

Breathing

LIFE

PF Awareness Month
September 2023

#BreathingLife

#PFMonth

2023 Campaign
Report





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1. Introduction

This report summarises the activities carried out by the think tank Patvocates on behalf of the European Pulmonary Fibrosis Federation (EU-PFF) for the [2023 #BreathingLife Awareness Campaign](#), a one-month-campaign run throughout the month of September and aimed at raising awareness of pulmonary fibrosis (PF) as well as idiopathic pulmonary fibrosis (IPF) specifically during IPF Awareness Week.

Firmly entrenched in its mission and identity since 2021, and as a common message of an international patient movement to improve the situation of people suffering from pulmonary fibrosis in Europe and beyond, EU-PFF again decided to design its 2023 awareness campaign around the tagline [#BreathingLife](#) as a focal point and core concept.

Drawing on the input, advice and suggestions of its dedicated members, and learning from past endeavours, the Federation decided to address 7 specific areas with tailored content this year, maximising the impact of its campaign and acting as an even stronger voice for this particular patient community. Health policy, better, faster and patient-centred research and patient involvement in research and care, all three linked with clear calls to action, as well as patient support were essential pillars of the 2023 Breathing Life campaign. In addition, in the area of the disease itself, education and information of both patients and healthcare professionals were central aspects.

Specific calls to action had previously been identified by members of the community in a dedicated brainstorming session held at EU-PFF's Annual General Meeting in Barcelona in April 2023. The session furthermore resulted in a clear definition of the respective key target groups that the 2023 campaign should target, namely general practitioners and HCPs, clinicians and researchers, industry, and regulators as well as policy makers.

To get its key messages across to the key target groups, the campaign used facts and figures - and, for the first time, interviews from a range of stakeholders in the field of pulmonary fibrosis, including patients and patient advocates, researchers, as well as clinicians, advocating for key concerns of this patient community, represented by EU-PFF and its members.

To promote the [2022 EU-PFF Consultation Guides](#) as an important source of information for patients (available in Bulgarian, Croatian, Czech, Dutch, English, French, German, Greek, Hungarian, Italian, Polish, Portuguese, Romanian and Spanish) and healthcare providers (available in English), the Federation published [short flyer versions](#) of both documents, including a QR

code linking to the full versions. The patient flyer was translated into 10 languages, while the HCP flyer was made available in English only.

2. Rationale for PF Awareness Month & the 2023 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 live with Pulmonary Fibrosis in Europe alone. Despite significant progress in recent years and treatments that can slow down the disease, it is often fatal: In Europe, about 100,000 patients die from PF each year, on average within 3–7 years of diagnosis. The most common type of PF is IPF (Idiopathic Pulmonary Fibrosis), accounting for 200,000 patients in Europe.

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.

Therefore, PF Awareness Month 2023 – for the third time in a row themed **Breathing Life** – sought to draw attention to pulmonary fibrosis, its implications and the challenges it brings to daily life, as well as the physical and psychological burden it places on patients and their families. However, this year's campaign not only had a purely informative mission, but also an active component: to call upon various stakeholders to accelerate research in this field, to push for the involvement of PF patients in the very same, as well as in their healthcare, and to urge healthcare professionals – and patients and their loved ones – to be vigilant and further educate themselves in this area.

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 diseases (fILDs)
- Disease course and progression
- Diagnosis
- Treatment (pharmacological and non-pharmacological)
- Self-care & Patient support
- Patient involvement
- Research & Health policy

3. Core concept of the 2023 Breathing Life campaign

Building on the two previous campaigns, Breathing Life 2023 again put a focus on

- **educating PF patients** (disease, diagnosis, treatment, self-care and support).
- **educating healthcare professionals** with tailored content.
- **promoting the consultation guides** as a trusted resource for health care practitioners to rapidly diagnose and appropriately refer patients, and as a means of empowering patients to manage their disease in an informed manner.

