Charity Registration No. 8727/2000 (Belgium)

### EUROPEAN PARKINSON'S DISEASE ASSOCIATION ANNUAL REPORT AND UNAUDITED FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2018

### LEGAL AND ADMINISTRATIVE INFORMATION

Trustees Mr K J Onarheim

Ms S G M Lindvall Ms M E Graham Ms V Clark Mr D Lavender Ms V Buxton

**Executive Board** Ms M E Graham

Ms S G M Lindvall Mr K J Onarheim

Charity number (England and Wales) 1163211

Charity number (Belgium) 8727/2000

Independent examiner N J Wharton FCA

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### TRUSTEES' REPORT

### FOR THE YEAR ENDED 31 DECEMBER 2018

The Trustees present their report and financial statements for the year ended 31 December 2018.

The accounts have been prepared in accordance with the accounting policies set out in note 1 to the accounts and comply with the charity's trust deed, the Charities Act 2011 and the Statement of Recommended Practice, "Accounting and Reporting by Charities", issued in March 2005.

The trustees have complied with the duty in section 17(5) of the 2011 Charities Act to have due regard to guidance published by the Charity Commission (i.e. public benefit statement).

### Objectives and activities

Overview of the EPDA

The European Parkinson's Disease Association (EPDA) is the only European Parkinson's umbrella organisation.

We have been championing and working with the global Parkinson's community for more than 25 years. It represents national Parkinson's associations in nearly 30 countries across Europe and advocates for the rights and needs of more than 1.2 million people with Parkinson's and their families. The EPDA is a non-political, non-religious and not-for-profit organisation.

As the leading voice for Parkinson's in Europe, its mission is to provide information and resources to all Parkinson's stakeholders, raise awareness of the disease's complexities and impact, and advocate for concrete policy change that benefits the Parkinson's community.

The EPDA's vision is to enable all people with Parkinson's to live a full life, while supporting the search for a cure.

### TRUSTEES' REPORT (CONTINUED)

### FOR THE YEAR ENDED 31 DECEMBER 2018

### Objectives

The EPDA has four overarching strategic objectives:

### Goal 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.

### Goal 2

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

### Goal 3

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

### Goal 4

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

We hope to achieve these objectives (and therefore our mission and vision) through the following strategies:

### Engage

We engage and connect with the Parkinson's community across Europe and the globe to champion collaborations and partnerships, help develop solutions to unmet needs, and raise awareness of the impact of the disease with decision makers.

Visit www.epda.eu.com/get-involved

### Inform

We provide up-to-date information, research and resources for Parkinson's stakeholders to educate, advise and share good practices.

Visit www.epda.eu.com/about-parkinsons

### Unite

We represent national Parkinson's associations – that collectively have more than 120,000 members in nearly 30 countries across Europe – and advocate for the rights and needs of more than 1.2 million people with Parkinson's and their families.

Visit www.epda.eu.com/our-members

### Advocate

We provide an authoritative voice on the impact of Parkinson's across Europe and advocate for policy change that benefits the European Parkinson's community.

Visit www.epda.eu.com/get-involved/advocacy

The main objective of the charity during the year was to continue working towards the goals listed above.

The main strategies for achieving the charity's objectives for the year was by engagement, facilitation and utilisation of the communication strategy, advocacy activities and project development..

The Trustees have paid due regard to guidance issued by the Charity Commission in deciding what activities the charity should undertake.

### Activities

The EPDA had four key work streams in 2018, linked closely to our four key objectives (see above): information and education; advocacy; awareness raising; research.

