



INTERNATIONAL FEDERATION
OF PSORIASIS ASSOCIATIONS

IFPA Code of Practice on Relationships with the Pharmaceutical Industry

Introduction

The International Federation of Psoriasis Associations (IFPA) is a non-profit organization made up of national and regional psoriasis associations from around the world. IFPA strives to be the global psoriasis advocacy organization. Its goals are to empower IFPA's members, improve living conditions for patients, raise awareness of psoriasis and psoriatic arthritis and cooperate with fellow stakeholders. Since its founding in 1971, IFPA has continuously sought to resolve the challenges facing the international psoriasis community.

Our **vision** is to achieve a world without suffering from psoriasis.

Our **mission** is to be the global psoriasis advocacy association, with a focus on empowering our members, improving living conditions for psoriasis patients, raising awareness and cooperating with fellow stakeholders.

Our **goals** are to (1) Empower national psoriasis organizations by uniting them, strengthening their work and acting as their global voice; (2) Improve patients' living conditions by advocating for correct diagnosis, universal access to treatment and less discrimination and stigmatization; (3) Raise psoriasis awareness through education, information and highlighting research results; and (4) Cooperate with relevant psoriasis stakeholders, including medical and pharmaceutical actors.

Collaboration between IFPA, IFPA member associations and the pharmaceutical industry

IFPA recognizes that:

- Psoriasis patient associations, as public charities and not-for-profit entities, often depend on voluntary/pro bono work to run their day-to-day operations and activities, and may be financed by public and/or private funds, i.e. membership fees, donations and corporate sponsorships, including the pharmaceutical industry; and
- Pharmaceutical companies engage in research, development and marketing of products that aim to prevent, control or eliminate psoriasis and related inflammatory diseases, and are viewed as a natural collaborative partner.

Through dialogue and cooperation with the pharmaceutical industry, the IFPA/IFPA member patient associations are able to express their opinion and influence the quality of a company's communication, services and products, and via this contribute to shape and optimize the company's deliverables to the benefit of psoriasis patients, nationally and globally. Also, pharmaceutical



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companies may contribute with resources (expertise and funding) to support the mission and vision of patient associations, to the benefit of the latter and the patients they represent. The collaboration

can promote, support and advance patient associations' efforts to establish and distribute (non-product related) patient disease information, consultation and education, i.e. initiatives central to any patients association, having as their common objective to pursue and contribute to ensure the best interest of their members and represented patients.

In order to further its mission and improve health outcomes for psoriasis patients, IFPA and IFPA members regularly interact with pharmaceutical companies in various ways, including:

- Participation with one or more pharmaceutical companies in alliances and other relationships (sometimes with other public bodies, governments, nongovernmental organizations and foundations) to address psoriasis and related health issues;
- Exchange of information, skills and expertise; and,
- Acceptance of cash and in-kind donations for operations, programs and projects.

Purpose of the Code

The purpose of this code is to ensure ethical, accountable, and transparent collaboration between IFPA/IFPA members and the pharmaceutical industry. This code draws upon the existing *EFPIA Code of Practice on Relationships between the Pharmaceutical Industry and Patient Organizations*ⁱ, the World Health Organization's *Guidelines on Interaction with Commercial Enterprises to Achieve Health Outcomes, EB107/20*ⁱⁱ, and the *Interaction PVO Standards* (pertaining to Pharmaceuticals and Medical Resources)ⁱⁱⁱ.

As implied, the dialogue and collaboration with the health care industry can contribute to promote and advance the objectives of IFPA/IFPA member patient associations. Moreover, any patient association and pharmaceutical company share an invested interest in ensuring that their individual integrity is maintained when collaborating. Hence, all types of collaboration between the two parties are not only to apply to any given rules and guidelines, but also to "good corporate governance" on both sides, including this document that defines agreed best practice for collaboration between the two parties.

In developing relationships with pharmaceutical companies to further the mission of a psoriasis patient association, consideration should be given as to whether the proposed relationship might involve a real or perceived conflict of interest and IFPA/IFPA members' reputation and values must be ensured.

Principles of the Code

- IFPA/IFPA members *shall not promote or show favor to* a particular prescription-only or non-prescription medicine, remaining completely unbiased.
- The pharmaceutical industry shall not request the promotion of a particular prescription-only or non-prescription medication.
- All partnerships between IFPA/IFPA members and the pharmaceutical industry shall be based on mutual respect, with views and decisions of each partner having equal value.
- The objectives and scope of any partnership shall be transparent. Financial and non-financial support provided by the pharmaceutical industry shall always be clearly acknowledged.
- IFPA/IFPA members shall welcome broad funding from multiple sources.



