

Collaborative Partnership Guidelines on working with sponsors, including the pharmaceutical and biotech industries and other grant providers

Relationship with sponsors

- Relationships between non-governmental organisations (NGOs) and sponsors (including pharmaceutical and biotech companies) can and should be based on equal partnership. Both sides must be prepared to move beyond the NGOs being passive recipients of money to a scenario where the two work together on policy development and practical initiatives, in the interests of the patients and their carers whom the NGO represents, while preserving its independence.
- Each party should remember that successful partnerships are those where both partners gain something, and each should make efforts to understand the internal culture of and external pressures on the other.
- NGOs should recognise that pharmaceutical and biotech companies have to be profitable, and commercial and non-commercial organisations all have their own particular agenda, to which no NGO should ever feel obliged to conform. Funding should be rejected if the alternative is compromising the NGO's independence in any way.

Funding

- Dystonia Europe (DE) encourages the use of available funding so long as the NGO's independence is not compromised and as long as the relationship is totally transparent. Contracts between the parties help in this respect.
- DE is opposed to relationships designed to give one company competitive advantage over another, and, where possible, favours the use of funding consortia composed of two or more companies from the same industry.
- Joint research initiatives must ensure that independence is not unwittingly eroded.
- DE itself accepts funding from the pharmaceutical and biotech industry groupings or companies, as well as non-industry sponsors when:
 - It believes it will result in benefit to DE and at least some of its member organisations
 - The Board is satisfied that accepting the funds will not court adverse publicity
 - The funder does not try to coerce or over-influence DE's policy or actions either explicitly or implicitly
- A voluntary organisation's good name is its most valuable asset. The effect of laws dealing with non-profit organisations, as well as agreed best practice, both preclude the exploitation of a voluntary organisation's name for non-charitable purposes. DE's name must not be used to imply approval or endorsement of any of the donor's products or policies, without the Board's prior written approval.

Product Endorsement

- DE endorses no individual treatments, because people living with brain disease need access to the widest possible range of treatment options, to integrate them as they wish. These may include medicines, surgery, complementary therapies, lifestyle changes, and non-therapeutic products
- We encourage active partnership between patient, carer and health professional as well as discussion of all available options to promote informed choice by the patient.
- Where medication exists in more than one version we encourage the use, in communications by the NGOs with patients, of either the scientific name or the several different brand names. Publications should show impartiality.
- DE supports the proper licensing of medicines and believes that the marketing of non-drug treatments to the public requires similar rules and standards.

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