### TRUSTEES' REPORT (CONTINUED)

### FOR THE YEAR ENDED 31 DECEMBER 2018

### Information and education

- The EPDA website (www.epda.eu.com)
- Our new website (launched April 2017) includes the largest online Parkinson's library in Europe. It
  includes comprehensive, up-to-date information on everything from diagnosis to end of life. Every piece
  of information has been thoroughly researched, reviewed and validated by European Parkinson's
  experts across the multidisciplinary team as well as people with Parkinson's and carers.
- Parkinson's Life (www.parkinsonslife.eu)
- Parkinson's Life is an award-winning online magazine for people affected by Parkinson's. Launched in 2015, it serves the global Parkinson's community by providing information and inspiration, and helps connect those impacted by the disease, wherever they are in the world.
- My PD Journey (www.mypdjourney.com)
- My PD Journey is an EPDA project that aims to develop solutions that contribute to comprehensive and individualised management of Parkinson's. Our current solution is the Parkinson's Disease Composite Scale – a new and simple clinical rating scale for Parkinson's.
- This simple new rating scale, to be used primarily by neurologists and other healthcare professionals, measures the severity of symptoms experienced by people with Parkinson's in a timely way. Designed to complement existing scales, the PDCS offers a comprehensive view of Parkinson's. It combines both motor symptoms and non-motor symptoms, as well as treatment-related complications.
- Data collection (www.epda.eu.com/get-involved/data-collection)
- In 2018, the EPDA, in partnership with long-term industry partner UCB, created a short online survey to better understand some of the issues people with Parkinson's and their families/carers across Europe face on a daily basis. Two thousand people from more than 20 countries took part in the survey. A report outlining the results of the survey was published in May 2019, and individual country-specific reports were shared with the relevant EPDA member organisations. The analysis of the answers will be used to inform advocacy and communication activities, and to design and propose solutions that can be used to campaign for improvements in healthcare management to enhance people's everyday quality of life.
- In late 2018 the EPDA, in partnership with the new industry partner Air Liquide, began to work on a new survey project; the goal of the survey is to understand the challenges carers of people with Parkinson's have to face. We aim to demonstrate the individual and societal cost consequences that caring has on individuals consequences that are often too ignored by governments and decision makers across Europe. The survey will develop throughout 2019, with the view to produce a report with results by the end of the year.

### Advocacy

- One of the EPDA's strategic aims is to increase political awareness of Parkinson's as a priority health challenge at the European and national levels, and build political support for concrete policy change.
- As such, the EPDA actively engages with European Union (EU) decision makers, partners and stakeholders to promote dialogue on policy gaps that negatively affect people with Parkinson's and their families, and to collectively advocate for long-lasting change.
- More specifically, our 2018 advocacy objectives were to:
- Gain political support to roll out the EPDA's new Parkinson's Disease composite Scale (PDCS) to measure Parkinson's symptoms.
- Secure political endorsement for or politicians' involvement in the PDCS roll out and the UniteforParkinsons online awareness campaign.
- Achieve greater recognition of the issues and challenges experienced by young onset people with Parkinson's.
- Build our member organisations' advocacy capacity to lobby by exploring with them new methods to support them in their local contexts.
   www.epda.eu.com/get-involved/advocacy

### TRUSTEES' REPORT (CONTINUED)

### FOR THE YEAR ENDED 31 DECEMBER 2018

### Awareness raising

- UniteForParkinsons
- This is an annual global online Parkinson's campaign, launched in 2017 and renewed for a second edition in 2018. It aims to raise awareness of Parkinson's around the world and to grow an active global Parkinson's community.
- In 2018, the #UniteForParkinsons hashtag was used 17,000 times from 97 countries, our campaign video was seen 18,000 times, and we created a staggering 880,000 social media engagements.
- www.epda.eu.com/get-involved/uniteforparkinsons
   The Parky Challenge
- The Parky Challenge is our fundraising campaign that encourages anyone and everyone no matter where they are in the world – to choose an exciting challenge that interests them and to then fundraise on behalf of the EPDA. The Parky Challenge began in 2015 as '100 Challenge' and is an ongoing EPDA activity.
- www.theparkychallenge.com

