

Breathing

LIFE

PF Awareness Month
September 2024



2024 Campaign Report

[#BreathingLife](#)

[#PFMonth](#)

EU-PFF
EUROPEAN PULMONARY FIBROSIS FEDERATION





1	Introduction	3
2	Rationale for PF Awareness Month & the 2024 Breathing Life campaign	4
3	Core concept of the 2024 Breathing Life campaign	5
4	PF Awareness Month: an established annual fixture 7	6
	A. Social Media concept of the 2024 campaign	6
	B. Social media short articles	8
	C. The EU-PFF Consultation Guides	8
5	Social media performance and statistics (1st September 1st – 2nd October 2024)	9
	A. X/Twitter	9
	B. Facebook	10
	C. Instagram	12
	D. LinkedIn	13
6	Sponsors of the 2024 Breathing Life awareness campaign	14

1 Introduction

This report summarises the activities carried out by the Secretariat of the European Pulmonary Fibrosis Federation (EU-PFF) for the **2024 #BreathingLife Awareness Campaign**. With the aim to raise awareness on pulmonary fibrosis (PF) and idiopathic pulmonary fibrosis (IPF), a one-month-online social media campaign run throughout the month of September.

As an established calendar fixture for the PF and IPF communities and beyond, the fourth annual iteration of the **#BreathingLife** campaign continued to drive a common message amongst the international patient movement to improve conditions of those experiencing pulmonary fibrosis through useful information and resources, compelling perspectives from different key community voices and firm call to actions for this year's theme of equitable oxygen access.

Building on feedback, insights and suggestions from its members and those from the PF community, the Federation shaped its 2024 campaign around a key theme: equitable access to oxygen. This focus emerged from ongoing conversations – including those that took place at the successful 3rd Pulmonary Fibrosis Patient Summit 2024 - about the critical need for supplementary or ambulatory oxygen for #PulmonaryFibrosis patients.

Drawing on lessons learned from previous editions, the year's initiative highlights the importance of health policy reform and equitable healthcare. Education and awareness also remain central, ensuring that both patients and healthcare professionals are empowered with the knowledge needed to consider treatment options and improve care outcomes.

To communicate its key theme and disseminate relevant messaging on equitable oxygen access across to the key target groups, the campaign shared informational posts whilst also highlighting useful resources. In addition, this year's approach more extensively featured interview response content from a range of pulmonary fibrosis stakeholders, including patients and patient advocates, researchers as well as clinicians.

This was also a timely opportunity to promote key materials and resources - particularly the **[EU-PFF Consultation Guide](#)**. With heightened conversations around pulmonary fibrosis throughout the month, it was the perfect moment to bring this valuable information source to the attention of patients, caregivers and healthcare practitioners.

2 Rationale for PF Awareness Month & the 2024 Breathing Life campaign

The need to address the issues around Pulmonary Fibrosis (PF) for those affected by remains a critical priority. It 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.

While there has been some headway in bringing this serious disease to light in recent years, there remains a lack of awareness about PF, which can result in late diagnosis, losing valuable treatment time and, above all, time to experience life. Furthermore, there is also the issue of there being gaps when it comes to the provision of equitable access to supplemental oxygen which necessitates firmer demands and education.



With the above in mind, this year's Breathing Life campaign incorporated specific calls to action for equitable oxygen access. This was reflected in the topics touched upon across the content including the interviews from key voices within the PF community such as the issues of stigma faced by patients, access bureaucracy and inconsistent practices on supplementary oxygen access.

