

Welcome to EU-IPFF's Newsletter September 2021



#BreathingLife: Patients around the world are united in their fight for better therapies and quality of life!



During Pulmonary Fibrosis (PF) Awareness Month in September 2021, the European Pulmonary Fibrosis Federation (EU-IPFF) wants to draw attention to PF by launching a campaign under the slogan "Breathing Life". The campaign aims to promote facts and understanding around PF and raise awareness, besides giving hope, creating a feeling of togetherness and showing our support to PF patients, their loved ones, and their carers. Even though there is currently no known cure, in view of medical progress and developments in therapy there are good reasons for optimism.

[> READ MORE](#)

Editorial by President of EU-IPFF Steve Jones



Why? Our focus on Pulmonary Fibrosis Awareness

September is one of the most important months in the calendar for the pulmonary fibrosis community in Europe and around the world. It's the time each year when we focus on raising awareness of pulmonary fibrosis and the impact it has on people living with the disease and their families.

The European Pulmonary Fibrosis Federation (EU-IPFF) was set up in 2016 by a group of patient organisations from different European countries, supported by leading doctors and nurses. A key aim of the new organisation was to raise awareness about this group of diseases, which is one of the greatest challenges facing our patients and their loved ones.

Living with pulmonary fibrosis is a challenge with patients and their families facing a range of problems, including late diagnosis and misdiagnosis, stigma, lack of adequate treatment and care, and lack of research. Every breath and every day is a battle for those living with pulmonary fibrosis. In view of this, EU-IPFF feels battling ignorance of the disease among the general public, policy makers and many clinicians is a battle, which patients, now and in the future, should not face alone.

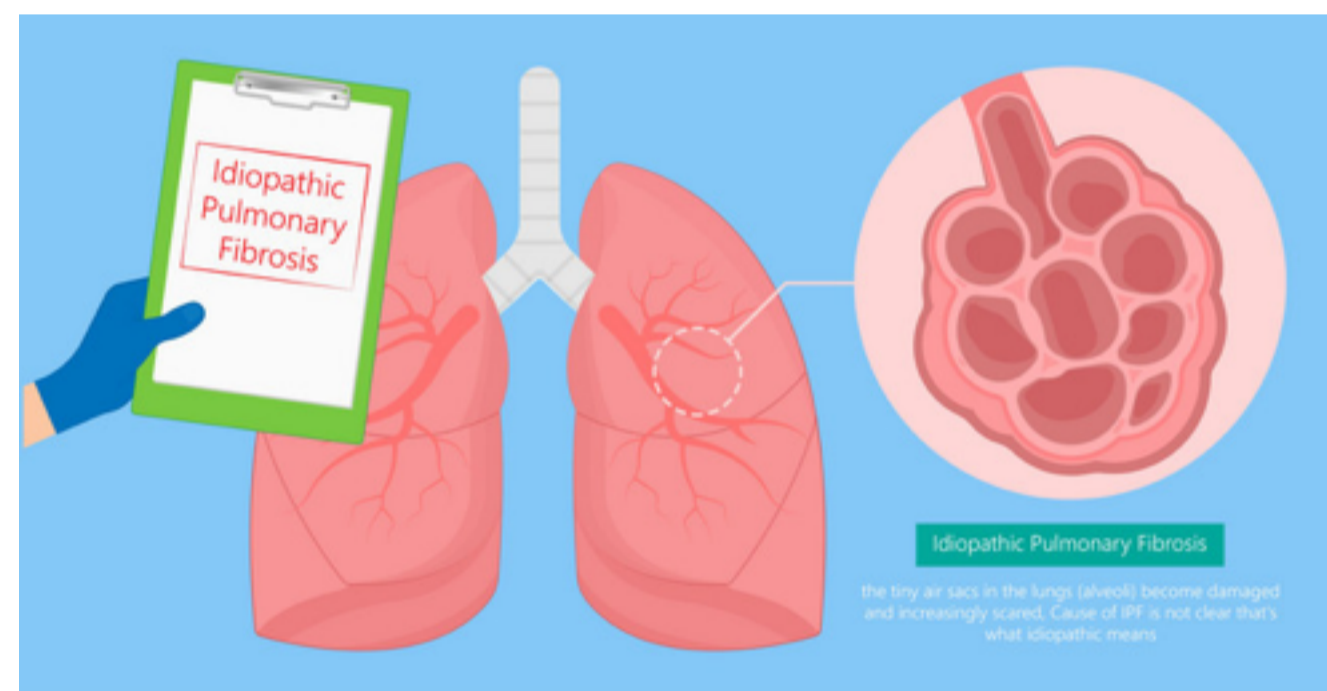
September each year is when we build on our everyday mission of awareness raising to join with the global community for #PFMonth, with one week specifically designated as #IPFWeek (IPF is the most common form of PF). This year our annual campaign focuses on the slogan #BreathingLife acknowledging the seriousness of pulmonary fibrosis but celebrating the hopes and positivity of our patient community. During recent years our campaigns have targeted the public, primary care health staff and general practitioners and of course patients.

