

Breathing

LIFE

#BreathingLife

#PFMonth

PF Awareness Month
September 2021

Outline: PF Awareness Month & IPF Awareness Week 2021

#BreathingLife / #PFMonth

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, but early diagnosis and early treatment could improve this. 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 wants to draw attention to PF/IPF by joining the worldwide PF Awareness Month during September and launching a dedicated IPF Awareness Week running from 18 to 25 September. Both will tackle unresolved issues and challenges in the field of PF/IPF such as lack of awareness as well as access to diagnosis and treatment – while also focusing on personal matters such as the physical and psychological strain the disease puts on patients and their loved ones. With its 2021 campaign under the slogan “Breathing Life”, EU-IPFF aims to convey a message of hope and support by emphasizing 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 will be threefold

1. Raise awareness about PF/IPF by

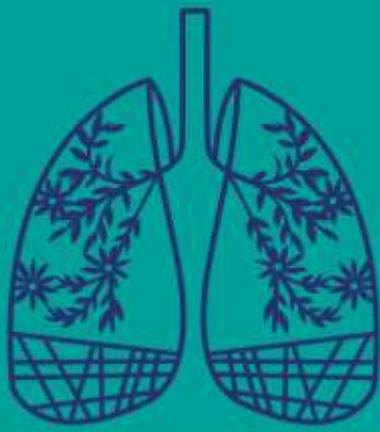
- Informing about the relevance of PF/IPF and the disease itself
- Informing about diagnosis, treatment options and the research being done in this disease area
- Calling attention to the challenges and unresolved issues that remain to this day

2. Create a feeling of togetherness by

- Demonstrating and at the same time creating a sense 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, emphasizing 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



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For the 2021 campaign, we have 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 slogan "Breathing Life".

By developing online and printed material for personal use and by asking patients/patient advocates to disseminate the materials, post on social media and share their personal stories using the hashtags #PFMonth and #BreathingLife, we aim to unite the PF/IPF community. By joining forces with all stakeholders, we seek to create a better understanding of the condition through different perspectives and experiences of PF/IPF.

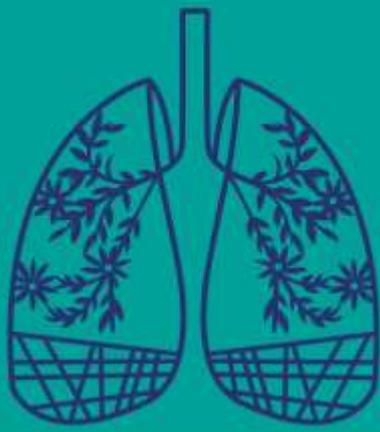
We will target audiences at a national level, whilst maintaining an overall European focus in our outreach to stakeholders.

We would like to ask you and everyone who has been affected by this disease in any way – patients, carers, clinicians, researchers and others – to join us and the worldwide PF community and share their story and the campaign messaging on social media using both #BreathingLife and #PFMonth during PF Awareness Month in September as well as IPF Awareness Week running from 18 to 25 September.

We also would like to encourage you to inform us of your potential events during PF Awareness Month 2021 so that we can share them with the community and beyond.

Target groups and main objectives





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Launch of and communication during PF Awareness Month

The coordinated outreach campaign will be **launched on September 1st 2021** and will run throughout the month of September, with IPF Awareness Week running from September 18th –25th.

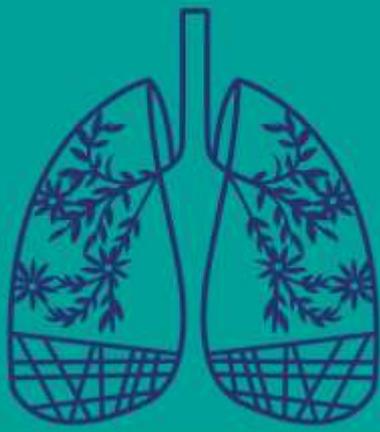
Campaign materials will be provided to you in advance to the official launch on September 1st, but PLEASE DO NOT POST ANY CAMPAIGN MATERIALS OR PROMOTE THE CAMPAIGN PRIOR TO THIS DATE IN ORDER NOT TO LOSE ALL IMPETUS BEFORE THE OFFICIAL START OF PF AWARENESS MONTH ON 1 SEPTEMBER.

Materials: digital and non-digital

We have developed a comprehensive **social media calendar**: using **digital news items** and posts on our website [EU-IPFF.org/awareness](https://www.eu-ipff.org/awareness) and platforms such as Facebook, Twitter and LinkedIn, we will underpin the campaign's key messages through statements related to the disease itself, diagnosis, research, treatment, quality of life and awareness of the disease.

