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Parkinson's Europe

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Parkinson's Europe 2023 highlights report

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Please note: this document contains an overview of the most important and relevant highlights achieved by Parkinson's Europe in 2023; it does not cover exhaustively all the work carried out by the organisation. For more information about our work, please visit our [website](#) or contact info@parkinsonseurope.org.



Research: a new workstream

Research Steering Group

To make sure the new Parkinson's Europe [research strategy](#) truly reflects the voice of the Parkinson's community, we created a Research Steering Group (RSG) in Q3 2022. The group represents our key stakeholders (people affected by Parkinson's, healthcare professionals, Parkinson's Europe Member Organisations and the treatment industry), and will focus and deliver on our research offer.

Research Strategy

The RSG's initial work was to guide the creation of the Parkinson's Europe Research Strategy, based on insights gathered from our Member Organisations and treatment industry partners about their patient involvement and engagement activities in the research space. The RSG then helped with the development and translation of the Research Strategy Executive Summary into nine languages.

The Research Strategy was then launched in Q2 2023 with a [new webpage](#) and a social media campaign, which achieved 11,500 impressions and 600 engagements.

Our Research Strategy will ensure all stakeholders have a clear understanding of Parkinson's Europe's aims and ambitions in the research space – and will be the foundation to deliver on our [Strategic Goal 4](#).

For more information about our activities on research, please contact amelia@parkinsonseurope.org.

Parkinson's Europe 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 (such as research, advocacy and knowledge sharing).

Having secured funding from CRO company IQVIA in 2023, we developed the technical infrastructure to make the Parkinson's Europe Engagement Network ([PEN](#)) possible. The PEN is an online network designed to connect people affected by Parkinson's with opportunities they can actively take part in that will impact their future. People who sign up to the PEN will benefit by having opportunities they are interested in sent directly to them via email, according to their own interests and preferences.

In the development phase, we involved our stakeholders when discussing how the PEN would function; we then connected with all our volunteers and friends (a mix of organisations and individuals) to support the alpha and beta phases of testing of the network.

The PEN was launched in December 2023, and we have been actively promoting engagement since then. Opportunities shared with the PEN members in the initial weeks had a very high rate of interest and participation – supporting the delivery of our [Strategic Goals 3 and 4](#).

For more information about the PEN, please contact amelia@parkinsonseurope.org.



Our advocacy activities at the European level

Campaign advocating for a ban of glyphosate

In 2023, the licence for the use of glyphosate – a herbicide associated with a perceived higher risk of developing Parkinson's – ended in the European Union (EU). A renewal process was started by a list of companies and led by the European Commission. To combat this plan, Parkinson's Europe started an advocacy campaign calling for the glyphosate licence not to be renewed for another 10 years. Instead, we asked that the licence be extended for only one year, to allow time to carry out further independent scientific research on glyphosate's safety.

Our [campaign](#) started in November 2023, involving a number of our Member Organisations and other Parkinson's organisations, as well as other pan-European organisations (including PAN Europe and EFNA) and important KOLs from the medical and scientific world. Our stakeholders joined a Parkinson's Europe-led pan-European campaign, and were provided information and lobbying materials that we developed such as information sheets, letter templates, social media content and press releases.

We also reached out to our online community via social media, news articles, press releases and social media infographics translated into six languages. The online campaign achieved:

- 31,000 impressions
- 1,800 engagements
- 175 new followers
- 1,100 visits to the Parkinson's Europe campaign webpage.

Although glyphosate was re-approved for 10 years in late November 2023 by the European Commission, we will continue our efforts to lobby against glyphosate and seek to involve more and a broader range of stakeholders. This campaign work supports our [Strategic Goals](#) 2 and 3.

Parkinson's Advocacy Group Forum

The treatment industry is a key stakeholder in the Parkinson's community, and we therefore acknowledge the need to involve industry representatives in our political advocacy work.

In October 2023, we launched the Parkinson's Advocacy Group (PAG) Forum, which brings together representatives of our Member Organisations as well as of our industry partners with the purpose of exploring political advocacy issues on which we could work together to find synergies and achieve win-win results for all parties.

