

EU-PFF

EUROPEAN PULMONARY FIBROSIS FEDERATION



ANNUAL REPORT 2023

The voice of pulmonary fibrosis patients in Europe

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This year saw the Federation expand once again both in terms of its membership and also its ambition. When first taking on the role of President I wanted the EU-PFF to demand earlier and stronger patient involvement in research and to become the voice of pulmonary fibrosis in Europe. In partnership with our members, our scientific advisory board and our many partners from research, advocacy and industry we have made great progress.

Our existing successful patient involvement in research has this year provided us many more opportunities to promote the value patients can bring to treatment development, to involve patients for patients. Each contribution, each review, each participation has shown to others within industry, regulatory and research that our model is working and so we are becoming embedded in the process.

This emphasis on patient involvement has led to the EU-PFF holding the first ever PF community advisory boards. These see our patient community set the agenda, to focus on what mutually could be done and allows above all for us promote and educate that successful and timely treatments start with patient involvement.

This year also saw the Federation take a next step by leading two Europe wide research projects, one on oxygen use and the other on adherence to anti-fibrotic medication, and I look forward to their completion in 2024. Another highlight of the year was our successful Annual Awareness Campaign based on our identity as the Voice of Pulmonary Fibrosis in Europe which also saw new resources for both patients and clinicians published.

Our 2023 webinar series added to our role as a provider of trusted and translated information to our community and these alongside previous webinars and the sessions from our patient summits can be found on our website www.eu-pff.org which was also been redesigned during the year.

STEVE JONES, EU-PFF PRESIDENT

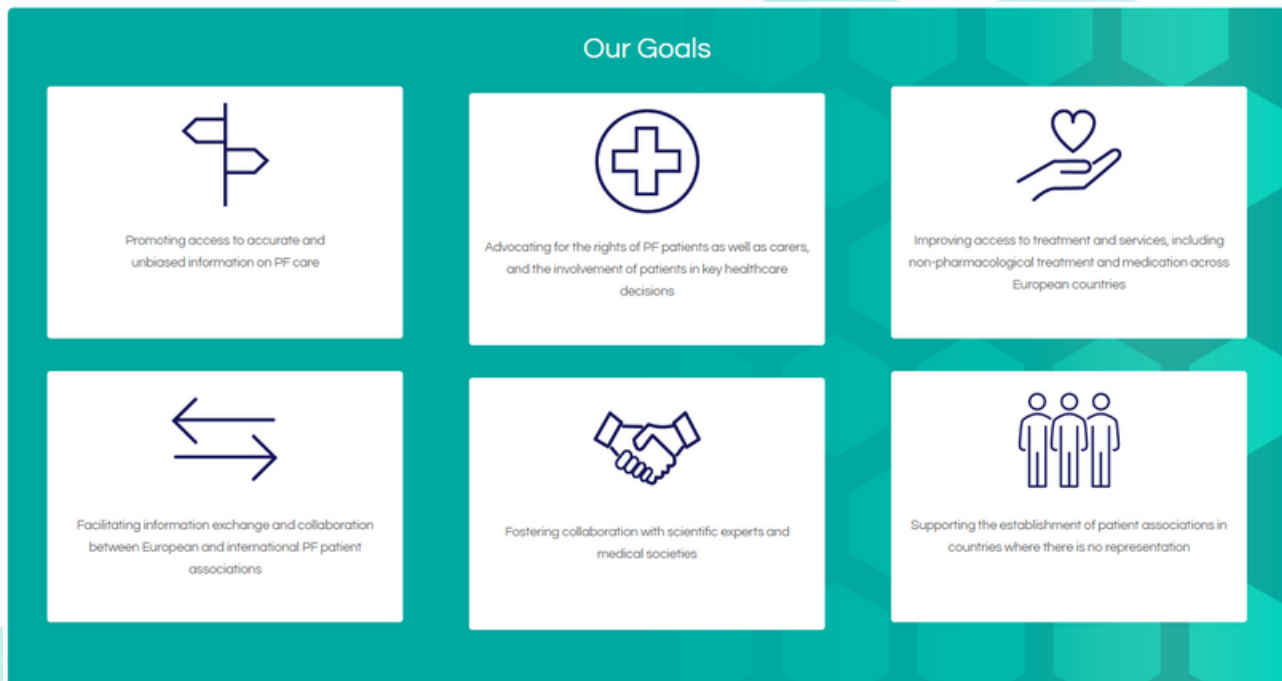


2.1. Our mission

Established in 2016, the European Pulmonary Fibrosis Federation (EU-PFF) is a Belgium Registered not-for-profit umbrella organisation for pulmonary fibrosis patient organisations in Europe. Together with our member organisations and partners, we work to raise awareness of pulmonary fibrosis on a political and public level, in healthcare and policy, treatment and research, and with a focus on differences and similarities from country to country across these areas.