At the same time, this year's campaign expanded this concept to include an active component in order to call on stakeholders to

- **drive and improve research** with the ultimate goal of stopping disease progression and curing PF as well as developing treatments with less side effects.
- **involve PF patients in research from the outset** to facilitate a more efficient and patient-centred approach.
- **provide a positive, strong impetus** for change for the benefit of these patients in health policy.

To underline and reinforce these demands and calls to action, EU-PFF conducted interviews with stakeholders from the research and clinical community as well as patient representatives. These interviews were published at regular intervals during PF Awareness Month across all social media platforms.

4. 2023 pilot: local event grants awarded to three EU-PFF members

With a grassroots approach to supporting member organisations in their work to raise awareness of PF – directly, practically and on the ground - 2023 saw a major innovation: EU-PFF invited its member organisations to apply for a 2,000 EUR grant to run local face-to-face awareness events. Three organisations were selected by an independent committee. These were: FIMARP (Italy), Hellenic PF Association (Greece) and the Polish IPF Society (Poland). Besides the grant, these groups were provided with a full set of physical campaign materials such as printed campaign flyers (translated into their local languages), pins, stickers, consultation guide flyers (also translated), and cardboard picture frames for distribution at their local event.

All three groups opted for carrying out educational events, either targeted at their members (patients and their carers) or the general public. One group used the event to formally launch a patient registry on PF, two of the three groups opted for offering free spirometry tests, and one group strategically decided to collaborate with the local labour unions to reach the outdoor workers who are often directly exposed to polluted air and therefore may be vulnerable to developing certain forms of pulmonary fibrosis.

By the time of finalising this report (6 November, 2023), two of the three winners had held their local events. While the Greek group was highly engaged on Social Media during the month of September, for internal reasons their event is taking place on 25 November, with EU-PFF's president, Steve Jones, having been invited to speak at the event as representative of the European Federation.

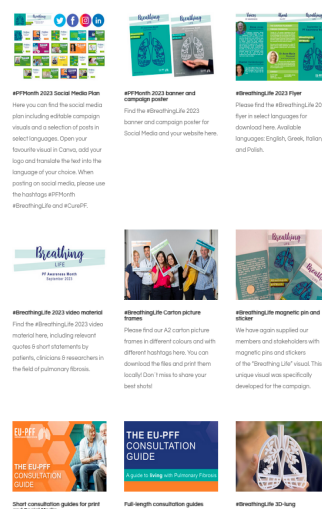
5. Campaign promotion at the ERS International Congress 2023

EU-PFF had a strong presence at this year's ERS International Congress held in Milan, Italy from 9 to 13 September. Representatives from the secretariat and board used the congress as an opportunity to promote PF Awareness Month and distribute campaign materials (mainly pins and Consultation Guide flyers targeting HCPs) at the EU-PFF exhibition booth, and to engage in constructive discussions with other stakeholders to work together to improve the situation of PF patients in Europe.



6. Continuing the journey: building on the success of 2021 & 2022

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”**.



What is more, with its move to a new website in early 2023, EU-PFF also **revamped its PF Month page**, redesigning and reorganising it to provide easy and quick access to all campaign materials for anyone interested in contributing.

A. Social Media concept of the 2023 campaign

Given the success of two previous Breathing Life campaigns, these materials and the core visual, including a teaser video ([with](#) and [without](#) voice over, and [underlaid with the lung crackles typical of PF](#)), were reused and updated for the 2023 campaign, as were the hashtags **#BreathingLife** and **#PFMonth**.

During the Annual General Meeting, which took place in 2023 in Castelldefels near Barcelona, Spain, the Patvocates team, which acts as the secretariat for EU-PFF, conducted interviews with representatives of the Federation's member organisations as well as with members of its Scientific Advisory Board (SAB), and others. These interviews sought to capture typical, individual and practical issues faced by patients and carers in the diagnosis, treatment and care pathway of PF and their daily lives on the one hand, and by healthcare professionals, clinicians and researchers in their work with PF patients on the other hand, and to identify possible solutions and suggestions.