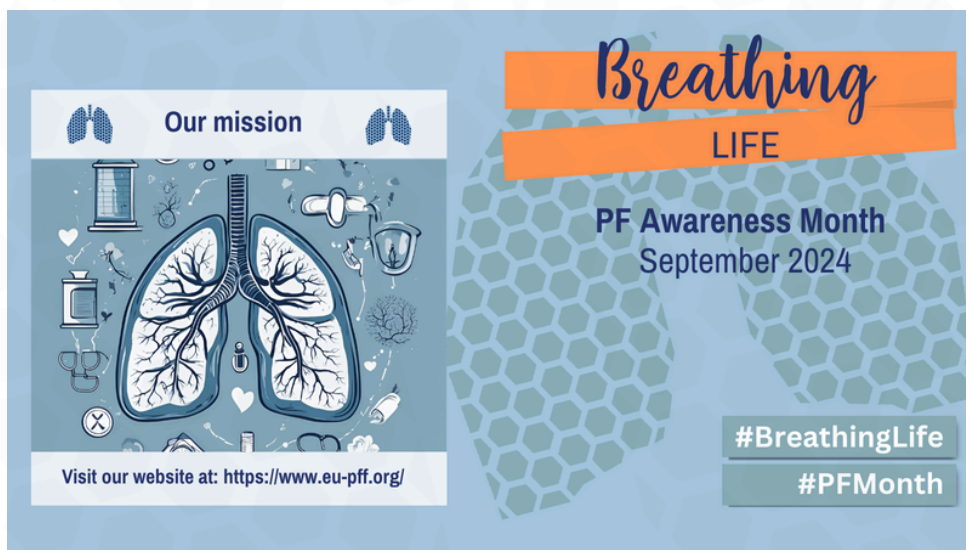
Each September, the EU-PFF runs PF Awareness Month which coincides with the globally recognised Pulmonary Fibrosis Awareness Month established to raise awareness of PF and to help patients, carers and families who have been affected by this terminal condition. Key topics covered include:

- 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 2024 Breathing Life campaign

The Breathing Life 2024 campaign again focused on

- **educating PF patients** (disease, diagnosis, treatment, resources, self-care and support).
- **educating healthcare professionals** with via tailored content.
- **promoting the consultation guide** 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.



However, this year's approach also incorporated a consistent call to action around the provision of equitable access to oxygen and around topics such as

- **the stigma** faced by those living with PF or having to manage a living experience with oxygen equipment.
- **the research** areas that impact PF care and treatment and issues including the lack of research into PF when compared to other respiratory diseases such as chronic obstructive pulmonary disease (COPD).
- **the lack of access** to supplementary oxygen due to various factors such issues around policy, supplier practices and more.

To emphasise and strengthen these urgent points and calls to action, the EU-PFF conducted interviews with stakeholders from the research and clinical community as well as patient representatives at the 3rd Pulmonary Fibrosis Patient Summit 2024. These interviews were recorded and published at regular intervals during PF Awareness Month across the Federation's social media platforms.

4 PF Awareness Month: an established annual fixture

Given the success of the recent Breathing Life campaigns, and the distinct visual identity and style it established, the key visual elements from previous years – including the iconic “lung” - were reused and updated for the 2024 campaign, as were the hashtags #BreathingLife, #PFMonth and #CurePF.



Breathing
LIFE

PF Awareness Month
September 2024

#BreathingLife
#PFMonth

However, we also added #OxygenAccess to emphasise our key theme this year on all our posts and as part of specific call to actions to make a clear appeal for its support from different audiences.

A. Social Media concept of the 2024 campaign

Based on the conversations that took place earlier at this year’s Pulmonary Fibrosis Patient Summit in Barcelona, Spain, and in prior discussions between the EU-PFF and the Patvocates team, which acts as the secretariat for the Federation, it emerged that a key issue that needed to be spotlighted was the equitable access to supplemental oxygen. While there is still a need for improved overall awareness of pulmonary fibrosis, it was evident that there needed to be a more extensive focus on this topic given the issues faced by members. The availability and access to oxygen has a direct impact on quality of life for PF patients.



It was decided that beyond raising awareness of PF and its profound impact on the daily lives of patients and their loved ones, we wanted to spark crucial discussions to ensure that all individuals with pulmonary fibrosis who need oxygen receive it. To provide more depth and convey the gravity of the need for equitable oxygen access, interviews with representatives of the Federation’s member organisations as well as with members of its Scientific Advisory Board (SAB), and others were conducted. These interviews covered the individual and practical issues faced by patients and carers in the diagnosis, treatment and care of PF and their daily lives.

