

EU-PFF
EUROPEAN PULMONARY FIBROSIS FEDERATION



ANNUAL REPORT 2022

The voice of pulmonary fibrosis patients in Europe

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The COVID-19 pandemic made 2022 was another difficult year for EU-PFF and patients and carers across Europe. Despite this, EU-PFF managed to achieve our aims and objectives. We continued to adapt our work to the challenges of the pandemic and focused on the needs of people living with pulmonary fibrosis. We also played a key role in voicing pulmonary fibrosis patients' concerns and those of their loved ones to policy makers across Europe.

In recent years, we have expanded our focus from idiopathic pulmonary fibrosis (IPF) to include all forms of progressive pulmonary fibrosis. These include, for example, connective-tissue related diseases such as rheumatoid arthritis-associated pulmonary fibrosis, hypersensitivity pneumonitis (for example, 'farmer's lung'), and occupational diseases such as asbestosis and silicosis.

Due to the hard work of our Board of Directors, Scientific Advisory Board and Secretariat, EU-PFF was able, with the support of our volunteers and sponsors, to successfully complete our 2022 work plan, including publication of our Consultation Guides, broaden our international cooperation and enter into new research partnerships.

The highlight of the year was the 2nd European Pulmonary Fibrosis Patient Summit, organised by EU-PFF. This was a virtual event, which brought together over 400 patients, carers, researchers and HCPs from around the globe for an excellent programme of talks and discussions. The Summit and the associated webinars were patient-led and provided education, inspiration and empowerment for a community who often feel isolated and ill-informed. The Summit sessions continue to be viewed online via our website.

The successful Summit reinforced the rallying cry from the pulmonary fibrosis (PF) community to transform and improve pulmonary fibrosis treatment and to find a cure for this devastating disease.

We have an exciting programme of activities planned in 2023. Please take part and add your voice to our work. We will also be working with patients, carers and HCPs on planning the 2024 European Pulmonary Fibrosis Patient Summit. This will be the first face-to-face Summit EU-PFF has organised and will take place in May 2024 in Barcelona. We look forward to seeing you there!

With best wishes to the pulmonary fibrosis community across Europe – patients, carers, doctors and other HCPs, researchers and industry. We look forward to continuing our active cooperation with all of you in coming years.

STEVE JONES, EU-PFF PRESIDENT

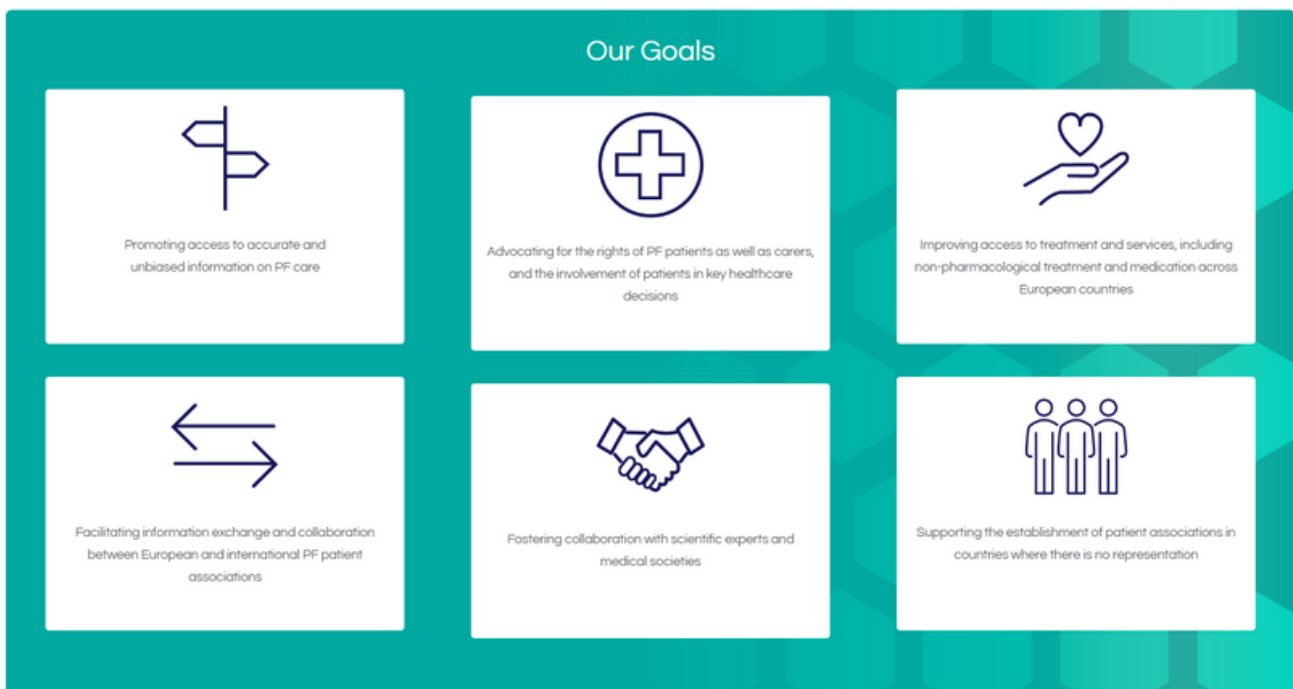


2.1. Our mission

EU-PFF is an umbrella organisation of pulmonary fibrosis patient organisations from across Europe. We are member-driven and work to raise awareness of pulmonary fibrosis in Europe among politicians, decision makers and the general public. We aim to promote a European patient voice, while recognising there are differences among countries, which may require varying approaches.

We collaborate closely with medical experts and researchers in Europe. We aim to highlight the impact of pulmonary fibrosis on patients and their families, campaign for faster and more accurate diagnosis and encourage research and development of new treatments. We contribute to scientific articles, surveys and reports; hold summits and webinars, in collaboration with our healthcare partners; provide updates on all aspects of the disease for our members; and raise awareness of pulmonary fibrosis through our public campaigns.