To this end, we collaborate closely with medical experts and researchers across Europe and the world, aiming to put a spotlight on this disease, its diagnostic pathway and existing treatment. We monitor and contribute to research and the potential development of new treatment modalities. We contribute to scientific articles, surveys and reports and are an established and trusted patient involvement partner. We provide trusted information and [webinars](#) in collaboration with our healthcare partners to provide updates on all aspects of the disease for our members and the PF Community. We have also organised the first ever held in Europe PF Patient Summits.

We raise awareness of pulmonary fibrosis through our annual awareness campaign each September. We strongly collaborate with other organisations around the world to exchange best practices, outreach to healthcare authorities and to provide education on pulmonary fibrosis.



2.2. The Board of Directors of the EU-PFF

Our membership consists of national patient associations from across Europe who form the General Assembly of the federation. From within this General Assembly, the membership selects representatives to form the Board of Directors who in turn select the President and Officers of the Federation. Strongly patient-led, the Federation's members are mainly patients, family members of patients or dedicated patient advocates.



STEVE JONES
President
United Kingdom (UK)



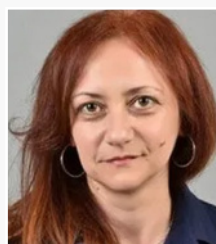
JEAN-MICHEL FOURRIER
Secretary
France (FR)



RALPH VAN LYSEBETH
Treasurer
Belgium (BE)



CARLOS LINES MILLÁN
Emeritus President /
Advisor
Spain (ES)



RADOSTINA GETOVA
Board Member
Bulgaria (BG)



STEFANO PAVANELLO
Board Member
Italy (IT)



CHANTAL VANDENDUNGEN
Board Member
Belgium (BE)



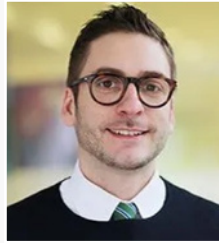
JOHN K SOLHEIM
Board Member
Norway (N)

2.3. The Scientific Advisory Board of the EU-PFF

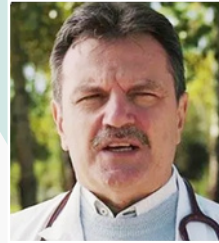
Based on a strong ethos of partnership with the clinicians and experts who serve our patient community, the membership groups of the Federation each nominate experts from their respective countries to serve on our Scientific Advisory Board.



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: Members and Changes in 2023

2.4.1. The EU-PFF Secretariat

The EU-PFF Secretariat is led by CEO Liam Galvin, former Secretary of the EU-PFF, and handled by a Patvocates team of consultants with a broad experience in patient advocacy, health policy and patient engagement in medical research.



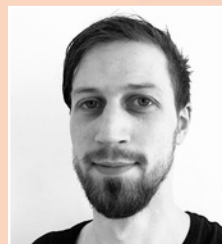
LIAM GALVIN
CEO of the EU-PFF
Ireland (IE)



JAN GEISLER
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)



MIRNA TOMAŠEVIĆ
Communications
Manager
Croatia (HR)



GERGELY MESZAROS
Policy Advisor
Hungary (HU)

2.4.2. Name change and expanded mission

Established in 2014, the Federation originated as an informal alliance of national groups primarily centred around Idiopathic Pulmonary Fibrosis. By 2016, it evolved into an international non-profit organisation, officially registered in Belgium.

Originally founded as the European Idiopathic Pulmonary Fibrosis & Related Disorders Federation, this membership organisation has an elected leadership. In 2016, the Federation experienced a significant evolution, expanding its membership, ambition, influence, and the patient community it serves. In response to this growth and commitment, the membership collectively decided to align the organisation's name more closely with its mission. Thus, the name was officially changed to the European Pulmonary Fibrosis Federation (EU-PFF), reflecting its dedication to serving all patients affected by various forms of progressive pulmonary fibrosis.

2.4.1. Report by Liam Galvin, EU-PFF CEO



2023 was again a fraught year for our community, with energy prices and cost of living having a greater impact for those so reliant on oxygen use, heat and transport for their health and social needs. With COVID-19 still in circulation, populations being displaced, air quality and climate change all looming large over the pulmonary fibrosis community, it was a year for the members of the Federation to redouble their efforts to provide support, education and to contribute to research.

As a Federation, we were delighted to add groups from Turkey and Hungary to our family of patient organisations. We welcomed the chance to work with many partners, from industry, from the research community and with numerous other patient organisations from the broader respiratory and rare diseases communities.

