

# Parkinson's Europe 2024 highlights report

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## Our new four-year strategy (2025–2028)

In 2024, we were at the end of our previous (2019–2024) strategy window. Through evaluating all the data we had collected about the needs and wants of our stakeholders, we decided a significant overhaul of the old strategy was needed. The purpose was to really focus and deliver on what our stakeholders had told us they wanted.

The new strategy development started in February 2024, but the collection and review of supporting data had been ongoing since 2022, and involved internal and external stakeholders from the Parkinson's community. We regularly consulted our Board and Member Organisations during the creation of the strategy to check if it was fit for purpose, and incorporated their needs and ambitions.

Our new four-year strategy was launched in January 2025 and is available via [our website](#) in five languages.

**For more information about our strategy, please contact [amelia@parkinsonseurope.org](mailto:amelia@parkinsonseurope.org).**



## Global reach, engagement and collaboration

### World Parkinson's Day 2024

Every year, World Parkinson's Day (WPD) on 11 April provides us with a unique opportunity to capture the world's attention with a far greater impact than usual. As founders of World Parkinson's Day, we feel it's our responsibility to lead the way, creating one of the biggest campaigns globally to create awareness and shine a spotlight on the needs of people with Parkinson's – as well as supporting and amplifying our Member Organisations' campaigns to a wider audience.

We decided this year to create a campaign that would prolong this global impact far beyond WPD itself, using the day to launch a six-month campaign we called the [Parkinson's Summer of Sport](#). This campaign was about raising awareness of the benefits of exercise for people with Parkinson's, helping people to find an exercise that's right for them, and giving advice on overcoming exercise barriers.

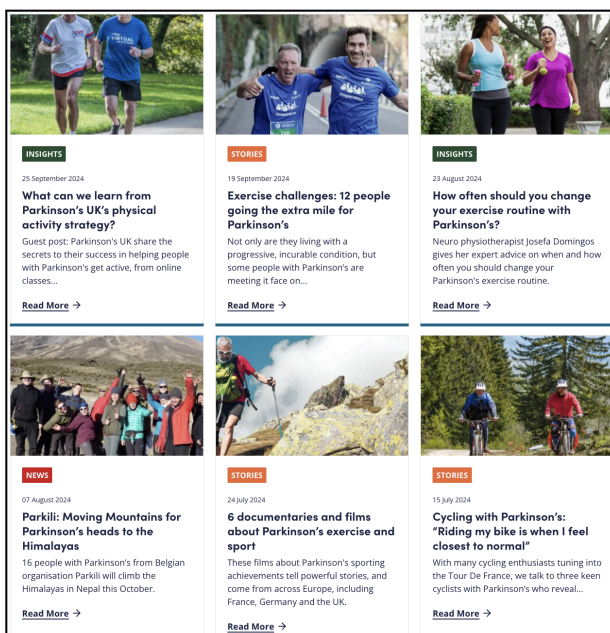
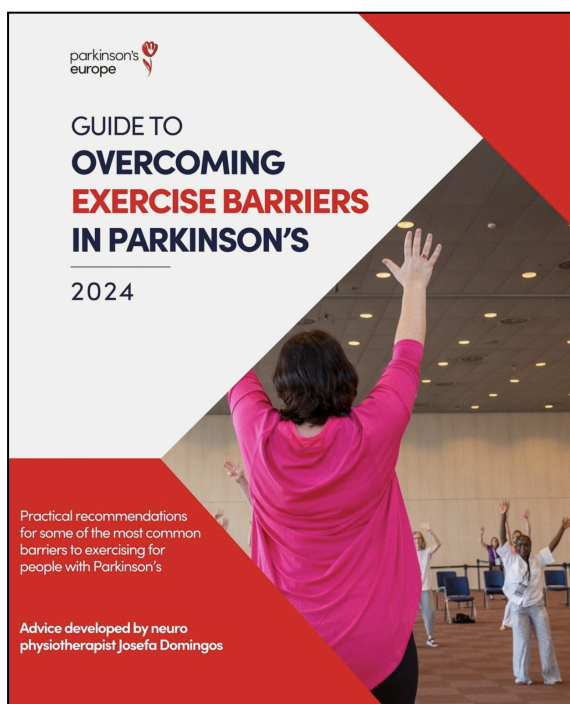
The Parkinson's Summer of Sport campaign ran from 11 April to mid-September 2024. It involved the participation of people with



