

# Parkinson's Europe Business Plan 2024

## Executive Summary

Parkinson's Europe is the only European umbrella patient organisation for Parkinson's. There is no other organisation like us or one that seeks to do what we do.

We were founded in 1992 and our members are national Parkinson's organisations across Europe (we currently have more than 30).

In addition to bringing our members together – along with individual people with Parkinson's and their families and other stakeholders – to provide a bigger and united European Parkinson's voice, we are also able to legitimately represent the European patient community at the global level.

We always attempt to be open and collaborative, and to be facilitative partners to the wider community. Our motto is to aim for the highest quality of work – exceeding expectations where possible – and be transparent and collaborative with all our stakeholders.

Parkinson's is the second-most common neurodegenerative disorder (after Alzheimer's) and, according to the World Health Organization, is the fastest growing neurological disorder worldwide in terms of disability and death.

Our vision is therefore to work and campaign with people with Parkinson's, their carers, families and supporters across Europe to ensure their voices are heard and listened to. We do this by advocating, raising awareness and working with other global Parkinson's organisations to provide current information, share good practices, and highlight research that will benefit the whole Parkinson's community.

Our mission is that people with Parkinson's and their families have access to the highest standards of treatment, support and care they need to live a full and comfortable life.

While these are lofty ideals, our niche as the only European Parkinson's organisation is our ability to represent the patient community at the European level via our advocacy, political lobbying and other activities such as facilitating dialogue, thought leadership, networking and sharing good practice across the region. We are in a unique position of being able to monitor issues, trends, challenges and solutions and communicate these with a wide range of stakeholders, as well as reflect the needs of the wider community – as clearly demonstrated in our Parkinson's Europe Manifesto.

Our funding has historically been driven by sponsorship agreements with treatment industry and tech companies focused on the area of Parkinson's. While this funding model has proved successful for decades, we are currently looking at ways to diversify our income streams to reduce our reliance on industry and tech companies.

---

## Activities, projects and services

An overview of Parkinson's Europe's 2024 projects and activities are outlined in the latest Team organogram (above). The areas of focus for our ongoing working are:

### Primary focus activities

#### Advocacy:

Parkinson's Europe believes that much more can be done to overcome key hurdles to effective diagnosis, treatment and care for people with Parkinson's at the European level.

As such, one of our strategic aims is to increase our advocacy work and presence, including political awareness of Parkinson's as a priority health challenge at the European and national levels.

Parkinson's Europe actively engages with EU decision makers, partners and stakeholders to promote dialogue on policy gaps that negatively affect people with Parkinson's and their families, and to collectively advocate for long-lasting change.

#### Research:

A key part of our mission is to highlight research that will benefit the whole Parkinson's community. Our research focus is to support and facilitate collaboration between people with Parkinson's and those stakeholders involved in research.

Our ambitions to support research are:

- to **unite** the Parkinson's community in Europe to want to be part of research and know it is their right to do so
- to **build** communication systems to help people find out more about what research is available and how they can connect with it
- to **connect** industry and academics with the Parkinson's community in Europe to ensure better quality future research and make sure that the voices of the community are represented in their work
- to **facilitate** the research conversation, breaking down the barriers associated with understanding research.

#### Membership:

As an umbrella organisation, our members are organisations, not individuals. One of our strategic aims is to "facilitate the free flow of good Parkinson's related practices across and between European countries" – and this statement lies at the heart of our membership offer.

---

Our membership offer includes:

- sharing information about what is happening in the wider world of Parkinson's, outside of our members' own countries
- giving our members visibility beyond their own country
- connecting our members with the wider Parkinson's community
- providing opportunities for our members to network with their European colleagues.
- supporting our members' national work
- allowing our members to get their voice heard at a European level
- allowing our members to put forward a representative to apply to become a Parkinson's Europe Board member.

Treatment industry partner projects:

More than 90% of Parkinson's Europe's funds have historically come from sponsorship agreements with the treatment industry and tech companies. As part of these agreements, we offer the opportunity to work on bespoke, win-win projects/activities with our partners. We therefore regularly work with our partners by providing the following offer:

- Insight and knowledge about Parkinson's and the needs and experiences of people living with the condition.
- Testing and feedback involving Parkinson's communities, to 'temperature check' specific issues of interest to them.
- Collaboration on projects when it matches our organisational objectives and those of the Parkinson's community.
- A variety of platforms to disseminate information for people with Parkinson's, their families and caregivers.
- Reviewing patient information our partners produce, to offer advice on whether it contains Parkinson's-friendly language.
- Introductions to those who can complement the work our partners do to combat Parkinson's.

Communications:

In many ways, Parkinson's Europe is a communications organisation at heart. Working with the Parkinson's community for more than 30 years has given us a rich knowledge of how Parkinson's affects people's daily lives – and our stakeholders actively seek the information we can offer.

We therefore strive to communicate to all our stakeholders in a variety of ways including:

- Online via our website, social media and other digital platforms (eshots etc)
- Online via virtual meetings and workshops

- 
- In person at events we organise, host and attend

We also endeavour to be an organisation who listens and responds to our members, partners and stakeholders through personalised information gathering. The purpose of this is to make sure we as an organisation are delivering on and listening to their needs.

## Secondary activities and projects

### Insights and engagement:

Our strategic aims include the collection, collation and mapping of Parkinson's data, knowledge and trends across Europe. We also aspire to identify the gaps and challenges that face our member organisations, and to share the best practices that exist.

### Fundraising:

As more than 90% of Parkinson's Europe's funds have historically come from sponsorship agreements with the treatment industry and tech companies, we will be developing a fundraising strategy in 2024 that seeks to diversify our funding streams to reduce our reliance on industry funding.

### Campaigns:

As an advocacy organisation, campaigning has always been an important part of our work. Every year, we actively support World Parkinson's Day (11 April), but we have historically also led campaigns with our members and the wider Parkinson's community.

## Internal organisation working activities and projects

### Admin support and logistics:

Most of our work requires some level of administration and logistics work, particularly our events and campaigns.

### Internal processes:

As an organisation, Parkinson's Europe requires a streamlined and consistent internal picture of what we do, as well as a standardised working practice that enables us to effectively track and evaluate our activities.

## Governance:

Good governance within not-for-profits and charities is fundamental to their success. It enables and supports an organisation's compliance with the law and relevant regulations. It also promotes a culture where everything works towards fulfilling the charity's vision. As a result, our Director General and Board Secretary prioritise Parkinson's Europe's governance adherence.

## IT systems and support:

Parkinson's Europe employs a Team and hosts a website – and carries out many projects and activities that rely on various forms of technologies – all of which require various IT systems and supports to be in place.







## Finance:

All not-for-profits and charities need financial controls, regardless of size. These financial controls help to protect Parkinson's Europe's assets and get the most out of our resources. Maintaining suitable internal financial controls helps us:

- identify and manage financial risks
- keep good-quality accounting records
- prepare timely and relevant financial information
- Ensure our financial reporting complies with the relevant legal requirements.

**For more information about our work, visit [parkinsonseurope.org](https://parkinsonseurope.org)**

### Get involved with our work:

 <b>Become a partner</b>	 <b>Become a member</b>	 <b>Donate</b>
 <b>Sign up to our newsletter</b>	 <b>Join our Engagement Network</b>	 <b>Follow us on social media</b>

If you have any questions about this Business Plan, please email [info@parkinsonseurope.org](mailto:info@parkinsonseurope.org)