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The nature and execution of collaboration between IFPA/IFPA members and a pharmaceutical company

Any collaboration between IFPA/IFPA members and a pharmaceutical company must be crafted and performed with a strong focus on ensuring and consolidating the integrity, reputation and continued success of the involved parties, and on adding value to patients.

A collaboration between IFPA/IFPA member and a pharmaceutical company must comply with (1) the respective IFPA member national laws and regulations, and (2) the existing pharmaceutical organization specific guidelines.

Collaborations should also have specific aims and meet the following basic criteria:

- a) The relationship should contribute to improving the health of psoriasis/psoriatic arthritis patients;
- b) The public health gains should be commensurate with the time and expense involved in establishing and maintaining the relationship; and,
- c) Relationships should be established on the basis of an exchange of clearly written letters or agreements indicating the contribution (financial or otherwise) that each of the parties brings to the relationship.

Evaluation criteria should be developed and applied to assess potential partnerships with pharmaceutical companies, including: the public image, financial stability and integrity of the company. IFPA members should develop and maintain written policies and procedures to evaluate potential pharmaceutical donations to ensure that they meet appropriate programmatic, cultural, and ethical criteria.

Once a patient association and a pharmaceutical company has agreed to enter a collaboration on a given project or sponsorship, a written agreement must be drafted between both parties, outlining the nature and roles implied in the collaboration, as well as financial aspects (if any) related to the collaboration.

Accepting Donations

All donations should be used in the furtherance of the stated mission, purpose, and program objectives of the patient association, and for the benefit of psoriasis patients without prejudice to race, class, sex, or political or religious affiliation.

Funds should not be sought or accepted from pharmaceutical companies that have a direct commercial interest in the outcome of the project toward which they would be contributing. Caution should be exercised in accepting financing from companies that have even an indirect interest in the outcome of the project.

Project Collaboration / Sponsorships

Project collaboration involving a pharmaceutical company should be based on an idea proposed by the patient association or by the pharmaceutical company, and developed in a close collaboration



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between the two parties. If a project has a significant nature, or involves financial support from the pharmaceutical company, the project is per default subject to a collaboration agreement.

Should a project be based on a partial or full sponsorship from pharmaceutical company, the company's representative is obliged to participate in the setup of the financial budget and framework. The responsibility for the actual planning and implementation of the project, however, lies at all times with the patients association. If a project is partly or fully supported by a financial sponsorship through a pharmaceutical company, the company will either pay any invoices of third party providers directly or provide a sponsorship to the patient association which then will pay the related invoices itself. As implied, in that case, the sponsorship will be administered by the patient association and is to cover actual costs as agreed by the two parties, referring to the relevant budget. The pharmaceutical company has the right to ask the patient association for documentation for the spending when a project has been implemented.

Written agreements

When pharmaceutical companies provide financial support, significant indirect support and/or significant non-financial support to IFPA/IFPA members, for any reason, there must be a written agreement. This must state the amount of funding and also the purpose (e.g. unrestricted grant, specific meeting, projects, etc.). It must also include a description of significant indirect support (e.g. the donation of public relation agency's time and the nature of its involvement) and significant nonfinancial support. (see Annex 1: Template for Written Agreement) IFPA/IFPA members should maintain documentation relating to the handling and use of all donations.

Transparency: Acknowledgement of Donations and Sponsorships

IFPA/IFPA members must make publicly available a list of pharmaceutical companies that provide financial support and/or significant indirect/non-financial support. This should include a short description of the nature of the support, updated yearly. The basic and most common approach to such recognition is to insert an acknowledgement in documentation relating to the activity concerned and by posting an acknowledgement on the member association website.

Acknowledgements shall usually be worded along the following lines: "IFPA [or patient association] gratefully acknowledges the financial contribution of [company's name] towards [description of the outcome or activity]". Contributions received from all sources, including pharmaceutical companies, must be listed in the patient association Financial Report and Audited Financial Statements.

ⁱ EFPIA code of practice on relationships between the pharmaceutical industry and patient organisations (5/10/2007). <http://www.efpia.eu/Content/Default.asp?PageID=559&DocID=3484>

ⁱⁱ World Health Organization (EB107/20, November 2000). Guidelines on interaction with commercial enterprises to achieve health outcomes

ⁱⁱⁱ Interaction PVO Standards (November 2009). http://www.interaction.org/sites/default/files/PVO_Standards_November16_2009_0.pdf, pp. 15-17



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