Parkinson's from around the world, who contributed to our campaign videos, and were featured in articles and interviews in our online magazine [Parkinson's Life](#). Our members were involved in helping us source contributors to the campaign, and informed us of their WPD activities, which were shared via social media and via our [interactive map](#). Several volunteers helped us translate our free [exercise guide](#).

The campaign delivered great results:

- we provided our members with a downloadable exercise guide in nine languages, and gave them greater reach by listing their events on our interactive map and sharing their social media posts with our audience
- we helped people with Parkinson's raise the profile of their sporting initiatives across Europe and highlighted the need for organisations and policymakers to ensure people with Parkinson's have access to exercise initiatives
- we published more than 20 articles on Parkinson's Life, which attracted over 25,000 website views
- our exercise guide was downloaded more than 3,000 times
- we achieved 2.5 million impressions, 1.8 million video views and more than 40,000 engagements on social media
- more than 50 pins from 25 countries were added to our interactive map.



## Parkinson's Engagement Network

Parkinson's Europe recognised the need to reach more people across Europe in a strategic and constructive way, to share calls to action that would help us achieve our current and future strategic activities and support the many significant advancements for the Parkinson's community that are continually taking place in different areas. Built with financial support from our partner IQVIA and launched in December 2023, the PEN is an online network designed to involve people from Europe (and beyond) in Parkinson's-related activities. The PEN helps efficiently communicate opportunities for participation to people interested and helps get more people involved.

The PEN caters for all audiences – but mainly people with Parkinson's, caregivers and healthcare professionals. People who sign up to the PEN benefit by having opportunities they are interested in sent directly to them via email, according to their own interests and preferences.

External stakeholders who want to [share an opportunity](#) have access to a pool of people actively interested and engaged in the Parkinson's world. Those who want to [receive information and call-outs](#) benefit from receiving tailored communication that will enhance their knowledge and wellbeing. Additionally, they can help shape the future of how Parkinson's is managed and treated by actively engaging with our network.

By the end of 2024, the PEN had 600 [members](#) signed up. During the year, we shared 46 calls to action:

- 6 advocacy activities
- 9 research opportunities
- 11 webinars and workshops
- 6 wellness opportunities
- 14 sharing insights and knowledge activities.

## Our attendance at events, panels and symposiums

Attending international events, congresses, panels and symposiums has always been a key priority for Parkinson's Europe. Over the past few years, we have been invited to more activities meaning we have increased our involvement and visibility. This has enabled us to engage with a wider network of stakeholders and establish new and important strategic partnerships.

In 2024, our President Josefa Domingos, our Director General Russell Patten and our Strategic Director Amelia Hursey attended the following events:

- International Conference on Alzheimer's and Parkinson's Diseases and related neurological disorders (AD/PD), Lisbon, Portugal, March 2024 – attendee and speaker
- Ace Clinical Trials Summit, London, UK, March 2024 – speaker and session chair
- Digital Health @ Reuters Events: Pharma 2024, Barcelona, Spain, April 2024 – co-presenting session
- European Patients' Forum (EPF) Annual General Meeting, Brussels, Belgium, April 2024 – attendee
- Outsourcing in Clinical Trials (OCT) Europe, Barcelona, Spain, May 2024 – speaker and panelist
- International Association of Parkinsonism and Related Disorders (IAPRD) World Congress, Lisbon, Portugal, May 2024 – attendee
- Patient Engagement Open Forum (PEOF), Baveno, Italy, May 2024 – attendee
- Patients as Partners Europe, London, UK, May 2024 – attendees
- Congress of the European Academy of Neurology (EAN), Helsinki, Finland, June-July 2024 – attendee
- EUPATI Annual General Meeting, Brussels, Belgium, September 2024 – moderator

