

EU-PFF POLICY ON WORKING WITH COMMERCIAL COMPANIES

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INTRODUCTION

About Pulmonary Fibrosis

Pulmonary Fibrosis (PF) is a progressive, irreversible, chronic lung disease causing scarring of the lung tissue with no known cure that typically occurs in people who are more than 45 years of age, with the average patient being 65 years old. In Europe, about 400,000 people live with Pulmonary Fibrosis and some 100,000 patients die each year from the disease. On average, PF patients die within 3–7 years after diagnosis.

The term Pulmonary Fibrosis – or Interstitial lung diseases (ILDs) – encompasses a large number of conditions, with a wide range of causes, clinical manifestations, and imaging and pathological features in the lung interstitium, as well as variable outcomes. The most common type of PF is IPF (Idiopathic Pulmonary Fibrosis), accounting for 200,000 patients in Europe..

About the European Pulmonary Fibrosis Federation (EU-PFF)

EU-PFF is a European federation of currently 19 national patient associations active in the field of PF.. Its mission is twofold:

- a) Supporting an immediate and sustainable improvement of the quality of life and survival time of pulmonary fibrosis patients and of patients suffering from other interstitial lung diseases, through directly influencing pharmacological and medical research and development, as well as the access to non-pharmacological assistance for patients.
- b) Defending the interests of pulmonary fibrosis patients within Europe with a focus on
 - access to treatment and services, including non-pharmacological treatment and medication
 - access to information on new and current clinical trials
 - promotion of research into new treatment/medication
 - information exchange and collaboration among European and international pulmonary fibrosis patient associations
 - supporting the establishment of patient associations in countries where no such associations exist

To achieve these goals, the Association will undertake the following activities:

- exchanging information and collaborating with relevant European and international organisations and bodies
- involving patients in research activities and studies to improve current treatment options for pulmonary fibrosis patients
- representation in and to relevant European and international organisations and authorities.
- organisation of symposia, workshops, educational and training events for different stakeholders
- providing information, for example via a website publishing material such as leaflets, brochures, books, audio-visual materials, etc.

Purpose of this Code

EU-PFF recognises that to conduct its ambitious programme and accomplish the missions set out in its statutes, it must enter into partnerships with a variety of external stakeholders, including commercial companies (whether healthcare-focused or not).

Establishing these partnerships must be based on a set of clear rules and principles that ensure that the relationship is mutually beneficial, while protecting EU-PFF's independence and freedom to conduct activities it deems essential to the realisation of its objectives.

Commercial partners are required to subscribe to this policy in order to enter into agreements with EU-PFF.

Acknowledgement of other codes

In developing this code, EU-PFF consulted codes and guidelines developed by other patient groups (e.g. EURORDIS, EHC, MPE, IAPO, Alzheimer Europe) and the EMA recommendations.

GUIDING PRINCIPLES

In alignment with the recommendations of the EMA Code, EU-PFF abides by the following principles in its relations with commercial sponsors:

- Independence
- Transparency and accountability
- Respect
- Diversity of sources of funding
- Mutual benefit

These principles are translated into clear policies that EU-PFF members and partners shall all abide by:

- EU-PFF remains independent and funding from commercial sponsors shall not interfere or determine, directly or indirectly, EU-PFF's positions on issues related to the condition
- EU-PFF discloses funding received from commercial sponsors in its annual report but also clearly displays on materials produced adequate statements such as "realised with the financial support of [name of the commercial companies]"
- EU-PFF refuses to take part in projects aiming at promoting or endorsing a specific pharmaceutical product and shall terminate any agreement attempting to force EU-PFF into such activities
- EU-PFF shall decline funding from companies producing or selling products which can harm the health of the lungs
- EU-PFF retains all the rights on all the materials that are produced thanks to grants or sponsorship given by commercial sponsors. The explicit authorisation of EU-PFF should always be sought before using any such materials in any way
- When seeking commercial sponsorship for projects, EU-PFF will seek funding from more than one sponsor, whenever possible
- EU-PFF only accepts funding for activities/ projects which have a public health objective aligned with the mission and objectives laid out in its statutes.

TYPES OF FINANCIAL SUPPORT

One-time donations

EU-PFF accepts one-off charitable donations from sponsors. This type of funding does not create any obligation from EU-PFF to publicly acknowledge support.

Corporate sponsorship programme

The corporate sponsorship programme is of an unrestricted nature and aims at supporting EU-PFF in covering core activities which are crucial to the development and the day-to-day running of EU-PFF. It aims at covering costs such as equipment, staff, external support, as well as administrative costs, travel expenses, etc.

There are four levels of corporate sponsorship: platinum/gold/ silver/ bronze and the details of the amounts and benefits associated with each level are determined in the sponsorship package document.

It is of utmost importance for the development and independence of EU-PFF that such sponsorship be allocated to ensure a constant and reliable stream of funding to support the federations' operations.

Funding for specific projects and activities

Projects and activities may be of diverse nature, e.g. communication activities (website, etc.), PF Awareness Month activities, Webinars, European PF Patient Summit, reports, policy events, trainings, etc.

The details of activities and projects for which EU-PFF seeks funding are available in the sponsorship package document. This information is updated every year on the basis of the annual workplans adopted by the General Assembly.

Funding for these activities can be done through the following mechanisms, in respect of EU-PFF's guiding principles:

Unrestricted sponsorship

- Commercial sponsors have no involvement in the project
- EU-IPFF retains editorial control on the final output of the project
- The grant is acknowledged on the project collaterals

PROCEDURES

EU-PFF requires that commercial companies that want to become sponsors sign up to this policy.

Prior to accepting to work with a commercial sponsors, EU-PFF reserves the rights to ask for information about the company's interest and commitment in IPF and related disorders. It may also look into the company's reputation and track record in working with other patient associations.

Once funding is approved, the cooperation must be formalised in a contract, whether it is a Memorandum of Understanding, a letter of agreement or any other form of written agreement.

EU-PFF discloses all information regarding corporate sponsors in its annual report. Details on how sponsorship is displayed depends according to the funding mechanism and the activity concerned. Details regarding the text, logo, etc. shall be agreed upon between EU-PFF and the sponsor in the written agreement formalising the partnership.

EU-PFF SPONSORSHIP PACKAGES

PLATINUM	GOLD	SILVER	BRONZE
Pharmaceutical Companies	Pharmaceutical Companies, Biotech	Pharmaceutical Companies Biotech and medical devices	Biotech and medical devices companies
€50,000	€35,000	€15,000	€10,000
<i>Benefits</i>	<i>Benefits</i>	<i>Benefits</i>	<i>Benefits</i>
Acknowledgement with logo on the website and recognition in social media			
Invitation to participate at individual Community Advisory Boards (CABs) *			
Invitation to specific sessions of the general assembly.			
Invitation to 1 meeting per year with the executive board			
Invitation to monthly meetings with the EU-PFF Secretariat and President	Invitation to quarterly meetings with the EU-PFF Secretariat and President		
Opportunity to develop a co-creation project with EU-PFF or have 2 extensive meetings a year with internal company teams			