

EPDA 2020 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

- ✓ Increased industry partnerships (reaching 20 partners in 2020)
- ✓ Numerous partnered projects:
 - *Keep ON Moving!* dual-task video exercise project, in collaboration with Bial
 - Survey on sialorrhea, in collaboration with Merz
- **Increased participation of the Parkinson's community (represented by the EPDA) in industry activities**

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 2022
- ✓ Presentation of abstract about the EPDA-Air Liquide survey on the challenges of Parkinson's carers at MDS 2020 virtual congress
- ✓ Advertisements and highlights on medical and scientific journals
- **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

- ✓ Preparing the EPDA outreach in the new EU landscape
- ✓ Mapping of stakeholders in EU institutions
- ✓ Decision-makers survey
- ✓ Hooks for future campaigning: carers, pesticides, access to medicines
- ✓ Involvement in the Brain, Mind and Pain EP intergroup
- ✓ 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

- ✓ Fulfilled a long-time collaboration as the main dissemination partner in the TreatER project led by Herantis Pharma
- ✓ Collaboration in the WPC clinical trials interest group: gathering information about the barriers and opportunities for Parkinson's communities interested in getting involved in research
- **Increased involvement of the Parkinson's community in the planning and design of treatment research**

5

Governance

- ✓ Completed the reform of our Statutes, with amends voted by the Members in 2020
- ✓ Three new full Board members and three new Board observers
- ✓ A new Project Manager
- ✓ A new Communications Lead
- **Improved the governance and internal working methodology of the EPDA**

6

Membership

- ✓ EPDA members' survey
- ✓ Completion of a set of guidelines aimed at Parkinson's organisations in the event of a shortage of medicines
- ✓ Involvement of 18 member organisations in the WPC clinical trials survey
- **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 2020 successes report

Introduction

2020 has been a very difficult year for the whole world, and in particular organisations working in the non-profit sector – including many EPDA member organisations – have been hit particularly hard by the COVID-19 pandemic. In spite of this, the EPDA has been able to adapt to the ‘new normal’ and achieve a series of accomplishments that, we believe, allow us to lay the foundations for a positive post-COVID-19 outlook.

In the past 12 months, we completed the process to substantially improve the EPDA’s internal governance – reforming our Statutes (with the help and collaboration of our Members), and striving for increased transparency and democracy. We also acquired new member organisations and started a process to improve and boost the two-way communication with our members – the first step being an important survey to better understand our members’ opinions, needs and challenges.

We have continued to develop our relationships with the treatment industry, securing a record number of funding partners going into 2021 and engaging in a number of win-win partnered projects that will benefit the Parkinson’s community – in many cases leading to better treatment options for people living with the condition.

We continued the roll-out of our EU advocacy strategy, and developed new EPDA strategic projects that are set to be carried out over the next four years.

Last but not least, we produced and delivered some impressive online resources (developed both independently and in partnership with the treatment industry) to provide support to the Parkinson’s community during the COVID-19 lockdown periods.

The EPDA Team would like to thank the EPDA Board members for contributing with their knowledge, expertise and constant commitment to the positive results of the projects and activities detailed below.

Governance

- Statutes:
 - Amendments proposed and discussed in late 2019, voted by Members in early 2020
 - Most proposed amends approved by a majority of the Members
 - Statutes changes ratified by the AGM in September 2020
 - Amendment procedure to be finalised in 2021
- Board:
 - A new President and Vice-President elected
 - Three new full Board members (former observers) elected by the AGM
 - Three new Board observers appointed in 2020

Results

- Increased transparency and democracy
- Smoother decision-making process and internal functioning
- Improved expertise and representation in the Board

EPDA strategy

- EPDA strategy reviewed by the EPDA Board at the end of 2020.
- Four strategic goals still fit for purpose:
 - a. To advocate for people with Parkinson's and their families to get the right information at the right time throughout their Parkinson's journey.
 - b. To strive for healthcare systems where people with Parkinson's receive early and appropriate treatment and individualised care.
 - c. To raise awareness of the complexity of Parkinson's and the impact it has on people's quality of life.
 - d. To support the global Parkinson's community in the search for a cure.
- Three new strategic themes for the next three years:
 - a. Uniting Europe
 - b. Big data
 - c. Research

Membership

- Three new member organisations approved by the AGM in 2020
- Member's survey
 - Most member organisations are 'satisfied' with being EPDA members
 - Most member organisations think the EPDA six-year strategy is fit for purpose
 - Most member organisations think the current level of communication with the EPDA is 'good' or 'excellent'

- Completion of a set of guidelines aimed at Parkinson’s organisations in the event of a shortage of medicines (this idea was initiated as a result of the panel discussion at the 2019 Members’ Meeting)
- Involvement of 18 member organisations in the WPC clinical trials survey, and eight in the subsequent in-depth conference calls
- Members’ Meeting 2020 (virtual): participation and engagement from 20 members
- Member-specific activities being planned for 2021:
 - Exclusive EPDA member virtual roundtable events
 - EPDA membership grant scheme

Results

- 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

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 Project Manager
- A new Communications Lead
- Team restructuring: increasing hours and streamlining roles and tasks for all Team members

