

EPDA 2021 successes: at a glance

1

To advocate for people with Parkinson's and their families to get the right information at the right time throughout their Parkinson's journey

- ✓ Sleep and Parkinson's awareness campaign
- ✓ Parkinson's and creativity project
- ✓ Increased industry partnerships (reaching 20 partners in 2021)
- ✓ Numerous partnered projects:
 - survey on 'advanced' Parkinson's, in collaboration with Britannia Pharmaceuticals
 - webinar on DBS sensing technology, in collaboration with Medtronic
- **Dissemination of high-quality information about different aspects of living with the condition to the Parkinson's community**

2

To strive for healthcare systems where people with Parkinson's receive early and appropriate treatment and individualised care

- ✓ Ongoing partnership and collaboration with WPC 2023
- ✓ Virtual workshop meeting on healthcare professional education, in collaboration with Kyowa Kirin
- **Increased knowledge and awareness of Parkinson's in the medical/scientific community**

3

To raise awareness of the complexity of Parkinson's and the impact it has on people's quality of life

- ✓ Two EPDA advocacy workshops
- ✓ EFNA membership and involvement in the 'Healthier Together' initiative
- ✓ Establishment of a Political Advocacy Working Group
- ✓ Parkinson's perception survey with 50 key EU decision makers
- ✓ Response to the European Commission's public consultation on the revision of the EU general pharmaceutical legislation
- ✓ Bi-monthly advocacy newsletter
- **Increased awareness of the complexity of Parkinson's and the impact it has on people's quality of life**

4

To support the global Parkinson's community in the search for a cure

- ✓ Establishment of EPDA Research Interest Group
- ✓ Collaboration in the WPC clinical trials interest group – identifying the barriers to accessing and taking part in research and exploring solutions
- ✓ Two Patient Insights Workshop to involve people with Parkinson's in the early stages of the clinical trial design process, in collaboration with Servier
- **Increased involvement of the Parkinson's community in the planning and design of treatment research**

5

Governance

- ✓ Amending our Statutes to introduce new membership criteria, with amends voted by the Members in 2021
- ✓ Three new full Board members
- ✓ A new Project Support Assistant
- ✓ A new Research Manager (starting 2022)
- **Improved the governance and internal working methodology of the EPDA**

6

Membership

- ✓ EPDA membership strategy for 2022
- ✓ Change to membership criteria to achieve more inclusivity
- ✓ One communication workshop aimed at members
- ✓ Two Members' Meetings highlighting opportunities for increased collaboration with our members
- **Improved two-way communication between EPDA and MOs**
- **Development of EPDA-members partnered activities on topics that are fundamental for the European Parkinson's community**

EPDA 2021 successes report

Introduction

2021 has seen once again the COVID-19 pandemic to cause continued uncertainty, impacting the EPDA and our member organisations, as well as the Parkinson's community as a whole. In spite of this, the EPDA has been able to achieve a series of remarkable results that will pave the way for **important developments** in 2022 and onwards.

In 2021, we consolidated the process to substantially improve the EPDA's **internal governance** – completing the reform of our Statutes with a focus on increased **inclusivity**. We also acquired a new member organisation and consistently increased and improved our communication with, and among, our members.

We continued to strengthen our relationships with the treatment industry, achieving a record number of **funding partners** and expanding in particular our collaboration with digital medical technology companies, and conducting win-win partnered projects benefiting the Parkinson's community directly.

After a slow-down due to the pandemic, our EU **advocacy** strategy is now being fully implemented. We have also been developing new EPDA **strategic projects** that are set to be carried out over the next three years – with an increased focus on research and the wellbeing of people with Parkinson's.

We have enlarged and deepened our relations with **Parkinson's stakeholders** in the global context – especially with the World Parkinson Congress and PD Avengers.

The EPDA also developed some impressive **online resources** (produced both independently and in partnership with the treatment industry) to provide information and support to the Parkinson's community on topics such as sleep, exercise, and nutrition.

Finally, the EPDA would not be where it is today without its members and its Board members. The EPDA Team would like to thank the EPDA Board members for contributing with their expertise, advice, and commitment to the positive results of the activities we will now describe in the following pages.

2022 is set to be an eventful year and we feel more than ready to embrace the opportunities and also the challenges as our ground work has been set in 2021.

