

parkinson's  
europe



# 2022

highlights



**This is a summary version** – for the full version of the Parkinson's Europe 2022 highlights report, [please visit our website](#).

For more information about any of the highlights outlined in this report, please contact Parkinson's Europe Operations Director, Dominic Graham at [dominic@parkinsonseurope.org](mailto:dominic@parkinsonseurope.org).

## 1 Name change

In 2022, the year of our 30th anniversary, we changed our name from the European Parkinson's Disease Association (EPDA) to **Parkinson's Europe**.



Previous name and logo



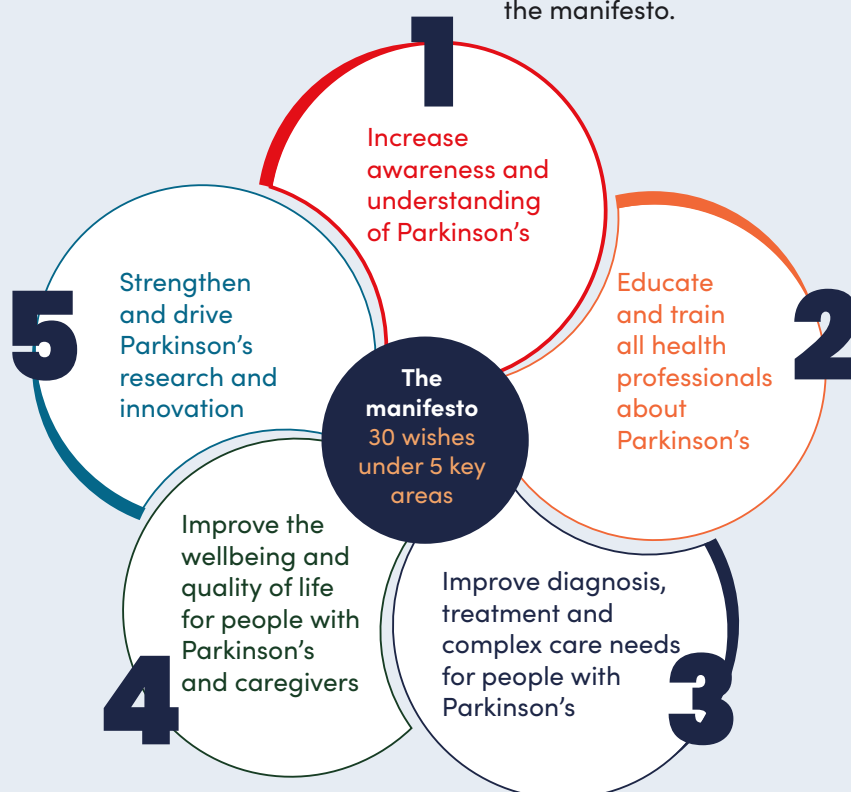
New and improved 2022 logo and name

## 2 Manifesto

We developed a **Parkinson's Manifesto for Europe** – using the views of more than 900 people from 39 different countries, including people with Parkinson's, caregivers, partners, family members and healthcare professionals, via a European survey and multilingual social media campaign. Summarising 30 wishes of the Parkinson's community, the Manifesto is divided into five key areas: awareness, training, diagnosis and treatment, wellbeing and research. It was launched in October and is available in nine languages, with further translations planned.

It has been endorsed by key Parkinson's opinion leaders such as Dutch neurologist Professor Bas Bloem as well as industry companies and the European Commission.

In 2023, Parkinson's Europe will identify the gaps, challenges and areas of good practice relating to each of the key areas outlined in the manifesto.



## 3 Updated strategy

Our amended Vision, Mission and Strategic Goals were approved by the Parkinson's Europe General Assembly on 29 June 2022, following a thorough review of our six-year (2019-2024) plan:

- **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:** To 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 will 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.

## 4 Research

Research is a new workstream for Parkinson's Europe, which began in January with the recruitment of a Research Manager, Amelia Hursey. Amelia spent 2022 creating our first ever research strategy and Research

Steering Group (RSG), which has 11 members from all of our key stakeholder groups. Next year (2023) will see Parkinson's Europe work closely with the RSG and begin implementing our new strategy.

## 5 Advocacy

Parkinson's Europe, supported by its Political Advocacy Group (PAG – a working group including members of the Parkinson's Europe Board and representatives from our Member Organisations, who meet regularly to agree on actions regarding the Parkinson's Europe political advocacy strategy), focused on five ongoing campaigns at European Union (EU) level in 2022: **pesticides** and Parkinson's; the EU action on **non-communicable diseases**; the revision of the EU **pharmaceutical legislation**; educating and influencing EU decision makers on

the urgent need to do more about Parkinson's; and ensuring that the EU's future initiative on neurological diseases focuses on Parkinson's.

Parkinson's Europe continued to work with the European Federation of Neurological Associations (**EFNA**), which has recently supported the World Health Organisation (**WHO**) on its Technical Report on Parkinson's, and has created momentum at EU level to directly tackle Parkinson's.