As the Voice of Pulmonary Fibrosis in Europe, we came together in 2023 to raise awareness of pulmonary fibrosis and to campaign for and to assist in research. Whilst the year saw some late-stage clinical trials fail, many more developments continue and the federation remains focussed on its advocacy for early and meaningful patient involvement in research as well as its central role of supporting its member organisations. I look forward to the 3rd European PF Patient Summit in 2024 and strengthening the voice of our members whether at national, European or World Health Organisation level.

Liam Galvin, EU-PFF CEO



EU-PFF
EUROPEAN PULMONARY FIBROSIS FEDERATION

2.5. Members and Networks

2.5.1. Our Member Organisations

Through its 21 member organisations from all over Europe who unite their voices, share experience and knowledge and communicate about pulmonary fibrosis (PF) care and treatment on a national level, the European Pulmonary Fibrosis Federation (EU-PFF) creates impact and exerts influence on how individual countries handle the disease.

In 2023, the Federation also welcomed two new members who were accepted as full members at the Annual General Meeting 2023: Tüdőfibrózis Egyesület, a pulmonary fibrosis patient organisation from Budapest, Hungary; and PAHSSc, a pulmonary hypertension, pulmonary fibrosis and scleroderma patient association based in Izmir, Turkey. Both were accepted by unanimous vote.



**Lungenfibrose
Forum Austria**

LUNGENFIBROSE FORUM AUSTRIA
– Austria (A)



ASSOCIATION BELGE CONTRE LA
FIBROSE – Belgium (BE)



BELGISCHE VERENIGING VOOR
LONGFIBROSE – Belgium (BE)



СДРУЖЕНИЕ
ИДИОПАТИЧНА
БЕЛОДРОБНА
ФИБРОЗА
IPF ASSOCIATION BULGARIA
– Bulgaria (BG)



AFPF
Association
Fibroses Pulmonaires
France

AFPF – ASSOCIATION FIBROSES
PULMONAIRES FRANCE –
France (FR)



Lungenfibrose e.V.

LUNGENFIBROSE – Germany (DE)



**Action for
Pulmonary Fibrosis**

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)



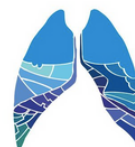
ASOCIATIA PACIENTILOR
CU FIBROZA PULMONARA
IDIOPATICA

APFPI – Romania (RO)



AFEFPI
Asociación de Familiares y Enfermos
de Fibrosis Pulmonar Idiopática

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



**TÜDŐFIBRÓZIS
EGYESÜLET**

Tüdőfibrózis Egyesület
– Hungary (HU)



PULMONER HIPERTANSİYON VE
SKLERODERMA – Turkey

2.5.2. Our Associated Members

The Federation welcomes patient groups from across the WHO definition of the European continent, but is committed to forging close partnerships internationally with groups and organisations that share its aims and focus on rare diseases, pulmonary fibrosis and lung health.



LUNG FOUNDATION- Australia



Canadian
Pulmonary
Fibrosis
Foundation

CANADIAN PULMONARY FIBROSIS
FOUNDATION – Canada



RESPIRIAMO INSIEME – Italy



AMA FUORI DAL BUIO– Italy (IT)



PULMONARY FIBROSIS FOUNDATION
– USA



AMERICAN LUNG ASSOCIATION
– USA



PF WARRIORS – USA

2.5.3. Professional Networks and Policy Partners

The EU-PFF is partnered on a European and global level with a variety of professional networks and policy partners working jointly with them, providing a voice for our patient community and supporting joint efforts in awareness, education, policy and research.



ELF EUROPEAN LUNG FOUNDATION
EUROPEAN LUNG FOUNDATION
– United Kingdom



EURODIS
RARE DISEASES EUROPE
EURODIS – Belgium, France, Spain



INTERSTITIAL LUNG DISEASE, ILD NETWORK – United Kingdom



MEP Lung Health Group
MEP LUNG HEALTH GROUP
– Switzerland



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

2.5.4. Support Groups

Across Europe and the world, EU-PFF members have forged relationships with local groups that support patients with pulmonary fibrosis, be it physically or online, and who support the aims and objectives of the EU-PFF.



Bolton Pulmonary Fibrosis Support Group – United Kingdom (UK)



Breathe Support Network - USA



Derby PF Support Group – United Kingdom (UK)



Northamptonshire Pulmonary Fibrosis Support Group - United Kingdom (UK)



Northern Trust Pulmonary Fibrosis Support Group - Northern Ireland



Papworth Hospital Pulmonary Fibrosis Support Group - United Kingdom (UK)



St. George's ILD Support Group - United Kingdom (UK)

Swansea Support Group - United Kingdom (UK)

3

WHAT WE DO – ACTIVITIES OF THE FEDERATION IN 2023

Patient advocacy, creating awareness, supporting national patient organisations and promoting and fostering Pulmonary Fibrosis research in Europe and beyond – as a European umbrella organisation, we use all the tools at our disposal and continue to look for new means of influence, with the ultimate aim of providing pulmonary fibrosis patients, their families and carers with timely and better access to diagnosis, improved care and treatment, and to help open new avenues in research and development within the disease area. This section gives an overview of the activities carried out by the EU-PFF in 2023.