Governance

- **Statutes:**
 - Amendments were proposed and ratified by the Board and the AGM in June 2021 pertaining to membership categories
 - Three membership categories were established:
 - *Membership (Parkinson's) organisations*
 - Not for profit organisations based in any European country that represent a membership of people with Parkinson's and carers.
 - *Affiliate*
 - Not for profit organisations who have a special interest in Parkinson's, with no individual members.
 - *Friends*
 - For individuals, including people with Parkinson's, carers, healthcare professionals and other people with a particular interest in Parkinson's.
 - These changes allow for a greater inclusivity and enable the EPDA to benefit from the wealth of expertise and experience supplied by a wider membership.
 - Amends ratified at the EPDA AGM on 29 June 2021
- **Board:**
 - Three new full Board members (former observers) elected by the AGM to serve for the next three years:
 - Gary Boyle – Ireland
 - Antonella Moretti – Parkinson Italia
 - Patricia Pérez Libroero – Federación Española de Párkinson

Results

- A more inclusive EPDA, open to a more diverse membership
- Improved expertise and representation in the Board

Membership

- **One new member organisation** approved by the AGM in June 2021:
 - Egas Moniz – Cooperativa de Ensino Superior, CRL – Portugal
- Implementation of a **members grant scheme** and the awarding of the first three winners
- Launch of a **weekly members' e-shot**
- Creation of a **membership strategy** for 2022 – with a strong focus on replicating successful projects carried out by EPDA member organisations across different countries
- **Virtual meetings** held with 21 EPDA member organisations to discuss respective priorities, needs and areas for possible collaboration – involving the EPDA President and Vice-President, as well as the EPDA Director General and Membership Lead
- **Membership benefits:**
 - Development of a simple brochure
 - Design of a new website page

- Changes to **membership criteria** (see above) approved with a majority of votes by the EPDA AGM – amendment of the Affiliate Members category and introduction of the Friends category, aimed at individuals
- One exclusive **communications workshop** aimed at Members
- Dissemination of Parkinson Italia’s #UnmaskParkinsons **social media campaign**:
 - translation into seven languages
 - eight Member Organisations inspired by the EPDA to run the campaign in their own countries
- Two successful **members’ meetings**:
 - in times of COVID, we believed it was essential to work more closely with our members and highlight the fundamental work they do for the European Parkinson’s community
 - the two members’ meetings were held in virtual form and focused especially on:
 - developing opportunities for increased collaboration and sharing of good practices between the EPDA and our members
 - highlighting opportunities for our members’ to get involved in EPDA projects
 - showcasing examples of meaningful activities carried out by our members at national levels.

Results

- A more inclusive EPDA open to a more diverse membership
- Improved two-way communication between EPDA and Member Organisations
- Development of EPDA-member partnered activities on topics that are fundamental for the European Parkinson’s community

The EPDA would be delighted to hear about any initiatives from our members and partners that we could support, help advertise and promote, or advise on. If you need any help, please do get in touch and ask us!

Team improvements

- A new Finance Manager
- A new Projects Support Assistant
- A new Research Manager (starting January 2022)
- Team restructuring: **streamlining roles** for all Team members

Results

- Improved expertise within the Team
- Increased our capacity to better respond to members’ needs and also to engage in more projects in partnership with the treatment industry, and generally build relationships with the broader Parkinson’s community
- Smoother internal functioning

Treatment industry collaboration

- **Funding**
 - **6 Diamond partners:**
 - AbbVie
 - Boston Scientific
 - Britannia Pharmaceuticals
 - Kyowa Kirin
 - Merz Therapeutics
 - Sunovion
 - **5 Gold partners:**
 - Abbott
 - Air Liquide
 - BIAL
 - Medtronic
 - Servier
 - **5 Silver partners:**
 - Biogen
 - Roche
 - Theravance Biopharma
 - UCB
 - Zambon
 - **4 Tech partners:**
 - Charco Neurotech
 - ConvaTec
 - GE Healthcare
 - Orbit Health
 - **Foundations:**
 - Boston Scientific Foundation Europe
- Partnered projects include:
 - **Abbott:** development of a content campaign to raise awareness of the DBS options available to people with Parkinson's
 - **AbbVie:**
 - EPDA Board members supporting AbbVie in the development of its Parkinson's research investigations
 - EPDA Board members supporting AbbVie in the development of patient-focused information material
 - **Air Liquide:** carers' survey – dissemination of results in 2021
 - **Bial:**
 - collaboration with Bial on the dissemination of multimedia information materials and resources from the *Keep it ON* website and online Training Area
 - continuation of the *Keep ON Moving!* dual-task video exercise project in collaboration with Bial
 - **Britannia Pharmaceuticals:**
 - development of a content campaign to raise awareness of advanced Parkinson's management and treatment options
 - development of a survey on advanced Parkinson's therapies awareness and information