We also collaborate with partners around the world to campaign for better healthcare and educate HCPs and others about pulmonary fibrosis.



2.2. The Executive Board of the EU-PFF

Our membership consists of national patient associations from across Europe, which are represented on the EU-PFF Executive Board or within the General Assembly by pulmonary fibrosis patients and family members.



STEVE JONES
President
United Kingdom (UK)



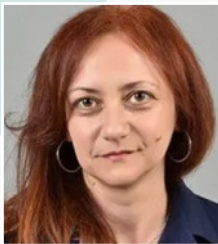
JEAN-MICHEL FOURRIER
Secretary
France (FR)



JOHN K SOLHEIM
Board Member
Norway (N)



CHANTAL VANDENDUNGEN
Board Member
Belgium (BE)



RADOSTINA GETOVA
Board Member
Bulgaria (BG)



STEFANO PAVANELLO
Board Member
Italy (IT)



HARRY DE WIT
Board Member
The Netherlands (NL)



CARLOS LINES MILLÁN
Emeritus President /
Advisor
Spain (ES)

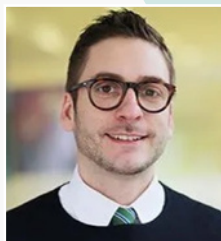


RALPH VAN LYSEBETH
Treasurer
Belgium (BE)

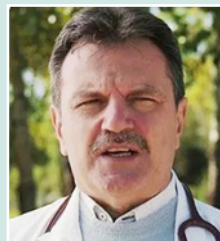
2.3. The Scientific Advisory Board of the EU-PFF



**DR ELISABETTA
BALESTRO**
Chair of Scientific
Advisory Board
Italy (IT)



**DR FRANCESCO
BONELLA**
Vice-Chair and
Founding Chair
of Scientific
Advisory Board
Germany (DE)



**DR ALEXANDER
SIMIDCHEV**
Bulgaria (BG)



**DR ANNA-MARIA
HOFFMAN-VOLD**
Norway (N)



**PROF ANDREAS
GÜNTHER**
Germany (DE)



**DR ANNE-MARIE
RUSSELL**
United Kingdom (UK)



**PROF BRUNO
CRESTANI**
France (FR)



**DR CLAUDIA
VALENZUELA**
Spain (ES)



**DR CORMAC
MCCARTHY**
Ireland (IE)



**PROF DEMOSTHENES
BOUROS**
Greece (GR)



**DR HELEN
PARFREY**
United Kingdom (UK)



**DR HELMUT
PROSCH**
Austria (AT)



**DR IRINIA
STRAMBU**
Romania (RO)



**DR KATARZYNA
LEWANDOWSKA**
Poland (PL)



**DR KATHERINE
O'REILLY**
Ireland (IE)



DR MARIA MOLINA
Spain (ES)



**DR MARLIES
WIJZENBEEK**
The Netherlands (NL)



**PROF DR MICHAEL
KREUTER**
Germany (DE)



**DR PAOLO
SPAGNOLO**
Italy (IT)



**PROF VINCENT
COTTIN**
France (FR)



PROF WIM WUYTS
Belgium (BE)



2.4. The EU-PFF Secretariat: 2022 in review

2.4.1. The EU-PFF Secretariat

The EU-PFF Secretariat is headed by Chief Executive (CEO) Liam Galvin and is staffed by a team of consultants from Patvocates, an organisation with broad experience in patient advocacy, health policy and patient engagement in medical research.



LIAM GALVIN
CEO of the EU-IPFF
Ireland (IE)



JAN GEISSLER
Patient Advocate
Germany (DE)



ALBA UBIDE
Project Manager
Spain (ES)



STEFAN HUBER
Project Manager and
Scientific Writer/
Editor
Germany (DE)



GINA UBIDE
Project Officer
Spain (ES)

2.4.2. Report by Liam Galvin, CEO of the EU-PFF

2022 was a year of change for the world and for the Federation. Whilst the world was slowly recovering from the worst of the COVID-19 pandemic, it was shocked by events in Ukraine and by their impact across the globe.

For our patients and families – the ongoing COVID threat and the energy costs associated with oxygen use, heat and transport left our communities even more isolated. Our members redoubled their efforts in grassroots support, whether in person when possible or through a variety of online initiatives.

The Federation built on the success of the 1st European Pulmonary Fibrosis Patient Summit in 2021 by continuing its series of webinars in the lead up to the 2nd European Pulmonary Fibrosis Patient summit in late 2022. Updated booklets and videos translated into multiple languages also accompanied our annual awareness campaign.

Partnerships around policy, research and respiratory health as well as member services continued to be at the core of our Secretariat's work whilst the support of industry and other stakeholders for our work remains strong as we look forward to 2023 and our next Summit in 2024.

LIAM GALVIN, CEO OF THE EU-PFF

2.5. Members and Networks

2.5.1. Our Member Organisations

The European Pulmonary Fibrosis Federation (EU-PFF) brings together 19 member organisations from 15 European countries. It aims to present a unified patient voice across Europe and to support its members in helping patients and their families and to campaign for improved treatment in their own countries.