You can help create awareness by

- Following and sharing our posts using the campaign hashtags **#BreathingLife** and **#PFMonth**.
- **Spreading online materials** (will be made available here: <https://www.eu-ipff.org/awareness>) and sharing **your posts, thoughts and personal stories** on Facebook or Twitter using the **campaign hashtags**.
- Cutting your easy-to-cut papercut lung and sharing your **selfie** on Social Media.
- Sharing a **video** about **your story and your moments of joy, lightness and happiness** that you experience in daily life despite the disease (see section below on personalised video messages).
- Following our member organisations and sharing their posts, adding the dedicated hashtags.
- Sending our online flyer and other digital campaign materials such as “Breathing Life” posters, etc. to friends, relatives, PF stakeholders, politicians, press offices and others in your country.
- Keeping an eye on **EU-IPFF's social media accounts** and on the website [eu-ipff.org/awareness](https://www.eu-ipff.org/awareness) during PF Awareness Month and IPF Awareness Week (<https://www.facebook.com/EUIPFF/>, https://twitter.com/EU_IPFF, <https://www.linkedin.com/company/eu-ipff>).



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Besides plenty of digital materials, we have developed **printed materials and a dedicated magnetic pin of the “Breathing Life” visual**, which we would like to ask you to use to further promote the campaign.

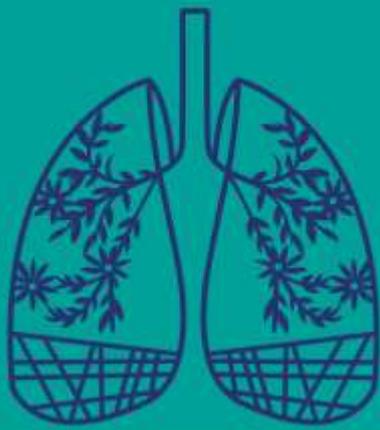
Please help drive the campaign by

- Handing out **printed campaign materials** (flyers, postcards, bookmarks and stickers) to members of patient organisations, in outpatient clinics, hospitals, GP waiting rooms, at the radiologist, in libraries and /or other places where people collect information.
- Disseminating our **dedicated magnetic pin** (as symbol to demonstrate unity among the PF community) among your membership and other stakeholders. Wear your pin with pride, show unity and raise awareness – and ask others to do so as well!
- Personalizing our **postcards** with a **personal message** (“My message to you”) and sending them to stakeholders, health care staff, relatives, friends and acquaintances.

Personalised video messages

We have asked our member organisations to provide us 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 will be edited and published by the EU-IPFF team on social media with the aim to engage a wider audience to share these as a more **personal means of communication**. We would also like to ask you to share your stories and moments of happiness by submitting **your video** (maximum length: 60 seconds; recorded with the standard iOS or Android video apps) to Randi.Krogsgaard@eu-ipff.org until August 15th 2021 at the latest. We will then edit the video and add a short intro and outro visual for consistency and recognition value, before sending it back to you or sharing it directly upon request. If you want to share your video yourself, please use the hashtags **#BreathingLife** and **#PFMonth** for each post to link it to PF Awareness Month and IPF Awareness Week respectively.

Please keep in mind **a few basic rules** when recording your video: make sure to shoot horizontally, keep your image still and avoid distracting backgrounds. What’s more, please check sound and video quality before filming and add 5 to 10 seconds at the beginning and end of your recording. Other than that, **please give free rein to your creativity and tell the community about your moments of joy and happiness!**



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How-To-Use-Guide – in brief

All digital materials will be available on the campaign site (<https://www.eu-ipff.org/awareness>) from 25 August (one week prior to the start of the campaign). The coordinated outreach campaign will be launched on September 1st 2021 and will run throughout the month of September, with IPF Awareness Week running from September 18th –25th.

Campaign materials will be provided to you in advance to the official launch on September 1st, but

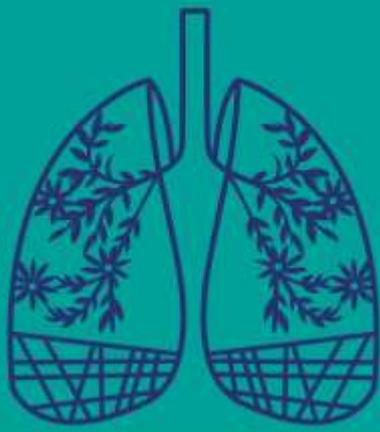
- **PLEASE ACTIVELY POST AND PROMOTE AS OF THAT DAY.**
- **DO NOT POST OR PROMOTE THE CAMPAIGN PRIOR TO THIS DATE IN ORDER NOT TO LOSE ALL IMPETUS BEFORE THE OFFICIAL START OF PF AWARENESS MONTH.**
- **WHERE POSSIBLE, DISSEMINATE THE MATERIALS IN YOUR LANGUAGE (IF AVAILABLE).**

FOR THOSE THAT HAVE ORDERED NON-DIGITAL MATERIALS:

The pins and all printed materials will be dispatched for arrival at their respective destination by end of August 2021.

