

# EPDA 2019 successes: at a glance

2019 has been a hugely busy but also productive and successful year for the EPDA and our members. The infographic below will provide at a glance an overview of what we deem to be the **EPDA's milestones** for each of our strategic goals, and the accompanying report provides the details to substantiate the many deliverables and successes throughout the year.

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 17 partners for 2020), including numerous partnered projects such as the Air Liquide carers' survey (2019-2020)
- **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*

- ✓ Attended high-profile international congresses (WPC 2019 and MDS 2019)
- ✓ Collaborated on the PDCS with high-profile researchers and healthcare professionals (HCPs), with an ongoing roll-out with EPDA members (see page 3)
- ✓ Conducted a comprehensive survey specifically on carers' challenges leading to the publication of a scientific paper
- **Increased knowledge and awareness of Parkinson's in the medical/scientific community and ensured a stronger focus on carers from a healthcare policy perspective**

3

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

- ✓ Building on an event held at the European Parliament in 2018 to raise awareness of young onset (YOPD) and helped establish a working group uniting YOPD people from all Europe, ensuring higher attention and awareness about YOPD at national and European level
- ✓ Launched a wide-ranging advocacy campaign for greater recognition of Parkinson's in Europe
- **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*

- ✓ Established a long-time collaboration as the main dissemination partner in the TreatER project led by Herantis Pharma
- ✓ Started the development of a European Parkinson's clinical trials advisory council that aims to ensure more inclusive, effective and patient-friendly clinical trials
- **Increased involvement of the Parkinson's community in the planning and design of treatment research**

5

*Governance*

- ✓ Reformed our Statutes, increasing transparency and democracy, and ensuring a smoother decision-making process and internal functioning
- ✓ Recruited four new Board members since late 2018, improving expertise and representation in the EPDA Board
- **Improved the governance and internal working methodology of the EPDA**

6

*Membership*

- ✓ Supported members in their outreach, engagement and networking
- ✓ Increased country visits to member organisations, in order to improve two-way collaboration between EPDA and our members
- ✓ Development of EPDA-member partnered activities on topics that are fundamental for the European Parkinson's community
- **Secured buy-in, support and involvement from our member organisations**

# EPDA 2019 successes report

## Introduction

From late 2018 to early 2020, we managed to substantially improve the EPDA's internal governance – reforming our Statutes, with the collaboration of our Members, and striving for increased transparency and democracy.

We engaged in multiple activities in support of our member organisations, doing what we do best: creating connections and facilitating partnerships.

We have been constantly increasing the EPDA's exposure – for example, through our participation in important scientific conferences – thereby raising the profile of the European Parkinson's community and ultimately on Parkinson's itself, and creating occasions for new and dynamic partnerships with the treatment industry.

We dedicated a substantial amount of time and resources to issues such as young onset people with Parkinson's (YOPD), carers and supporting the search for a cure, as these issues are too often neglected at a European public health and decision-making level. And we plan to continue this trend in the years to come.

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

## Governance

- Statutes:
  - Clearer rules for a smoother functioning of the organisation
  - Increased transparency
  - Input and approval from our 30+ members
- Board:
  - Four new Board members since late 2018, bringing the total to 10

## Results

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

## Membership

- Support in outreach, engagement, networking
  - Spanish Parkinson's Federation (FEP) and WPC: EPDA contacting the WPC about FEP wanting to be involved in WPC 2022 planning.
  - Roche symposium in AAT-AD/PD 2020 for Parkinson's conference in Vienna: we were asked to chair a symposium and we put forward Josefa Domingos (Portugal).
  - Nominees for the EFNA development group traumatic brain injury and Parkinson's – from our outreach we put forward Patricia Pérez (Spain), Josefa Domingos (Portugal), Antonella Moretti (Italy) and Kadri Medijainen (Estonia)
  - Facilitating meetings and cooperation between Boston Scientific Italy and Parkinson Italia, which may turn into new collaborations and funding for our member organisation (2020)
  - Facilitating meetings between Boston Scientific and Parkinson's UK
  - FEP – Lundbeck introduction
  - EPDA involvement in project 'The Associative Movement of Neurodegenerative Diseases' by the Spanish Parkinson's Federation, which has been selected in the Projects for Reflection call of Obra Social 'la Caixa'.
  - European Parkinson Therapy Centre and survey on working life – the EPDA helped with the dissemination and translation of the survey by mobilising our networks and contacts. This helped increase outreach and gathering meaningful data
- Country visits
  - Portugal
  - Spain
  - Nordic Council meeting
  - Air Liquide workshop in Paris: Belgium, Czech Republic, France, Ireland, Italy, the Netherlands, Portugal, Slovenia, Sweden, Spain
- Members' Meeting 2019
  - New sessions with experts:
    - Clinical trials – developed into 2020 Clinical Trials panel, with involvement of 10 MOs representatives
    - Shortage of medicines – developed into 2020 guidelines

