campaign pins and stickers.

The 2022 PF Awareness Campaign is kindly supported by an unrestricted grant from *Boehringer Ingelheim and Chiesi*

> 2022 CAMPAIGN SITE

### We need videos for the PF awareness campaign in September



As part of our PF awareness campaign we would welcome self recorded videos from patients, their loved ones or patient organisations to be used as campaign posts in September.

Like we did last year we will use the videos as posts on both our website and social media during #PFMonth. We are delighted to have already received some videos but we would love to receive more.

#### What do we need:

Video from patients or carers, talking about life with Pulmonary Fibrosis. What do you for instance do to maintain quality of life?

The video should be shot in landscape version. Length: max 1 minute and we might edit it as required to include for instance a brief introduction.

Use your phone's video function or use Zoom.

Send it via **What's app** to +4520488384 or to [randi.kragsgaard@EU-IPFF.org](mailto:randi.kragsgaard@EU-IPFF.org) at your earliest convenience and we will come back to you if we have any questions.

> SEE EXAMPLE FROM 2021

### EU-IPFF PF patient Summit on 3rd-5th November 2022



The 2nd EU-IPFF PF Patient Summit takes place virtually on the 3rd to 5th of November 2022. Save the date and keep an eye on the calendar and the website, where we will post updates regarding registration, the summit agenda, speakers and more.

The EU-IPFF have been hosting a series of six webinars leading up to the Summit with recordings of the first four available [on our website](#) in English with shorter summary videos of each webinar with translated subtitles also available.

Next webinars:

**Webinar #5** The role and importance of ILD nurses takes place on 19. September 2022

**Webinar #6** ERS Congress update and Summit Preview takes place on 10. October 2022

> READ MORE

### Introducing our NEW event calendar



Please check out this new feature where we will post EU-IPFF activities and other events to keep you updated and up to date on what is happening around Europe and the world in #PF and #RespiratoryHealth

> EVENTS