

Breathing

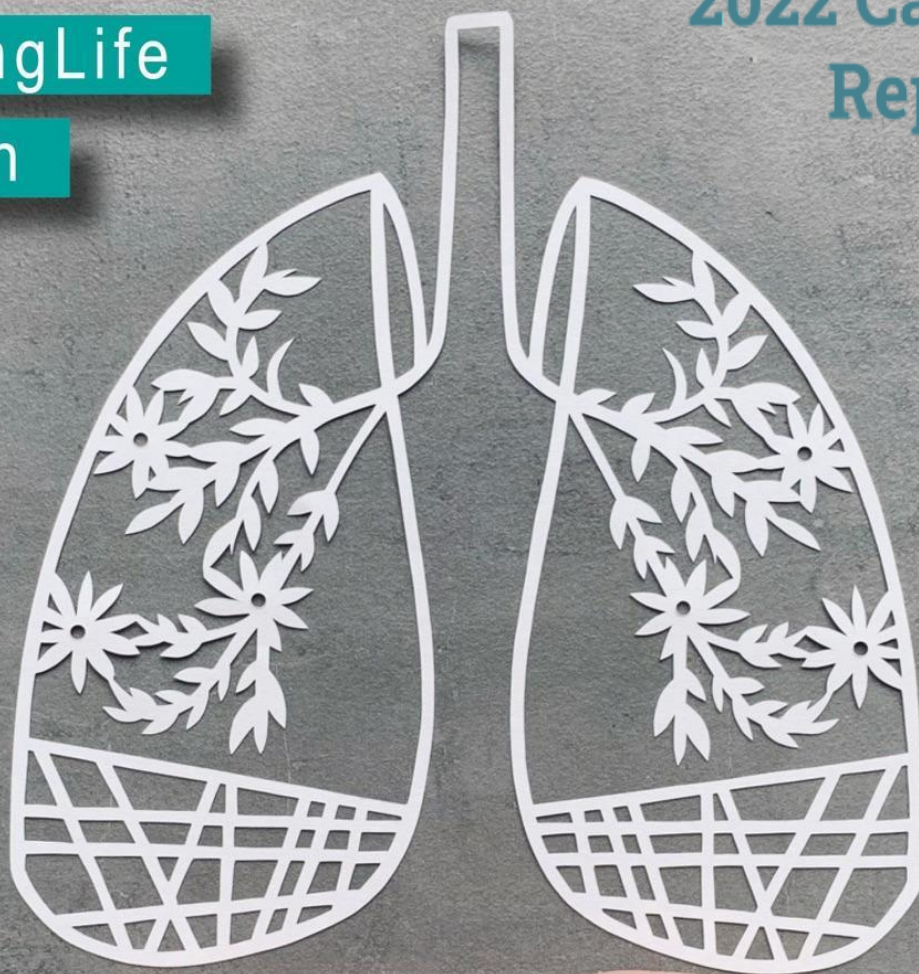
LIFE

PF Awareness Month
September 2022

2022 Campaign
Report

#BreathingLife

#PFMonth





Breathing LIFE

#BreathingLife

#PFMonth

PF Awareness Month
September 2022

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1. Introduction

This report summarises the activities carried out by Patvocates on behalf of the European Pulmonary Fibrosis Federation (EU-PFF) for the [2022 #BreathingLife Awareness Campaign](#).

Building on the concept of the [Breathing Life Awareness Campaign established in 2021](#) and following its success, the **second iteration in 2022** saw a continuation of its core principles and topics: using facts, figures and stories of patients suffering from PF, and with an additional focus on education and on the recently published [consultation guides for both healthcare practitioners and patients](#), this one-month-campaign run throughout the month of September was aimed at raising awareness of Pulmonary Fibrosis (PF) and specifically of Idiopathic Pulmonary Fibrosis (IPF) during IPF Awareness Week, and creating a broader public impact.

2. Rationale for PF Awareness Month & the 2022 Breathing Life campaign

Pulmonary Fibrosis (PF) is a progressive, irreversible, chronic lung disease causing scarring of the lung tissue with no known cure. About 400,000 people in Europe live with Pulmonary Fibrosis and some 100,000 patients die each year from the disease. The most common type of PF is IPF (Idiopathic Pulmonary Fibrosis), accounting for 200,000 patients in Europe. On average, PF patients die within 3–7 years of diagnosis.

