



Parkinson's Association of Ireland

Policy for dealing with Pharmaceutical and Medical Devices Industry

September 2023

Summary

The purpose of this document is to outline the Association's position on any working relationships with healthcare industries that make a profit. This policy applies to those who manufacture and market treatments and medical devices for Parkinson's Disease ("PD"), including but not exclusive to, pharmaceutical companies, biotechnology companies, cannabis industries, and medical device companies.

The Association's vision is a world free from the effects of PD. The Association recognises the importance of working collaboratively with all stakeholders with an interest in PD to achieve this vision. Those who market and manufacture drugs and devices to treat PD are an important stakeholder in achieving our vision. At the same time, we need to be open and transparent about these working relationships. It is vital that the Association maintains its independence, integrity, impartiality and transparency in all that we do.

The Association works with industry when we are confident it is in the interest of people with PD. Any collaboration with industry must clearly support the Association's strategic aims and objectives and be in line with its organisational strategy.

The Association will not enter into any relationship which could in any way jeopardise its independence or impartiality. We will never give one company a competitive advantage over another, and will always seek support from multiple companies where possible. The Association will at all times fully meet the requirements of the Charities Regulator.

The Association recognises the need for industry to comply with relevant laws.

This policy has been prepared in line with relevant best practice guidance.

All Association staff and volunteers and anyone operating on behalf of the Association are expected to adhere to this policy and the Association will make this policy available to any industry organisations it works with to inform and guide these relationships.

Key definitions

Pharmaceutical company: A pharmaceutical company, or drug company, is a commercial business licensed to research, develop, market and/or distribute drugs, most commonly in the context of healthcare. They can deal in generic and/or brand medications.

Medical devices: A medical device is described as any instrument, apparatus, appliance, software, material or other article, whether used alone or in combination, including the software intended by its manufacturer to be used for human beings for the purpose of: diagnosis, prevention, monitoring, treatment or alleviation of disease, or investigation, replacement or modification of the anatomy or of a physiological process, and which does not achieve its principal intended action in or on the human body by pharmacological, immunological or metabolic means, but which may be assisted in its function by such means.

Biotechnology company: company that uses live organisms or their products, such as bacteria or enzymes, to manufacture drugs.

Cannabis company: A cannabis company is a commercial business regulated to research, develop, market and/or distribute cannabis-based products, most commonly for medicinal purposes. They can deal in generic and/or brand medications.

1. Independence and impartiality

1.1. Any direct collaboration with industry will be governed by a clear written agreement, in line with the most up to date ABPI Code of Practice for the Pharmaceutical Industry. Written agreements will identify requirements and expectations from each party, including intellectual property, publications and exploitation. The written agreement will be developed in line with this policy and with the Association's intellectual property policies. The agreement will also include reporting requirements, or any other obligations, which should be agreed with all companies during the planning stages of a project. The Association will ensure that there is a mechanism for monitoring and evaluating the outcomes of each collaboration.

1.2. The Association will ensure that its activities and publications are non-promotional and do not aim to stimulate demand for a particular treatment nor promote it over its competitors. The Association will not actively encourage people affected by PD to seek a particular product or service from a healthcare provider. However, it may draw attention to specific products or services if we believe this could benefit people affected by PD. References to products or services in any of the Association's publications or information services by generic or trade name do not constitute a recommendation of the product or service.

1.3. The Association will never consent to being quoted in press releases developed by pharmaceutical and medical device industries.

1.4. Companies will not be allowed to edit Association publications or other resources. No information resource or materials produced by the Association will be influenced in any way by the acceptance of pharmaceutical or medical device industry sponsorship. All Association information is based on the latest evidence and is informed by people affected by Parkinson's, health and care professionals and others with relevant expertise.

1.5. Where the Association works with any company or companies on a specific project the Association will retain editorial control over all publications and printed materials and will maintain copyright. The Association's logo and any of its materials may not be used by any industry partner in any internal or external publication or document without the Association's written consent.

1.6. The Association will always seek to work with multiple industry partners to ensure no one company has undue influence. Joint funding arrangements for specific projects are favoured. We will only work with one industry partner as an exception, such as when multiple industry partners have been asked and only one company has agreed to collaborate on a project. All funding collaborations will be governed by a written agreement.