The PAG Forum will be meeting regularly every three months. These meetings deliver great value both to Parkinson's Europe, our members and our industry partners, in support of our [Strategic Goal](#) 3.

For more information about our political advocacy activities, please contact russell@parkinsonseurope.org, fiona@parkinsonseurope.org or adrien@parkinsonseurope.org.



Our global reach, engagement and collaboration

World Parkinson's Day 2023

World Parkinson's Day (WPD) is one of Parkinson's Europe's key focuses, and for 2023 our key campaign objectives were:

1. To support members and the wider Parkinson's community to raise awareness of Parkinson's via their own campaigns and activities
2. To showcase and promote campaigns across the globe on our online map and social media campaign
3. To gain support for World Parkinson's Day to be officially recognised and observed as a global health day.

With our 2023 campaign, we aimed to primarily reach and engage with local, national, regional and international Parkinson's organisations, as well as with global health organisations (such as the World Health Organisation, WHO). In addition, we also targeted individuals affected by Parkinson's, influencers, the academic world and the industry.

We consistently involved and supported our Member Organisations throughout the planning and development of the campaign by:

- producing a [campaign toolkit](#)
- organising a communications workshop
- adding our Members' events to our online WPD map.

On an individual level, anyone from the Parkinson's community was able to join our call to raise the profile and increase the recognition of WPD across the world.

We produced a wide array of campaign communication materials (meeting updates, e-shots, social media posts, website updates, [articles](#)) to make sure all our partners and Members were aware of our plans and how to get involved. Our Members and all organisations involved benefited by having a platform to amplify their campaigns, which helped increase awareness of Parkinson's in general – consistently with our [Strategic Goals 2 and 3](#).

The figures below show the wide reach and engagement of our campaign:

- 90 events recorded from 40 countries
- 1,000+ supported us to make WPD an official world health day
- [What does Parkinson's mean to me?](#) was the most viewed video ever for Parkinson's Europe
- 3,800 engagements on social media
- 355,000 impressions (1,430% increase compared with 2022)
- 350 new followers
- 5,000 visitors to the Parkinson's Europe website
- 34,000 video views
- 340% increase in engagements.

World Parkinson Congress 2023

The World Parkinson Congress (WPC) is the only international Parkinson's congress. The 2023 edition was held in Barcelona, Spain, and it saw a very high participation from the European Parkinson's community – it was therefore a key event for Parkinson's Europe to attend and be actively engaged with.

Parkinson's Europe's key goals from participating in the WPC were:



1. Networking, engagement and increasing brand awareness
2. Scientific, research and working group input
3. Fundraising and engagement with the treatment industry
4. To develop an advocacy plan to shape political thinking and engagement.

We supported our Member Organisations to attend the WPC, providing a €1,000 grant to seven organisations.

Members of the Parkinson's Europe Team, including our Director General, were consistently involved in the WPC Leadership Forum and supporting Working Groups in the years leading up to the WPC, which meant that our organisation helped shape the Congress agenda and priority focus.

By attending the WPC, we achieved a significant level of engagement and interaction with all Parkinson's community stakeholders – which will help us deliver all our four [Strategic Goals](#):

- +350 followers, 169,000 impressions and 7,000 engagements to our social media campaign
- Dozens of individuals completed the 'Connect with us' forms at the Parkinson's Europe booth
- Engagement with 30 new Parkinson's organisations
- 15 meetings with treatment industry companies (pharmaceutical and technology)
- 150+ people attended our social networking event
- 4 poster presentations
- 1 prestigious Robin A Elliott Award for Outstanding Community Service awarded to Parkinson's Europe co-founder Lizzie Graham.

For more information about our global stakeholder engagement activities, please contact fiona@parkinsonseurope.org.

Online communication: delivering information and boosting Parkinson's awareness

Our new website

The Parkinson's Europe website had not had a major upgrade or restructure in several years, and we discovered it was no longer serving our audience in the best way – making it harder for users to find what they need, and affecting our SEO and traffic potential as a result.

As our website serves the whole Parkinson's community and is a key part of our organisation's brand and offering, we needed to develop a new platform to better meet the needs of our audience, increase our traffic, and help us communicate our core goals and campaigns in a more effective, up-to-date and impactful way.