The campaign team then edited these interviews for campaign purposes and published them on Facebook, Twitter/X, Instagram, LinkedIn and the EU-PFF website.

In addition to the individual videos, the team prepared a [short video presenting the many voices of pulmonary fibrosis](#), showing representatives of the wider community from different countries speaking with one voice ("We are the voice"). This video illustrates how broadly and internationally the Federation is positioned, and the important mission and great responsibility it bears as the representative of the European PF patient community and its national organisations.

As in previous years, **Patvocates took over the management of EU-PFF's social media accounts** ([Twitter/X](#), [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 2023. The complete [social media schedule](#), including visuals, was made available for download at the start of the campaign. In response to the request received from the EU-PFF board, in 2023 all campaign visuals were made available in Canva, an easy-to-use graphic design platform, giving member organisations and other stakeholders the option to personalise their

favourite visuals by adding their logo and translating the text on the visual into the language of their choice.

What is more, **key posts (about one post per day) were translated into 7 different languages** (Italian, Portuguese, Hungarian, Spanish, French, Turkish, Greek) to enable the Federation's national member organisations to get the key messages out to their patient communities. A "Canva - How to use" guide was provided on the website to help those less familiar with Canva find their way.

B. Physical campaign material

Besides distributing campaign material at ERS congress 2023, to arouse members' and other stakeholders' interest in the campaign, Patvocates also distributed a set of campaign materials (magnetic pins, stickers and printed consultation guide flyers) to all April 2023 AGM attendees. A full set of printed campaign materials (including the above plus additionally printed campaign flyers and consultation guide flyers in the respective language, and carton picture frames) was made available exclusively to the grant winners to support their local events. In total, 3000 pins, 3000 stickers, 3750 consultation guide flyers and 3 sets of picture frames had been ordered.



EU-PFF invited all those interested to get creative and take pictures with a **dedicated Breathing Life A2 cardboard picture frame** in different colours and with different hashtags, and to post them online to join and support the campaign. The [print files](#) were provided on the campaign website for download.



In addition, [the 3D print files](#) for a 3D model of the Breathing Life lungs were made available for download for this year's iteration.

C. The EU-PFF Consultation Guides: flyer versions

In 2022, the Federation published two [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. It is available in Bulgarian, Croatian, Czech, Dutch, English, French, German, Greek, Hungarian, Italian, Polish, Portuguese, Romanian and Spanish. And the

"**Guide to Treating fILDs**", available in English, 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 are also available as **audio-visual versions** which can be found [here](#) – as **full videos** or split into **chapters**.

The guides, on the one hand as an **indispensable resource for HCPs** to treat patients with Pulmonary Fibrosis adequately, and as a **means of self-empowerment for patients** on the other hand, **are some of the most essential tools offered by EU-PFF** and were once again an integral part of the 2023 campaign. To further disseminate, highlight and make available to the general public these two guides, as part of its 2023 Awareness campaign EU-PFF produced **short flyer versions**, including a QR code with a link to the full documents. The flyers are available in 10 languages (Bulgarian, Dutch, English, French, Greek, Hungarian, Italian, Norwegian, Polish and Spanish) for patients and in English for HCPs.



D. European Pulmonary Fibrosis Patient Summit 2024

EU-PFF used the occasion of the Breathing Life campaign to announce and invite all those affected and interested to the [3rd European PF Patient Summit](#). From April 26-28, 2024 patients, patient advocates, industry, research and healthcare representatives and experts, as well as policy makers will gather in Castelldefels, Spain to present, discuss and share insights on current, existing and future challenges, issues and innovations in the field of PF.

This time it will be a hybrid event, and attendees will have the opportunity to participate face-to-face. For those unable to attend on-site, the sessions will be streamed live. More information will be shared in the run-up to the event.