3.1. New website

In the course of its name change to EU-PFF and thus the expansion of its mission, the Federation also saw the need to rebuild its web presence from scratch. The [new website](#) is now much easier to navigate, more accessible and offers patients, carers and their loved ones as well as our partners, sponsors and others all the necessary information, resources and links in a clear structure and layout.

In addition to information on pulmonary fibrosis, resources such as the EU-PFF Consultation Guides, the recordings of our webinars and summit sessions as well as information on our activities and projects, the website also offers a PF focussed clinical trial finder that enables patients to find a trial that suits their particular condition and location.

The Federation also sends out a newsletter several times a year and at regular intervals to provide information about current EU-PFF projects and events as well as other events, meetings, research projects or initiatives relevant to patients in the field of pulmonary fibrosis.



About us ▾ About PF ▾ PF Patient Summit 2024 Library & Resources ▾ News & Events ▾ Contact us ↗

English ▾



WELCOME TO THE WEBSITE OF THE EUROPEAN PULMONARY FIBROSIS FEDERATION

With member organisations representing countries all over Europe, who unite their voices in the European organisation sharing experiences, sharing knowledge and communicating about PF care and treatment in the various countries the **European Pulmonary Fibrosis Federation** creates impact and influence on how the individual country handles the disease.

We serve as the trusted resource for a united PF patient voice by raising awareness, providing disease education, advancing care, and funding research.

[Read more about us here](#)

3.2. The EU-PFF Breathing Life Campaign 2023

Building on the two previous campaigns, the 2023 Breathing Life campaign, which ran throughout the month of September, again put a focus on

- **educating PF patients** (disease, diagnosis, treatment, self-care and support).
- **educating healthcare professionals** with tailored content.
- **promoting the EU-PFF Consultation Guides**

At the same time, last 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 these calls to action, EU-PFF conducted interviews with stakeholders from the research and clinical community as well as patient representatives. Short clips from these interviews were then published as part of the campaign's social media schedule.

Via a sophisticated social media concept and around 100 posts tailored to different target groups – patients and their loved ones, general practitioners and HCPs, clinicians and researchers, industry, and regulators as well as policy makers – this content was published over the month of September across all platforms. Key posts (about one post a day) were translated into 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. The campaign team also sent out magnetic pins, stickers and printed consultation guide flyers and dedicated Breathing Life cardboard picture frames to all interested parties.

What is more, 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: FIMARP (Italy), Hellenic PF Association (Greece) and the Polish IPF Society (Poland).

You can find more information on the concept, content and execution as well as an analysis of the campaign in the official report [here](#).



3.3. The EU-PFF Annual General Meeting 2023 in Castelldefels

The EU-PFF held its Annual General Meeting in April 2023 at Castelldefels, Spain. Over three days, representatives of the Federation's member organisations, experts from its Scientific Advisory Board, guest speakers and industry representatives gathered to reflect on 2022 and look forward to 2023 and beyond. EU-PFF welcomed new member organisations from Hungary and Turkey, took stock of achievements and decided together on future projects and discussed the overall mission and direction of the Federation. As a membership organisation, EU-PFF also took the opportunity to strengthen its commitment to working together, and forged new partnerships with its advisors, sponsors and other networks across Europe. In addition, John Solheim, Harry De Witt and Radostina Getova were confirmed as Board Members until 2025. However, Harry De Witt stepped down from his position at the end of 2024. We take this opportunity to thank Harry for his work and efforts within the Board.



3.4. Webinars in 2023

In 2023, the Federation continued its series of informative webinars for the patient community. The webinars were also supplemented by short summaries, including subtitles in English, Dutch, French, German, Greek, Hungarian, Italian, Polish, Romanian, Spanish and Turkish languages.

The following seminars were hosted within 2023 whilst others will feature in Q1 2024

- Webinar 1: New treatments for PF - What's in the pipeline?
- Webinar 2: Key issues in management of ILD in patients with RA, SSc & other connective tissue diseases
- Webinar 3: Key developments in pulmonary fibrosis research – highlights from the 2023 ERS Congress
- Webinar 4: Pulmonary Hypertension associated with interstitial lung disease (PH-ILD)



3.5. Pulmonary Fibrosis CAB

In 2023, EU-PFF set up a Pulmonary Fibrosis Community Advisory Board (PF-CAB) as a working group of EU-PFF. It comprises a panel of leading European patient advocates who can also call on other international experts. PF-CAB members work together to address issues of strategic importance to the PF community. They advocate for the best possible research and improved and equal access to innovative treatments and are for PF patients. PF-CAB monitors pharmaceutical developments, research and other developments in PF through long-term cooperation and continued dialogue with pharmaceutical partners, regulators, medical experts, and the scientific PF-community.