The new website redevelopment kicked off in the summer of 2023, involving a web design agency, and launched in March 2024. Several of our industry partners sponsored this work and to whom we are most grateful.

Throughout the process, we carried out user surveys with people from the Parkinson's community and key stakeholders to understand what they would like from the new website.

Our website is crucial to our 4 [Strategic Goals](#), and the new website's core features have been designed to support and enhance all of them. The new platform will be easier to navigate, and will include new functionalities such as:

- An exclusive area for our Member Organisations to share resources and information
- An interactive map to help users find relevant events, initiatives, research and information in their country



- Integrating our online magazine Parkinson's Life into the new website.

Growing our social media presence

While enjoying a strong presence across all our core social media channels ([Twitter/X](#), [Facebook](#), [LinkedIn](#) and [Instagram](#)) for years, we wanted to accelerate our growth, engagement and overall impact on social media in 2023 to help us achieve all four [Strategic Goals](#) more widely, and deliver a positive impact by amplifying the voices and messages of people with Parkinson's, our Member Organisations and our industry partners.

Activity took off in early 2023 and is currently ongoing. It has so far seen the active participation of:

- people with Parkinson's, who helped us create several meaningful videos to help our key campaigns for the year
- our Member Organisations, who were involved in social media workshops and in our different awareness campaigns
- our industry partners, as we ran several successful partner campaigns on social media.

All these stakeholders received significant exposure and engagement thanks to Parkinson's Europe sharing their content to a growing and increasingly engaged audience.

Throughout 2023, our social media presence has grown significantly:

- our social media audience grew by 20% to 26,000 followers
- our post engagement grew by 167% to an average of 120 engagements per post (across our four main channels) compared with 2022
- our post impressions grew by 9% in 2023 despite spending significantly less on paid advertisements and posting less frequently than 2022 (according to our new 'quality over quantity' approach)
- for the first time, we consistently got more than 100 likes per post on Instagram, and also got our first two posts with more than 200 likes.

This growth has helped us boost our influence, as we were able to share and interact with key figures in 2023 such as the WHO (on World Parkinson's Day), Paul McCartney (during the WPC), and Jeremy Paxman. It also helped boost our brand visibility by developing a consistent visual brand identity on social media.

For more information about our communication work, please contact laura@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 that aim to benefit the wider European Parkinson's community. Below are two examples of successful projects we developed or concluded in 2023.

Parkinson's Europe would like to sincerely thank our treatment industry partners for providing funding and support to our activities in 2023. 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.**



Multi-company 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, Parkinson's Europe 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. The group subsequently agreed 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. This work will continue in 2024.

This project is successfully bringing together different stakeholders to collaborate and share knowledge and good practices from their existing work areas (consistent with our [Strategic Goal 2](#)). It also aims to develop information resources aimed at people with Parkinson's and their families (consistent with our [Strategic Goal 1](#)).

Survey on awareness of advanced Parkinson's and treatment options

Evidence and testimonies show that a significant number of people with Parkinson's may be at the advanced Parkinson's stage but are not gaining access to, or information about, appropriate available treatment options. Topics such as symptom progression and decline in the effectiveness of oral medication are not always discussed with healthcare professionals – potentially resulting in sub-optimal treatments and reduced quality of life.

In 2021, Parkinson's Europe (in collaboration with industry partner Britannia Pharmaceuticals) launched an online [multi-language survey](#) focused on advanced Parkinson's and awareness about treatment options.

The results showed, among other things, that people with Parkinson's experience variations in effects of oral medications, but lack expert advice. The full results were published in three scientific posters (presented at three international scientific congresses, in 2022 and 2023). In June 2023, a [report](#) aimed at the Parkinson's community was published and disseminated widely, helping to increase the knowledge and awareness (both among people with Parkinson's and healthcare professionals, consistent with our [Strategic Goals 1 and 3](#)) about advanced Parkinson's diagnosis, management and treatment options.

Although this project is now concluded, the results of this survey are being used to inform further work carried out around the topic of advanced Parkinson's and non-oral therapies.