LUNGENFIBROSE FORUM AUSTRIA
– Austria (A)



ASSOCIATION BELGE CONTRE LA
FIBROSE – Belgium (BE)



BELGISCHE VERENIGING VOOR
LONGFIBROSE – Belgium (BE)



IPF ASSOCIATION BULGARIA
– Bulgaria (BG)



AFPF – ASSOCIATION FIBROSES
PULMONAIRES FRANCE –
France (FR)



LUNGENFIBROSE – Germany (DE)



ACTION FOR PULMONARY FIBROSIS
– United Kingdom (UK)



Asthma & Lung
UK
– United Kingdom (UK)



PULMONARY FIBROSIS TRUST
– United Kingdom (UK)



HELLENIC PULMONARY FIBROSIS
ASSOCIATION – Greece (GR)



LONGFIBROSE PATIËNTENVERENIGING
– The Netherlands (NL)



IRISH LUNG FIBROSIS ASSOCIATION
– Ireland (IE)



FIMARP – Italy (IT)



UNIONE TRAPIANTATI POLMONE DI
PADOVA – Italy (IT)



LHL
Norwegian Association
of Heart and Lung Patients

LHL – NATIONAL ORGANISATION FOR
HEART AND LUNG PATIENTS – Norway (N)



IPF POLISH SOCIETY – Poland (PL)



RESPIRA – Portugal (P)



ASOCIATIA PACIENTILOR
CU FIBROZA PULMONARA
IDIOPATICA

APFPI – Romania (RO)



AFEFPI
Asociación de Familiares y Enfermos
de Fibrosis Pulmonar Idiopática

ASOCIACIÓN DE FAMILIARES Y
ENFERMOS DE FIBROSIS PULMONAR
IDIOPÁTICA – Spain (ES)

2.5.2. Our Associated Members



2.5.3. Professional Networks and Policy Partners

EU-PFF partners with professional networks and policy organisations to provide a voice for our patient community and to support joint efforts in awareness, education, policy and research. Our partners are European and global.





INTERSTITIAL LUNG DISEASE, ILD
NETWORK – United Kingdom



MEP Lung Health Group

MEP LUNG HEALTH GROUP
– Switzerland

A banner image for the Central European IPF All Patients Network, showing a person's face and neck. The text 'CENTRAL EUROPEAN IPF ALL PATIENTS NETWORK' is overlaid on the image.

CENTRAL EUROPEAN
IPF ALL PATIENTS NETWORK

CENTRAL EUROPEAN IPF NETWORK
– Central Europe



European
Reference
Network

Respiratory Diseases
(ERN-LUNG)

ERN-LUNG – Germany

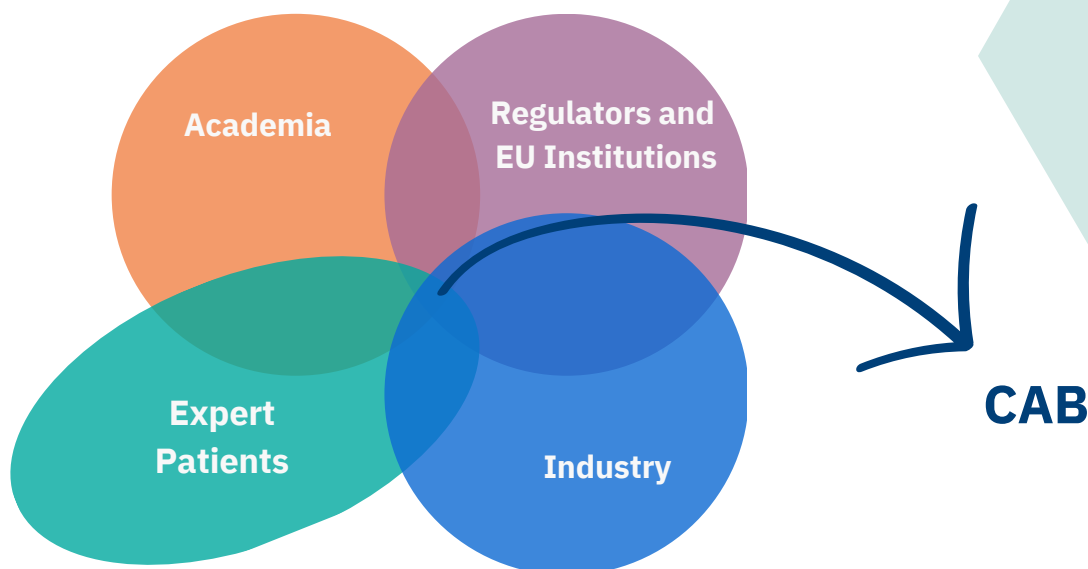
EUROPEAN LUNG HEALTH GROUP

This section gives an overview of the activities carried out by the EU-PFF in 2022.

3.1. The Pulmonary Fibrosis Community Advisory Board

In 2022, the European Pulmonary Fibrosis Federation (EU-PFF) has set up a Pulmonary Fibrosis Community Advisory Board (PF-CAB) as a working group. It comprises a panel of leading European patient advocates who work together to address issues of strategic importance to the pulmonary fibrosis community and advocate for the best possible research as well as improved and equal access to innovative treatments. They can also call on other international experts.

What is more, the PF-CAB monitors pharmaceutical developments, research and other developments in pulmonary fibrosis through long-term cooperation and continued dialogue with pharmaceutical partners, regulators, medical experts, and the scientific pulmonary fibrosis community.



3.2. PF Adherence Survey

In 2022, EU-PFF started to work on a Europe-wide survey on treatment adherence in patients suffering from pulmonary fibrosis. Its primary objective is to assess the extent to which people adhere to their medications and to investigate motivations and patterns of adherence, including identifying factors, which increase the likelihood of missing a dose of the medication. Recommendations will be made to improve support and information for patients with the aim of improving adherence within the patient population.

3.3.1. Webinars 2022

In the lead-up to the European Pulmonary Fibrosis Patient Summit, the Federation each year hosts a series of complementary webinars providing useful information for patients. The webinars focus on research, person-centred care, policy and advocacy and are recorded with short summaries including subtitles in 9 languages (English, Dutch, French, German, Greek, Italian, Portuguese, Romanian and Spanish).

