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## Parkinson's Europe policy for working with the treatment industry

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### 1. Glossary

In this policy the definition of the terms we use:

- **Member organisations** describe Parkinson's Europe members – namely, organisations that are not-for-profit organisations based in any European country, or in countries bordering the Mediterranean Sea, that represent a membership of people with Parkinson's and caregivers.
- **Affiliate members** describe Parkinson's Europe affiliate members – namely, not-for-profit organisations based in any European country, or in countries bordering the Mediterranean Sea, who have a special interest in Parkinson's, with no individual members.
- **Industry partners** are companies and organisations that have agreed to become a Bronze, Silver, Gold or Diamond funding partner of Parkinson's Europe. All such partners are of high standing and reputation that agree with Parkinson's Europe's overall strategic direction and help support the integrity of our organisation. Our partnerships with these companies are established on shared interest, transparency, trust and mutual benefit, and do not imply Parkinson's Europe's endorsement of any corporation (or their products or services).



## 2. Our policy for working with the industry

This document aims to clearly outline the working parameters for our collaborations with industry organisations and personnel so we make sure we maintain our independence and transparency. As we cannot access any funding at a national level (for example through national government funding, or private legacies or donations) we do not compete for funding with our national member organisations. Historically we have relied (and continue to do so) on partnerships with the industry that amount to approximately 90% of our funding.

Our mission is to work and campaign with people with Parkinson's, their partners, caregivers, families and supporters across Europe to ensure their voices are heard and listened to. All that we do is focused on bringing benefit to people affected by Parkinson's including all working activities we conduct with industry personnel or organisations.

## 3. What's included and excluded from our working practice

1. **Consultation** – we provide Parkinson's insights and knowledge to those who need it
  - a. **What's included:** providing information on topics such as Parkinson's symptoms and daily life, scientific developments, Parkinson's organisations and the Parkinson's community at large, aimed at increasing our partners' awareness of the needs of people living with the condition and of the Parkinson's community, and inform the development of more relevant and patient-focused company initiatives.
  - b. **What's excluded:** we do not provide information protected by privacy legislation, personal and/or medical data, or reserved information on the internal structure and functioning of Parkinson's organisations. We also do not provide information to be used in marketing, commercial and promotional materials, unless specific permission is granted.
2. **Co-development of projects** – we offer win-win bespoke activities designed to support the European Parkinson's community
  - a. **What's included:** we aim to establish an equal partnership to develop activities that have the primary goal of benefiting people with Parkinson's and their families – the content and focus of such activities being normally developed with the input of Parkinson's Europe experts (eg. our Board members or scientific experts)
  - b. **What's excluded:** we do not work on activities that have been developed primarily by the industry partner, or those that have the primary goal of benefiting the company and/or its commercial objectives
3. **Outreach/information sharing** – we share partner information about specific Parkinson's projects and issues via our various networks
  - a. **What's included:** the sharing of factual, objective information developed by our partners aimed at empowering people with Parkinson's and their families and at increasing their awareness about Parkinson's symptoms, management and treatment options
  - b. **What's excluded:** the sharing of commercial and/or marketing information, promotional materials, or any kind of information that may be biased towards suggesting one treatment option over another



