Breathing Life

PF Awareness Month
September 2021

#BreathingLife
#PFMonth

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#PFMonth

2021 Campaign Performance Overview
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1. Introduction

This report summarises the activities carried out by Patvocates on behalf of EU-IPFF for the 2021 #BreathingLife Awareness Campaign.

**Newly established under the motto #BreathingLife**, the 2021 campaign aimed at raising awareness of Idiopathic Pulmonary Fibrosis (IPF) as well as Pulmonary Fibrosis (PF) using facts, figures and stories of patients suffering from PF/IPF as well as carers during the month of September. This year’s campaign also saw a broader focus on Pulmonary Fibrosis (PF) during PF Awareness Month and focused on IPF specifically during IPF Awareness Week from September 18th–30th.

As for content, the campaign was designed to follow a script and successively cover key disease-related topics such as the disease area itself, diagnosis, treatment, research, and quality of life – culminating in the topic awareness and a call to action.

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, visualizes the scarring of the lung tissue, with natural elements such as flowers and leaves symbolizing the concepts of “life” and “breathing”.

The 2021 campaign also encouraged patients to tell their personal story by sharing a video about their experience of living with PF or IPF¹, emphasising their individual moments of light heartedness, ease and happiness and using the campaign hashtags #BreathingLife or #PFMonth. The campaign team then edited the videos for campaign purposes and published them on Facebook, Twitter, Instagram, LinkedIn and the EU-IPFF website.

Patvocates also took over the social media management of EU-IPFF’s Twitter, Facebook and LinkedIn accounts, set up an Instagram account to promote the #BreathingLife Campaign and produced tailored social media posts and visuals, and a teaser video (with and without voice over) targeted at patients, carers, nurses and other stakeholders as well as the general public between September 1st and September 30th 2021.

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¹ Links to the respective videos:

https://vimeo.com/606391485
https://vimeo.com/598789232
https://vimeo.com/598789819
https://vimeo.com/598788341
https://vimeo.com/598785890
https://vimeo.com/598785206
https://vimeo.com/598788199
https://vimeo.com/598788776
https://vimeo.com/598786593
https://vimeo.com/598786782
https://vimeo.com/598784366
To increase the reach of the campaign, Patvocates set up a dedicated Facebook group for members to provide them with social media material to share on their respective platforms. All campaign materials, including social media posts and digital materials, were also made available on the dedicated EU-IPFF Awareness website.

To further raise awareness of the campaign’s cause and support the ERN-LUNG (the European Reference Network on Respiratory Diseases) an artistic version of the human lungs in an oak frame and hand-cut by Marie-Christine Hollerith, papercut artist and creative mind behind the #BreathinLife campaign (https://zauberundzunder.de), was sold by auction during IPF Awareness Week, with a winning bid of 250 Euros.

In addition, Samantha Nier, member campaign team and certified yoga instructor, offered daily yoga sessions tailored to the needs and capabilities of IPF patients throughout IPF Awareness Week. The offer was well received, often with more than 20 participants per session.

2. PF Awareness Month & IPF Awareness Week 2021(#PFMonth & #BreathingLife: Creative Concept)

Pulmonary Fibrosis (PF) is a progressive, irreversible, chronic lung disease causing scarring of the lung tissue with no known cure. In Europe it currently affects more than 300,000 people with over 50,000 losing their lives to PF each year. The most common type of PF is Idiopathic Pulmonary Fibrosis (IPF), accounting for 200,000 patients in Europe. The average life expectancy following diagnosis is about three to five years, with a better prognosis depending on early diagnosis and adequate treatment. Despite the severity of the disease, there is still a lack of awareness of PF/IPF, which can result in late diagnosis, losing valuable treatment time.

Therefore, this year EU-IPFF wanted to draw attention to PF/IPF by joining the worldwide PF Awareness Month during September and also by launching a dedicated IPF Awareness Week running from 18 to 25 September. Both tackled unresolved issues and challenges in the field of PF/IPF such as lack of awareness as well as access to diagnosis and treatment – but they also focused on personal matters, for instance the physical and psychological strain the disease puts on patients, their loved ones and carers. What is more, EU-IPFF aimed to convey a message of hope and support by emphasising the essential moments of lightness, normalcy and happiness that patients with PF and IPF still experience despite this burden.
To achieve these goals, the campaign’s aims were threefold

1. **Raise awareness of PF/IPF by**
   - Informing about the relevance of PF/IPF and the disease itself
   - Informing about diagnosis, treatment options and the research being done in this disease area
   - Calling attention to the challenges and unresolved issues that remain to this day

2. **Create a feeling of togetherness by**
   - Demonstrating and at the same time creating a sense of unity amongst the PF/IPF community, including all stakeholders, driven by a common cause to improve the lives of PF/IPF patients in Europe and across the world
   - Promoting IPF Awareness Week as an international movement of a strong patient community
   - Strengthening EU-IPFF members’ ability to run awareness campaigns or activities by
     - providing tools, concepts, ideas, material and supporting their own initiatives
     - Intensifying contacts with its members (organisations and patient advocates)
     - Strengthening the partnership of EU-IPFF with other stakeholders

3. **Provide hope and support for PF/IPF patients, their loved ones and carers by**
   - Creating a feeling of togetherness through a common identity
   - Giving courage to those affected by PF/IPF, emphasising that there are good reasons for hope in view of medical progress and developments in therapy
   - Providing a silver lining by inviting patients to share their individual advice and stories as well as moments of happiness, ease and normalcy, and thereby creating a feeling of optimism and hope

**PF Awareness Month & IPF Awareness Week**

For the 2021 campaign, Patvocates created a unique, hope-giving and connecting visual for all target groups: an abstract representation of the human lungs, visualising the effect the disease has on the organs as well as a leaf pattern symbolizing this year’s motto and key message “breathing life”.