[This](#) report covers the first PF-CAB meeting, which was organised with Boehringer-Ingelheim.

3.6. The EU-PFF Adherence Project

In 2023, EU-PFF ran a Europe-wide [survey on treatment adherence](#) in patients suffering from pulmonary fibrosis. The aim of the survey, which was available in English, French, German, Greek, Italian, Polish, Romanian and Spanish languages, was 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 medication.

Based on the survey results, recommendations will be made to improve support and information for patients with the aim of improving adherence within the patient population.

Amongst other things, the findings of this survey will be used to provide the patient community and EU-PFF with the evidence to make recommendations to other stakeholders, in order to improve adherence within the patient population.

3.7. Pulmonary Fibrosis: a supportive guide

Together with the European Lung Foundation (ELF), EU-PFF has developed a guide for pulmonary fibrosis patients and their carers. In its 24 pages and 8 chapters, “Pulmonary Fibrosis: a supportive guide” covers essential aspects such as the disease itself, treatment, supportive care and living well. You can download the guide, which will be made available in more languages in the future, [here](#).



Pulmonary fibrosis: a supportive guide

EU-PFF
EUROPEAN PULMONARY FIBROSIS FEDERATION



ELF
EUROPEAN
LUNG
FOUNDATION

3.8. EU-PFF Consultation Guides: more languages added

Over the course of 2023, the [EU-PFF guide to living with PF](#) has been translated into more languages and is now available in Bulgarian, Croatian, Czech, Dutch, English, French, German, Greek, Hungarian, Italian, Polish, Portuguese, Romanian and Spanish. The guide is a free resource for newly diagnosed patients and contains key information on the most important aspects of living with PF, e.g. managing the disease, diagnosis and treatment, self-care and support groups.

The **EU-PFF guide to treating fILDs** is available in English only and provides essential information and an overview of the most important aspects of the disease – from prevalence 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.

These publications were prepared jointly by advocates from the EU-PFF membership and members of its Scientific Advisory Board led by Dr. Elisabetta Balestro

Bulgarian | Croatian | Czech | Dutch | English | French | German | Greek | Hungarian | Italian
Polish | Portuguese | Romanian | Spanish



3.9. Attendance at congresses, events and meetings

Delegates and members of the Federation and its Scientific Advisory Board were present at various congresses and events in 2023 to engage in dialogue with other relevant stakeholders, for example from healthcare policy, research and industry, to exchange knowledge and to adequately represent the concerns and unmet needs of all PF patients in Europe. Some examples from our Patient Advocates include

a) CILDAPANET, September 1-3, 2024 in Sofia, Bulgaria

The annual meeting of the Central & Eastern European ILD Patient Network was attended by Liam Galvin (Ireland), Stefano Pavanello (Italy) and Radostina Getova (Bulgaria) as well as leading physicians and patient advocates from across the network.

b) ERN-LUNG Annual Board Meeting, March 22, 2023 in Frankfurt, Germany

This annual meeting of experts from Europe's leading centres of excellence alongside patient advocates detailed the many developments being led by ERN-LUNG and planned the next steps as the ERNs increase their role within the EU and national healthcare systems. It was attended by Liam Galvin (Ireland), Stefano Pavanello (Italy) and Johann Hochreiter (Austria).

c) ERS Congress 2023 in Milan, Italy

EU-PFF delegates played an active role at this year's ERS International Congress and gave presentations on various topics: Chantal Vandendungen (Belgium) spoke together with her husband on the topic of palliative care, Jean-Michel Fourier (France) on the positive impact of exercising for patients with PF, John Solheim (Norway) on symptom burden, and Stefano Pavanello on getting involved in international research networks. CEO Liam Galvin (Ireland) co-chaired the ELF Patient Organisation Networking day and spoke at the joint ERS/ERN-Lung Symposium. EU-PFF President Steve Jones (United Kingdom) led our delegation in forging relationships via the many meetings the Federation held with stakeholders including sponsors, industry, clinicians and researchers.



d) EU HTA Stakeholder Network

EU-PFF successfully applied to join this newly established network within the EU structure to ensure that the PF community is represented alongside other colleagues from the European Lung Health Group as the EU begins its deliberations on how to improve the European HTA landscape. The EU-PFF is represented by Chantal Vandendungen (Belgium).

e) European Lung Foundation Patient Advisory Committee

This twenty-member committee is designed to ensure that the European Lung Foundation remains deeply connected to the diverse patient community it serves. The committee feeds into the leadership council of ELF and is also central to the annual ELF Networking event at the ERS Congress. Places on the committee are limited and subject to a selection and voting process. EU-PFF is represented by Liam Galvin (Ireland), Stefano Pavanello (Italy), and Jean-Michel Fourier (France), who were re-elected at the end of 2023.