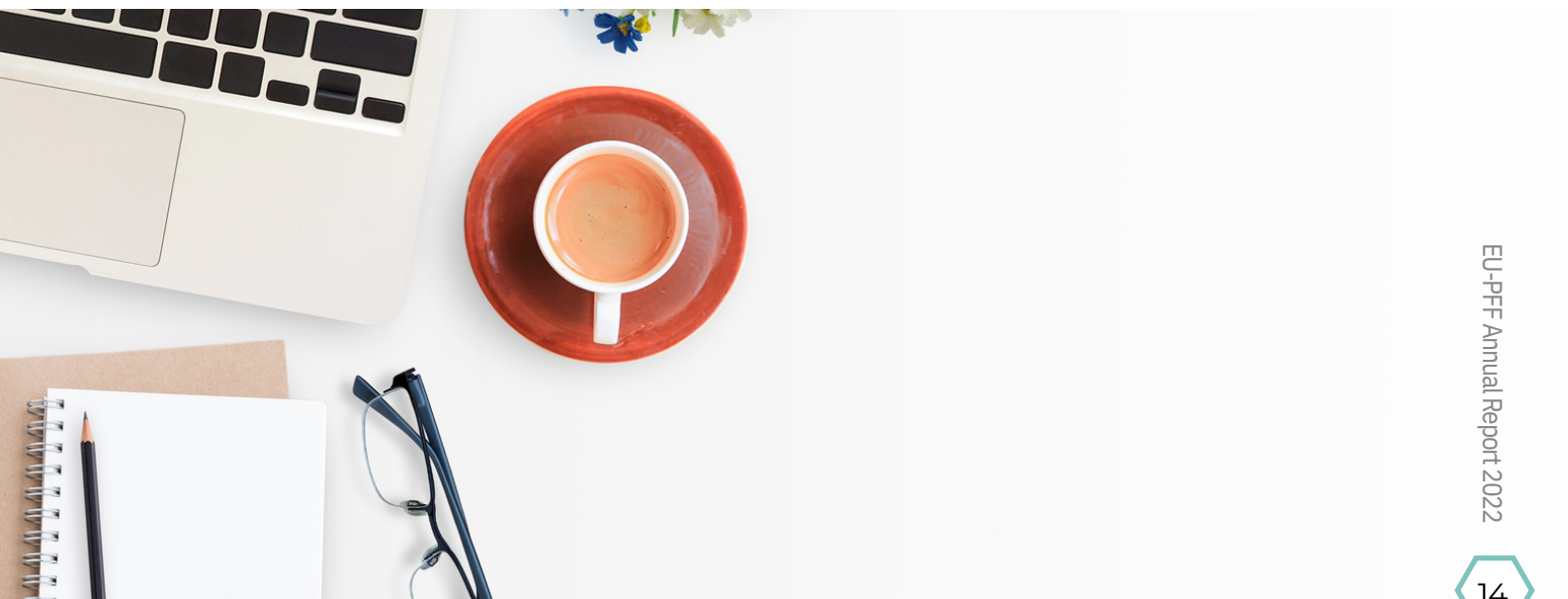
In the period before the Second European Pulmonary Fibrosis Patient Summit in 2022, the EU-PFF ran a series of six webinars, moderated by EU-PFF President Steve Jones and Board member John Solheim.

Each of these webinars was attended by over 100 people and the recordings were later made publicly available. Speakers included leading experts and researchers in pulmonary fibrosis: Dr. Simon Hart, Dr. Richard Allen, Dr. Tamás Bereczky, Colin Edwards, Geraldine Burge, Dr. Karen Moor, Dr. Elisabetta Renzoni and Dr. Muhunthan Thillai.

Webinars leading up to the 2022 PF Patient Summit:

- How did I get pulmonary fibrosis?
- The Genetics of pulmonary fibrosis
- The importance of Clinical Trials
- Novel AI diagnostics and technology in pulmonary fibrosis
- The Role of the ILD Specialist Nurse
- ERS 2022 – key takeaways for patients

You can find the recordings of the webinars, kindly sponsored by Boehringer Ingelheim and Roche, [here](#).



3.3.2. European Pulmonary Fibrosis Patients Summit 2022

The 2nd European Pulmonary Fibrosis Patient Summit took place as a virtual event over three days from November 3-5 2022. It brought together almost 400 patients, carers, researchers and HCPs from around the globe for an excellent programme of talks and discussions. The event was designed jointly with patients and over 50% of participants were either patients or caregivers.

The 12 sessions included presentations by 37 leading researchers, clinicians, healthcare professionals, policy makers and industry representatives. Patients were also actively involved as presenters and speakers in the sessions.

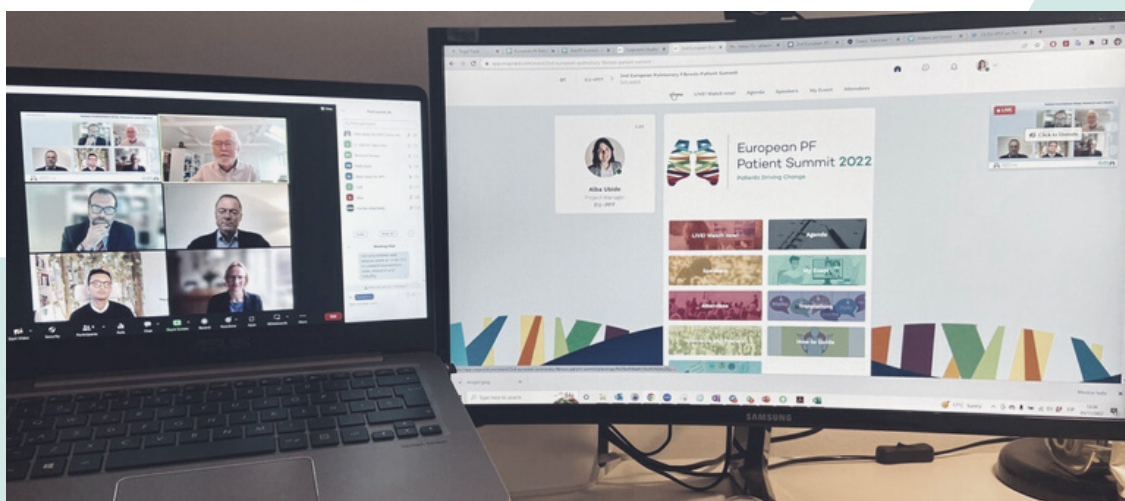
The Summit covered a wide range of topics in research, person-centred care and advocacy, and included two industry symposia by Boehringer Ingelheim and Chiesi. All summit sessions were streamed live via the virtual event platform Swapcard. During the sessions, the attendees were able to ask questions and add comments in the live discussion panel.