The campaign team then edited these interviews for the campaign and published them on X/Twitter, Facebook, Instagram and 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 making a firm call to action: “Oxygen is a human right!”.



This was the perfect way to bookend a campaign and to make equitable access front and centre as a point of broader discussion.

As in previous years, Patvocates took over the management of EU-PFF’s social media accounts ([Facebook](#), [Twitter/X](#), [Instagram](#), [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 1st and 30th September, with preview posts peppered throughout the week preceding the month to generate interest in the campaign. [The complete social media schedule](#), including visuals, was made available for download at the start of the campaign.

New to the social media approach this year is a shift to focus on content styles that are more reflective of the individual platforms, i.e. longer content for LinkedIn and Facebook, while having shorter posts for X/Twitter. Previously, we took a one-size-fits-all approach with high volumes per day of the same short content on X/Twitter (280 characters or less) then replicated onto other platforms. With the more diverse content mix, we were able to give more space to topics that called for content with added depth.

Another major shift in content implementation was the way the videos were posted. This year’s campaign introduces native video posting directly on social media platforms. Unlike in previous years, when we shared external links to Vimeo, posting videos natively will prevent content from being deprioritised. Social media platforms tend to favour content hosted on their own sites over external links.

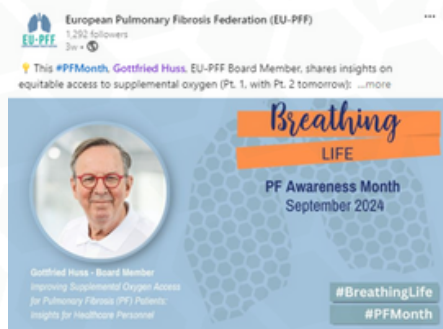
All campaign visuals were made available in Canva, an easy-to-use graphic design platform, giving member organisations and other stakeholders the option to personalise their favourite visuals by adding their logo and translating the text on the visual into the language of their choice. A “Canva - How to use” guide was provided on the website to help those less familiar with Canva find their way.

B. Social Media Short Articles – Views from the EU-PFF Board Members

In line with our updated content strategy for social media this year - moving beyond predominantly quick-read or short-format content - we also invited Board members to submit short articles for inclusion. Each week featured one to two different entries, providing deeper insights into the specific challenges faced by those within the PF community. These articles highlighted key community members who offer thought leadership on PF-related issues and shared valuable perspectives on lived experiences.



By incorporating these contributions, we aimed to foster more meaningful engagement and provide our audience with well-rounded viewpoints on the complexities of PF care and advocacy.



C. The EU-PFF Consultation Guides

The Federation published two essential Consultation Guides: the EU-PFF **Guide to Living with PF** and the **Guide to Treating fILDs**. The **Guide to Living with PF**, a free resource for newly diagnosed patients, provides key information on crucial aspects of living with PF, such as disease management, diagnosis and treatment, self-care, and support groups. Published in 2022, it is available in 14 languages, including Bulgarian, Croatian, Czech, Dutch, English, French, German, Greek, Hungarian, Italian, Polish, Portuguese, Romanian, and Spanish.



The Guide to Treating fILDs, available in English, offers healthcare professionals essential information on the disease - from symptoms and diagnosis to treatments and disease progression. It supports practitioners in making informed decisions and helps them quickly refer patients to the right specialist.

These guides serve as indispensable resources - empowering healthcare professionals to provide optimal care for PF patients and equipping patients with the knowledge to take charge of their own health. Both guides were prominently featured in the 2024 campaign.

5 Social media performance & statistics (Posts from 1 September – 2 October)

During the 2024 Breathing Life campaign, there were a total of **180** campaign period posts (plus **12** pre-campaign teaser posts). This translated to about **6 posts/day** across all social media platforms ([Twitter/X](#), [Facebook](#), [Instagram](#) and [LinkedIn](#)).