### Research

- EU-funded projects (TreatER)
- The EPDA receives many invitations every year to partner in European and EU-funded projects (run by academia and other stakeholders) that seek to improve the lives of people with Parkinson's and their families. Due to our limited resources, however, it is rarely possible for us to become a full partner in these sorts of projects; on average, we only accept such invitations once every three years. In addition to this, we provide several letters of support for EU-funded projects each year.
- The EU project we are currently partnering in is TreatER, which aims to conduct a first-in-human clinical study with intracerebrally administered CDNF protein in people with Parkinson's using a neurosurgically implanted drug delivery system (DDS).
   www.epda.eu.com/get-involved/european-projects

### Achievements and performance

The achievements of the charity during the year were as follows:-

### Website

- Our new website was successfully launched in April 2017 and was immediately met with positive reviews from many of our users.
- We successfully redesigned and restructured our multiple websites to work seamlessly within one easyto-use, modern and responsive platform to better support our overarching objectives.
- The new website has been reaching and helping new audiences across the world.
- Throughout 2018, the EPDA website had nearly 170,000 users and more than 400,000 page views.
- Most of the users were from the USA and the UK, with a general majority of accesses from Englishspeaking countries.

### Parkinson's Life

- Throughout 2018, Parkinson's Life received:
- nearly 202,296 visitors from 204 countries
- nearly 2,000 email subscribers, more than 5,000 Facebook followers and nearly 2,500 Twitter followers.

### TRUSTEES' REPORT (CONTINUED)

### FOR THE YEAR ENDED 31 DECEMBER 2018

### My PD Journey

- At the end of 2017, My PD Journey's main project the development of the Parkinson's Disease Composite Scale (PDCS) – was undergoing a second validation study involving 700 patients in 14 European countries across 22 centres.
- The first validation study (completed in 2016) concluded that the PDCS appears to be a feasible, acceptable, reproducible and valid scale. (Results of the first validation study on the Parkinson's Disease Composite Scale were published in the European Journal of Neurology in January 2018.
- The results of the second validation study, aimed at reaffirming the first study's findings, were published in April 2019 in the European Journal of Neurology.

### Advocacy

- The EPDA held a series of events in Brussels in October 2018 with the aim of advocating at EU level for greater recognition of young onset people with Parkinson's.
- MEP Rory Palmer hosted an exhibition in the European Parliament displaying the photography of Anders M. Leines which presented a powerful portrayal of what it means to live with Parkinson's as a younger person. The exhibition, This is Parkinson's, was on display from Monday 8 October until Friday 12 October and attracted many visitors. We also held a policy roundtable in the European Parliament where we heard from MEP Marian Harkin on the work being done at EU level to help those with neurological diseases find quality of life and paid work.
- Throughout 2018, the EPDA continued to work at an EU level to push its advocacy objectives as outlined above.

### Members

- The EPDA held its annual members meeting in November 2018 in the UK with more than 60 member representatives from 20+ organisations attending. This event:
- forms partnerships that directly benefit people with Parkinson's and their families
- highlights national and regional good practices at a European level
- provides a forum where Parkinson's-related organisations and individuals can work, share and innovate together
- promotes our members' activities to Parkinson's stakeholders across Europe.
- Visit www.epda.eu.com/our-members for more information.

### UniteForParkinsons

- In 2018, we wanted to build on the foundations of #UniteForParkinsons 2017 and create a bigger and better campaign. So, the EPDA and Parkinson's UK teamed up with Parkinson's organisations in Africa, Australia, India and the US, including the Michael J Fox Foundation and the World Parkinson Coalition to broaden the #UniteForParkinsons campaign scope and ambition. This time, we wanted to reach the general public and to turn #UniteForParkinsons into an impactful campaign to show the world what Parkinson's truly is.
- We did this by creating an official #UniteForParkinsons promotional film using emotive video footage from people all over the globe. The #UniteForParkinsons film was seen 18,000 times, and we created a staggering 880,000 social media engagements. The #UniteForParkinsons hashtag was used 17,000 times from 97 countries

The association continues to seek funding on an annual basis by external organisations and companies to enable the EPDA to maintain the organisation including: auditors, member organisation meeting, management, board meetings, administration, political advocacy and project development.