Sessions of the 2022 European PF Patient Summit

1. Opening session
2. Pulmonary fibrosis and Covid-19
3. Latest Research on pulmonary fibrosis: trials and treatments
4. PF – ILD – A big tent disease
5. Caregivers – the unrecognized patients
6. Challenges in diagnosing familial pulmonary fibrosis
7. Oxygen use in pulmonary fibrosis
8. Patient Involvement – roles, research and industry
9. Digital health and electronic devices and pulmonary fibrosis patients
10. Closing Session.

You can find the detailed report for the 2022 European Pulmonary Fibrosis Patient Summit [here](#).

The second virtual European Pulmonary Fibrosis Patient Summit was kindly sponsored by Boehringer Ingelheim, CSL Behring, Roche, Chiesi and Three Lakes Foundation.

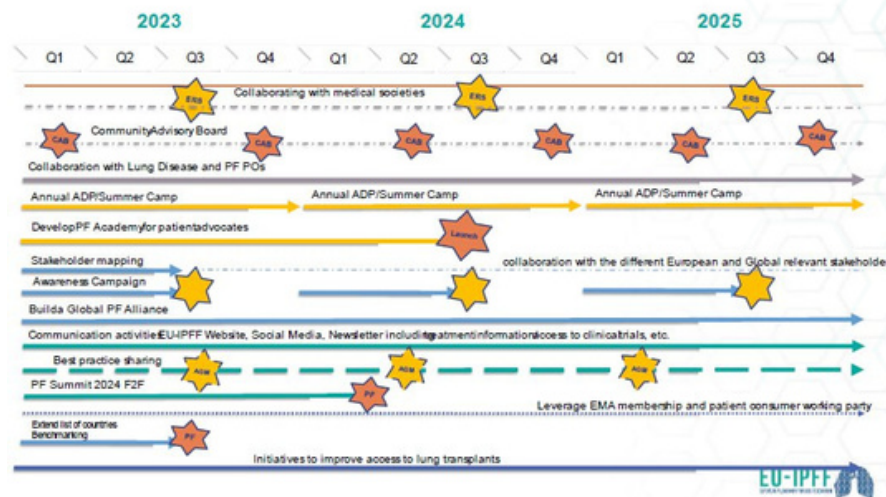


3.4. Annual General Meeting 2022

The Annual General Meeting 2022 took place, as a virtual event, from July 15-16. During the AGM, the Articles of Association were approved (you can find them [here](#)) and four members of the Executive Board were elected or re-elected:

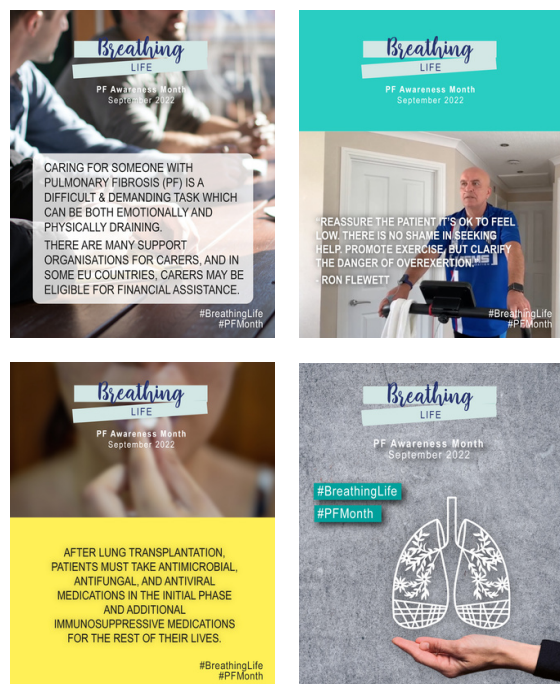
- Jean-Michel Fourrier (France)
- Chantal Vandendungen (Belgium)
- Stefano Pavanello (Italy)
- Steve Jones (UK)

At the meeting, the EU-PFF Secretariat reported on completed activities in 2021 and on 2022 projects, members approved the Strategic Plan for the years 2023-2025 and the work plan for 2023.



3.5. EU-PFF Awareness Campaign 2022 (1-30 September 2022)

Building on the successful 2021 ‘Breathing Life’ campaign, the 2022 awareness campaign used facts, figures and stories of patients living with pulmonary fibrosis and focused on education and on the recently published EU-PFF Consultation Guides for healthcare practitioners and patients. It took place over one month in September and aimed to raise awareness of pulmonary fibrosis, and create a broad public impact.



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

1. **Educating pulmonary fibrosis patients** (disease, diagnosis, treatment, self-care and support).
2. **Giving patients a platform** and a voice by publishing short video statements – the “Voices of Breathing Life”.
3. **Targeting healthcare professionals** with tailored content once a day.
4. **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.

In 2021, Patvocates created a range of digital and non-digital materials translated in 10 languages. These included booklets, flyers, postcards which could be customised, stickers and enamel pins, and a unique visual developed for the campaign, which aimed to demonstrate the vulnerability of the lungs and convey a message of hope: an abstract representation of the human lungs, visualised the scarring of the lung tissue, with natural elements such as flowers and leaves symbolising the concepts of “life” and “breathing”.

