

WORKING AND COLLABORATING WITH PHARMACEUTICAL INDUSTRY



ECL GUIDELINES



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Cancer leagues play a significant role in providing advice and empowering patient organizations in their collaboration with the pharmaceutical industry. Leagues in different countries have diverse experiences, and maintain different levels of relationship and levels of formality between patient organizations and the industry. Despite these different relationships, the importance of cautious and safe collaboration with the industry is shared among all ECL members. The leagues shall ensure that, in order to sustain a good reputation, grants, donations and sponsorships from the pharmaceutical industry do not intervene with the leagues' sovereignty over their decision-making, and do not breach their ethical standards.

It is up to the leagues and patient organisations to adopt these recommendations.

BACKGROUND

In recent years, patients have gained more focus in the media, in the health sector, and among policy-makers. Hence, patient groups have become attractive as partners for the pharmaceutical industry. It is important that patient associations are aware of what may or may not lie behind the solicitations of the industry.

Sponsorships of patient associations are, and should be perceived, as marketing investments for the pharmaceutical companies. A company financially supporting a patient association customarily expects returns in the forms of:

- improved image in the eyes of the relevant patient group;
- increased confidence of the patients in the company's products and in their work in general;
- lobbying by patient associations to introduce newly-developed products quickly;
- increased widespread use of an existing product; and most recently,
- insight into patient experiences which can be used for further development/new products.

SPONSORS' INTENTIONS

Financial support offers are often linked to intentions such as:

- ✓ visibility
- ✓ information and communication
- ✓ dialogue
- ✓ overall goal of increasing profits
- ✓ benefits, drawbacks, and pitfalls

A sponsorship implies opportunities for:

- enhanced activities
- better newsletters through professional assistance
- participation in conferences and training courses
- purchase of expensive equipment

A sponsorship can have drawbacks, such as:

- Financial dependence on contributions;
- Lack of awareness toward sponsors' shortcomings;
- Clouded thinking, I.E. the collaboration is so close that the organisation thinks like the sponsor;
- Expectations or demands for positive acknowledgement;
- Unawareness of being exploited for the promotion of certain interests; and
- Limit the scope and agenda of the organization.

PRECAUTIONS: 10 RECOMMENDATIONS

1. **Have good overview**, i.e. know what is right for your organisation and define what activities you feel are suitable for pharma-funded sponsorship.
2. **Do not accept** any contribution which is accompanied by **a demand** for a recommendation or positive mention of certain products.
3. Accept contributions from the **corporate**, not marketing, level.
4. **Reject offers** which directly or indirectly are **in conflict** with the interests of the members, or which are otherwise **unethical**.
5. **Define the collaboration** as precisely as possible in the contract which is signed by both parties.
6. Make it clear that the **patient association is responsible** for planning and implementing of the activity(ies).
7. Ensure that your **finances and accounts are transparent and clear**.
8. Ensure that there is a sound **balance between contributions from the industry and non-industrial enterprises**.
9. Try to get support from **more than one pharmaceutical company** for a specific project.
10. Try to **minimise your dependence** on pharma funding.

PRACTICAL ADVICE: HOW TO START A COLLABORATION

- i. Participate in discussion forums with other patient organisations to explore the opportunities and threats.
- ii. Be pro-active, not re-active.
- iii. Conduct a thorough information search on the company in question to be completely informed.
- iv. Apply for sponsorship on time - most pharmaceutical companies prepare their budgets in June-August.
- v. Prepare yourself as much as possible prior to a discussion with a sponsor. Ideally, prepare a number of different strategies for the negotiation.
- vi. Cooperate with the sponsor to develop ideas for mutual collaboration.
- vii. Be aware that products and materials can more readily be made available to you than financial support.

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- viii. Indicate that competing companies have agreed to support your organisation, but do not divulge how much they are contributing.
 - ix. Do not break off negotiations at the conclusion of the first meeting with a potential sponsor, instead remain open and friendly.
 - x. Always get both commitments and rejections in writing, perhaps with a request for an explanation of the rejection.
 - xi. In developing of the sponsorship agreement, the following sections shall be included:
 - ✓ Description of the activity(ies) to be supported
 - ✓ Description of obligations the sponsor should assume
 - ✓ Description of the obligations of the patient association

IMPORTANT POINTS

TO BE RAISED DURING THE NEGOTIATION WITH PHARMACEUTICAL INDUSTRY

- 1) Make it clear that the patient association cannot recommend specific companies, their products and/or their services.
- 2) Make it clear that the patient association is responsible for any media contact and other sources of communication (e.g. content of company's website, press releases, brochures etc.).
- 3) For all important changes in your activities: agree as far as possible with the sponsor.
- 4) Specify conditions for premature termination of the agreement.
- 5) Set a period of validity for the agreement.
- 6) The agreement needs to be signed by both parties.