f) European Medicines Agency (EMA)

EU-PFF continued its successful relationship with the EMA as an eligible group within its stakeholder group. In exchanges, workshops and webinars, EU-PFF is kept informed and has the opportunity to submit on issues affecting its patient community and the wider population. EU-PFF was represented in this regard by Harry de Witt (Netherlands).

g) EURORDIS Council of Federations Meeting

EURORDIS is the umbrella organisation for rare diseases in Europe, working at a high level on policy, awareness and data. EU-PFF is a member in its council of federations, whose annual meeting was attended by Gergely Meszaros (EU-PFF) and Liam Galvin (Ireland). EU-PFF is committed to actively working with EURORDIS, particularly with respect to ERN-Lung.

h) ILD-IN Annual Conference, October 8th and 9th, 2023 in Birmingham, UK

This novel network of specialist nurses and other healthcare professionals organises an annual educational conference focusing on the latest best practice, research and sharing of experience on PF and ILD. This conference was attended by Liam Galvin (Ireland).

i) International Respiratory Coalition Summit, June 26–27, 2023 in Lisbon, Portugal

Following its launch in 2022, which EU-PFF also attended, the IRC has begun to support pilot projects in ten European countries focused on the main goal of each country worldwide having its own respiratory programme. This event was attended by Liam Galvin (Ireland)

j) WASOG 2023, June 19-21 2023 in Stockholm, Swede

This annual scientific conference is attended by the international members of the World Association of Sarcoidosis and Other Granulomatous Disorders. 2023 was the second year that the conference welcomed patient advocates to attend. With its focus on Sarcoidosis and PF, it provides an intense educational experience on the very latest advances in research, data and novel developments. John Solheim (Norway) and Liam Galvin (Ireland) attended.

Over the years, EU-PFF has provided support and endorsement for numerous research funding applications, actively participated in research consortiums, and contributed its expertise and the patient perspective to various research papers and publications. The federation also collaborates with pharmaceutical companies on trial simulations, creates patient-facing materials, establishes patient advisory groups, community advisory boards, and involves patients in clinical trial design.

Additionally, EU-PFF participates and collaborates in various other important projects, including the following:

4.1. COCOS-IPF

It aims to co-design with patients a core patient-reported and clinical outcome set for IPF/PF 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. 2023 was a busy year for the COCOS-IPF consortium, which includes many of the EU-PFF Scientific Advisory Board, and in which the literature review, an international survey and patient focus groups have been completed or are nearing completion.

4.2. RARE-ILD

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 as the project continued in 2023. Led by Prof Andreas Günther (Germany) from our Scientific Advisory Board, its consortium includes several other Scientific Advisory Board members.

4.3. ERN LUNG

A clinical and patient project funded by the European Union to promote the exchange of education, research and clinical expertise among centres of excellence across Europe. Formed in 2017 the ERN-Lung was strongly welcomed by the EU-PFF who supported the inclusion of an ILD Core Network within its structure. The ILD Core Network includes EU-PFF patient members as well as clinicians from our Scientific Advisory Board. In 2023, Liam Galvin (Ireland) was elected Patient Co-Chair of the entire ERN-Lung as well as continuing the role of Patient Lead for the ILD Core Network.

4.4. European Lung Health Group

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. The EU-PFF were founding members and its focus is on policy change at European and World Health Organisation level and to ensure that respiratory health becomes a policy focus for politicians and health care systems across Europe. It is partnered with a special interest group of Members of the European Parliament called the MEP Lung Health Group with which it works closely.

4.5. International Respiratory Coalition

The IRC is an 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 policy makers recognise respiratory health as a priority within each state. EU-PFF is a proud supporter of the IRC and was invited to its launch in 2022 and has maintained its attendance and its support as the IRC's work has continued in 2023.

4.6. REMAP-ILD

The REMAP-ILD consortium, dedicated to enhancing the lives of individuals with pulmonary fibrosis (PF), is an international initiative funded through a collaboration between Imperial College London and NIHR and led by Professor Giesli Jenkins. Supported by partner organisations such as Action for Pulmonary Fibrosis, Scleroderma and Raynaud's UK, Pulmonary Fibrosis Trust, Asthma+Lung UK, Pulmonary Fibrosis Foundation, FIMARP and EU-PFF, the consortium uses a unique approach in its REMAP trials. Unlike traditional clinical trials, the recruitment process follows a tunnel model, allowing for greater participation. The trials, which compare multiple treatments simultaneously and employ randomisation, constantly adapt to new information, expediting results and benefiting patients sooner. The primary goals include discovering treatments that slow, stop or reverse lung scarring and enhance patients' lives, while also standardising and optimising global patient care.