## 6 2023 World Parkinson Congress

Ahead of this event, which is being held in Barcelona in July 2023, we forged closer relations with its organisers, the World Parkinson Coalition. Parkinson's Europe's Director General, Russell Patten, was appointed as co-chair of the 2023 WPC Leadership Forum.

The 2023 WPC will see the launch of a Political Manifesto – developed by the **WPC Leadership Forum**

thanks to Russell's lead – which will call on all political leaders to tackle Parkinson's head on.

In addition, Parkinson's Europe has been an active partner in four themed initiatives ahead of the WPC. These are: the Anti-Stigma Working Group; the Young-onset Parkinson's (YOPD) Working Group; the Clinical Trials Working Group; and the Technology Working Group.



## 7 The Innovation Lab – an immersion into Parkinson's creativity

In July 2022, Parkinson's Europe held a two-day **Innovation Lab** at the Market Hall in Devonport, Plymouth, UK – a new centre for immersive technology with a state of the art, "first in Europe" immersive dome.

The Innovation Lab brought together artists with Parkinson's, neurologists and technologists to explore the potential of immersive digital technologies to

communicate, develop and enhance the 'creative burst' experienced by people with Parkinson's – with the ultimate aim of creating an immersive experience that would act as a tool to raise awareness, inspire and encourage exploration of Parkinson's creativity.

For more information, visit our **Parkinson's Creativity page**

## 8 International congresses

Parkinson's Europe Team and Board members attended a number of high-profile international congresses and conferences, raising the profile of Parkinson's Europe and awareness of Parkinson's research, symptoms, treatment and management.

Key highlights include Team and Board members who were chairs and speakers at the International Association of Parkinsonism and Related Disorders (**IAPRD**) Congress, the **European Academy of Neurology (EAN) Congress**, and **Clinical Trials Europe**.

## 9 Governance

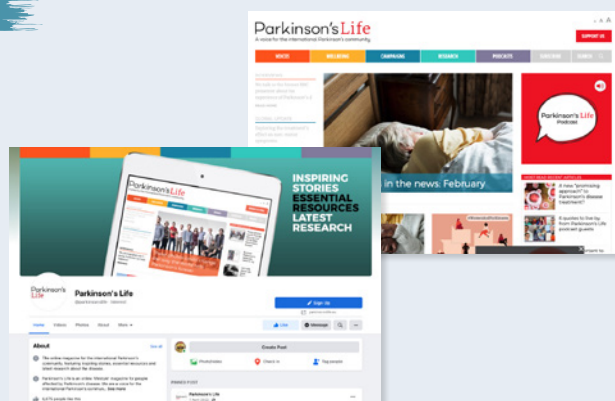
Parkinson's Europe recruited four new Board observers in 2022, all of whom hope to be elected as full Board members by the Parkinson's Europe General Assembly in June 2023. They are: **Andy Butler (UK)**, of support group Parkinson's

People; **Brian Magennis (Ireland)**, Parkinson's nurse specialist; **Barbara Morandi (Italy)**, collaborator of the Comitato Italiano Associazioni Parkinson; **Karl Wouters (Belgium)**, Board member of of Vlaamse Parkinson Liga.

## 10 Digital communication

In 2022, Parkinson's Europe contracted a new Social Media Consultant, Laura Vickers-Green, and consolidated our presence on different social media platforms – with a view to developing an enhanced social media strategy for 2023.

The readership of our online magazine Parkinson's Life has continued to grow, with more than 180,000 readers from 230 countries.



## 11 Membership

One new Parkinson's Europe Member Organisation, Parkinson Youngster (Germany), was approved by the General Assembly in November.

## 12 Grants

Three projects that received a Parkinson's Europe grant in 2021 were completed by our Member Organisations in:

- **Malta** – Malta Parkinson's developed a specialised Parkinson's training programme for healthcare professionals
- **Portugal** – Associação Portuguesa de Doentes de Parkinson (APDPK) developed a post-COVID

exercise and socialising programme for people with Parkinson's, based on table tennis

- **Slovenia** – Društvo Trepetlika created a prep school for people newly diagnosed with Parkinson's, their caregivers and relatives.

Our 2022-23 Parkinson's Europe grants will be focused on helping representatives of our Member Organisations attend the World Parkinson Congress (WPC) in Barcelona in July 2023.

## 13 Funding partnerships

In 2022, Parkinson's Europe secured 16 funding partners, including Diamond partners AbbVie, Boston Scientific, Britannia Pharmaceuticals and Merz Therapeutics.

Co-created projects included: reviewing and developing the MY PD-CARE symptoms monitoring tool (with AbbVie); disseminating the results of the 2021 survey on advanced Parkinson's awareness and information (with Britannia Pharmaceuticals); disseminating the results of our 2020 survey on sialorrhea in Parkinson's (with Merz); and supporting the trial of a digital app for music therapy (with Air Liquide).

**Parkinson's Europe would like to sincerely thank our treatment industry partners for providing funding and support to our activities in 2022.**

For more information about all of Parkinson's Europe's partners, please visit our partners webpage.



Parkinson's Europe sialorrhea survey report, supported by Merz Therapeutics



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