## Results

- Improved two-way collaboration 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 discuss 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!*

## EPDA exposure

- High-profile international congresses:
  - WPC 2019 and promising extensive collaboration for WPC 2022
  - MDS 2019, which lead to good contacts with healthcare professionals and industry funding opportunities
  - INSIGHT into Parkinson's 2019 – presentation on the EPDA history and the importance of unity
- Medical/scientific journals:
  - Advertisements and highlight of our website and the Parkinson's Disease Composite Scale (*Oruen, touchNeurology*)
  - Scientific articles about the Parkinson's Disease Composite Scale (*EJN, npj Parkinson's Disease*)

### Results

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

## Parkinson's Disease Composite Scale (PDCS)

- Successful conclusion of a long-term project
- Profitful collaboration with high-profile researchers and HCPs
- Publications in high-profile scientific journals:
  - *EMJ*
  - *EJN*
  - *npj Parkinson's Disease*
- Roll-out (2019-2020)

### Results

- Increased education of healthcare professionals about Parkinson's
- Improvements in patient consultations and delivery of care for people with Parkinson's

## European young-onset people with Parkinson's (EYOPD) working group

- Started with an important event at the European Parliament (2018)
- A working group uniting YOPD people from all Europe – involving 7 member organisations now (2019-2020) – leading to a number of important activities in 2019:

- A 2019 international awareness campaign (#UNITED) was inspired by 2018 EPDA events (EU event and meeting) and the #UniteForParkinsons campaign
- A conference on women and Parkinson's (2019)
- A conference on YOPD (2020 – unfortunately cancelled due to COVID-19)
- A research project on Parkinson's and working life (2019)

## Results

- Higher attention and awareness about YOPD at national and European level

## Carers

- A comprehensive survey specifically on carers' challenges
- A successful workshop with 19 people from all over Europe (people with Parkinson's, carers, healthcare professionals, experts): Belgium, Czech Republic, France, Ireland, Italy, the Netherlands, Portugal, Slovenia, Sweden, Spain
- Leading to promising results and significant exposure:
  - Abstract presented for 2020 MDS Congress
  - Scientific paper to be published in a peer-reviewed journal
  - Report will become important advocacy tool

## Results

- A stronger focus on carers from an advocacy and public health policy point of view

## Treatment industry collaboration

- Funding (work done in 2019 led to partnerships in 2020)
  - 5 Diamond partners:
    - AbbVie
    - Boston Scientific
    - BIAL
    - Kyowa Kirin
    - Sunovion
  - 5 Gold partners:
    - Abbott
    - Air Liquide
    - Medtronic
    - Merz
    - UCB
  - 6 Silver partners:
    - Biogen
    - EVER Neuro Pharma

- Lundbeck
  - Servier
  - Theravance Biopharma
  - Zambon
- long-term partners, ongoing positive relationships
- Partnered projects include:
  - Air Liquide carers' survey (2019-2020)
  - UCB survey (developed in 2018, but results published in 2019)
  - Herantis and TreatER (started in 2017, results expected in 2020)
  - Website section with information for healthcare professionals – developed with Lundbeck

## Results

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

## Research

- TreatER project
  - Long-time collaboration with Herantis Pharma and lead academic universities
  - Started in 2017, results expected in 2020
  - Scientific conference in November 2020
- European Parkinson's clinical trials advisory council
  - Involvement and support from important experts (Critical Path for Parkinson's/Parkinson's UK, The Cure Parkinson's Trust, The Michael J Fox Foundation)
  - Potential involvement of 10 member organisations, EPDA Board members and healthcare professionals
- Collaboration with The Michael J Fox Foundation (MJFF)
  - Participation in clinical trials panel at Members' Meeting 2019
  - Dissemination of MJFF information materials via EPDA website
- Sunovion CTH-302 trial
  - Collaboration with treatment company and research institutions in 6 European countries
  - Driving trial participation for the development of a new Parkinson's medicine
- 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

## 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

- Start of a wide-ranging advocacy campaign for greater recognition of Parkinson's in Europe
- Contact with key EPDA MEPs
- Interaction with the Brain, Mind and Pain EP intergroup

## 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

## Digital communication strategy

- Parkinson's Life:
  - Podcast: six episodes in 2019 about important topics: parenting, caring, creativity, consultations with healthcare professionals
  - Women and Parkinson's: an upbeat information/awareness campaign about how Parkinson's affects women specifically
- EPDA website
  - Page views: 94% increase from December 2018 to December 2019
  - Users: 65% increase from December 2018 to December 2019
  - New sections:
    - Clinical trials engagement
    - Resources for healthcare professionals
- Social media:
  - Facebook:
    - 44% increase in page views over the year
    - 20% increase in engagement over the year
  - Twitter:
    - 43% increase in impressions over the year
    - 182% increase in retweets over the year
- Information & Education posts: 65% increase in reach and 70% increase in engagement over the year