In 2023 the EU-PFF were proud to support the European domain of the Global REMAP-ILD project by providing secretariat services as well as supporting the development of a large funding submission which if successful will kick-start the European element of this huge project.

4.7. EURORDIS

Since its formation, EU-PFF has actively engaged with EURORDIS as the main umbrella organisation for rare diseases in Europe. EU-PFF is an active member of EURORDIS' Council of Federations and also its partner in its activities with the European Reference Networks, including ERN-LUNG.

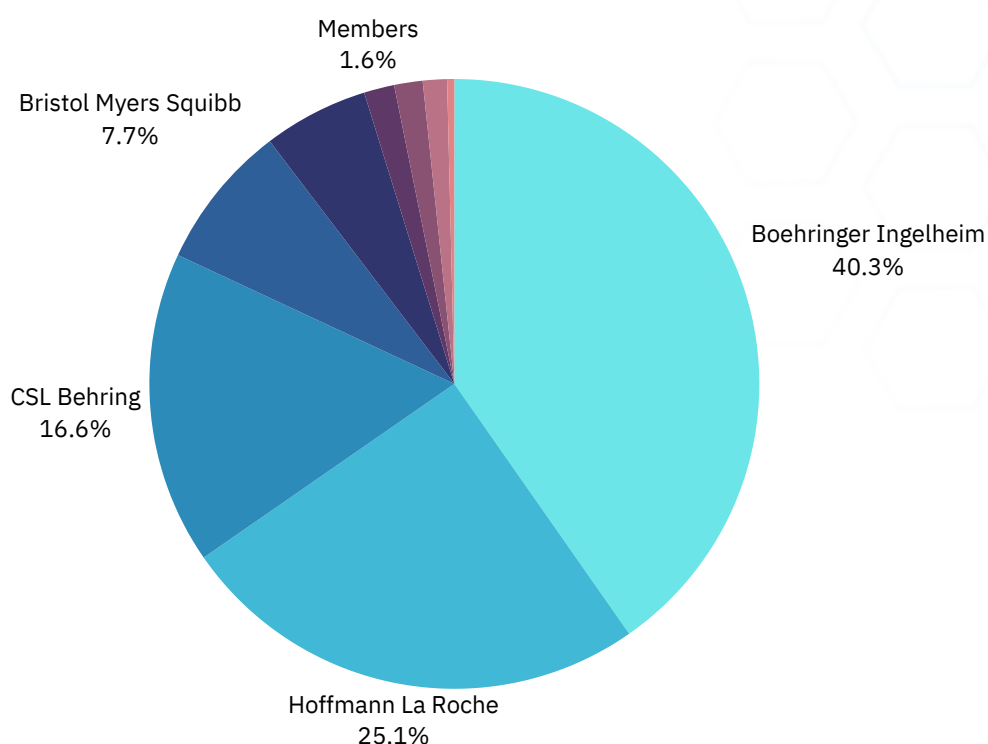
5 FINANCIAL REPORT

5.1. Report for Fiscal Year 2022: Income – Part 1

The first part of the 2022 Fiscal report (June 2021 to May 2022)

5.1.1. Income

From June 2021 to May 2022, the EU-PFF received a total of **391,178.21 €** as operating income.



Sponsor	Amount of income €	% of overall EU-PFF's income
Boehringer Ingelheim	157,870.71	40.29%
Hoffmann La Roche	98,202.50	25.07%
CSL Behring	65,000.00	16.59%
Bristol Myers Squibb	30,200.00	7.71%
Vicore Pharma	21,840.00	5.57%
Members	6,300.00	1.61%
Evolution Medical Communications	5,900.00	1.51%
Three Lakes foundations	5,000.00	1.28%
Galapagos	1,475.00	0.38%
Grand Total	391,788.21	100.00%

5.1.2. Expenses

From June 2021 to May 2022, EU-PFF had operating costs of **€ 313,333.21**.

The table below is abstracted from our approved and professionally prepared accounts submitted to the Belgium regulators. Category descriptions are those used under Belgium norms. Full details can be found on our website www.eu-pff.org. Accounts are also provided to the Europa Transparency Register, the European Medicines Agency, whilst support from the pharmaceutical industry is also a matter of public transparency with details published by them respectively.