These included **written content** that mentioned core themes such as equitable access to oxygen, as well as 31 interview clips featuring patients, healthcare professionals, and researchers. Longer member-perspective articles were also shared on LinkedIn and Facebook, contributing to further depth of the information being shared. Video content was posted directly on each platform, rather than relying on external hosting.

With the [campaign materials and calendar](#) also made available publicly for members, they were able to adapt or plan ahead to feature relevant content on their platforms for their respective communities and audiences.

Note: While the posts from the campaign were done between 1 and 30 September, data until 2 October was collected to account for results generated from 30 September posts.

A. X (Formerly known as Twitter)

During the 2024 Breathing Life campaign, the [@EU_IPFF](#) account gained **133K*** impressions, **165** reposts (previously termed “retweets”) and **559** likes. This translates to an average of **4.43K** impressions, **5.5** reposts and **18.6** likes per day.

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

• Top Posts



The campaign's **most popular post** (by likes) on X gained **2,115** impressions, **109** total engagements and **43** likes and **21** reposts. This was also the most reposted content throughout the campaign.



The campaign’s **second most popular post** (by likes) on X gained **929** impressions, **64** total engagements and **27** likes and **11** reposts.



The campaign’s **third most popular post** (by likes) on X gained **1,041** impressions, **48** total engagements and **23** likes and **7** reposts.

B. Facebook (1 September – 2 October)

For the 2024 Breathing Life campaign, the EU-PFF Facebook page reached **117,622*** users (**13,130** from organic, **106,418** from promoted/paid posts) and gained **2.6K** interactions (i.e. likes, reactions, saves, comments and shares). Over the course of the reporting period, the EU-PFF page received **1.2K** visits and **34** new followers.

The campaign’s 31 videos were watched for a total of **25.5K** minutes (**425** hours) and gained **558** interactions, of which included **282** likes/reactions.

*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, checkins and page or profile visits. This number also includes reach from posts and stories that were boosted. Reach - the total number of people who see your content - is only counted once if it occurs from both organic and paid distribution.

- **Top Post (boosted)**

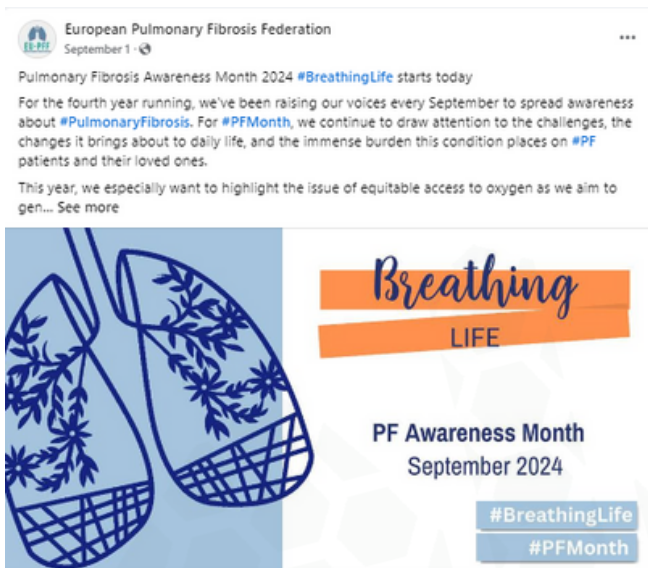


The EU-PFF’s **most popular boosted** post on Facebook (by likes and reactions) reached **10.3K** users, gained **11,756** impressions, **500** interactions and generated **487** reactions.

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)**



The EU-PFF's **most popular non-boosted post** on Facebook (by reactions) reached **4,105** users and gained **4,626** impressions, **105** interactions and **44** reactions.

- **Top Video Post (boosted)**



The EU-PFF's **most popular boosted video** post on Facebook reached **15.9K** users and gained **19K** impressions, **34** interactions and **21** reactions. It was viewed for **3,696** minutes (61.6 hours).