- International Congress of Parkinson's Disease and Movement Disorders (MDS), Philadelphia, USA, September–October 2024 – booth
- European Medicines Agency Accelerating Clinical Trials in the EU (ACT-EU) annual meeting, Amsterdam, the Netherlands, October 2024 – moderator
- Online Order and Home Delivery of Medicines (OnHOME) Alliance launch event, Brussels, Belgium, October 2024 – panelist
- First European Non-Pharmacological Intervention Society (NPIS) Forum, Brussels, Belgium, December 2024 – speaker

**For more information about our global reach and stakeholder engagement, please contact [jessie@parkinsonseurope.org](mailto:jessie@parkinsonseurope.org).**

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## Online communication: delivering information and boosting awareness

### Our new website

Following a major redesign project in the latter half of 2023, which included consulting a large number of people with Parkinson's (see our [2023 Highlights report](#) for details), our brand-new [website](#) went live in March 2024.

The new website allows our audience to benefit from:

- much improved navigation, helping people to find the information they need quickly;
- an [interactive map](#) for users to easily find Parkinson's events, organisations and initiatives in their country;
- a new and improved home for our online magazine [Parkinson's Life](#), with more regular articles, stories and podcasts;
- an exclusive Members area filled with useful tools and resources for our Member Organisations.

We have continued to add new features and updates to our website over the course of 2024. Results included:

- 300,000 views since the site launched, including users from every European country;
- a 91% engagement rate (which is a 57% increase on the old site);
- hundreds of new pins added to our map, including 50 for World Parkinson's Day covering 25 countries;
- 80 new articles on Parkinson's Life (an 80% increase on our pre-launch numbers), covering stories from 19 European countries (a 73% increase on last year).

We have plans for exciting new website features in 2025.

## Our increased social media presence

In 2024, we wanted to build on our success from 2023, where we grew our social audience by 20%. This is necessary in order to reach more people with Parkinson's who need help and information, to support our Member Organisations and partners in achieving a higher visibility, reach and impact – and to position Parkinson's Europe as a fundamental part of the digital Parkinson's community.

Throughout the year, people with Parkinson's and our Member Organisations provided moving, authentic and engaging stories for our campaigns and video content. Among others, we collaborated with artist Barbara Salsberg Mathews on her new book, [What Parkinson's Feels Like](#): we used social media and other channels to crowdsource contributions to the book, and we launched the book on our website and social media. It has had more than 600 downloads, and helped to raise thousands of pounds in charity donations.

We also worked with our treatment industry partners on important awareness campaigns on topics such as [DBS surgery](#), [OFF periods](#), and Parkinson's [care pathways](#).

In 2024 we achieved the following results on social media:

- Our social media audience has grown by 57% on our existing channels, to more than 43,000 across X, Facebook, Instagram, LinkedIn and YouTube.
- We have achieved more than 2,000 followers on our new platforms, Threads and Bluesky.
- Our impressions have increased by 828% to more than 12 million.
- Our engagements have increased by more than 250% to almost 250,000.
- We had our first viral post, on Instagram, a video that got more than 1 million views and 30,000 likes.

- Our Instagram video views have grown by more than 2,500%, to over 1.3 million.

Overall, our campaigns now have a much bigger impact, both for us and our partners, and a greatly increased reach and engagement. Our information is now reaching and helping more people with Parkinson's than ever, and establishing Parkinson's Europe as a key player on the global stage. We are now approached by more and larger figures and organisations to collaborate on social media, which is a sign of our greater influence on the Parkinson's community.

