



Policy on Financial Support by Companies

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The objective of this document is to establish clear rules to regulate IPPOSI relationships with commercial companies. IPPOSI believes it is essential to establish transparent rules about financial support from companies, and in particular about what companies may - or may not - expect from IPPOSI in return.

Rather than setting out to provide a definition of every possible funding opportunity or relationship, this document aims to define a set of principles. It has been inspired by existing examples of such statements by the likes of EURORDIS and the European Patients' Forum (EPF) at the European level.

Financial support from companies is acknowledged in IPPOSI projects and initiatives' reports and documents, as well as in public presentations, other relevant documents. The IPPOSI Annual Report is available on the IPPOSI website¹ and has a section where financial information is provided which includes a list of all donors to IPPOSI.

¹ <https://www.ipposi.ie/our-work/publications/annual-reports/>

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About IPPOSI funding

Like any other organisation, IPPOSI needs funds to carry out its mission. When it was first established, IPPOSI was funded 100% by a Government grant from the Dept. of Health, with a view to matching that grant eventually through member subscriptions, towards a 50%:50% public-private split.

IPPOSI has gradually diversified its sources of funding from the European Commission, as well as other public and private sources. The European Commission, The Health Research Board, The Health Service Executive have all supported IPPOSI activities through Research, Education and/or Public Health grants. Private sources of funding include commercial companies from the health sector.

Like many other patient organisations, IPPOSI is dependent on the financial support it receives from companies for a proportion of its activities and projects.

To maintain its independence, IPPOSI has set itself the objective to balance revenues, both monies and in-kind, from its different sources in its Strategy 2021-2025. The ideal goal is to maintain the 50:50 distribution mentioned above, to be broken down approximately as follows:

- 1/3 from industry membership fees to IPPOSI
- 1/3 from the public sector including the Health Research Board (HRB) and other national authorities, the European Commission (EC)
- 1/3 from the private sector including not-for-profit organisations and commercial companies, both from the health and non-health sectors.

Note: IPPOSI does not engage in public fundraising activities.

To avoid the risks inherent in an economic relationship with a single company, or a limited number of companies, IPPOSI diversifies the types of financial support it receives from companies and gradually increases the number and profile of its corporate donors.

To avoid the risks inherent in a relationship between a charitable organisation and commercial companies, and to avoid potential conflicts of interest, the following activities of IPPOSI are never funded by companies:

- All activities related to governance, mainly the Board meetings and the AGM;
- All activities related to IPPOSI representation in different fora, such as relevant health-related committees or the Rare Disease Taskforce

About the IPPOSI Policy on Financial Support by Companies

On the Irish political scene, IPPOSI is credited with being a legitimate voice of people living with chronic/rare diseases. IPPOSI has played a major role in creating a favourable framework for research, development and access to treatments for people living with chronic and/or rare diseases. IPPOSI is therefore bound to attract the attention of companies that have a particular interest in the development of treatments and other services for patients in Ireland. IPPOSI therefore felt the compelling need to establish clear rules to regulate its relationships with commercial companies.

Since 2005, IPPOSI has been at the forefront of the promotion of both good practices in the field of charities' transparency and the regulation of relations between patient groups and companies. This two-fold goal has been mainly pursued at a number of levels:

- The adoption in 2020 of the Charities Governance Code, under the Charities Regulator.
- IPPOSI believes that transparency cannot be restricted to the narrow issue of transparency on funding - a necessary but not sufficient condition of transparency. Any policy on transparency should provide clear answers to the following questions:
 - Who does the organisation represent? What is its representativeness?
 - How is the organisation's policy on financial support by commercial companies funded and which public or private interests does it represent?
 - Does the organisation have a track record of credible work?
 - Does the organisation really contribute to the debate?
 - Does it have clear written public statements on its positions?
- IPPOSI believes that the transparency of an organisation lies primarily in:
 - its mission and values;
 - the legitimacy of its membership base;
 - its governance practices;
 - its internal and public policy practices.
- Consequently, the transparency of an organisation also lies in the transparency of its financial information;
 - the internal and external financial control by independent audits;
 - the transparency of its financial relationships with funding sources, both public and private;
 - the transparency of its financial relationships with companies;
 - the prevention of potential conflicts of interest, both public and private.

In all of its activities IPPOSI respects and promotes the fundamental value of transparency, by following the principles of legitimacy, credibility, responsibility, independence and accountability.

