

The British Porphyria Association

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Charity No: 1089609
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Working with Pharmaceutical Companies Policy

Many charities and pharmaceutical companies collaborate to achieve common objectives, such as improving patient information or access to medicines, raising awareness of clinical trials and improving patient outcomes. Collaboration with pharmaceutical companies that undertake research or market treatments for the porphyrias can be beneficial in terms of the knowledge and expertise gained by the BPA. Industry also benefits as they learn more about medical conditions and what matters to patients.

To ensure that any risks of working with industry are minimised and that the BPA's integrity is never compromised, the BPA will follow the guidelines outlined below.

Guidelines

All interactions will take place with the principles of transparency, clarity of purpose, integrity and independence in mind. To fulfil this aim, when working with pharmaceutical companies/industry, the BPA will ensure that:

- All interactions are transparent and well documented.
- The purpose of any collaboration is clear, e.g. disease awareness campaigns, events and meetings, market research events, training events, advisory boards, or information and support for patients.
- Interactions align with the strategic goals and mission of the BPA.
- The BPA's independence is not compromised or dictated to in any way by pharmaceutical companies, including editorial independence about companies or their products.
- The BPA will not accept funding from a company where promotion of a treatment is required or demanded, whether explicitly or implicitly.
- Sponsorship/grants/fundraising from pharmaceutical companies will not influence or change the mission/aims of the BPA or influence the information created by the BPA.

Funding sources

The BPA is able to fulfil its aims due to funding from various sources, including donations from members, patients and the general public, fundraising events and grants from relevant bodies, including the pharmaceutical industry.

Additionally, trustees or members acting on behalf of the BPA may receive expenses payments from such bodies for activities undertaken. Expenses usually take the form of travel, accommodation and subsistence expenses or fees to cover lost earnings when attending events.

To ensure independence and transparency for all such eventualities, the BPA will publicly recognise support from pharmaceutical companies/industry, by:

- Keeping clear records of all payments received from pharmaceutical companies within an Income/grants log and register of interests. Ensuring that this full list of received funds is maintained and available from the Trustees.
- Ensuring that we work with a variety of pharmaceutical companies, giving no preference to any one company in particular.
- Ensuring that funds received do not influence, dictate or change BPA aims.
- Ensuring that conflicts of interest are declared and recorded for transparency, and that any individual with a conflict of interest is prohibited from taking part in discussions that relate to the pharmaceutical company (see **Conflict of Interest Policy**).

Further reading

www.nationalvoices.org.uk/sites/default/files/public/publications/working-together-delivering-for-patients.pdf

Responsibility

Overall responsibility for this policy and its implementation lies with the board of trustees and the executive committee.

Review

ice view
his policy is reviewed regularly and updated as required.
dopted on: May 2020
ast reviewed: May 2020
igned: S Chemberlayne
osition:BPA Chair