### **Our enhanced newsletter**

Our 2024 communications strategy has seen us growing our audience and engagement across every channel. We achieved the following results regarding our email marketing:

- We grew our general e-shot audience by 21% to over 4,100.
- We increased our open rate by 5% to almost 49%.
- We established a purpose-driven email campaign schedule, sending regular e-shots highlighting our core campaigns and top content.
- We redesigned our email templates in line with our new branding.
- We increased the visibility of our newsletter to expand our subscriber base – for instance adding a sign-up box on our website homepage, on relevant campaign landing pages, and on our LinkTree profile.

Further growing our email subscriber base will be a much more significant focus for our 2025 communications strategy.

**For more information about our communication activities, please contact [laura@parkinsonseurope.org](mailto:laura@parkinsonseurope.org).**

## Members outreach and support

We have worked hard to support our Member Organisations in 2024, and are pleased to say we've shared a very [productive year](#) with all of them.

A number of memorable events have been held by our members this year, and we have been proud to play a part in supporting them in different ways:

- [Parkinson Italia](#)'s *Parkinson's disease – strategies for the future* event took place in Rome, in March. The event focused on the challenges around Parkinson's management in Italy and Europe, as well as sharing Parkinson Italia's political advocacy activities. We used our Europe-wide partnerships to connect the organisation with relevant treatment industry companies in Italy, who were then invited to attend this successful event. Attendance was high, and we were also pleased to present information about Parkinson's Europe's work with Parkinson Italia at the event.
- We introduced our industry partner IQVIA to national Parkinson's organisations in Nordic countries at the start of the year. This led to a collaboration with [Cure4Parkinson](#) in Denmark, and in March, they began working together to develop collaborative health data and patient education projects. The work culminated in the successful [Folkemødet 2024](#) event in June. Cure4Parkinson founder Elisabeth Ildal was thrilled with the connection, saying: "Together, we're organising public policy events focused on raising awareness and addressing critical issues surrounding Parkinson's. Currently, we're analysing data from a unique perspective that involves patients, caregivers, and volunteers. We believe this new approach will provide important insights in the field."
- In autumn, we supported events such as Parkinson's UK's 2-day [Par-Con](#) and France Parkinson's first [Parlons Recherche](#) event,

promoting the events across our website, member e-shots and social media platforms. We also made a donation to [Društvo Trepetlika](#), helping the Slovenian organisation host the [Ping Pong Parkinson World Championship](#) in Laško in October. Društvo Trepetlika former President Cvetka Likar said: "I thank Parkinson's Europe. The event was extremely successful, to the satisfaction of all the competitors and companions present and us, the organisers."

While we are still looking into ways we can all connect in person for 2025, this year our Strategic Director [Amelia Hursey](#) was able to host some members for a networking dinner at the International Congress of Parkinson's Disease and Movement Disorders (MDS), Philadelphia, USA, in September. Parkinson's Europe President Josefa Domingos said: "The dinner provided an excellent opportunity for Parkinson's Europe to foster meaningful connections and engage in person in productive conversations with like-minded organisations and individuals." Guest John M Dean, Chair of the Allied Health Professionals Special Interest Group (AHPSIG), called the event "remarkable". He added: "I see a pressing need for more events like this—where these key stakeholders can engage in meaningful conversations about the important issues shaping Parkinson's research and care." France Parkinson Director of Science Marie Fuzzati enjoyed the opportunity to "discuss future actions to improve the lives of people living with Parkinson's" in an informal setting. Richelle Flanagan, inventor of the Parkinson's self-care app My Moves Matter, added: "I really enjoyed the Parkinson's Europe meal as it gave me a chance to meet colleagues and learn from each other's experiences from MDS."

Parkinson's Europe was pleased to welcome two new member organisations this year:

- [PAR.KIN.S.O.N.](#) (Greece)
- the [Catalan Parkinson's Association](#) (Spain)

Both organisations are keen to grow and collaborate with other European associations, and we look forward to working with them in the coming months. Laura Morer Benages, Director General of the Catalan Parkinson's Association, said: "Joining Parkinson's Europe this year has been one of our goals [as we start to] work with other organisations at a European level."