- **Kyowa Kirin:**
 - participation of the EPDA in an advisory panel on patient organisations' engagement, organised by Kyowa Kirin
 - development of a multimedia content campaign on wellbeing and the impact of the Coronavirus pandemic
 - development of a virtual workshop meeting on healthcare professional education
- **Medtronic:**
 - development of a webinar on DBS sensing technology
 - development of a content campaign to raise awareness of advancement in DBS technology
- **Merz:** survey on sialorrhea (drooling) in Parkinson's – dissemination of results and planning of 2022 information and awareness activities on sialorrhea
- **Servier:** organisation of a workshop with people with Parkinson's, carers and advocates in collaboration with Servier

Results

- Increased participation of the Parkinson's community (represented by the EPDA) in industry activities
- Ultimately, the development of better treatment, support and care solutions for people with Parkinson's

Research

- **Establishment of an EPDA Research Interest Group**
 - The Research Interest Group is open to all EPDA member organisations and partners that are interested and passionate in becoming more active in Parkinson's research regardless of experience, skills, or knowledge.
 - The group's goal is to provide a friendly forum to discuss and identify research gaps and needs and equip and enable EPDA members to engage in research and clinical trials.
- **Successful delivery of two Patient Insight Workshops**
 - In March 2021, the EPDA collaborated with one of its Gold Partners (Servier) to run two virtual 'Patient Insight Workshops'.
 - The aim of the workshops was to involve people with Parkinson's in the very early stages of the clinical trial design process in order to provide research teams with new approaches and ideas.
 - Discussions focused on issues such as personalised therapy, improving communication with healthcare professionals, holistic approach to treatment, digital devices for monitoring Parkinson's, and a need to improve the efficacy and safety of existing symptomatic treatment.

Results

- Increased involvement of the Parkinson's community (represented by the EPDA, EPDA members and Parkinson's advocates) in the planning and design of treatment research
- Ultimately, the development of better treatment solutions for people with Parkinson's

Stakeholder engagement

- **EPDA participation in WPC working groups**

Six working groups set up by World Parkinson's Coalition Partners are developing a series of themed initiatives for the World Parkinson's Congress 2023. In 2021, various members of the EPDA Board and staff participated in four of the working groups and supported the delivery of a virtual presentation at the WPC Leadership Forum in June 2021.
- **Young-onset Parkinson's (YOPD) Working Group:** this working group is co-chaired by Russell Patten (EPDA Director General) and Gaynor Edwards and supported by Adrien Moyroud (EPDA Project Support Assistant). The group is focused on developing a global survey for YOPD called PROMISE (Patient Research On Medication, Information, Symptoms & Experience). It has also created sub-groups to focus on genetics and women.
- **WPC Clinical Trials Working Group:** in 2021, Fiona Montague (EPDA Project Manager) and Dominic Graham (EPDA Operations Director) represented EPDA on the WPC Clinical Trials working group. The group has focused on identifying the barriers to accessing and taking part in research and exploring solutions with the aim of engaging more people with Parkinson's in clinical research, and ensuring that each research opportunity is a good experience for all involved – regardless of the outcomes of the study. EPDA supported this work by surveying its member organisations to better understand the barriers to accessing and participating in research in different territories. The survey results were followed up by focus group discussions, which, in turn, led to the creation of the EPDA Research Interest Group (see above).
- **WPC Newly Diagnosed Working Group:** in 2021, Francesco De Renzis (EPDA Project Officer) represented the EPDA on the WPC Newly Diagnosed Working Group. The group has focused on identifying the barriers preventing people who are diagnosed with Parkinson's to engage with and seek support from Parkinson's patient organisations. The EPDA interviewed some of the EPDA members to gain a diverse, Europe-wide perspective on the topic. This resulted in identifying stigma as the main factor preventing people from seeking support; the group started exploring the possibility of developing an awareness campaign focused on stigma at a global level.
- **WPC Technology Working Group:** in 2021, EPDA President Veronica Clark represented the EPDA on the WPC Technology Working Group. The group goal is to explore existing technology that could improve life with Parkinson's and to promote innovative action, as well as to find areas of improvement that respond to unmet needs. The group is working towards developing a platform to increase access to technology services, and/or social networking that would

provide better levels of care and help link people with Parkinson's, healthcare professionals and other stakeholders to technology options available.