Elaboration on the IPPOSI Policy on Financial Support by Companies

This policy was initially drafted in July 2021, and is due to be reviewed in 2023, 2026 and 2029

It does not set out to provide a definition of every possible funding opportunity or relationship, but rather to define a set of principles.

IPPOSI believes it is essential to establish transparent rules about financial support from companies, and in particular about what companies may - or may not - expect from IPPOSI in return.

The current Policy Paper covers issues related to financial support, in-kind support and involvement of IPPOSI in companies' activities.

It is aimed at ensuring that IPPOSI' members, the general public and all relevant stakeholders are aware of the IPPOSI policy as validated by our Board members/directors.

IPPOSI directors, staff and volunteers are expected to adhere to this policy and to perform their duties accordingly.

This policy may be further reviewed when needed.

GENERAL PRINCIPLES

Principles to be applied by IPPOSI in its relationship with Companies

The relationship between IPPOSI and companies is based on (the stated IPPOSI principle of) partnership, while preserving IPPOSI independence and integrity.

IPPOSI believes it is important to establish and maintain relationships with companies in order to enhance communication between patients, whose interests we represent, and companies, whose decisions will affect the provision of health services or treatments to patients. To ensure a successful partnership, each partner should learn to understand each other's internal culture and external constraints.

IPPOSI welcomes financial support by companies as long as the relationship between IPPOSI and these companies is based on the following principles:

- relevance of a public health objective driven by unmet patient need in Ireland
- full independence of IPPOSI
- mutual respect
- mutual benefit
- accountability and transparency

IPPOSI sees corporate donation programmes as a good practice in corporate governance and one of the ways commercial companies can support people affected by the diseases they are working on, or redistribute to the patient community some of the profits they are making.

IPPOSI supports the availability of the widest range of and other national authorities medicinal products, other medicines, treatments and health services; it does not endorse individual products or treatments; it encourages active partnership between patients and healthcare professionals as well as discussion of all available options to ensure patients make informed choices.

Financial support resulting from partnerships with companies is dedicated to activities in the areas of health information; patient education & training, access to innovation; patient & public involvement; public awareness and capacity-building.

In any case, funding by companies:

- must be for the benefit of the patients IPPOSI represents,
- must not entail product advertisement,
- cannot influence in any way IPPOSI policy, positions or decisions, whether explicitly or implicitly.

As long as these principles are respected, IPPOSI does not foresee any potential conflict of interest with commercial companies at large, with the important exception of companies in the health sector.

Exclusion factors

- IPPOSI does not support any specific product, brand, or health service. It must not be – or appear to be - associated with any specific company.
- IPPOSI refuses financial support from companies generating a public health risk, making unsubstantiated or misleading claims about their products, or not taking into consideration the specific needs of chronic/rare patients. IPPOSI is particularly cautious of situations that are brought to its attention by its members or other patient communities in Ireland.
- Should a company's strategy evolve over time and potentially conflict with IPPOSI positions and need to maintain its independence, financial support from this company would not be accepted or would be discontinued.

Inclusion and exclusion decisions about membership to the IPPOSI membership are made by IPPOSI. Exclusion can be decided by IPPOSI on grounds such as a breach of the IPPOSI Industry member Code of Conduct or of the IPPOSI Policy on Financial Support by Companies.

Types of Financial Support by Companies to IPPOSI activities

Funding of IPPOSI projects

IPPOSI may accept financial or in-kind commercial companies' support for a specific project. It provides IPPOSI with a reliable source of income over a number of years to cover direct costs such as personnel, equipment, consultants or suppliers, mission and travel expenses, as well as related indirect costs (telephone, administrative follow-up of project...).

Companies providing support for a project are publicly acknowledged by IPPOSI (printed documents, website, and electronic communications) to ensure transparency and recognition.

The companies' support has no influence on the design and the conduct of the project, its participants or publication, which will be the property of IPPOSI. Companies supporting a project may be regularly consulted through transparent ad hoc processes such as a donors' committee.

Funding of IPPOSI events

IPPOSI may accept financial or in-kind contribution by commercial companies for its conferences, workshops, education programme, training days, capacity-building sessions and other specific events it organises. It provides IPPOSI with a reliable source of income to cover direct costs such as personnel, equipment, consultants or suppliers, mission and travel expenses, as well as related indirect costs.

Note: Funding for IPPOSI events should always come from more than one source.

Companies providing support for an event are publicly acknowledged by IPPOSI (printed documents, website, electronic communications and onsite display) to ensure transparency and recognition. Sponsors do not exercise any influence on the design of the programme, the choice of speakers and the selection of attendees.