A new benefit of membership introduced in 2024 is an interview on Parkinson's Life, allowing new member organisations to introduce themselves, tell the story of their organisation, and share their work with the wider European Parkinson's community. Examples include our interviews with [PAR.KIN.S.O.N.](#), the [Catalan Parkinson's Association](#) and [Cure4Parkinson](#) in Denmark.

Finally, an exclusive members-only section launched on our new website in the spring. Members can now log in to access advocacy toolkits, exclusive travel discounts and more, and we will be adding some exciting new developments to this area in 2025.

**For more information about how we work with our Member Organisations, please contact [jessie@parkinsonseurope.org](mailto:jessie@parkinsonseurope.org).**

## Collaboration with the treatment industry

Parkinson's Europe has a 30-year history of positive and fruitful collaboration with the treatment industry – a key stakeholder in the Parkinson's community and a key player in the development of new treatments – and hopefully a cure – for Parkinson's.

We often engage in important mutually beneficial partnership projects with our industry partners. In 2023 and 2024, we were happy to lead a number of multi-company projects, which saw the collaboration of different Parkinson's Europe industry partners in the development of activities, content and resources to benefit the wider European Parkinson's community.

Parkinson's Europe would like to sincerely thank the following treatment industry partners for providing funding and support to our activities in 2024:

- Abbott
- AbbVie
- Bial
- Biogen
- Boston Scientific
- Britannia Pharmaceuticals
- Centogene
- Charco Neurotech
- ConvaTec
- Esteve
- Insightec
- IQVIA
- Lundbeck
- Medtronic
- Merz
- Nordic InfuCare
- Novartis
- Parexel
- Roche
- Servier
- UCB
- Zambon

For more information about our funding partners, please [visit here](#).

**For more information about the projects below and our collaboration with the industry, please contact [francesco@parkinsonseurope.org](mailto:francesco@parkinsonseurope.org).**

## Working group on device-assisted therapies

Device-assisted therapies (DATs) have proven effective in improving the quality of life of people with Parkinson's. Yet, testimonies and evidence increasingly tell us that not all people who may be suitable for these treatments receive them – which results in sub-optimal treatment and reduced quality of life for people with Parkinson's, their families and caregivers.

Understanding this challenge, in 2023 Parkinson's Europe had invited representatives of companies developing infusion pumps for levodopa, infusion pumps for apomorphine and deep brain stimulation devices to join a working group to a) explore common challenges and b) identify possible joint actions to improve people with Parkinson's engagement with – and access to – DATs.

The working group firstly identified, mapped and prioritised specific challenges and pinch points in the pathway from the development of a DAT product to its distribution – pointing out common challenges along the way and identifying those that are considered as a priority and which fall within the work remit of Parkinson's Europe. In 2024, the group worked together to develop a knowledge-sharing resource aimed at people with Parkinson's and their families to increase their awareness of DATs and empower them to discuss these therapy options with healthcare professionals. All members of the working group contributed their knowledge, expertise and available materials. An initial draft of this knowledge-sharing resource was developed in 2024, and will be launched in the first half of 2025.

The working group involves eight treatment industry companies.

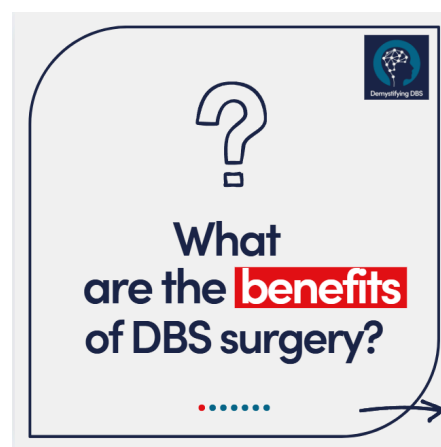
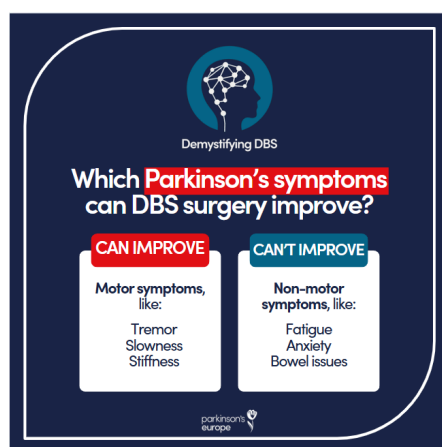
## Online campaign on deep brain stimulation and surgery

A survey conducted in 2022 on access to deep brain stimulation (DBS) identified fear and misconceptions about surgery as one of the main barriers preventing people with Parkinson's from considering DBS as a possible treatment option.