Results

- Our growing relationship with the WPC is critical given on the one hand their tremendous value and outreach to the Parkinson's community and on the other the World Parkinson Congress to be held in Europe, on our doorstep, in 2023. By actively participating in some of the leading Working Groups, we have increased our involvement with the Parkinson's community in the planning and design of treatment research, the development of better treatment solutions for people with Parkinson's and enhancing the awareness of YOPD.

Advocacy

- We ran **two workshops** that addressed why and how the EPDA needs to undertake political advocacy in EU-Brussels while also supporting actions carried out by EPDA members at national level.
- With our **membership of the European Federation of Neurological Associations (EFNA)**, we have raised the profile of neurological diseases (NDs) in EU-Brussels with the support of many like-minded patient groups and the WHO. This has led to the first ever EU targeted action on NCDs – the 'Healthier Together' initiative – which will focus on neurological diseases in particular, with dedicated EU and national level support and funding streams, in 2023.
- We have set up a new **Political Advocacy Working Group (WAGs)**, which will work with the EPDA Team to embark on an expanded scope of activities.
- We have completed an in-depth **political stakeholder mapping** of all our key decision makers by country, which will support our Member Organisations to work with EU decision makers in their respective countries and for the EPDA to build relationships with them in EU-Brussels.
- We have undertaken a **perception survey** which was carried out between September 2020 and September 2021 with 50 key EU-decision makers in Brussels on their perception/understanding of Parkinson's.
- We submitted a **response to the European Commission's public consultation on the revision of the EU general pharmaceutical legislation**, due at the end of 2022. In the response, we highlighted that the new legislation should allow the EU and member states to take action to address shortages and availability, not only during times of crisis but also in the long-run to address this serious on-going issue.

Results

- Raised the profile of the EPDA with policy-makers in the European institutions and with partner organisations
- Increased awareness of the complexity of Parkinson's and the impact it has on people's quality of life
- Ultimately, better policies and public interventions in support of people with Parkinson's, their families and carers

Sleep and Parkinson's awareness campaign

- **Overarching objective:** Provide and promote enhanced access and availability of sleep resources for people with Parkinson's, so they can make a more informed choice on how to improve their sleep.

Results

- The campaign was a success and resonated well with people with Parkinson's.
- Significant increase in engagement across all EPDA platforms as a result of the sleep content.
- Feedback by a large majority was that the campaign was timely, interesting and of interest.
- Involvement of several member organisations.
- Coverage and reach of key messages on electronic media
 - 3,000+ web page views in May 2021
 - Average reach for Facebook posts: 4,000+ in May 2021
 - Total tweet reach: more than 364,000 in May 2021
 - Parkinson's Life articles that resonated with readers
 - Successful TouchNEUROLOGY online seminar
- A full campaign evaluation document is available [here](#).

Digital communication

- *Keep ON Moving!* exercise video series 2 (created in collaboration with our partner, Bial)
- World Parkinson's Day 2021 video (created in collaboration with our partner, Bial)
- EPDA website
 - Traffic from more than 200 countries
 - High engagement to the About Parkinson's and Living Well sections
- Parkinson's Life
 - Parkinson's Life podcast awarded Gold Award for 'Best Branded Podcast' at the 2021 International Content Marketing Awards
- Social media channels
 - A new Instagram page set up in May 2021

Parkinson's and creativity

- In 2021, the EPDA embarked on a journey to develop a **3D immersive arts experience** that focuses on the link between the brain, Parkinson's and creativity.
- The goal of this project is to raise awareness, inspire and encourage exploration of **Parkinson's creativity**.
- The EPDA is partnering with a range of stakeholders including digital and interactive design specialists, artists, neurologists and researchers to deliver an online platform and immersive experience that all our stakeholders across Europe will have the opportunity to participate in.