Due to the economic climate and restrictions in funding from Pharmaceutical companies it has been another difficult year to raise funding, and the association's total income has reduced by 31%.

In addition to providing non-restricted core funding, there are opportunities for companies to partner with the EPDA on individual projects, which are of mutual benefit to all concerned.

### TRUSTEES' REPORT (CONTINUED)

### FOR THE YEAR ENDED 31 DECEMBER 2018

The charity is reliant on external sources of funding mainly from the Pharmaceutical industry which is outside the control of the charity and constitutes the charity's principle risk. The trustees manage this risk by careful control of overheads and only carrying out projects when funding has been agreed to cover the anticipated costs.

### Financial review

The financial position of the charity is satisfactory but difficulties have been experienced over recent years in obtaining adequate levels of funding for the projects that it would like to undertake.

It is the policy of the charity that unrestricted funds which have not been designated for a specific use should be maintained at a level equivalent to between three and six month's expenditure. The Trustees considers that reserves at this level will ensure that, in the event of a significant drop in funding, they will be able to continue the charity's current activities while consideration is given to ways in which additional funds may be raised. This level of reserves has not been maintained throughout the year due to the difficulty in obtaining funding.

The Association is seeking to increase its reserves to cover 6 months annual running costs of the administration team. At the year-end date the balance on unrestricted reserves was £95,309. In addition, the Association held restricted reserves of £186,154 at the year-end date.

The principal sources of income is from membership organisation subscriptions and from funding from pharmaceutical companies in order to maintain the organisation including: auditors, member organisation meeting, management, board meetings, administration, website and project development.

In addition to providing non-restricted core funding, there are opportunities for companies to partner with the EPDA on individual projects, which are of mutual benefit to all concerned.

During the year the charity received funding from the following sources:-

Pharmaceutical Companies:

Abbott
AbbVie Biopharmaceuticals Sarl
Acorda Therapeutics
Air Liquide Healthcare
BIAL
Britannia Pharmaceuticals Ltd
Boston Scientific International SA
Ever Neuro Pharma GmbH
Herantis Pharma Plc.
Medtronic International Trading
Pfizer
UCB Biopharma SPR
Zambon SPA

Other:

Bionova

Fundraising events and general donations

The Trustees has assessed the major risks to which the charity is exposed, and are satisfied that systems are in place to mitigate exposure to the major risks.

### TRUSTEES' REPORT (CONTINUED)

### FOR THE YEAR ENDED 31 DECEMBER 2018

The level of funding for 2019 is expected to be maintained due to continued fundraising efforts. This will enable the association to continue the amount of projects undertaken in the year.

### Structure, governance and management

The charity was established by a charitable trust deed on 25 April 1998 in Belgium and registered as a Charitable Incorporated Organisation in the UK on 19 August 2015.

The Trustees who served during the year and up to the date of signature of the financial statements were:

Mr K J Onarheim

Ms S G M Lindvall

Ms M E Graham

Ms V Clark

Mr D Lavender

Ms V Buxton

### TRUSTEES' REPORT (CONTINUED)

### FOR THE YEAR ENDED 31 DECEMBER 2018

### **Administration Board Members**

The EPDA is administered by a Board of between five and ten members who are elected at the Members general assembly meeting for a term of three years. They may be re-elected by the Members meeting at the end of their term, for a further two terms of three years.

### Selection committee

In order to select potential EPDA Board nominees, the existing Board must appoint a selection committee that includes:

- one elected Board member
- one present-elected Board member if NOT standing for re-election (if all Board members are standing for re-election, the Board will select a alternative representative)
- one other chosen by the existing Board, normally the Executive Director
- a member organisation representative, who may or may not have Parkinson's.

The committee will search for and select nominations during the year immediately following the election of the present Board. It will then provide their written recommendation to the Board along with an evaluation of their discussions/communications with interested nominees.

### The existing board

It is the existing Board's responsibility to:

- confirm that the EPDA budget can support the full participation of the proposed number of Board members
- strive for the widest possible geographic representation by its Board members
- submit successful nominations to the General Assembly for ratification by the delegates.