7. Social media performance and statistics (September 1st – 30th 2023)

During the 2023 Breathing Life campaign, **an average of 100 campaign-related posts (3,33 posts/day)** were posted across all social media platforms ([Twitter/X](#), [Facebook](#), [Instagram](#) and [LinkedIn](#)).

The posts - identical on each social media platform - consisted of **written content** on the core topics and concerns of this year's campaign, as well as **19**

interview clips that featured powerful, engaging statements from various stakeholders in patient advocacy, research, and healthcare; several **teaser videos** for the campaign, an updated version of the video **Alice's Story**, and the aforementioned **We are the Voice** clip.

What is more, **key posts (about one post a day) were translated into 7 different languages** Italian, Portuguese, Hungarian, Spanish, French, Turkish, Greek) and provided to the Federation's member organisations in order to enable them to get the key messages out to their respective patient communities.

A. Twitter/X

Over the course of the 2023 Breathing Life campaign, @EU_IPFF tweets gained **63,5K*** impressions, **240 retweets** and **745 likes**, i.e. an average of 2,1K impressions, 8 retweets and 25 likes per day. Besides, the account gained 35 new followers.

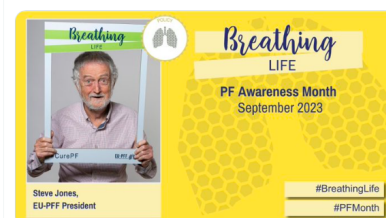
For comparison: in a normal month, the EU-PFF account gains between 5-6K impressions.

*For each tweet, Twitter/X displays the total impressions, i.e. how many times it appears in a user's feed or in search results.

• Top Tweets

The campaign's **most popular post** (by likes) on Twitter/X **gained 815 impressions, 44 total engagements and 24 likes and 8 retweets.**

"The specialist nurse is the most important person for patients during their treatment – it's somebody they can talk to, get advice quickly & easily on drugs, side effects and other issues." – @ActionPFsteve, EU-PFF President #PulmonaryFibrosis #CurePF #BreathingLife #PFMonth #PF



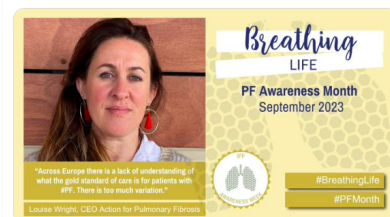
The campaign's **second most popular post** (by likes) on Twitter **gained 1,305 impressions, 44 total engagements and 17 likes and 9 retweets**

#PF Awareness Month takes place every year in September and wants to draw attention to #PulmonaryFibrosis, its challenges & the changes it brings about in daily life, and the burden it places on patients and their loved ones.
tinyurl.com/ycxjwnbc
#BreathingLife #CurePF



The campaign's **third most popular post** (by likes) on Twitter **gained 695 impressions, 34 total engagements and 17 likes and 3 retweets.**

"Across Europe there is a lack of understanding of what the gold standard of care is for patients with #PF. There is too much variation." – @louisewright1, CEO Action for Pulmonary Fibrosis #PulmonaryFibrosis #CurePF #BreathingLife #PFMonth #IPF



B. Facebook

During the 2023 Breathing Life campaign, the EU-PFF Facebook page reached **257.481* users** (252,183 from ads, 7,118 organically) and **466,819 impressions**. Over those 30 days, the dedicated campaign posts gained **13,321 likes, 191 shares** and **98 comments**, and the EU-PFF Facebook page gained **3,492 profile visits, 62 new followers** and **37 page likes**.

