



**PATIENT ORGANISATIONS
AND COLLABORATING WITH
THE PHARMACEUTICAL
INDUSTRY:
*ECL RECOMMENDATIONS***

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Leagues have a role in providing advice and in empowering patient organizations in their collaboration with the pharmaceutical industry. Leagues and countries have different experiences, levels of relationship, and levels of formality with patient organizations and with the pharmaceutical industry. It is up to the leagues and patient organizations to adopt these recommendations.

BACKGROUND

In recent years, patients have come more into focus as apparent in the media, in the health sector, and among politicians. Patient groups have become very interesting 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 seen 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**:

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

A sponsorship can have **drawbacks**:

- Financial dependence on contributions;
- Lack of awareness toward sponsor's shortcomings;
- Clouded thinking – 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



Get an overview: know what is good for your organization and describe what activities you feel are suitable for sponsorship.

Do not accept a contribution which is accompanied by a demand for recommendation or positive mention of certain products.

Accept contributions from the corporate, not marketing, level.

Reject offers which directly or indirectly are in conflict with the interests of the members, or which are otherwise unethical.

Define the collaboration as precisely as possible in a contract which is signed by both parties.

Make it clear that the patient association is responsible for planning and implementing the activity (ies).

Ensure that your accounts are transparent.

Ensure that there is a sound balance between contributions from industry and from non-industrial enterprises.

Try to get support from more than one pharmaceutical company.

Ensure that your finances are sound.



PRACTICAL ADVICE

Participate in discussion forums with other patient organizations to explore opportunities and threats.

Be pro-active, not re-active.

Conduct a thorough information search on the company in question to be completely informed.

Apply for sponsorship on time - most pharmaceutical companies prepare their budgets in June-August.

Prepare yourself as much as possible prior to a discussion with a sponsor.

Prepare a number of different strategies for the negotiation.

Cooperate with the sponsor to develop ideas for the collaboration

Be aware that products and materials can more readily be made available to you than financial support.

Explain that competing companies have agreed to support, but do not divulge how much they are contributing.

Do not break off negotiations at the conclusion of the first meeting with a potential sponsor, but remain open and friendly.

Always get both commitments and rejections in writing, perhaps with a request for an explanation of the rejection.

DEVELOPING THE SPONSORSHIP AGREEMENT

Main Sections for the Agreement:

- ◆ 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:

- ◆ Make it clear that the patient association cannot recommend specific companies, their products or their services.
- ◆ Make it clear that the patient association is responsible for any media contact.
- ◆ For all important changes in the activities: agree as far as possible with the sponsor.
- ◆ Specify conditions for premature termination of the agreement.
- ◆ Set a period of validity for the agreement.
- ◆ The agreement needs to be signed by both parties.



These recommendations are based on a report by the Danish Cancer Society and include input from the second ECL roundtable discussion on working with the pharmaceutical industry, and from the ECL 2006 Annual Conference.