Online materials will be available on <https://www.eu-ipff.org/awareness>

Online material	Available in the following languages (in alphabetical order)	Use
Web Banner	English	Website, Social Media (top banner)
Animated campaign video	No spoken text – one version for all	Website, Social Media
Papercut lung available for download (3 different formats to choose from)	One single version for all	Website, Social Media (download, cut, take a picture of yourself and “your” lung - then join the photo campaign by posting on Social Media)
Fact sheet	English Local translation and adaptation (if required)	To be used as background information to stakeholders, journalists
Flyer	Bulgarian Dutch English French German Greek	Website, Social Media, for distribution via E-mail



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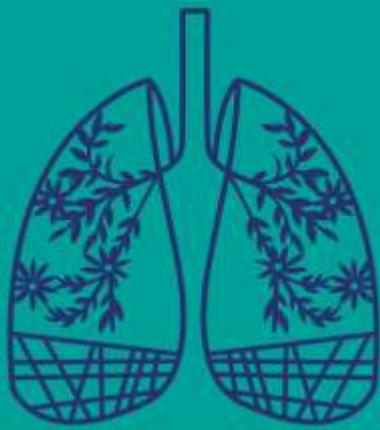
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	Italian Polish Portuguese Spanish	
Campaign Poster (3 different styles)	Bulgarian Dutch English French German Greek Italian Polish Portuguese Spanish	Website, Social Media
Postcard	Bulgarian Dutch English French German Greek Italian Polish Portuguese Spanish	Website, Social Media, for distribution via E-mail
Bookmark	Bulgarian Dutch English French German Greek Italian Polish Portuguese Spanish	Website, Social Media (bookmarks are of course used mainly non-digitally – can however be used on Social Media to show the variety of materials)
Sticker	One single version for all	Website, Social Media (stickers are of course used mainly non-digitally – can however be used on Social Media to show the variety of materials)



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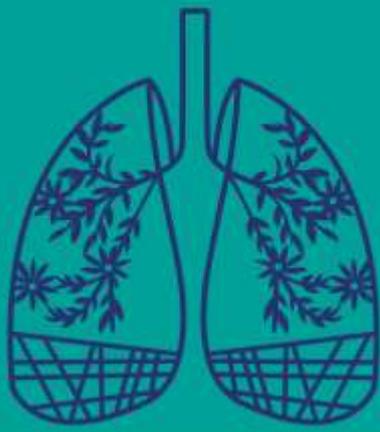
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Printed and other non-digital materials (shipped exclusively to those that have placed an order)

Non-digital Material	Available in the following languages (in alphabetical order)	Use
Magnetic campaign pin	One single version for all	Disseminate the campaign pin (as symbol to demonstrate unity among the PF community) among your membership and other stakeholder. Wear your pin with pride, show unity and raise awareness – and ask others to do so as well. Donees / presentees could be: <ul style="list-style-type: none"> ▪ patient advocates (for their commitment and restless fight against the disease) ▪ patients (for withstanding and sharing their stories) ▪ family members (for caring and supporting those affected) ▪ other stakeholders (GPs, staff, patients, outpatient clinics, GPs waiting room, etc.)
Campaign Flyer (hardcopy/printed version)	Bulgarian Dutch English French German Greek Italian Polish Portuguese	Disseminate widely amongst: <ul style="list-style-type: none"> ▪ patient advocates ▪ patients ▪ family members ▪ other stakeholders (GPs, staff, patients, outpatient clinics, GPs waiting room, public spaces, etc.)
Campaign Postcard (hardcopy/printed version)	Bulgarian Dutch English French German Greek Italian	Send a message of THANK YOU or simply inform your audience: <ul style="list-style-type: none"> ▪ patient advocates ▪ patients ▪ family members



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	Portuguese	<ul style="list-style-type: none"> other stakeholders (GPs, staff, patients, outpatient clinics, GPs waiting room, etc.)
Campaign Bookmark (hardcopy/printed version)	Bulgarian Dutch English French German Greek Italian Polish Portuguese	Disseminate widely amongst: <ul style="list-style-type: none"> patient advocates patients family members other stakeholders (GPs, staff, patients, outpatient clinics, GPs waiting room, public spaces, etc.)
Campaign Sticker (hardcopy/printed version)	One single version for all	Disseminate widely amongst: <ul style="list-style-type: none"> patient advocates patients family members other stakeholders (GPs, staff, patients, outpatient clinics, GPs waiting room, public spaces, etc.)

Thanks for joining PF Awareness Month and IPF Awareness Week and helping raise awareness!

Your 2021 PF Awareness Month campaign team