

## EU-IPFF POLICY ON WORKING WITH COMMERCIAL COMPANIES

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## INTRODUCTION

### About Idiopathic Pulmonary Fibrosis

Idiopathic Pulmonary Fibrosis (IPF) is a progressive, irreversible chronic disease of the lungs. The disease is associated with a progressive decline in lung function as the scar tissue prevents oxygen from properly moving into the bloodstream. As a result, the brain and other organs do not receive enough oxygen, which leads to initial symptoms such as shortness of breath and chronic cough and can lead to respiratory failure and death. There is no known cause for this fibrosis, meaning that it is categorised as 'idiopathic'. There are currently between 80,000 and 111,000 people living with IPF in Europe and approximately 30,000-35,000 new patients will be diagnosed with IPF in the EU each year. Presently, there are two EMA-approved treatments for IPF in Europe; however, IPF has no cure so far. Difficulty in diagnosis and rapid deterioration in some patients means that many people live only about 2 to 5 years after diagnosis.

### About the European Idiopathic Pulmonary Fibrosis & Related Disorders Federation (EU-IPFF)

EU-IPFF is a European federation of currently 14 national patient associations active in the field of IPF and related disorders. Its mission is twofold:

- a) Supporting an immediate and sustainable improvement of the quality of life and survival time of IPF 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 *IPF* patients at European level with emphasis on:
  - access to treatment and services, including non-pharmacological treatment and medication
  - access to information on new and current trials
  - promotion of research into new treatment/medication
  - information exchange and collaboration between European and international IPF 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 IPF patients
- representation in relevant European and international organisations
- organisation of symposia, workshops, educational and training events for different stakeholders
- providing information, e.g. via a website
- publishing materials such as leaflets, brochures, books, audio-visual materials, etc.

## Purpose of this Code

EU-IPFF 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-IPFF'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-IPFF.

## Acknowledgement of other codes

In developing this code, EU-IPFF 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-IPFF 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-IPFF members and partners shall all abide by:

- EU-IPFF remains independent and funding from commercial sponsors shall not interfere or determine, directly or indirectly, EU-IPFF's positions on issues related to the condition
- EU-IPFF 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-IPFF refuses to take part in projects aiming at promoting or endorsing a specific pharmaceutical product and shall terminate any agreement attempting to force EU-IPFF into such activities
- EU-IPFF shall decline funding from companies producing or selling products which can harm the health of the lungs
- EU-IPFF 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-IPFF should always be sought before using any such materials in any way
- When seeking commercial sponsorship for projects, EU-IPFF will seek funding from more than one sponsor, whenever possible
- EU-IPFF 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-IPFF accepts one-off charitable donations from sponsors. This type of funding does not create any obligation from EU-IPFF to publicly acknowledge support.

### Corporate sponsorship programme

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

There are three levels of corporate sponsorship: 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-IPFF that such sponsorship be allocated to ensure a constant and reliable stream of funding to support the federations' operations.

This is why, a key benefit of EU-IPFF's corporate sponsorship programme is to allow commercial companies to fund specific activities. Companies that are members of the corporate sponsorship programme are the only ones eligible to fund specific projects identified by EU-IPFF in its annual workplans.

### Funding for specific projects and activities

Projects and activities may be of diverse nature, e.g. communication activities (website, etc.), IPF World Week activities, reports, policy events, trainings, etc.

The details of activities and projects for which EU-IPFF 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-IPFF's guiding principles:

#### ***Project grants/ project sponsorship***

- EU-IPFF works in partnership with commercial sponsors (e.g. by receiving regular updates on progress made)
- EU-IPFF retains editorial control on the final output of the project
- The grant is acknowledged on the project collaterals

#### ***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-IPFF requires that commercial companies that want to become sponsors sign up to this policy.

Prior to accepting to work with a commercial sponsors, EU-IPFF 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-IPFF 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-IPFF and the sponsor in the written agreement formalising the partnership.

### EU-IPFF SPONSORSHIP PACKAGE 2017

GOLD	SILVER	BRONZE
<b>€35,000</b>	<b>€10,000</b>	<b>€5,000</b>
<i>Benefits</i>	<i>Benefits</i>	<i>Benefits</i>
Invitation to specific sessions of the General Assembly		
Acknowledgement with logo on the website		
Invitation to 1 meeting per year with the Executive Board	Access to sponsorship of core projects derived from the annual workplan	
Priority to access to sponsorship of core projects derived from the annual workplan		