**Paper-cut visual of lung:**

- The lung as THE organ we wanted to put the spotlight on
- Filigree work illustrating the fragility and vulnerability of the lungs
- The material (paper) symbolizing the “lightness” and “ease” that is usually associated with the concept of “breathing”
- Nature and plants in the upper part of the paper-cut lung symbolizing “life” and “breathing”
- Rigid structures in the lower part of the paper-cut lung symbolizing the “stiffness” of a PF lung
By developing online and printed material for personal use and asking patients to post them on social media and share their personal stories using #PFMonth and #BreathingLife, the campaign team aimed to unite the PF/IPF community. By joining forces with all stakeholders, the 2021 campaign sought to create a better understanding of the condition through different perspectives and experiences of PF/IPF.

The #BreathingLife campaign targeted audiences at a national level, whilst maintaining an overall European focus in the outreach to stakeholders. This was done through sharing key facts about PF/IPF and its symptoms via visuals and videos provided by patients and carers for social media as well as press releases for the broader public.

**Comms strategy outline incl. target groups**

**Launch and communication during PF Awareness Month**

The coordinated outreach campaign was launched on September 1st and ran until September 30th 2021, with IPF Awareness Week running from September 18th – 25th.

**Materials: digital and printed**

Using digital news items and posts on EU-IPFF.org/awareness and platforms such as Instagram, Facebook, Twitter and LinkedIn, the campaign aimed to underpin the campaign’s key messages through statements related to the disease itself, diagnosis, research, treatment and quality of life as well as a call to action. *Everybody involved could help creating awareness by*

- following and sharing EU-IPFF’s posts using the campaign hashtags #BreathingLife and #PFMonth
- cutting their own easy-to-cut papercut lung (different templates were provided on the campaign website) and sharing their selfie using the campaign hashtags
• spreading online material and sharing posts, thoughts and personal stories on Instagram, Facebook or Twitter using the campaign hashtags

• sharing a video about their story and moments of joy, lightness and happiness that patients experience in daily life despite the disease

• following EU-IPFF member organisations and sharing their posts, adding the dedicated hashtags

• sending the online flyer to friends, relatives, PF stakeholders, politicians, press offices et cetera in their respective country

• keeping an eye on EU-IPFF’s social media accounts and on the eu-ipff.org/awareness during PF Month and IPF Awareness Week

Patvocates also developed printed and physical materials and asked all stakeholders to use them in order to promote the campaign and its key messages. The materials, translated and available in 10 languages (Bulgarian, Dutch, English, French, German, Greek, Italian, Polish, Portuguese and Spanish), were sent out in time to member organisations in the respective countries. Everybody involved could help driving this campaign by

• handing out printed materials (postcards, bookmarks and stickers), for instance in outpatient clinics, hospitals, GP waiting rooms, at the radiologist, in libraries and /or other places where people collect information

• wearing the dedicated pin to represent the PF community and raise awareness amongst the general public and friends and family
• personalizing the campaign **postcards** with a **personal message** and sending them to stakeholders, health care staff, relatives, friends and acquaintances

**Personalised video messages**

Patvocates also asked all EU-IPFF member organisations to provide the campaign team with personal videos which reflect patients’ and/or carers’ perspectives of living with PF/IPF and to **share their individual stories of hope and their moments of joy and happiness**. These videos – recorded on mobile phones – were edited by Patvocates and published on social media, with the aim to engage a wider audience to share these as a more **personal means of communication**.

3. **Social media performance and statistics (September 1st – 30th 2021)**

**A. Twitter**

The campaign team posted **117 dedicated tweets** highlighting the #BreathingLife campaign, including **10 personal video messages** provided by PF/IPF patients.

**Over the course of the 2021 campaign, @EU_IPFF tweets reached 73,000 impressions, were retweeted 324 times and received 940 likes**, i.e. an average of 2,400 impressions, 11 retweets and 31 likes per day.

**@EU_IPFF posts also registered 153 link clicks** leading to its website, articles and videos, and **8,201 Twitter users** visited the @EU-IPFF Profile.

**Top Tweet**

The campaign’s **top tweet** gained **4,784 impressions, 100 total engagements and 29 likes.**
B. Facebook

From September 1st–30th, EU-IPFF posted 117 Facebook posts highlighting the various key messages the campaign wanted to bring across. Each post included either a photo, a link, a dedicated visual or a video.

During the 2021 campaign, the EU-IPFF Facebook page reached 66,936 users, gained 5,182 interactions and 973 link clicks as well as 1,453 reactions (= comments, shares and likes).

The campaign’s 10 dedicated videos, provided by patients and edited by the campaign team, gained 421 interactions and were viewed for a total of 1,871 minutes.

Top Post (Promoted)

Reached 41,643 users and gained 1,296 interactions, 120 reactions, comments and shares as well as 628 link clicks to date.

Top Post (Organic)

Reached 1,875 users and gained 342 interactions. The post was shared 15 times and received 153 reactions, comments and shares as well as 189 clicks to date.
Top Video (Promoted)

**Reached 7,948 users** and gained 341 interactions. The post was shared 12 times and received 98 reactions, comments and shares as well as 245 clicks to date.

Top Video (Organic)

**Reached 601 users** and gained 43 interactions. The post was shared 6 times and received 43 reactions, comments and shares as well as 44 clicks to date.

C. Instagram

- Account set up on August 25th 2021
- 85 followers to date
- 100 posts from **September 1st-30th**
  - 6,421 impressions
  - 215 profile visits
  - 15 website clicks
  - 765 post interactions
  - 420 accounts reached (52 followers, 368 non-followers)