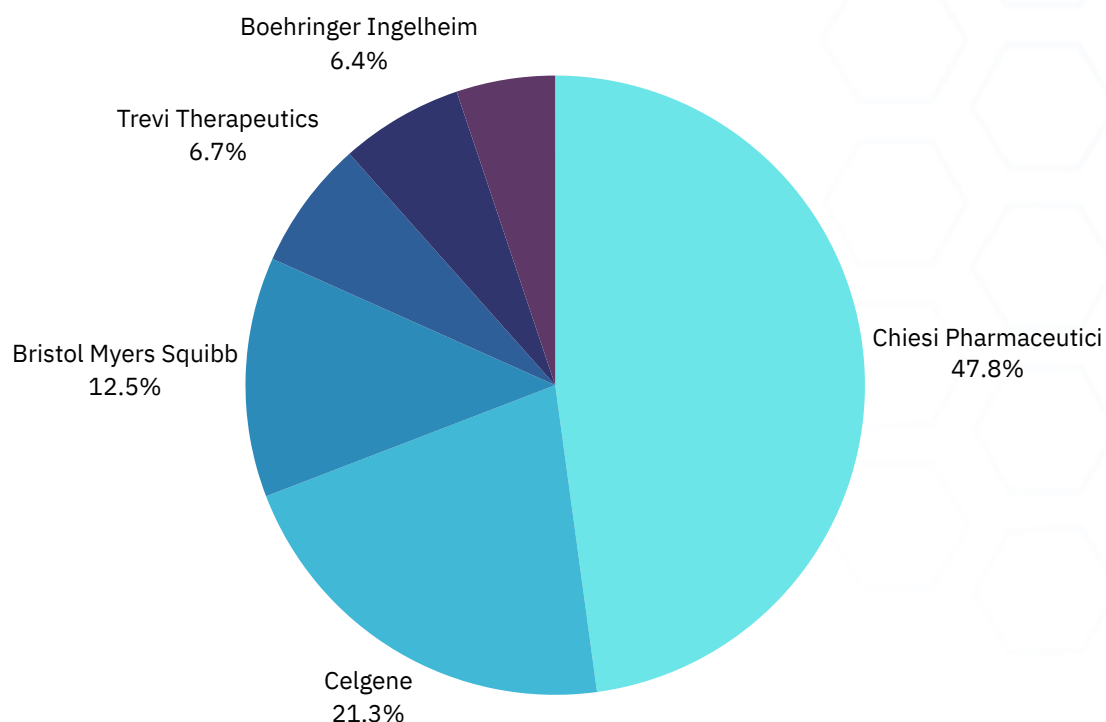
II. Costs on sales and services	-101,472.71	-313,333.21	-326,464.37	-654,608.83
A. Goods for resale, raw materials and consumables	-42,596.19	-233,612.73	-225,781.81	-575,550.31
603000 Subcontracting	-42,596.19	-233,612.73	-225,781.81	-546,940.41
606000 Rechargeable costs	0.00	0.00	0.00	-28,609.90
B. Services and other goods	-50,030.49	-38,550.19	-66,541.15	-79,058.52
G. Other operating charges	-8,846.03	-41,170.29	-34,141.41	0.00

5.2. Report for Fiscal Year 2022: Part 2

The second part of the 2022 Fiscal report (June 2022 to December 2022).

5.2.1. Income

From June 2022 to December 2022, the EU-PFF received a total of **141,013.47 €** as operating income.



Sponsor	Amount of income €	% of overall EU-PFF's income
Chiesi Pharmaceutici	70,700.00	50.14%
Celgene	31,503.15	22.34%
Bristol Myers Squibb	18,518.52	13.13%
Trevi Therapeutics	9,970.00	7.07%
Boehringer Ingelheim	9,471.80	6.72%
Hoffmann la Roche	7,620.00	5.40%
Members *	1,000.00	-0.71%
Galapagos*	5,770.00	-4.09%
Grand Total	€ 141,013.47	100.00%

The percentages in the diagram and in the table differ due to the two entries with a negative value. However, the total values are identical. Excluding the negative entries, there is no sponsor that contributes more than 50% of the total income.

Please note that this does not represent a full operating year, as it only covers 6 months due to the change in the fiscal year from June-May to January-December.

5.2.2. Expenses

From June 2022 to December 2022, EU-PFF had operating costs of **€ 101,472.71**.

The table below is abstracted from our approved and professionally prepared accounts submitted to the Belgium regulators. Category descriptions are those used under Belgium norms. Full details can be found on our website www.eu-pff.org. Accounts are also provided to the Europa Transparency Register, the European Medicines Agency, whilst support from the pharmaceutical industry is also a matter of public transparency with details published by them respectively.

II. Costs on sales and services	-101,472.71	-313,333.21	-326,464.37	-654,608.83
A. Goods for resale, raw materials and consumables	-42,596.19	-233,612.73	-225,781.81	-575,550.31
603000 Subcontracting	-42,596.19	-233,612.73	-225,781.81	-546,940.41
606000 Rechargeable costs	0.00	0.00	0.00	-28,609.90
B. Services and other goods	-50,030.49	-38,550.19	-66,541.15	-79,058.52
G. Other operating charges	-8,846.03	-41,170.29	-34,141.41	0.00

EU-PFF
EUROPEAN PULMONARY FIBROSIS FEDERATION