1.7. The Association will only work with pharmaceutical and medical device companies where it can ensure compliance with the most recent ABPI Code of Practice. Where a company is not a member, we will require written assurance of compliance with these principles.

1.8. The Association reserves the right not to work with a company.

2 Openness and Transparency

2.1 The PAI neither endorses nor recommends any products or medications that have not received the necessary approval from the Health Products Regulatory Authority (HPRA) in Ireland.

2.2 The PAI emphasises the importance of seeking medical advice from qualified healthcare professionals, including general practitioners (GPs) and specialist consultants such as neurologists, and acknowledges the crucial role played by these medical professionals in the provision of optimum care and advice for people living with Parkinson's Disease.

2.3 Where the Association works with pharmaceutical or medical device companies on a specific project, the charity will acknowledge this publicly through openly declaring commercial sponsorship of a project, where relevant, and what input each company had, if any.

2.4 In strict compliance with GDPR regulations, the Association will not, under any circumstances, disclose any of its members' or supporters' information to any other organisation or third-party organisations working on behalf of a company.

2.5 Any Association volunteers or staff who have a relationship industry that directly relates to their role at the Association must declare and manage any conflict of interest that may arise in line with our Managing Conflicts of Interest or Potential Conflicts of Interest Policy.

2.6 The Association will consider participation in independent market research funded by Pharmaceutical and Medical Device Industries. At all times involvement will only consist of staff time and will not involve Association staff sourcing external participants for their research.

2.7 Branches are required to refer any requests for approval of products to the Board.

2.8 No Branch or member should promote products or treatments.

3. Financial support

3.1. The Association will only accept funding from companies when it fulfils all of the following criteria:

- That a partnership will result in benefit to people affected by Parkinson's and is in line with our vision and organisational strategy.
- The named lead from the Association is satisfied that accepting support is in line with this policy, and will not result in any significant reputational damage.
- There is no attempt by the funder to directly or indirectly influence the charity's strategy or activity.
- The donation or contribution is in line with the Association's Acceptance and Rejection of Donations Policy.

3.2. Wherever possible, funding requests will be sought from a number of companies for a particular programme of work. The Association will negotiate with all its sponsors on an equal basis to ensure that no individual company is treated differently from any other in regard to funding of any particular project.

3.3. The acceptance of funding from industry will be confirmed by a written agreement as outlined in section 1.

3.4. Any donations offered to staff, volunteers or any person acting in the name of the Association must be made directly to the charity and are governed by the terms of this policy and Association sign off procedures. Please refer to Section 6 for further guidance.

3.5. The Association will not accept honorarium for staff participation in an event unless the responsible Director is satisfied both that participation in the event is consistent with this policy, whether or not an honorarium is paid, and that the receipt of an honorarium does not create a risk of a perceived loss of independence, impartiality, openness or transparency. If honorarium is appropriate, it will be donated back to the Association.

3.7. Fundraising activities by groups of individuals who happen to work for a particular pharmaceutical or medical device company are outside the scope of this policy.

4.Campaigning and influencing

4.1. Financial support from companies to support Association campaigning activities to external audiences where the objectives of the work directly support the financial gain of one company will not be accepted, as this may be interpreted as promoting a particular treatment or product.

4.2. Where the Association becomes involved with a collaborative campaign, the terms of the collaboration will be governed by a written agreement between the parties involved. This ensures that the Association's corporate policies are observed.

4.3. Where working with an organisation that may be funded or otherwise linked to industry, we will seek to ensure that we are aware of any such links and that our collaborators are open and transparent about their existence of those links and meet the principles contained in this policy.

4.4. The Association reserves the absolute right to make public comment based on its impartial view of the evidence and data relating to treatments and services.

5.Research

5.1. The Association will make available information on clinical trials that it is funding on its website for the purpose of bringing them to the attention of people with Parkinson's.

5.2. Where there is a partnership between the Association and pharmaceutical companies, a policy will be agreed regarding research publications and data access. This would be set out by the Association in advance of any agreements of this type.

5.3. The Association will consider requests to signpost to patient and public involvement (PPI) activities that industry plans to run in research subject to those requests meeting the Association's criteria.

6.Guidelines for working together

6.1 Further operational guidance on how the Association works with the pharmaceutical and medical device industries at a national and regional level, as well as template written agreements, are available on request.