- **Top Video Post (organic)**



The EU-PFF's **most popular organic video post** on Facebook reached **126** users and gained **144** impressions, **19** interactions and **18** reactions. It was viewed **200** times for a total of **16** minutes.

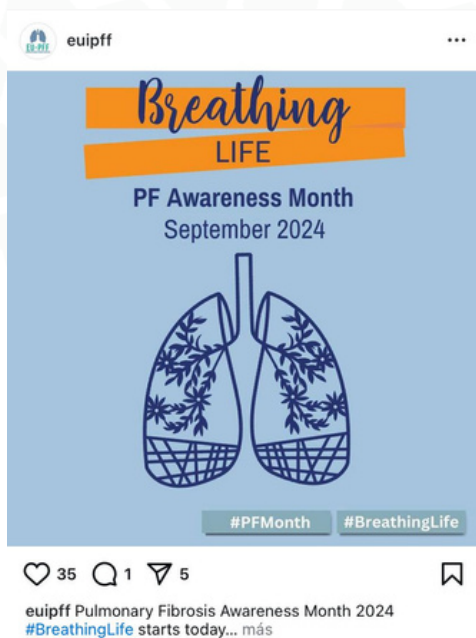
C. Instagram (1 September – 2 October)



The target audience, reach and user behaviour does not make Instagram the ideal platform for a campaign to raise awareness of PF. However, the results were nevertheless positive, bringing in promising figures indicating that our campaign messaging and content managed a degree of traction on this channel.

For the reporting period, **44** posts on the EU-PFF Instagram account reached **14K** users (**1,715** organic and **12,583** from ads) and generated **3.9K** interactions, **470** likes and **45** shares. This is a solid performance given the page's modest follower count of 297, which was still a 36.87% increase over the 217 followers from the preceding reporting period in 2023.

• Top post

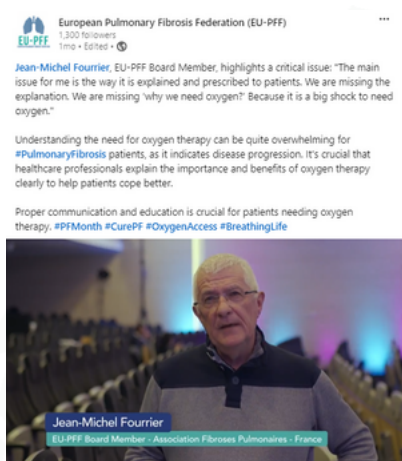


The EU-PFF's most popular post on Instagram (by reactions) reached **592** users and gained **635** impressions, **48** interactions and **35** reactions.

D. LinkedIn (1 September – 2 October)

For the campaign reporting period, posts from the EU-PFF gained **12.368** organic impressions and **142,531** sponsored impressions, **710** reactions (of which 32 were sponsored reactions). In addition, the EU-PFF profile gained **139** new followers in the same timeframe and attracted **95** unique visitors.

• Top Post (Sponsored)



The EU-PFF's **most popular paid post on LinkedIn** (by likes/ reactions) received **4,993** impressions, **34** reactions, **1,476** video views and **54** clicks.

• Top Video (Sponsored)



The EU-PFF's **most viewed video post (sponsored)** on LinkedIn received 3,212 views, 5,546 impressions, 28 reactions, and 36 clicks.

• Top Post (Organic)



EU-PFF's **most popular organic post** on LinkedIn (by likes/ reactions) received **1,891** impressions, **80** reactions, and **36** clicks.

• Top Video (Organic)



The EU-PFF's **most viewed video post (organic)** on LinkedIn received 276 views, 649 impressions, 32 reactions, and 40 clicks.

6 Sponsors of the 2024 Breathing Life awareness campaign

The EU-PFF would like to express its sincere thanks to the sponsors - Boehringer Ingelheim and Chiesi – for ensuring that the Federation was able to run this year’s Breathing Life awareness campaign to raise awareness of PF and the need for equitable oxygen access amongst the Pulmonary Fibrosis community, the public and beyond. Their commitment and continuous support are deeply appreciated.

