HUK Position Statement on working

with pharmaceutical, healthcare (and similar) organisations

1. Introduction

HUK recognises the importance of investment by pharmaceutical, medical device manufacturers, diagnostics/prognostics companies and biomedical companies in research, development and clinical trials of treatments for genetic haemochromatosis (GH). We recognise the value of a well-functioning National Health Service, free at the point of need, funded through taxation.

We welcome information on new treatments, drugs, devices and digital technologies aimed at improving the health and quality of life of people affected by GH and illnesses associated with it.

2. Purpose

The purpose of this policy is to provide clear principles and guidance about how HUK will work with pharmaceutical companies, medical device manufacturers, diagnostics/prognostics companies and similar biomedical companies (referred to in this document as "pharmaceutical companies") and organisations within the NHS. Such partnerships will enable us to achieve the charity's mission without compromising our integrity.

This policy exists to ensure our work with pharmaceutical companies and NHS organisations does not affect our ability to provide independent and unbiased patient information and support and influence our research or fundraising activities.

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HUK recognises that working with pharmaceutical companies that manufacture and market drugs and treatments could provide us with important knowledge and expertise. Such companies may also be willing to sponsor and fund certain activities undertaken by us. However, pharmaceutical companies and NHS organisations are not charitable organisations and we will take particular care in how we work with them.

Below are the principles which HUK will adhere to when entering into partnerships or relationships with pharmaceutical companies and NHS organisations to ensure that all relationships are consistent with our organisation's mission, vision and objectives

3. Principles

The following guiding principles will be adhered to:

1. All partnerships will be based on the principles of integrity and openness and will bring benefit to HUK through funding or through supporting the HUK to achieve its mission.

2. Any joint activity must fit within HUK's mission and strategic objectives and comply at all times with our published statement of values and ethics policy.

3. All donor or funding partnerships between pharmaceutical companies or NHS organisations and HUK including employee fundraising relationships will be subject to our Fundraising & Donations Policy.

4. Any partnership entered into will not compromise the independent status of HUK.

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5. We will ensure that our editorial independence is maintained so that we are free to comment both positively and negatively about pharmaceutical companies and their products and NHS organisations and their services.

6. We will work with members of the pharmaceutical industry and the NHS to share knowledge and expertise. This may involve participation in events organised by the pharmaceutical industry or NHS organisations such as:

    - Private or public meetings, conferences or webinars
    - Training events
    - Market research events

8. No commercial partnership will be entered into with a company or NHS organisation whose product or service is considered to be detrimental to people living with genetic haemochromatosis (or conditions or diseases caused by genetic haemochromatosis), or any product or service with unsupported claims of positive benefits to those affected by genetic haemochromatosis (or conditions or diseases caused by genetic haemochromatosis).

9. Partnerships with pharmaceutical companies and NHS organisations will not compromise the charity's independent status and – where relevant - will comply with the ABPI Code of Practice for the Pharmaceutical Industry, particularly Clause 27 *"Relationships With Patient Organisations"* and the British In Vitro Diagnostic Association (BIVVDA) Code of Conduct.

    When a company is not a member of ABPI or BIDVA we will require written assurances that any partnership work will be conducted to the standards laid out in these codes. Each partnership will have a written agreement.

    The written agreement must include:

- Name of the activity
- Names of the organisations involved (pharmaceutical companies, patient organisations and any third parties which will be brought in to help)
- Type of activity (e.g. unrestricted grant, specific meeting or publication etc)
- Objectives
- Respective roles of the company and the patient organisation
- Time frame
- Amount of funding
- Description of significant indirect/non-financial support (e.g. the donation of public relations agency time or free training courses)
- Statement that all parties are fully aware that sponsorship must be clearly acknowledged and apparent from the start
- Code or codes of practice that will apply
- Signatories to the agreement
- Date of the agreement

10. We will not accept financial support for activities which lie outside our objectives. We will consider entering into strategic partnerships with individual pharmaceutical companies or NHS organisations if it is deemed to be in the best interest of those affected by genetic haemochromatosis.
11. HUK will not undertake any joint work with, or accept funding from, a pharmaceutical company or NHS organisation where promotion of a specific drug or therapy or diagnostic is required or demanded by the organisation (either explicitly or implicitly).

12. There may be occasions where we will campaign for equitable access to a treatment, on behalf of patients and their supporters. Under no circumstances will we accept funding from pharmaceutical companies or NHS organisations to support campaigning activity for access to specific treatments.

13. Information of any funding by pharmaceutical companies will be publicly available and published annually in the trustees' report .

14. Pharmaceutical companies must not use the name of HUK in any promotional materials without the prior written consent of HUK.

15. This policy was revised in March 2022. It will be reviewed & revised by the board of trustees bi-annually.

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