Results

- Improved expertise within the Team
- Smoother internal functioning

EPDA exposure

- High-profile international congresses:
 - Continued partnership and collaboration with WPC 2022, which will lead to very exciting EPDA-led activities in 2021 and 2022
 - MDS 2020: presentation of abstract about the EPDA-Air Liquide survey on the challenges of Parkinson’s carers
 - INSIGHT into Parkinson’s 2020: presentation on the EPDA survey on the challenges of Parkinson’s carers
- Medical/scientific journals:
 - Advertisements and highlights from our website and the Parkinson’s Disease Composite Scale (*Oruen, touchNeurology*)

Results

- Increased knowledge and awareness of the EPDA and Parkinson's in the medical/scientific community
- Increased knowledge and awareness of the EPDA work in the Parkinson's community

Treatment industry collaboration

- Funding (including work done in 2020 that has led to partnerships in 2021).
Note: details below correct as at 8 February 2021
 - Diamond partners:
 - AbbVie (2020)
 - Boston Scientific (2020 and 2021)
 - Britannia Pharmaceuticals (2021)
 - Kyowa Kirin (2021)
 - Sunovion (2020 and 2021)
 - Gold partners:
 - Abbott (2021)
 - Air Liquide (2020 and 2021)
 - BIAL (2020 and 2021)
 - Medtronic (2020 and 2021)
 - Merz (2020 and 2021)
 - Servier (2021)
 - UCB (2020)
 - Silver partners:
 - Biogen (2021)
 - EverPharma (2020)
 - Servier (2020)
 - Theravance Biopharma (2021)
 - UCB (2021)
 - Zambon (2020 and 2021)
 - Tech partners:
 - GE Healthcare (2020)
 - Insightec (2020)
 - Other partners:
 - Herantis (2020)
 - Lundbeck (2020)
- 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
 - **Air Liquide:** carers' survey (dissemination of results in 2020 and 2021)
 - **Bial:** collaboration with BIAL on the *Keep it ON* video awareness campaign, developing a series of awareness videos involving people with Parkinson's from five European countries

- **Bial:** development 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 the non-oral treatment options available to people with Parkinson's
- **Herantis and TreatER:** EU-funded project concluded and results published in a virtual webinar held in November 2020
- **Kyowa Kirin:** participation of the EPDA in an advisory panel on patient organisations engagement organised by Kyowa Kirin
- **Medtronic:** support of Medtronic's new Percept device launch, and review of World Parkinson's Day awareness materials
- **Merz:** survey on sialorrhea in Parkinson's developed in collaboration with Merz (carried out in 2020, results expected in 2021)
- **Servier:** organisation of a workshop with people with Parkinson's, carers and advocates (preparation in 2020, virtual workshop to be held in 2021) in collaboration with Servier
- **Sunovion:** awareness communication campaign on Sunovion's clinical trial of sublingual apomorphine – developed in 2020, to be launched in early 2021

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

- TreatER project
 - Long-time collaboration with Herantis Pharma and lead academic universities
 - Started in 2017
 - Results presented at a virtual scientific conference in November 2020
- Sunovion CTH-302 trial
 - Collaboration with treatment company and research institutions in six European countries
 - Raising awareness of the clinical trial opportunities available to the Parkinson's community
- Servier clinical trial design
 - Involving the Parkinson's community in the guiding, planning, design and development of Servier's upcoming clinical trial
 - Organisation of a collaborative workshop with people with Parkinson's, carers and patient advocates
- WPC clinical trials interest group
 - Working with Parkinson's associations from around the world on surveys and conference calls in order to gather information about the

barriers and opportunities for Parkinson's communities interested in getting involved in research

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
- More inclusive, effective and patient-friendly clinical trials
- Ultimately, the development of better treatment solutions for people with Parkinson's

Advocacy

- 2020 was the year to prepare the ground for the EPDA's outreach for the next four years. A new EU came into power in 2020 and we have been assessing how they view health and indeed whether they know about Parkinson's.
- We are completing an in-depth political mapping of who's who in the Institutions directly but also indirectly influencing/impacting health policy. We have undertaken a decision-makers survey to assess their understanding of the disease and we have reached out to them to both introduce ourselves and to lay out our needs and asks.
- We have developed a number of hooks for future advocacy campaigning in EU-Brussels around the role of carers as a follow-up to the EPDA/Air Liquide survey; around the role of pesticides and their impact on Parkinson's, and most recently on the EU's review of the pharmaceutical industry which will be a on-going issue for the year to come, looking at, for example, equal access to medicines, shortages of medicines, and many other key topics
- The EPDA has been engaged closely with EFNA and played a role in developing their strategy for the Brain, Mind and Pain EP intergroup
- We have developed the EU-Brussels Political Advocacy bi-monthly newsletter aimed at member organisations and other EPDA stakeholders
- Ongoing support to the PD Avengers advocacy group throughout 2020 and into 2021

Results

- 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

Resources and digital communication

- Sleep and Parkinson's awareness campaign: initiated in Q4 2020 and to be launched in 2021
- EPDA ExerciseCast: our own online video exercise series for people with Parkinson's (which led directly to the incredibly successful *Keep ON Moving!* exercise video series we created in collaboration with our partner, Bial)
- #BrainLifeGoals: educational video for HCPs focusing on cognitive-motor exercise programmes
- EPDA website
 - Nearly 370,000 users and more than 850,000 page views
 - 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 'Best Global Audio Campaign of the Year' at the Global Content Awards 2020
 - Nearly 270,000 users and 400,000 page views
- EPDA strategic communications review – initiated in 2020, due to be finalised and implemented in 2021

Results

- Increased awareness of the complexity of Parkinson's and the impact it has on people's quality of life
- Delivery of high-quality information and resources to the Parkinson's community