Despite PF being such a serious disease, there is still a lack of awareness, which can result in late diagnosis, losing valuable treatment time and, above all, time to enjoy life.

PF Awareness Month - again using the slogan "Breathing Life" in 2022 - wanted to draw attention to PF, its implications and the challenges it brings about in daily life as well as the physical and psychological strain that the disease places on patients and their loved ones - but also to the essential moments of lightness, normalcy and happiness that patients with PF still experience despite this burden.

EU-PFF's PF Awareness Month takes place each September and coincides with the globally recognised Pulmonary Fibrosis Awareness Month established to raise awareness of PF and to help patients, carers and families who have been affected by this terminal condition. Additionally, EU-PFF puts emphasis on key topics such as:

- The disease Pulmonary Fibrosis (PF) / fibrotic interstitial lung disease (fILD)
- Disease course and progression
- Diagnosis
- Treatment (pharmacological and non-pharmacological)
- Self-care
- Support

3. Core concept of the 2022 Breathing Life campaign

The 2022 Breathing Life campaign followed a script and was built on **four pillars**:

- a) **Educating PF patients** (disease, diagnosis, treatment, self-care and support).
- b) **Giving patients a platform and a voice** by publishing short video statements – the “Voices of Breathing Life”.
- c) **Targeting healthcare professionals** with tailored content once a day.
- d) **Promoting the consultation guides** as a new resource for health care practitioners to quickly diagnose and appropriately refer patients, and as a means of empowering patients to manage their illness in an informed manner.

4. Continuing the journey: building on the success of 2021

In 2021, with the help of a **graphic designer**, Patvocates created [a range of consistently designed digital and non-digital materials](#) translated in 10 languages, including **booklets, flyers, customisable postcards, stickers as well as enamel pins** – and a unique visual specifically developed for the

campaign which aimed to demonstrate the vulnerability of the lungs and – at the same time – convey a message of hope. The central campaign visual, an **abstract representation of the human lungs**, visualises the scarring of the lung tissue, with natural elements such as flowers and leaves symbolising the concepts of “life” and “breathing”.

A. Social Media concept of the 2022 campaign

Given the success of the 2021 campaign, these materials and the core visual, including a **teaser video** ([with](#) and [without](#) voice over), **were reused and updated for the 2022 campaign**, as were the hashtags **#BreathingLife** and **#PFMonth**, encouraging **patients to tell their personal story by sharing a video about their experience of living with PF**. The campaign team then edited the videos for campaign purposes and published them on Facebook, Twitter, Instagram, LinkedIn and the EU-PFF website.

Like last year, **Patvocates took over the management of EU-PFF’s social media accounts** ([Twitter](#), [Facebook](#), [Instagram](#) and [LinkedIn](#)) to promote the #BreathingLife Campaign. The team produced **tailored social media posts and visuals**, targeted at patients, carers, health care professionals and other stakeholders as well as the general public between September 1st and September 30th 2022.

What is more, for this year’s campaign **key posts (about one post a day) were translated into 8 different languages** (French, German, Greek, Italian, Polish, Portuguese, Romanian and Spanish) to enable the Federation’s national member organisations to get the key messages out to their patient communities.

B. Physical campaign material

To further support local patient organisations and their respective awareness campaigns and activities during Pulmonary Fibrosis Month, Patvocates also shipped **2050 magnetic pins** and more than **1000 PF Awareness Month stickers** to different destinations in **10 European countries**.



C. The EU-PFF Consultation Guides: leaflets and videos

2022 saw the publication of two new [EU-PFF Consultation Guides](#): the EU-PFF "**Guide to Living with PF**", a free resource for newly diagnosed patients containing key information on the most important aspects of living with PF, e.g. managing the disease, diagnosis and treatment, self-care and support groups; and the "**Guide to Treating fILDs**" which provides essential information and an overview of the most important aspects of the disease – from symptoms to diagnosis and treatments to disease course and progression – and supports practitioners and HCPs working in the field of fILD in diagnosis and their decision-making process, and helps them quickly refer patients to the right specialist.

