

The European Patients' Forum and Funding Partners

A Framework for cooperation

APPROVED BY THE EPF BOARD, 9 DECEMBER 2008

Background

This brief document outlines how EPF works with partners who provide unrestricted sustainable funding to contribute to EPF's strategic plan and annual work programme, and why this is important.

This partnership is not solely financial and focuses also on open and transparent dialogue and the exchange of independent views and positions between EPF and these partners. This framework document also describes how this is undertaken in practice, without comprising either party.

Introducing EPF

The European Patients' Forum (EPF) is a European non-governmental organisation which was set up in 2003 to become the collective patients' voice at EU level, manifesting the solidarity, power and unity of an emerging EU patients' movement.

Through its 38 member organisations (which are chronic disease specific patients organizations operating at European level, and national coalitions of patients organizations), EPF reflects patients' and their carers' and families' unique and direct experience and expertise in healthcare.

Vision

EPF's vision for the future is high quality, patient-centred, equitable healthcare throughout the European Union.

Mission

EPF's mission is to provide a strong and united patients' voice to put patients at the centre of EU healthcare policy and programmes.

The need for a diversified portfolio of funding

EPF is in its formative years. Our AGM made a decision in 2005, two years after the foundation of the organisation to seek unrestricted support from industry to establish the secretariat, recruit a staff team, set up an office, build capacity and knowledge among the EPF membership through advocacy seminars, and develop policy influence through an annual conference. This pump-priming was crucial in ensuring the organisation could grow

- to reflect effectively the views of our diverse members and the needs and perspectives of 150 million patients across the European Union;
- to be pro-active in and respond effectively to an enlarging EU health agenda;
- to enlarge and support a growing membership;
- to build strong relationships with other health stakeholders.

Three years on, following successful efforts to diversify the funding base, notably by obtaining substantial funding from the European Commission, industry funding is now one important component of a broader portfolio of funding. This diversified support from both the public and private arena will continue to be crucial, providing baseline resources to enable EPF to continue to build and sustain momentum as the unique EU umbrella organisation of patients' organisations. To this effect, EPF endeavours to engage with a wide range of eligible partners.

Core principles in relation to funding

In order to make funding partnerships work in practice, to ensure the integrity of both the funder and EPF is maintained, and to demonstrate to other stakeholders that our relationships are absolutely scrupulous, the following key principles underpin our acceptance of funding.

INDEPENDENCE

- EPF will maintain at all times an independent and strong patients' voice on behalf of its member organisations. The potential effect of EPF positions on funders (either private or public) will never be a relevant factor in EPF's policy development and decision-making process.

MUTUAL RESPECT

- EPF and our sustainable funding partners undertake to cooperate on a basis of mutual respect as fellow stakeholders in healthcare systems and delivery.

UNRESTRICTED

- Funding received by EPF for our operational programme to fulfil our vision and mission should be unrestricted in nature, to contribute to the overall work programme to fulfil our strategic goals and objectives.
- EPF will however lead and/ or cooperate in specific projects funded by the European Commission and other public sources, where these are in accordance with our policy and criteria for getting involved in projects.

SUSTAINABLE

- The funding support provided by partners should, wherever possible be part of a long term commitment to funding (ideally a minimum of three years) supported by a written agreement.
- The funding support may also be allocated to building reasonable reserves for EPF to ensure the sustainability of the organisation

NO SINGLE COMPANY/ GOVERNMENTAL SOURCE

- EPF events should be supported with an unrestricted grant by more than one company, and/ or government; or the European Commission or a Federation composed of several companies. The content of such events should be developed by an independent EPF working group of members established for the purpose.

TRANSPARENCY

- A written agreement between the funder and EPF outlines the nature and amount of the funding and the period covered.
- The funding sources will be acknowledged with thanks on relevant publications linked to an event.
- The amount of funding received and the sources are included in the EPF Annual Report and published separately on the EPF website within one month of the Annual Audited Accounts being approved by the Annual General Meeting of the following year.

FUNDING FROM THE PHARMACEUTICAL INDUSTRY

- EPF will apply the EFPIA Code of Good Practice on working with patients' organisations in relation to any funding received from the pharmaceutical industry whilst also building in the above principles adopted, and other relevant European codes.
- EPF will ensure that the funding received from one single company will be proportional to the overall budget and reflect our commitment to diversity of funding sources.

Dialogue with Sustainable Partners

In order to ensure and promote open and transparent dialogue to share respective views and perspectives on issues of common interest and that advance our mission, EPF undertakes to

- Distribute the EPF Mailing (a six weekly newsletter with the patients' perspective on EU health developments) and policy documents/publications to funding partners, as fellow stakeholders in EU health debates
- Hold an Annual Funders' Event to which partners share information with EPF board and staff members on EPF's progress during the preceding year and core challenges, and our direction for the following year.
- Engage in dialogue on current EU health policy issues.
- Be present at specific company/ federation/ governmental/ Commission events on request to outline EPF 's position on one of its policy priority areas
- Invite funding partners to EPF Annual Conferences, and to selected other events.