

November 2022

Parkinson's Europe: who we are and what we do



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We are the umbrella organisation for European national Parkinson's associations. We have been championing and working with the global Parkinson's community for 30 years.

Our vision

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.

Our mission

We work and campaign with people with Parkinson's, their caregivers, 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 strategic goals

Providing trusted
information

Advancing and
sharing good
practices

Raising
awareness and
improving
understanding

Facilitating
research
collaboration

How we work with our partners

1. **Consultation** – we provide Parkinson's insights and knowledge to those who need it
2. **Co-development of projects** – we offer win-win bespoke activities designed to support the European Parkinson's community
3. **Outreach/information sharing** – we share partner information about specific Parkinson's projects and issues via our various networks
4. **Facilitation** – we help connect and involve Parkinson's stakeholders with people and organisations our partners cannot easily connect with
5. **Reviewing** – we provide feedback on our partners' content, offering advice on how it should be communicated in as patient-friendly language as possible
6. **Horizon scanning** – we offer partners the chance to get a 'temperature check' from our networks about specific issues of interest to them
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?

Why you need to work with us

By working with Parkinson's Europe, you/your organisation will:

- Engage more effectively with the Parkinson's community
- Build your organisation's skills and confidence when engaging with patient groups
- Help us to carry out our strategic goals on behalf of people with Parkinson's and their supporters
- Be in partnership with a long-standing, highly reputable and well-respected not-for-profit organisation
- Enhance your visibility at a European – and also national – level
- Demonstrate your commitment to corporate social responsibility
- Help the fight against the effects of Parkinson's, which have an impact across nearly every cultural, social and economic boundary

Parkinson's Europe people



Our team

- 12 full and part-time members including: Director General, Operations Director, Research Manager, Insight and Engagement Manager, Project Managers, Communications Consultant, Social Media Consultants

Our Board

- 11 members (and two new observers), ranging from people with Parkinson's, caregivers, healthcare professionals, advocates and patient organisation representatives
- From a broad European geographical spread: Belgium, Ireland, Israel, Italy, Malta, Portugal, Slovenia, Spain and the UK

Our member organisations

- We have 25 member organisations from 21 countries (including Eastern Europe)

Our industry partners

- Currently we have 13 industry partners, some of whom have been our partners for 20+ years

Our priorities in 2023

Research

- **Consultation:** we have appointed a full-time Research Manager to increase our consultation capacity for anyone reaching out to us.
- **Knowledge and skill building:** we've now assembled our Research Steering Group to embed the voice of the Parkinson's community in all our work internally and externally.
- **Creating a relevant research strategy:** we've put the framework of our new research strategy together, building on data provided by our member organisations and industry partners. The strategy incorporates more effective engagement, involvement and outreach between all stakeholders linked to Parkinson's research in Europe.

Our priorities in 2023

Advocacy

Our 2023 advocacy strategy aims is to increase political awareness of Parkinson's as a priority health challenge at the European and national levels, and build political support for concrete policy change on key topics such as:

- **Pesticides:** working with some of our member organisations to raise awareness of the potential increased Parkinson's risk connected to the use of pesticides, and lobby for concrete change at EU policy level
- **EU actions on non-communicable diseases:** raising the profile of Parkinson's in the context of the EU 'Healthier Together' initiative
- **Revision of the EU pharmaceutical legislation:** shaping the pharmaceutical legislation in a way that makes life better for people with Parkinson's by campaigning for equal access to medicines across Member States, securing more affordable medicines and addressing medicine shortages

Our priorities in 2023

Engagement

Next year we will be widening our stakeholder network base via a more systematic approach.

Our main objectives are to:

- **Increase** Parkinson's Europe's visibility, reputation and brand
- **Support** the delivery of Parkinson's Europe's and other partnered projects
- Become a **central hub** for knowledge and information sharing

We will also be building on the work that has resulted in our newly launched **30 year manifesto**. The next 'discovery' phase will bring together numerous stakeholders across Europe (including the industry) to make sure we continue to represent the wishes of the Parkinson's community as a whole.

Our reach and connections

Besides our member organisations, we interact directly with the global Parkinson's community in different ways:

- **Our online magazine Parkinson's Life:** has an average organic readership of 20k+ a month (with no marketing spend), and has been read in more than 200 countries since its launch in 2015.
- **Our database:** we regularly connect with engaged people in the Parkinson's community via e-shots about our own initiatives and those of our partners.
- **Our social media platforms:**
 - Facebook: 10,000+ likes in the last six months
 - Very active on Twitter: currently 5,600+ followers
 - Instagram (our newest channel): 1,000+ followers
 - LinkedIn contacts from 98 cities

The European/global organisations we work closely with

We are among the eligible patient and consumer organisations that regularly provide the **European Medicines Agency (EMA)** with feedback and input on activities relevant to the Parkinson's community. We do this by appointing 'patient experts' to take part in advisory panels and support review activities.

We also work closely with a number of other European patient organisations to advocate for a more robust policy response to Parkinson's. Our partners include the **European Patients Forum (EPF)**, the **European Federation of Neurological Associations (EFNA)**, the **European Brain Council (EBC)**, and **Eurocarers**.

More globally, we are actively partner with the **World Parkinson's Coalition (WPC)**. Ahead of the 2023 World Parkinson's Congress, we are a respected partner of the WPC Leadership Forum, and a key representative on three of the 2023 WPC Leadership Forum Working Groups. We have been a collaborative WPC partners since its inaugural event in 2006.

How we can work together

- Our partnership model is flexible – whoever you are, whatever your needs, we should be able to work with you provided your focus is on improving the lives of people with Parkinson's and their caregivers in Europe and around the world.
- For industry partnerships, we have Silver, Gold and Diamond options available, depending on the company's aims and ambitions. Partnerships are reviewed on an annual basis. For more information about how we partner with industry, visit our [website](#).
- We also offer one-off activity opportunities but their scope may be limited until a formal partnership is established.
- We are currently creating an 'Index' so partners and stakeholders can clearly understand and map the value of working with Parkinson's Europe.

Thank you

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