Given the success of the 2021 campaign, many of the materials were reused and updated for the 2022 campaign, as were the hashtags #BreathingLife and #PFMonth. The 2022 campaign encouraged patients to tell their personal stories by sharing videos about their experience of living with PF. The campaign team edited the videos for campaign purposes and published them on Facebook, Twitter, Instagram, LinkedIn and the EU-PFF website.

Patvocates also managed EU-PFF’s social media accounts (Twitter, Facebook, Instagram and LinkedIn) during September to promote the #BreathingLife campaign. The team produced tailored social media posts and visuals, which were targeted at patients, carers, health care professionals and other stakeholders and the general public.

Additionally, key posts (about one each day) were translated into 8 different languages (French, German, Greek, Italian, Polish, Portuguese, Romanian and Spanish). This enabled national member organisations to get the key messages out to their patient communities.

To further support local patient organisations in their awareness campaigns during Pulmonary Fibrosis Month, Patvocates sent 2050 magnetic pins and over 1000 Pulmonary Fibrosis Awareness Month stickers to destinations in 10 European countries.

You can find the in-depth report for the 2022 Awareness Campaign, which was kindly sponsored by Boehringer Ingelheim and Chiesi, [here](#).



3.6. The EU-PFF Consultation Guides

2022 saw the publication of two new EU-PFF Consultation Guides:

- the EU-PFF guide to living with pulmonary fibrosis, a free resource for newly diagnosed patients containing key information on living with the disease
- the EU-PFF guide to treating fibrosing interstitial lung diseases for health care practitioners. It describes key aspects of the disease and aims to help in diagnosis and decision-making to ensure that patients are quickly referred to the correct specialist

The guides also highlight the importance of adequate nutrition, psychological and peer support from patient organisations and support groups.

The guides serve as cornerstones of EU-PFF's mission to support, educate and empower PF patients in Europe and globally. They are also available as videos and as short and informative clips on the individual chapters of the guides. You can find the guides [here](#).

The EU-PFF Guide to living with pulmonary fibrosis was translated, with the help of the EU-PFF members, into nine European languages: French, German, Greek, Italian, Polish, Portuguese, Romanian and Spanish. You can find them [here](#).

The EU-IPFF Consultation Guides were kindly sponsored by Boehringer Ingelheim, Roche and Vicore Pharma.

3.7. EU-PFF Advocate Development Programme 2021/2022

The ADP aims to develop a cadre of pulmonary fibrosis patient advocates to represent the needs of patients and their families. In 2021/22, five pulmonary fibrosis patient advocates from the Netherlands, UK and Greece took part in the ADP, which was designed by EU-PFF and the think-tank Patvocates. It comprised regular webinars and interactive training sessions, and aimed to enable each participant to become an influential and expert patient advocate on behalf of patients and carers in their country.

The EU-PFF ADP 2021/2022 was kindly sponsored by Boehringer Ingelheim, Galápagos and Roche.



3.8. Attendance at the ERS Congress (4-6 September 2022)

EU-PFF attended the European Respiratory Society (ERS) International Congress 2022 in Barcelona. We were represented by Stefano Pavanello, member of the Board of Directors, CEO Liam Galvin and the EU-PFF Secretariat. Additionally, EU-PFF President Steve Jones gave a presentation on *Holistic management and rehabilitation of pulmonary fibrosis*. The EU-PFF delegation met leading scientists, physicians, sponsors and partners in order to learn about the latest research and development in pulmonary fibrosis.



3.9. Partnerships and Partner Activities

A key aim of EU-PFF is to encourage public and patient involvement in pulmonary fibrosis research funded by public bodies and pharmaceutical companies. Over the years, we have supported and endorsed several research funding applications, been active members of research consortiums and contributed our expertise and the views of patients to many research papers and publications.

CIG-16125

The EU-PFF and its Irish group ILFA supported this successful application under the European COST Innovators Grant programme. Led by RSCI University of Medicine and Health Sciences in Ireland, it aims to develop an open access repository of pluripotent stem cells from children and adults with interstitial lung disease. Its work is ongoing and EU-PFF presented at its kick off meeting in Dublin.

¹ van der Sar IG, Jones S, Clarke DL, Bonella F, Fourrier JM, Lewandowska K, Bermudo G, Simidchiev A, Strambu IR, Wijsenbeek MS, Parfrey H. Patient Reported Experiences and Delays During the Diagnostic Pathway for Pulmonary Fibrosis: A Multinational European Survey. *Front Med (Lausanne)*. 2021 Aug 4;8:711194. doi: 10.3389/fmed.2021.711194. PMID: 34422866; PMCID: PMC8371687.

COSCO- IPF

The EU-IPFF is a patient organisation partner for this multi-partnership academic research project led by the University Hospital Leuven in Belgium which aims to co-design with patients a core patient reported and clinical outcome set for IPF Patients. Successfully funded in 2021, the project began post-pandemic in 2022 with the EU-PFF working closely with its partners on this three-year research project.

European Lung Health Group (ELH)

In late 2021, the EU-PFF came together with the ERS and other large European patient organisations to form the ELH. As a collective initiative driven by European level patient groups and healthcare professionals, it is an informal grouping of 179 member associations from 34 European countries. Its mission is to bring together know-how to support its organisations in empowering patients with lung disease, improving quality of life, optimising multidisciplinary care, early diagnosis and research. As a group, the ELHG will be collectively promoting the need for better respiratory health care, increased patient involvement and improved prevention at European and global levels and has engaged at high level to present its joint recommendations on a variety of policy consultations impacting respiratory health from Air Quality to Orphan Medicines.

RARE-ILD

The EU-PFF is a patient organisation partner for this successfully funded project led by the University Hospital of Giessen and Marburg, Germany. A large consortium of partners from across Europe, it aims to develop novel, primarily non-invasive diagnostic algorithms and biomarkers for rare ILDs, including pulmonary fibrosis. Successfully funded in 2020, background work continued during the COVID-19 pandemic with the EU-PFF attending its kick off meeting in 2022 and participating in its steering committee.