In 2024, we invited the three main DBS industry companies (Abbott, Boston Scientific and Medtronic) to support an online multimedia, multi-language campaign aimed at developing an honest, comprehensive and clear picture of the main aspects to take into account when considering DBS surgery. The campaign focuses on demystifying common fears and misconceptions but also on objectively considering common challenges and critical aspects – with the goal to empower people with Parkinson's to make more informed treatment choices.

In 2024, as part of the campaign we developed:

- a Parkinson's Life [article](#):
  - published in five languages
  - achieved more than 95,000 views
- a set of social media infographics
  - published in five languages
  - achieved nearly 8 million impressions and nearly 30,000 engagements
- a Parkinson's life [podcast](#) episode
  - achieved more than 600 downloads by the end of the year.



The campaign assets were published and disseminated via our website, newsletter and social media channels, and supported via paid promotion. Nearly 8 million impressions and a very high engagement rate make this the most successful Parkinson's Europe campaign so far. The campaign will continue in 2025 with the production of video testimonies, a social media quiz and a webinar.

## Online campaign on Parkinson's OFF periods

OFF periods are among the most important symptoms of Parkinson's, affecting the majority of people living with the condition and significantly impacting people's wellbeing and social life – as well as those of their family members and caregivers.

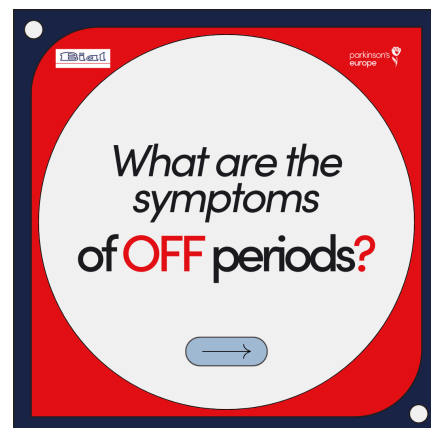
In late 2023 and early 2024, we launched an online awareness campaign supported by our industry partner Bial, aimed at raising awareness of the impact of Parkinson's OFF periods, informing people about how to recognise and anticipate them, as well as about available treatment options.

As part of this campaign, we developed:

- a Parkinson's Life [article](#)
- a set of social media infographics
- a set of video testimonials.

The campaign was very successful, with nearly 250,000 impressions and a very high engagement rate.

In 2024, we invited our industry partner companies Bial and Esteve to support an extension of the campaign, with the goal of translating the campaign content into several languages and further disseminating it to a broader European audience. The translated campaign assets were developed in 2024 and will be launched and disseminated in 2025.



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## **Information and awareness about disease-modifying therapies**

All Parkinson's treatments currently available are symptomatic. The topic of disease-modifying therapies (DMTs) is therefore of extreme interest and importance to the wider Parkinson's community, with several ongoing clinical trials and significant investments into this area being carried out by different companies.

In this context, it is fundamental for Parkinson's organisations to deliver a coherent narrative on the topic of DMTs to the Parkinson's community, to correctly inform people with Parkinson's and their families about the status of research and about the opportunities and challenges of DMTs currently in development.

In 2024, Parkinson's Europe worked with our industry partners UCB and Novartis around the development of an information and awareness campaign about DMTs. By being involved in several advisory boards and review activities (which involved other important international stakeholders such as Parkinson's UK and the Michael J Fox Foundation), we contributed extensively to the development of a clear and consistent narrative and set of main messages on the topic of DMTs for Parkinson's.

