



Huntington's
Disease
Association

Working with commercial organisations policy

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Introduction

Collaborations between a charity and other parties who are part of the pharmaceutical, biotechnology, diagnostic and devices industries and other commercial organisations can result in significant advances in technology, and significant benefits for patients. These collaborations can help to further the development of services, equipment, new treatments, medications, therapies and tests, as well as improving those that already exist. These projects can have long-standing benefits that provide a lasting positive change to society for the better.

As the primary charity for Huntington's disease in England and Wales, the Huntington's Disease Association has a central involvement in Huntington's related research and care. We are open to grants for research, support and services related to Huntington's. We also play a role in facilitating relationships between academia and the pharmaceutical and commercial industries. We act as an objective governor and ensure clear guidelines are met to ensure openness, independence and impartiality between all parties. It is important to ensure that the collaborative work can be done without affecting the Huntington's Disease Association's independence and principles.

We recognise the benefits that can emerge from working alongside these industries, and have been involved in a number of these projects in pursuit of beneficial technologies, treatments and enhanced support for families affected by Huntington's. However, at the same time, we recognise the complications of working with third parties and as such this policy stands to lay out our position on collaboration with these industries and to provide clear principles and guidance on how the Huntington's Disease Association works with them.

Scope

This policy applies to all employees and volunteers of the Huntington's Disease Association.

This policy applies when working with commercial organisations to ensure openness, independence and impartiality between all parties when working collaboratively.

Support for appropriate projects

We will only seek support from commercial partners for projects that directly fit in with the Huntington's Disease Association's strategy as outlined in our governing document, the Memorandum and Articles of Association and our Strategic Plan. This involves projects concerned directly with the understanding, detection, care of, treatment and prevention of Huntington's disease, as well as otherwise improving the quality of life for

people affected by the disease. Where a commercial company has interest in improving the measurement of patient outcomes following treatment, and support and information, then we will consider entering into appropriate projects alongside the company.

Impartiality and independence

We will take appropriate steps to ascertain information regarding any party that we engage with and will take all reasonable steps to ascertain its financial state, its values and ethics before entering into any partnership. We will not enter into a partnership, and reserve the right to terminate any relationship, with any party who may damage the reputation of the Huntington's Disease Association. We will similarly not enter into, or will terminate, any relationship where another party seeks to influence the policy, behaviour or direction of the Huntington's Disease Association, or is attempting to abuse the relationship in any way. We will not accept funding from any pharmaceutical companies where the promotion of a specific drug is required or demanded by the company. Where funding or sponsorship is received from other commercial organisations for the advertisement of their products or services, the Huntington's Disease Association will ensure that the information is appropriate to share with the Huntington's community and will make clear that we do not endorse the product or service.

All projects that are financially supported through collaborative relationships with various industries will be managed according to our established processes and will be subject to a written agreement that defines the purpose and scope of the project as well as making clear the position of all involved parties. Projects will be governed by the Huntington's Disease Association and will be led by principal's appointed by us. Following the initial consultation and involvement by the industry partners, they will take a more distant role, and responsibility will be handed over to the principal investigator and in other projects, it would be the project lead.

We may involve clinical experts and lay members of the Huntington's disease community to comment on public consultations. Where these may concern particular products, we will ensure that we will always act in the best interests of people affected by Huntington's, free from any external influence.

We will also ensure that their editorial independence is maintained in order to freely comment both positively and negatively about both the commercial companies and their products / services, and will make such comments with the best interests of those affected by Huntington's in mind. All comments will be based on the latest information and evidence and will not be influenced by the acceptance of funding and support.

We will sometimes be involved with working with commercial organisations to share knowledge and experience. Sometimes this can involve participating in events funded by them that may be in public or private settings. These events may be meetings, training events, advisory meetings and market research events.

Openness and transparency

We will ensure that projects are run according to the principles of independence, integrity and transparency and all partnerships will bring benefit to people affected by Huntington's disease. As a result, we will make available for public viewing reports of funding received from commercial projects and the total amount received from these companies.

To prevent the perception of undue influence, we would never accept a single grant of more than £50,000 from any one company. If a grant of more than £50,000 was offered, this would be referred to our board of trustees for consideration.

In the case of the pharmaceutical industry, we would seek to ensure that any relationship or funding meets the Association of British Pharmaceutical Industry's Code of Practice.