We use our annual campaigns to highlight the signs and symptoms of the disease, the need for early referral to specialist centres, the facts and figures, and above all stories from patients, carers, and healthcare professionals.

At EU-IPFF, we believe every month should be awareness month and try hard to get issues for pulmonary fibrosis patients the same level of support and public recognition that is rightly given to those of cancer patients. Sadly, although the life expectancy of pulmonary fibrosis patients is worse than many common cancers, we do not receive the same levels of care as cancer patients. The lack of awareness needs to change which is why we need to take awareness seriously. We need to speed up the process of diagnosis and get people onto appropriate treatments as soon as possible and to get policymakers and health care systems to recognise the impact this little-known disease has on us and the health care systems we rely upon.

Steve Jones

Several research strategies pave the way for a revolution in the management and treatment of IPF



We have asked **Francesco Bonella**, Center for interstitial and rare lung diseases, University of Essen, Germany, to review current research in IPF.

[> READ THE REVIEW HERE](#)

PUBLIC AUCTION Hand cut filigree, artistic papercut lung under the hammer!



As part of the PF Awareness Month campaign, during IPF Awareness Week (18-25 September) we are launching a public action to raise funds for IPF research.

Beneficiary is ERN-LUNG, the European Reference Network on Respiratory Diseases. ERN-LUNG is a non-profit, patient-centric network of European healthcare providers and patient organisations, committed Europe-wide and globally to reducing morbidity and mortality from rare lung diseases in people of all ages through patient care, advocacy, education, research and knowledge-sharing.

[> READ MORE](#)

Free and daily online YOGA classes during IPF awareness week



Please feel free to join our YOGA classes from 18th - 25th September.

**As part of the #BreathingLife campaign during #PFMonth and our strong focus on quality of life, EU-IPFF offers daily online yoga sessions for everyone during IPF awareness week (18<sup>th</sup> to 25<sup>th</sup> September).**

Join us for 6 sessions of **chair yoga** and 2 sessions of **eye yoga** (a nice way of finding relaxation) by **Samantha Nier**.

[Register for classes](#)

[> READ MORE AND SEE PROGRAM](#)

#BreathingLife campaign



Campaign materials have been produced in 10 languages. The materials include flyers, bookmarks, postcards, stickers and posters, and pins to be distributed nationally to create and raise awareness of PF.

Digital versions of all material are available for download on the [awareness page](#) on the EU-IPFF website.

Use the hashtags below in your posts on social media and also tag #EU-IPFF

- #PF
- #PFmonth
- #BreathingLife
- #PFAwarenessMonth
- #pulmonaryfibrosis

[> READ MORE](#)

What is it to live with Pulmonary Fibrosis ?



Videos from members displaying life with Pulmonary Fibrosis

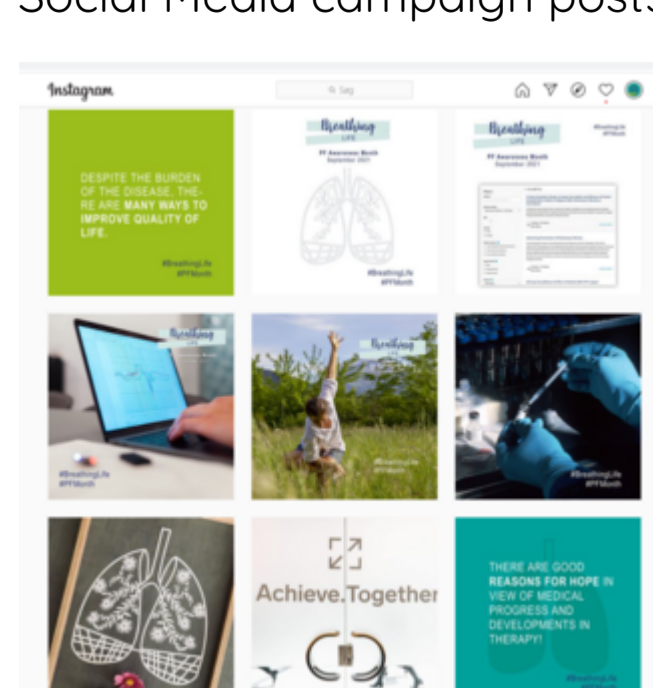
"Cycling became my second and favourite therapy" - says Achille Abbondanza. See Achille's [testimony](#)

Robert di Rocco had a double lung transplant. See his [testimony](#).

In this picture, Ron Flewett: "Using oxygen can make breathing and exercise easier, prevent or lessen complications from low blood oxygen levels, reduce blood pressure in the right side of your heart, and improve your sleep and sense of well-being"

[> SEE RON FLEWETT'S TESTIMONY](#)

Social Media campaign posts



The #BreathingLife campaign runs on the website and the social media Facebook, LinkedIn, Twitter and EU-IPFF's newest channel: Instagram

Various ways to be in touch!

Share our posts using the hashtags

- #PF
- #PFmonth
- #BreathingLife
- #PFAwarenessMonth
- #pulmonaryfibrosis

[> SEE INSTAGRAM](#)