

POLICY ON PARTNERSHIP WITH COMMERCIAL ORGANISATIONS

Neuroendocrine Cancer UK (formerly NET Patient Foundation) - NCUK

Introduction

NCUK understands the importance of working in partnership with all stakeholders with an interest in neuroendocrine cancer and related diseases to achieve common goals. The pharmaceutical industry is a key stakeholder for NCUK and NCUK wishes to work in collaboration with different pharmaceutical companies. NCUK recognises the need for such collaboration to be transparent and able to stand up to scrutiny. As a result, NCUK has developed [this policy document](#) that defines how we engage with the pharmaceutical industry. This will ensure we can withstand external scrutiny of our decisions and actions whilst at the same time allowing us freedom to work in a way which ultimately benefits neuroendocrine cancer patients and their families.

Purpose of policy

The purpose of this policy is to:

- Ensure that NCUK has a consistent and transparent approach to working with and accepting financial support from pharmaceutical companies
- Demonstrate how NCUK maintains its independence and clarify its position to its various stakeholders
- Ensure that pharmaceutical companies are aware of our policy in regard to working with them

Funding: guiding principles

NCUK will foster dialogue and establish appropriate relations with any company whose products, actions and commercial decisions affect the chance of survival and quality of life of neuroendocrine cancer patients.

Patient groups working with the pharmaceutical industry are sometimes viewed with scepticism by decision-makers and the general public. In order to protect NCUK's reputation and demonstrate that it does not conform to commercial agendas, NCUK will adhere to the following principles when soliciting or accepting project funding, sponsorship, grants or donations from the pharmaceutical industry:

- NCUK will maintain an open and transparent relationship with every company it works with

- Before soliciting or accepting funding, the NCUK Trustee Board must be satisfied that:
 - There are strong grounds for believing the donation, grant or sponsorship will help NCUK achieve its mission and not undermine NCUK's credibility
 - No adverse publicity will result from accepting the funds
- NCUK will closely review the corporate governance policies and reputation of every company it solicits or accepts funds from. NCUK will reject the funding if there is any reasonable or demonstrable cause for concern
- NCUK will not endorse or promote individual products or services
- A company's support will be acknowledged in an appropriate way following discussions with the company concerned
- NCUK will sign a memorandum of agreement with all companies outlining each partner's contribution and responsibilities. The company must agree to abide with the guidelines outlined here
- If a company makes any attempt to coerce NCUK to conform to its marketing agenda, either explicitly or implicitly, or does not conform to the memorandum of agreement, NCUK will reject the funds or terminate an on-going project
- Where possible, NCUK will solicit funding from consortia composed of two or more companies working in the field of neuroendocrine cancers

Honoraria paid by industry to the NCUK for talks or similar services relating to NCUK activity should be paid directly to the NCUK. Honoraria paid by industry to NCUK staff for talks or similar services should be paid to NCUK, unless talks are done outside of reasonable NCUK working hours.

Ways in which industry can support NCUK financially

Project funding:

This is where NCUK will work in partnership with a pharmaceutical company to undertake a project relating to an issue of mutual interest. The following features will apply to these projects:

- NCUK maintains editorial control over all materials (hard and soft copies) produced in connection with the project
- The company will be appropriately acknowledged according to the following appendix
- NCUK will not endorse or promote individual products, devices, procedures, tests or services
- The wording and/or position of the acknowledgement will be agreed in negotiations with the company

Sponsorship:

This is where a company funds a single activity such as a meeting or newsletter. In this case the following will apply:

- The company has no involvement in the activity for which the sponsorship is granted
- NCUK maintains editorial control over all materials or meeting programmes

- NCUK will not endorse or promote the sponsor's products or services
- Sponsorship shall be appropriately acknowledged in the activity, according to the following appendix
- The wording and/or position of the acknowledgement are part of the sponsorship negotiations with the company

Unrestricted grants:

The following features will apply:

- The company has no involvement in the project for which the grant is used
- The grant will be appropriately acknowledged according to the following appendix
- NCUK controls the wording and position of the acknowledgement

Other:

Companies may offer financial donations and in-kind support to NCUK. All donations and support will be acknowledged in an open and transparent manner.

Appendix 1: Guidelines for pharmaceutical companies proposing to work with or provide funding to NCUK

NCUK will not embark on any project or venture with industry that might damage its reputation or result in the dissemination of biased and inaccurate information. Therefore, when working with NCUK, pharmaceutical companies should adhere to the following guidelines:

- NCUK must be consulted whenever and wherever its name is used, particularly in external communications. Approval must be sought for any copy produced which refers to a network initiative supported by a commercial organisation.
- At no time can the NCUK logo be used without its written permission.
- NCUK may contribute to press releases produced by the industry, upon approval. If there is an interest in the topic reported by a company, NCUK can do its own press release or public statement.
- NCUK retains a veto over all materials produced in connection with an initiative. Adequate approval time needs to be allowed for this as it may require approval from one or more trustees and require feedback from the NCUK Medical Advisory Committee.
- Where more than one branded version of a product exists, any materials produced, as part of an initiative will use either the scientific name or several different brand names. It may not be practical to mention every brand at every stage in a publication but overall the effect will be one of impartiality.
- NCUK agrees to work with PR/advertising and marketing agencies of commercial organisations once a project is underway. However, in the first instance when a project is being planned or suggested NCUK requires a representative from the company to be present as well as the agency.
- One point of contact should be identified within the company and/or agency to liaise with the appropriate contact person in NCUK. Clear lines of communication need to be established at an early stage with respective responsibilities and assignments agreed to ensure smooth progress with a project.