4. **Facilitation** – we help connect and involve Parkinson's stakeholders with people and organisations our partners cannot easily connect with
  - a. **What's included:** the facilitation of connections and meetings with individuals and/or organisations from the Parkinson's community who are interested in entering into a dialogue and in exploring opportunities of collaboration with the company – provided they explicitly agreed to these connections
  - b. **What's excluded:** the introductions to, or sharing contact details of, individuals and organisations without their explicit agreement, or for the company to promote treatments or engage in commercial initiatives towards them
5. **Reviewing** – we provide feedback on our partners' content, offering advice on how it should be communicated in as patient-friendly language as possible
  - a. **What's included:** the reviewing of materials that provide objective, factual information on topics relevant to the Parkinson's community, and that are aimed at empowering people with Parkinson's and their families to make informed decisions about living with the condition, their treatment or the relationship with their healthcare professionals.
  - b. **What's excluded:** the reviewing of marketing, commercial or promotional materials that include biased information and/or that promotes the adoption of one treatment over another.
6. **Horizon scanning** – we offer partners the chance to get a 'temperature check' from our networks about specific issues of interest to them
  - a. **What's included:** the dissemination of brief surveys developed by our partners on topics of interest to them but that are relevant and useful to the Parkinson's community. This includes also connecting partners with individuals who may choose to be involved in interviews or focus groups on such topics, provided appropriate rules for involvement of patients in industry-developed activities (including those regarding compensation) are followed
  - b. **What's excluded:** the dissemination of market research surveys or involving individuals in market research activities focused only on a specific product or treatment
7. **Ad hoc partner project support** – what simple and achievable value-added ways can we support our partners improve the lives of people with Parkinson's and their families?
  - a. **What's included:** the collaboration with our partners on an advisory, ad-hoc basis with a reasonable commitment in terms of time and resources, providing our expertise and knowledge to support the design and development of activities that have a clear, tangible and obvious benefit to the Parkinson's community
  - b. **What's excluded:** the collaboration on the development of marketing and commercial activities or the endorsement and/or dissemination of initiatives developed by the company without a substantial involvement and input by Parkinson's Europe.

#### 4. Our working practices with industry

When considering partnering with a company or external organisation, we always ensure that the company's objectives, area of work and current policies do not conflict with our vision, mission and goals. Collaboration will be declined when there is a clear conflict of interest.



Whenever the possibility of a conflict of interest of this kind arises, the Parkinson's Europe Board of Directors will carefully consider all implications and make an informed decision on a case-by-case basis.

Companies' activities must intend to improve the lives of people with Parkinson's, their families and supporters.

We encourage transparency of all findings collected in our partnership activities and aim to share them with our Parkinson's audiences through our strategic communication channels.

## **5. Our funding model in relation to industry partnerships**

Parkinson's Europe would not exist without industry funding because, being a European organisation, we are unable to secure funding for our running costs from sources normally accessible to national Parkinson's organisations.

We have four main tiers to choose from when considering becoming a Parkinson's Europe funding partner: Bronze, Silver, Gold and Diamond. For more details about our 2024 partnership tiers, see the diagram below.