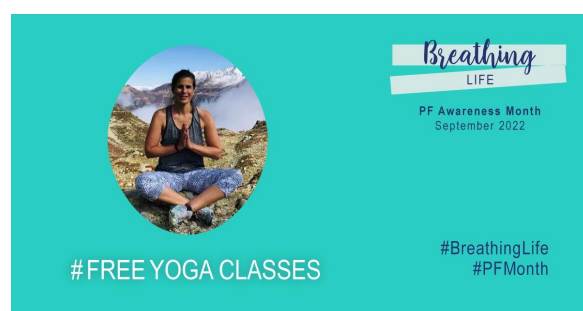


Both guides, on the one hand as an **indispensable tool for HCPs** to treat patients with Pulmonary Fibrosis adequately, and as a **self-empowerment tool for patients** on the other hand, were **cornerstones of the 2022 Awareness Campaign**, the **central aim** of which is to **educate PF patients and the general public whilst improving clinical pathways for PF patients around the world**.

Therefore, Patvocates commissioned a design studio with the creation of **two audiovisual versions of said guides** which can be found [here](#) – as **full videos** or split into **chapters**.

D. Yoga and meditation sessions

Throughout Pulmonary Fibrosis Awareness Month, the EU-PFF also offered free yoga and meditation sessions (2 online classes per week) tailored to the needs and capabilities of PF patients. Meditation and yoga both demonstrably improve general well-being, reduce stress, increase energy levels, and improve quality of life. Yoga furthermore improves breathing and lung capacity. True to the motto "laughter is the best medicine", once a week, laughter yoga instructor Marian Reilly taught patients how to bring more laughter to their lives, while chair yoga & eye meditation instructor Samantha



Nier led the second session of the week. Courses were free of charge and open to everyone interested.

E. European Pulmonary Fibrosis Patient Summit 2022

The 2022 Breathing Life Campaign also **shed light on the second European Pulmonary Fibrosis Patient Summit** which took place virtually from November 3-5, and invited patients, experts, clinicians and



European PF
Patient Summit **2022**
Patients Driving Change

researchers to discuss, network and learn about the latest insights in Pulmonary Fibrosis. The programme of the Summit, its 12 sessions and dozens of expert speakers offered plenty of variety, new and relevant insights from research and care - and, above all, put the patients' perspective at the centre of the event.

Conceived as a European Patient Summit, the event also offered live translations for each session in the following languages: Spanish, Italian, French, Greek, Bulgarian, Dutch, Polish, German, Romanian & Portuguese.

5. Social media performance and statistics (September 1st – 30th 2022)

During the 2022 Breathing Life campaign, **an average of 118 posts (3,93 posts/day)** were posted across all social media platforms ([Twitter](#), [Facebook](#), [Instagram](#) and [LinkedIn](#)). What is more, for this year's campaign, **key posts (about one post a day) were translated into 8 different languages** (French, German, Greek, Italian, Polish, Portuguese, Romanian and Spanish), published on these for Social Media platforms and provided them to the Federation's member organisations in order to enable them to get the key messages out to their respective patient communities.

A. Twitter

The campaign team posted 126 dedicated tweets highlighting the #BreathingLife 2022 campaign, including **8 personal video messages** provided by PF/IPF patients and healthcare professionals as well as **3 additional videos by patients as well as healthcare professionals with the aim to promote the two EU-PFF Consultation Guides**. In addition, **a total of 17 short**

clips - created by a design studio and edited by Patvocates - to promote the new Consultation Guides and to provide useful information as well as raise awareness of the disease were published. Besides these short clips, **2 full-length audiovisual versions of said guides were produced and promoted.**

Over the course of the 2022 Breathing Life campaign, @EU_IPFF tweets reached 80,020 impressions, were retweeted 406 times and received 1.122 likes, i.e. an average of 2,667 impressions, 13,53 retweets and 37,4 likes per day.

• Top Tweets

The campaign's **most popular post** (by likes) on Twitter **gained 8,254 impressions, 175 total engagements and 52 likes and 33 retweets.**



The campaign's **second most popular post** (by likes) on Twitter **gained 2,330 impressions, 96 total engagements and 24 likes and 12 retweets**



B. Facebook

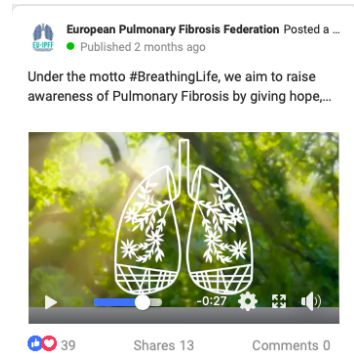
From September 1st–30th, EU-PFF posted 121 Facebook posts. Each post included either a photo, a link, a dedicated visual or a video.

During the 2022 Breathing Life campaign, the EU-PFF Facebook page reached 20.630 users and gained 1.053 reactions (= comments, shares and likes).