Funding of IPPOSI communication activities

IPPOSI may accept financial or in-kind commercial companies' support for its communication activities, including awareness campaigns and communication tools, such as newsletter, leaflets, reports, and website. It provides IPPOSI with a reliable source of income to cover direct costs such as personnel, equipment, consultants or suppliers, mission and travel expenses, as well as related indirect costs.

Companies providing support will be mentioned in paper and electronic materials. The companies' logo size will be modest to avoid being perceived as an advertisement. Furthermore, the companies' mention is corporate-related and not product-related.

Membership of the IPPOSI Round Table of Companies

The IPPOSI Round Table of Companies was created in 2021 to establish a long-term educational relationship between IPPOSI and those companies operating in the health sector that have an interest in IPPOSI priority areas. This relationship is driven by the principles stated in the IPPOSI Industry member Code of Conduct signed by every company becoming a member of IPPOSI.

The specific aims of the IPPOSI Round Table of Companies are:

- To educate IPPOSI member companies on the common goal of facilitating improved development and availability of health treatments, information and services for people affected by chronic and/or rare diseases in Ireland.
- To network with leaders of the health innovation community in Ireland, patient organisations, regulatory agencies and policy makers and promote open and frank sharing of information, in a neutral forum, on the process, obstacles and incentives for the development of health innovations.
- To stimulate IPPOSI member companies to address patient's needs and to encourage other companies not yet involved in this field to focus on unmet needs for Irish patients, and to involve patient communities in their development processes.
- To offer a space to educate companies on working with patient groups and help them build partnerships and collaborations with both the patient & scientific communities.
- To enable the exchange of views between leaders of patient organisations and industry, in order to provide insights as to why, when, and how to work with patients.

The Round-table meets at least once per annum. Meetings are organised by IPPOSI staff and are (to date) funded by IPPOSI resources. If future meetings are held in-person, IPPOSI may seek a registration fee to cover costs associated with running these meetings.

One-off charitable donations

One-off charitable donations are not linked to a specific project or activity. They do not create any obligation by IPPOSI to publicly acknowledge the financial support it receives. However, this information may be shared at times such as the IPPOSI Annual Financial Report and AGM.

Other In-kind support

Companies may also make non-monetary contributions to IPPOSI, such as:

- Seconded staff or professional services provided without charge
- Equipment donations (e.g. computers and other equipment)
- Meeting rooms
- Other non-monetary contributions (e.g. printing services)

IPPOSI involvement in activities of the healthcare industry

This section deals with IPPOSI involvement in activities related to products, devices or services which are marketed or distributed by industry or still under development.

Promotional activities related to approved prescription medicines

All promotional activities related to approved medicines are not permitted within the current EU legislation and industry codes of ethics. IPPOSI does not get involved in activities that can be possibly associated with a promotional strategy. IPPOSI always keeps in mind potential conflicts of interest and is guided by its own agenda, lead by the interests of patients in Ireland.

Types of activities that can be considered promotional under European and national legislation:

- Disseminating unbalanced, non-validated or partial information on products, services or devices distributed or marketed by a company;
- Being quoted in the company's communication in favour – or against – a product;
- Participating as a speaker/attendee in a company's product launch event;
- Participating in an ad hoc meeting sponsored by an individual company to inform patients on their products;
- Agreeing that a company displays or disseminates a patient organisation's own material on the company's exhibition stand at any trade exhibition or scientific conference;
- Appearing in promotional materials for a certain product or to testify as a "consumer" of that medicine. Contact information to patient organisations can be included in a separate section.

Industry press releases

- IPPOSI refuses to be quoted in industry press releases that relate to a marketed product or a product under development;
- If IPPOSI feels the need to communicate to media about a product, it will issue its own press release, independently of industry;
- If a company quotes IPPOSI' opinion or refers to IPPOSI' own communication materials without IPPOSI' permission, IPPOSI will object to the company by registered letter (copy to the industry association of the company).

Training organised by industry or a group of companies

IPPOSI is aware that not all themes for a potential training provided by a commercial sponsor are neutral, either about general themes or on more product related themes. Some programmes may have an influence on IPPOSI representatives' way of thinking.

In this context, it is important that the programme is sponsored by several companies, rather than a single one, and that IPPOSI representatives have been involved in the preparatory phase of the training programme.

Generally speaking, it is preferable to find an equivalent programme run by a Patient Group and advisable to ask commercial companies to sponsor IPPOSI participation in the training.