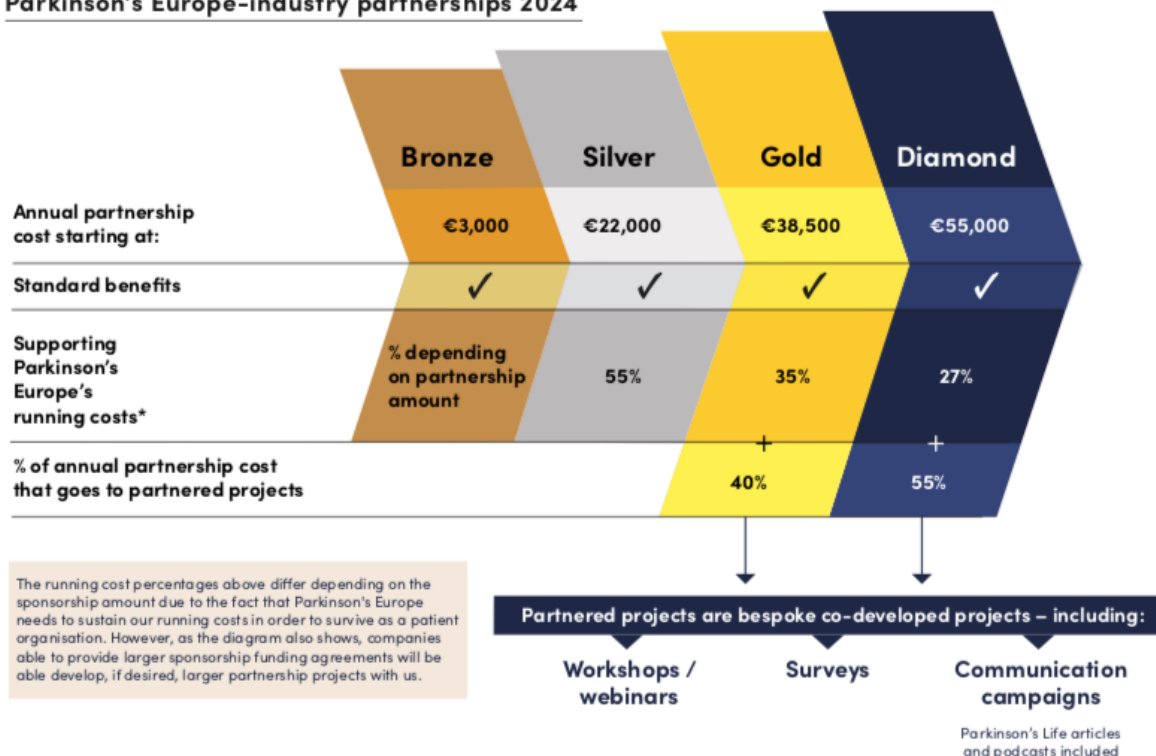
All our partnership options include as standard a set of benefits plus a percentage contribution towards our running costs (depending on the total sponsorship amount provided). Depending on the type of partnership selected, any remaining funds can potentially be used by our partners to co-develop mutually beneficial projects with Parkinson's Europe that will ultimately support the Parkinson's community.

The Bronze tier is the ideal option for companies that are initially only able to allocate limited resources to partnership but hope to develop a long-lasting partnership with us over the years. Bronze partners include smaller technology companies and start-ups among others. We are committed to working with companies of all sizes that are developing new tools and treatments that aim to benefit the Parkinson's community.

The Silver tier is for companies with relatively limited funds that still wish to help enable Parkinson's Europe to carry out its strategic goals on behalf of people with Parkinson's and their families; engage with a long-standing, highly reputable and well-respected not-for-profit organisation (Parkinson's Europe); enhance their visibility at a European – and also national – level; and demonstrate their commitment to corporate social responsibility.

The Gold and Diamond tiers can take advantage of bespoke Parkinson's Europe partnered projects to be discussed on a case-by-case basis. All projects need to fit within the scope of Parkinson's Europe's key strategic objectives.

#### Parkinson's Europe-industry partnerships 2024



**Please note:** The minimum cost for any Parkinson's Europe-industry activity is €3,000. This price enables a) the industry company to become a Bronze partner and b) Parkinson's Europe is covered from a project management, administration and financial management time perspective. Being the only Parkinson's European umbrella organisation, we get approached by many companies and organisations throughout the year meaning we need to tread carefully to ensure our own work plan isn't sacrificed in the support of others'. The €3,000 minimum price helps us to achieve this.

## 6. Declaring sources of income and following charity policy

As a non-profit organisation registered in Belgium (Numéro de l'association: 8727/2000, No. d'entreprise: 465299201) and a charity registered in England and Wales (registered Charity Number 1163211), Parkinson's Europe follows the rules and regulations detailed in the Belgium Code on Companies and Associations, as well as by the UK Charity Commission.

Parkinson's Europe is also guided by the European Medicines Agency (EMA) and the European Federation of Pharmaceutical Industries and Associations (EFPIA) codes of practice – as well as, when entering into partnerships with companies legally registered in the UK, by the Association of the British Pharmaceutical Industry (ABPI) code of practice.

To ensure full transparency, Parkinson's Europe is legally required to publicly declare annual sources of funding, as well as to publish annual financial reports. These documents clearly state the percentage and amount of funding provided by each of our industry partners, and are available at these links on our website:



- [sources of funding](#)
- [financial reports.](#)