The campaign's 20 dedicated videos gained 404 interactions and were viewed for a total of **1.999 minutes or 20 hours.**

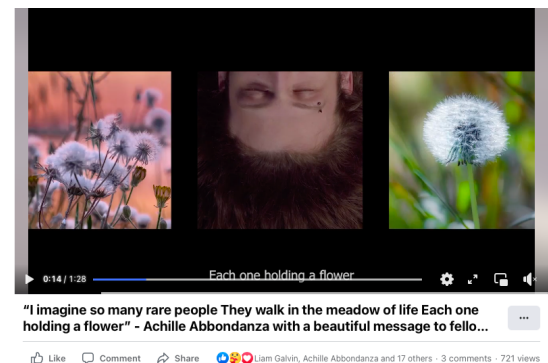
Top Post

The EU-PFF's [most popular campaign post](#) on Facebook **reached 2K** users and gained 52 reactions, comments and shares as well as 68 clicks **to date**.



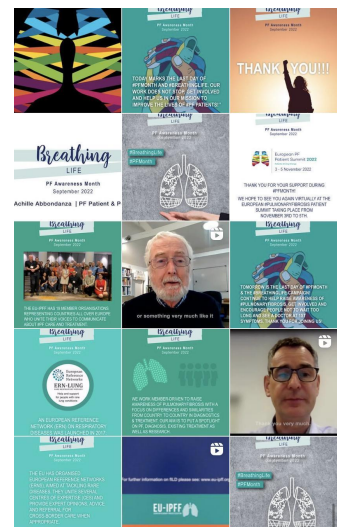
Top Video Post

The EU-PFF's [most popular video post](#) on Facebook received **80 likes** and **17 comments**, was **shared 16 times**, and was viewed for a total of **4,7 hours**.



C. Instagram

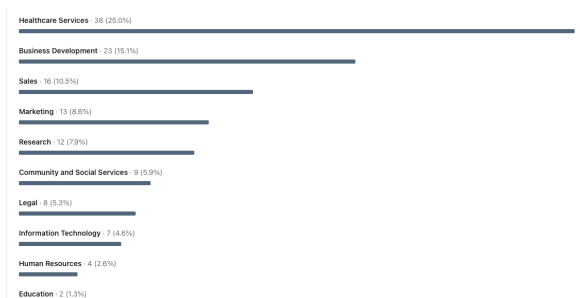
While Instagram, in terms of target audience, reach and user behaviour, **is certainly not an ideal platform** for a campaign raising awareness of Pulmonary Fibrosis, **there are positive results to report**: From **September 1st-30th**, **119 posts** dedicated campaign posts garnered **5.738 impressions** and **403 likes** and reactions - impressive numbers, also considering a relatively small number of 147 followers to date.



D. LinkedIn

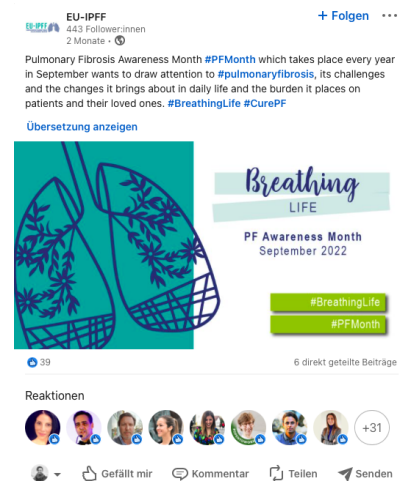
On LinkedIn, 109 posts from **September 1st-30th** gained **143.911 impressions** (127.707 sponsored), **850 clicks** (666 sponsored), **573 reactions** (4 sponsored) and **113 shares**. In addition, the EU-PFF's profile gathered 70 new followers during this period.

What is more, **152 users visited the EU-PFF profile** from Sep 1-30. The chart on the right-hand side shows distribution of new followers by industry.



Top Post

The EU-PFF's [most popular post on LinkedIn](#) received **42 reactions, 6 shares** and **96 clicks**.



6. Sponsors of the 2022 Breathing Life awareness campaign

EU-PFF would like to sincerely thank its sponsors - Boehringer Ingelheim and Chiesi - for making it possible for the Federation to run this year's Breathing Life awareness campaign and raise awareness of PF amongst the Pulmonary Fibrosis community, the public and beyond. Thank you for your commitment and continuous support.



**Boehringer
Ingelheim**



Chiesi