Participation in conferences or seminars held by industry

If IPPOSI representatives participate in an industry launch or promotion of a product, no photo must be taken or released without prior authorisation of the person involved. To this end, arrangements in writing prior to the event are recommended.

IPPOSI representatives will insist that multiple sources of information are involved in an ad hoc meeting sponsored by a single company, aimed at informing patients about their products. Information meetings without the presence of independent experts could be considered as an infringement of the Pharmaceutical Advertising Directive.

Individual compensation

There are several situations where industry may propose honoraria to IPPOSI representatives:

- Participation in meetings or Conferences organised by the company;
- Participation in meetings or Conferences organised by a third party;
- Reviewing industry materials, leaflets, protocols, etc.
- Consultancy on industry policy, advisory committees and Boards, etc.

IPPOSI representatives are as much entitled as healthcare professionals to receive honoraria for similar circumstances/services. Nevertheless, IPPOSI internal policies and agreements guarantee full transparency:

- For volunteers: Before receiving any individual compensation, all IPPOSI volunteers will ask clearance approval to the CEO and who will inform the Board of Officers of his decisions.
- For staff: All IPPOSI staff members may not directly receive individual compensation, this compensation will be received by IPPOSI, after the CEO's explicit clearance approval.

Involvement in industry-source websites or other material

Diseases awareness campaigns by industry

Disease awareness campaigns can be considered as an indirect form of advertising. It is unwise that IPPOSI be associated unless these campaigns have the backing of the Dept. of Health/HSE/other public health authority. IPPOSI must ensure that any campaign its representatives participate to is not only an industry initiative but does respond to a well

characterised public health need. Any product information disseminated by the industry during these campaigns must be based on the Summary of Products Characteristics (SmPC). Companies wishing to mention the name of IPPOSI must ask prior written permission.

Process

Documentation

When approaching or being approached by a commercial company, IPPOSI usually requests information such as the main business activities of the company. IPPOSI also does background research such as the company's reputation with concerned patient groups and regulators. IPPOSI provides companies with its activity and financial reports, and its Policy on Financial Support by Commercial Companies. IPPOSI requests every commercial company it collaborates with to carefully read and approve this Policy. A copy of this Policy remains with the company.

Accountability

Commercial companies supporting IPPOSI receive the annual activity report and the annual financial report covering the period of the donation, after these documents have been approved at the AGM.

The company receives interim and final reports concerning the project. When financial support is provided in the context of a special initiative, the company receives a copy of relevant documents.

Recognition and visibility of the relationship

Companies may wish to be publicly acknowledged for their financial support. Prior agreement will be reached on communication matters and detailed in the contract. As part of its transparency policy and for 'fair' partnership reasons, IPPOSI may provide adequate recognition to a commercial company for its financial support and commitment.

The level of visibility given to the company, including the logotype used and the wording in the communication material, require prior agreement from both parties.

When a commercial company does mention the financial support it gives to IPPOSI, the wording used and/or IPPOSI' name and logotype cannot be used without prior approval by IPPOSI. Any public information should be jointly agreed between the Chairperson or the Chief Executive Officer of IPPOSI and the commercial company.

Transparency policy

By adopting and publishing a transparency policy on relationships with commercial companies, IPPOSI acknowledges that the financial support it receives will never compromise its independence and future policy decisions.

The Annual Financial Report of IPPOSI reflects the level of financial support it receives from corporate donors and provides fair and reliable information to members and the public. The Annual Financial Report is published on the IPPOSI website.

Financial support is acknowledged in projects and initiatives' reports and documents, as well as in public presentations, other relevant documents, and on the IPPOSI website. The IPPOSI Annual Report has a section where financial information is provided; it includes a list of all donors to IPPOSI. This information is available on the IPPOSI website².

Derogation

In case of force majeure or situation not foreseen in this IPPOSI Policy on financial support by commercial companies, a derogation is possible. Any derogation to this policy, and in particular to the transparency rules applied for commercial companies in the health sector, has to be officially and transparently discussed, duly motivated, and adopted by the Board of IPPOSI. If such decision was to be significant, it would be mentioned in the Annual Report and the members would be informed through the reports at the Annual General Meeting.

Final Remarks

The scope of this IPPOSI Policy is its relationships with commercial companies and responds to the need felt by IPPOSI to establish clear rules on financial support it may receive from commercial companies, in particular from commercial companies in the health sector. While being a IPPOSI Policy Paper, any other patient organisation, whether a member of IPPOSI or not, may feel inspired and encouraged by this Policy when elaborating its own rules in this field.

² <https://www.ipposi.ie/our-work/publications/annual-reports/>