ERN LUNG

The European Reference Network on Rare Respiratory Diseases is a clinical and patient project funded by the European Union to promote education, research and clinical expertise among its centres of excellence across Europe. Since its inception in 2017, EU-PFF has been an active member of the ERN-Lung and continues to support and engage with the network, taking a patient leadership position within its core network on ILD.

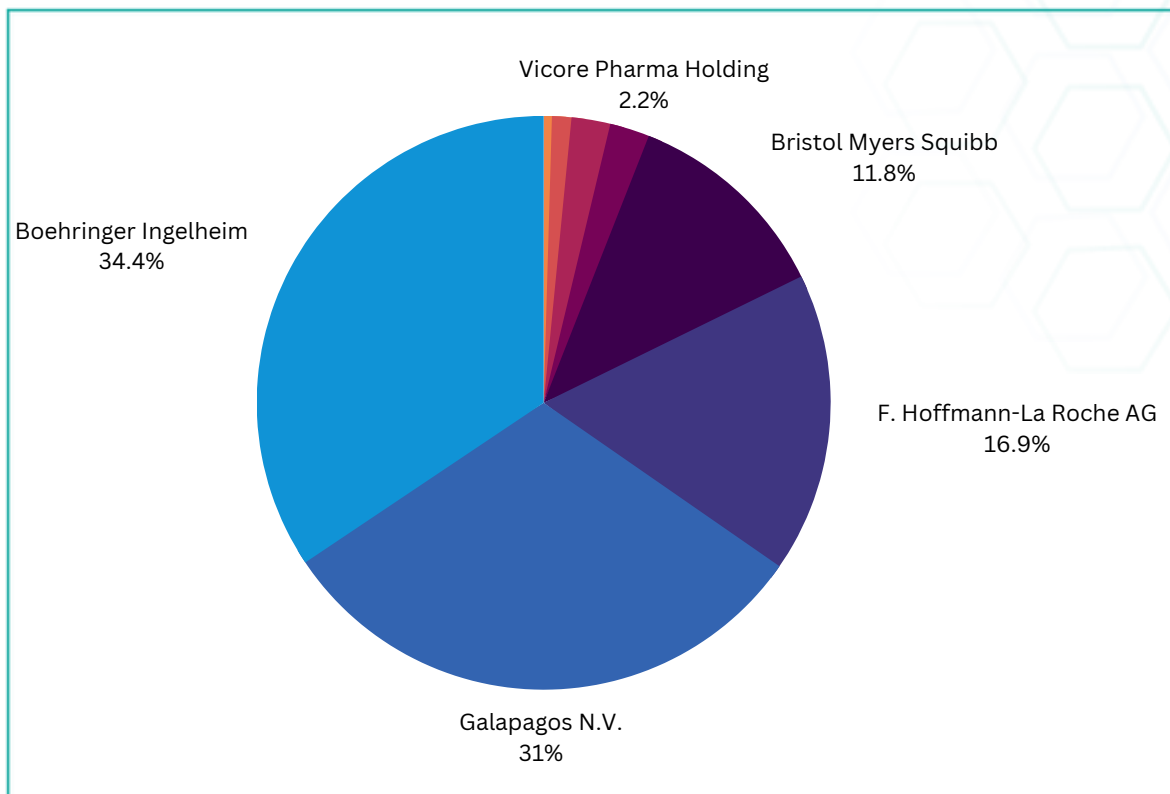
International Respiratory Coalition

Established in 2022, the IRC is a international movement dedicated to the establishment of national respiratory programmes in all global countries. Led by the medical societies in partnership with patient organisations, industry and other stakeholders it is focused on ensuring policymakers recognize Respiratory Health as a priority within each state. The EU-PFF were invited to its launch meeting and support its ongoing activities.

During Fiscal year 2021 (June 2020 to May 2021), the EU-PFF received a total of **457,934.16 € as operating income** ([see here](#) the audited accounting report as provided to the Belgian authorities).

The following graph shows the distribution of the overall funding received by the Federation by name of company/funder and an overview of the percentage provided by each party. The table provides further details on the amount received by each funder.

The pharmaceutical company Boehringer Ingelheim provided 34.2% of the overall income followed closely by Galapagos N.V. with 30.96%. See graphic and table below with further details.



Name of company/ funder	Amount of income	% of overall EU-PFF's income
Boehringer Ingelheim	€ 157,509.00	34.40%
Galapagos NV	€ 141,760.00	30.96%
F.Hoffmann - La Roche Ltd	€ 77,430.00	16.91%
Bristol Myers Squibb	€ 53,885.16	11.77%
Vicore Pharma Holding	€ 10,250.00	2.24%
Chiesi Farmaceutici	€ 10,000.00	2.18%
Action Pulmonary Fibrosis	€ 5,000.00	1.09%
Membership Fees	€ 2,100.00	0.46%

The income received by the EU-PFF is of three types:

- Corporate Sponsorship/General Grants
- Project Funding
- Patient Engagement Activities

