

Heart Valve Voice

Patient Groups and Industry relationships

(Guiding principles)

Introduction

The objective of these principles is to provide fundamental guidance for productive and ethical collaboration between Heart Valve Voice Alliance and their industry funders. Patient organisations and industry partners share mutual aims of improving awareness and treatment of the disease. Therefore, this ethical and transparent collaboration helps to give a voice to patients, ensures a comprehensive healthcare debate and ultimately leads to improved outcomes for patients.

Principles

A) Mutual transparency of funding

- 1) All industry funding should be sought and made in an open and transparent manner
- 2) The patient organisations should disclose the names and/or logos of all of its industry funders on its website. It should also disclose the names and/or logos of industry funders on materials related to campaigns and activities which have been specifically funded by an industry sponsor or sponsors.
- 3) Industry funders should disclose on their corporate website the names of any patient organisations they support.
- 4) The patient organisations should seek donations in a fair and transparent manner among multiple partners to avoid real or perceived exclusive relationships and to preserve their autonomy.

B) Manner of funding

- 5) Financial contributions from industry to the patient organisations should be made either as a) unrestricted funding or b) sponsorship of a specific activity initiated by the patient organisation to support its stated mission
- 6) Companies should not offer funding in return for the patient organisation offering product promotion activities.
- 7) Companies should not use their funding in return for the patient organisation supporting company-only advocacy for health policies or campaigns.
- 8) The patient organisations should avoid taking payment from industry that could be perceived as buying special privileges such as directing a meeting agenda, guiding content of educational materials, promoting participation in a specific clinical trial, influencing the outcome of a specific research programme or providing exclusive support of a particular research programme
- 9) While it is understood that a new patient charity may need to rely upon a single source of funding in its set-up phase, it should always seek funding from multiple sources and ensure it has multiple funding sources within, at the latest, 24 months of achieving charitable status.

- 10) Patient organisations should only solicit and accept financial contributions that support its stated mission and allow the PO to maintain its autonomy.
- 11) Any transfers of value or benefits provided to a patient organisation by industry should be documented by a signed agreement between the charity and the company

C) Patient organisation and industry interactions

- 12) The patient organisations should maintain proper documentation of all requests they make for financial support from industry sources. All requests should be documented on the charity's letterhead and clearly state the mission and activities of the organization and reasons for the request
- 13) Patient organisations are permitted to seek information and education from industry partners on the disease state and therapies, but the information and education provided by industry should be fair, balanced and non-promotional. Patient organisations should request information and education from all industry funders in a balanced manner.
- 14) Patient organisations may provide consultation to industry, if it is consistent with its mission and allows it to maintain autonomy. The terms of these services will be documented by mutual agreement between the patient organisation and the company.
- 15) Patient organisation leaders and supporters are permitted to attend meetings of all industry partners in order to provide information on the charity's activities.
- 16) Travel expenses incurred to participate in company events, advisory board meetings and disease awareness activities may be reimbursed directly to the individual patient or to the patient organisation.
- 17) The patient organisation should establish metrics to evaluate the effectiveness of an activity or initiative in which it has collaborated with industry and regularly communicate back the results of the specific project or use of funds to the company
- 18) The leaders of the patient organisations will not operate as independent consultants to industry outside of their roles within the charity
- 19) The leaders of the patient organisations will not accept personal honoraria to speak on behalf of the organisation, but may have the honoraria given to the charity.

D) Underlying principles

- 20) Any initiatives between patient organisations and companies shall be documented in a written agreement and be developed in the spirit of mutual respect and trust, based on sound medical, educational and policy grounds.
- 21) Company funding must always have as its core objective the advancement of patient health and the improved awareness, diagnosis and treatment of the disease for the benefit of patients.
- 22) Interactions between patient organisations and companies will always be ethical and comply with local laws and regulations