This important information will be translated and disseminated to the Parkinson's community, with the involvement of national Parkinson's organisations, as part of a multi-media awareness campaign in 2025.

## **Addressing barriers to care for people with advanced Parkinson's – call to action**

In January 2024, Parkinson's Europe and our industry partner AbbVie co-hosted a roundtable on the topic of care pathways for people with advanced Parkinson's. Expert panelists from different European countries – movement disorder specialists, nurses, researchers, people with

Parkinson's and representatives of Parkinson's organisations – gave insights about barriers and best practices around care pathways for advanced Parkinson's, highlighting gaps and common areas for improvement and identifying possible solutions. The main findings of this roundtable were published into a [report](#) and an [infographic](#).

Following the success of the roundtable, we have been working with AbbVie and other important stakeholders (the European Federation of Neurological Association, EFNA, and the International Parkinson and Movement Disorder Society European Section, MDS-ES) in the development of a [joint call to action](#) aimed at European policymakers – calling for a commitment to improving healthcare services for people with Parkinson's and a pledge to make progress in the following three key areas:

- the recruitment and retention of essential healthcare workforce
- the formalisation of neurodegenerative nurses in healthcare systems
- access to innovation to optimise healthcare resources.

**Addressing barriers to care for people with advanced Parkinson's**  
Results of the roundtable hosted by AbbVie and Parkinson's Europe in Jan. 2024

**OBJECTIVES**  
Collectively identify effective solutions to **improve advanced Parkinson's care pathways** to accelerate patients' access to the most suitable treatment option

**PARTICIPANTS**

- Movement disorder specialists
- Nurses
- Researchers
- People with Parkinson's and caregivers
- Representatives of Parkinson's organisations



Geographical scope was limited to countries in Europe where best practices had already been identified

**THE CHALLENGE**  
4 areas of improvement were identified

- Lack of delays in referral of people with advanced Parkinson's
- Inadequate **funding** or resources (ex. workforce capacity)
- **Geographical disparities** between and within countries
- Gaps in **patient home support systems**

**CALL TO ACTION**

**Enhancing Parkinson's Care in Europe**

Parkinson's is a progressive, neurodegenerative disorder affecting 1.2 million people in Europe, with this number expected to double by 2030. As the condition progresses, people with Parkinson's experience a decline in health, motor abilities, and quality of life, with most current treatments only managing symptoms through dopamine regulation.<sup>1</sup>

While initiatives such as the European Union's (EU) Belgian Presidency Health Workforce Strategy or the EU Non-Communicable Diseases Initiative represent significant steps towards improving Parkinson's care, research points to significant gaps in the healthcare provision of people with Parkinson's, particularly pronounced between rural and urban areas across Europe.<sup>2</sup>

The shortage of medical staff across the EU<sup>3</sup> leads to delays in diagnosis and treatment, with existing healthcare professionals lacking the capacity to manage the growing clinical burden.<sup>4</sup> Innovations in Parkinson's care, such as advanced therapies, require a well-trained multidisciplinary team – a resource that is often lacking in EU healthcare systems.<sup>5</sup> Additionally, neurodegenerative nurses, crucial for reducing referral times and hospital stays,<sup>6</sup> are not uniformly integrated across EU member states.<sup>7</sup> Moreover, data sharing practices, information about<sup>8</sup> and access to innovative therapies<sup>9</sup> and technologies like telemedicine<sup>10</sup> are not systematically adopted into standard care practices – even if these could optimise<sup>11</sup> healthcare resources<sup>12</sup>, improve patient outcomes<sup>13</sup>, and enable a more informed decision-making.<sup>14</sup>

September 2024, ALL-NEP-240202

The call to action was launched on 29 November 2024 (World Movement Disorders Day), and endorsed by 11 European Parkinson's organisations. In 2025, we will work on a series of awareness activities to leverage this call to action and call for better healthcare for people with Parkinson's in Europe.