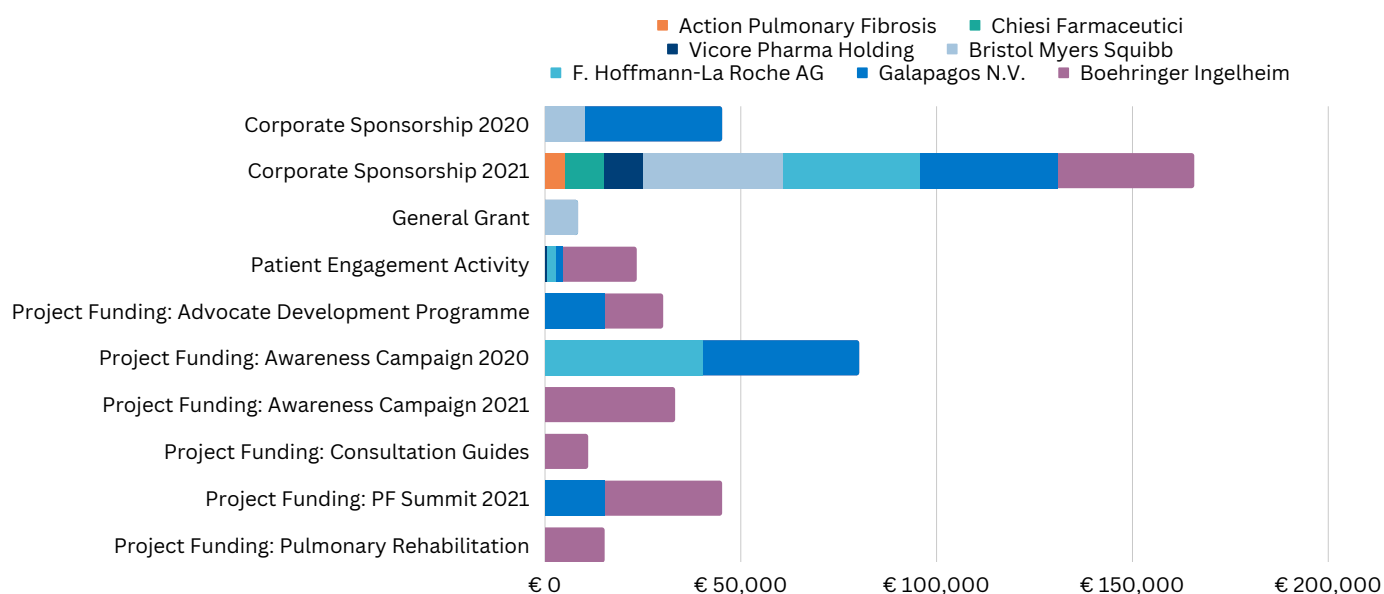
Corporate Sponsorship/General Grants allows EU-PFF to pay for the running costs of the Secretariat and Board of Directors, and general meeting costs, software and IT.

Project Funding is allocated to cover the costs of each individual project, including staff time from the Secretariat team and other third party providers (translators, Audio visuals, etc.) to pass-through costs.

Patient Engagement Activities refer to the involvement of EU-PFF Member representatives in sponsor-led activities, such as patient advisory boards and clinical trials. EU-PFF acts as an intermediary between the member representatives and the pharmaceutical companies and makes payments to member representatives and charges the sponsor an administration fee.

The following table shows the different income per type to project as described above provided by each sponsor. As the fiscal was not yet running in parallel to the normal calendar year that is used for the EU-PFF projects, there will be funding corresponding to 2 different calendar years.

Type of funding	Action Pulmonary Fibrosis	Chiesi Farmaceutici	Vicore Pharma Holding	Bristol Myers Squibb	F. Hoffmann-La Roche AG	Galapagos N.V.	Boehringer Ingelheim	Grand Total per type
Corporate Sponsorship 2020				€ 10,000.00		€ 35,000.00		€ 45,000.00
Corporate Sponsorship 2021	€ 5,000.00	€ 10,000.00	€ 10,000.00	€ 35,679.00	€ 35,000.00	€ 35,000.00	€ 35,000.00	€ 165,679.00
General Grant				€ 8,206.16				€ 8,206.16
Patient Engagement Activity		€ 250.00		€ 2,430.00		€ 1,765.00	€ 18,754.00	€ 23,199.00
Project Funding: Advocate Development Programme						€ 14,995.00	€ 14,955.00	€ 29,950.00
Project Funding: Awareness Campaign 2020					€ 40,000.00	€ 40,000.00		€ 80,000.00
Project Funding: Awareness Campaign 2021							€ 33,000.00	€ 33,000.00
Project Funding: Consultation Guides							€ 10,800.00	€ 10,800.00
Project Funding: PF Summit 2021					€ 15,000.00		€ 30,000.00	€ 45,000.00
Project Funding: Pulmonary Rehabilitation							€ 15,000.00	€ 15,000.00
Grand Total	€ 5,000.00	€ 10,000.00	€ 10,250.00	€ 53,885.16	€ 77,430.00	€ 141,760.00	€ 157,509.00	€ 455,834.16



For the Fiscal Year 2021, EU-PFF had operating costs of € 326,464.37, of which € 225,781.81 was for subcontracting costs to Patvocates GbmH to run the Secretariat and staff time on the different projects. Subcontracting costs include translation services, audio-visual services, IT and logistics provided by third parties.

See below the details in the extract of the accountant report.

II. Operating costs	-326.464,37
A. Trade goods, raw and auxiliary materials	-225.781,81
603000 Subcontracting	-225.781,81
B. Services and miscellaneous goods	-66.541,15
611010 Computer supplies	-1.597,86
611020 Website	-8.008,09
612800 Gifts and liberalities	-50,00
612900 Reception costs limited	-87,71
613000 Travel expenses Belgium	-75,00
613100 Transport costs abroad	-14.369,00
615200 Honorary accountants	-6.381,58
615600 Remuneration miscellaneous	-35.971,91
G. Other operating expenses	-34.141,41
640700 Non-deductible V.A.T.	-34.141,41

EU-PFF is registered in Belgium as an International Not-for-Profit-Organisation. Fully compliant with Belgium law and financial regulations, it is committed to transparency in its financial matters. Its audited accounts are prepared by FIDIAZ (previously known as Finivo) on an annual basis and are available publicly in Belgium. They can also be accessed on our website. EU-PFF is registered with the Europa Transparency Register.

The full accounts for 2021 linked to this annual report are for the income and expenditure for the financial year from June 2020 to May 2021. From January 2023 the financial year of EU-PFF will be changed to run from January to December. The EU-PFF is a membership-based organisation and its Board of Directors are all volunteers.



EU-PFF
EUROPEAN PULMONARY FIBROSIS FEDERATION