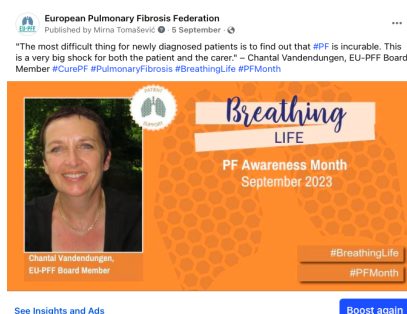
The campaign's 34 dedicated videos were watched for a total of **15,500 minutes** (or 258.3 hours) and gained **85 post reactions** (= likes, comments and shares).

*This metric counts reach from the organic or paid distribution of your Facebook content, including posts, stories and ads. It also includes reach from other sources, such as tags, check-ins and page or profile visits. This number also includes reach from posts and stories that were boosted. Reach is only counted once if it occurs from both organic and paid distribution.

Reach is the total number of people who see your content. Impressions are the number of times your content is displayed, no matter if it was clicked or not.

Top Post (boosted)

EU-PFF's **most popular boosted post** on Facebook (by likes) reached **26,931 users** and gained 56,702 impressions, as well as **1,936 likes** and 1,941 total engagements.

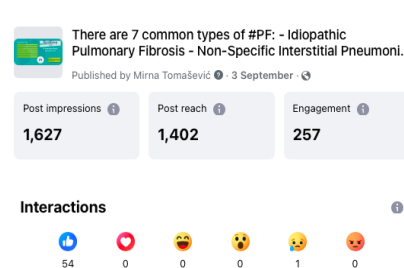


However, these numbers must be viewed critically and put in relation to non-boosted posts and organically generated responses and reactions.

Therefore, find below the most popular non-boosted post for comparison.

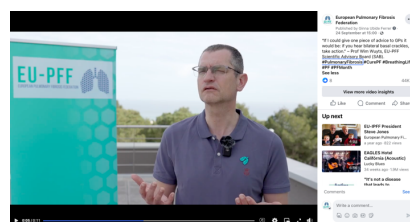
Top Post (organic)

EU-PFF's most popular non-boosted post on Facebook (by reactions) reached **1,402 users** and gained **1,627 impressions**, **257 engagements** and a total of **78 likes, shares and comments**.



Top Video Post (boosted)

EU-PFF's most popular boosted video post on Facebook received a total of **53 likes, comments and shares**, and was viewed for a total of **141.7 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**, **100 posts** on the EU-PFF Instagram account reached **5349 users** (and 4954 impressions according to the stats per tweet provided by meta; reach according to meta business insights: 116,247) and gathered **622 likes** and 41 shares - impressive numbers, also considering a still relatively small number of 217 followers (147 in 2022, an increase of 47 %) to date.



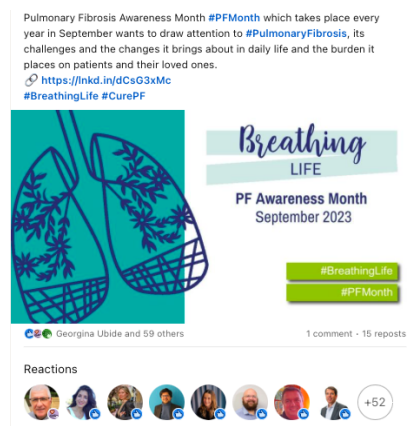
D. LinkedIn

Given the high proportion of sponsored outreach on LinkedIn in previous years, EU-PFF decided to aim for organic responses only for 2023.

From September 1st-30th, EU-PFF posts gained **17,854 organic impressions**, **288 clicks**, **936 reactions** and **62 reposts**. In addition, EU-PFF's profile gathered 103 new followers during this period, and **98 unique users visited the EU-PFF profile**.

Top Post

EU-PFF's [most popular post on LinkedIn](#) received **1,046 impressions, 60 reactions, 15 reposts** and **20 clicks**.



8. Sponsors of the 2023 Breathing Life awareness campaign

EU-PFF would like to sincerely thank its sponsors - Boehringer Ingelheim, Bristol Myers Squibb, Chiesi and Trevi - 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.