### Nominees

### Nominees must:

- meet personally with the elected board
- be enthusiastic and committed individuals who are familiar with and have participated in the EPDA's work during the previous three years
- understand the importance of the EPDA's aims and objectives, and commit to furthering these during their term of office for the benefit of the members and those individuals that they represent
- be either a person with Parkinson's, carer, patient organisation representative or healthcare professional
- must reflect the geographic spread of the EPDA
- have been actively involved in pursuing their respective organisation's initiatives, achievements and goals for a period of no less than five years
- confirm that the organisation they represent has fully paid its EPDA membership fees in the current year and for the last five years
- attend board meetings as an observer (in the year of the election).

### General nominee requirements

### Nominees must:

- have the ability to work and communicate in English
- demonstrate communication skills with a variety of people from different cultural backgrounds
- be a good team player and appreciate the importance of partnership and working together
- act as an ambassador and advocate for the EPDA
- have the willingness to accept and handle responsibility within the Board structure, if required
- show motivation and commitment
- have a sense of humour
- be available to travel widely and attend EPDA meetings in person, if required
- be willing to devote the time required to attend or participate (via conference call facilities) the EPDA meetings
- have flexible working arrangements and be able to fit in with weekend meetings and mid-week telephone conference calls

### TRUSTEES' REPORT (CONTINUED)

### FOR THE YEAR ENDED 31 DECEMBER 2018

The charity's current policy concerning the payment of trade creditors is to:

- settle the terms of payment with suppliers when agreeing the terms of each transaction;
- ensure that suppliers are made aware of the terms of payment by inclusion of the relevant terms in contracts; and
- pay in accordance with the company's contractual and other legal obligations.

Trade creditors of the company at the year-end were equivalent to 138 day's purchases, based on the average daily amount invoiced by suppliers during the year. Trade creditors at the year-end included one supplier account amounting to £112,609 which had been issued late by the supplier. Excluding this invoice, the remaining trade creditors were equivalent to 54 day's purchases.

The day to day running of the Charity is carried out by the administration team under direct supervision of the management team i.e. Executive Director and Head of Operations.

On appointment, new trustees are provided with a welcome pack which includes a brief history of the charity, copy administration board minutes, a copy of the last three years of annual report and accounts, a copy of the governing trust deed and a copy of the Charity Commission's guidance "The Essential Trustee: What You Need to Know" and "Public Benefit: running a charity".

All trustees give their time freely and no trustee remuneration for the services rendered as trustee was paid in the year. Ms M E Graham, a trustee of the charity, receives payments for consultancy work in connection with her role as Executive Director.

Details of trustee expenses and related party transactions are disclosed in note 10 to the accounts.

The Trustees' report was approved by the Board of Trustees.

Ms M E Graham

Trustee

Dated: 11 July 2019

### INDEPENDENT EXAMINER'S REPORT

### TO THE TRUSTEES OF EUROPEAN PARKINSON'S DISEASE ASSOCIATION

I report to the Trustees on my examination of the financial statements of European Parkinson's Disease Association (the charity) for the year ended 31 December 2018.

### Responsibilities and basis of report

As the Trustees of the charity you are responsible for the preparation of the financial statements in accordance with the requirements of the Charities and Trustee Investment (Scotland) Act 2005 (the 2005 Act), the Charities Accounts (Scotland) Regulations 2006 (as amended) and the Charities Act 2011 (the 2011 Act). You are satisfied that your charity is not required by charity law to be audited and have chosen instead to have an independent examination.

I report in respect of my examination of the charity's financial statements carried out under section 44 (1) (c) of the 2005 Act and section 145 of the 2011 Act. In carrying out my examination I have followed the requirements of Regulation 11 of the Charities Accounts (Scotland) Regulations 2006 (as amended) and all the applicable Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

### Independent examiner's statement

Since the charity has prepared its accounts on an accruals basis and is also registered in Scotland your examiner must be a member of a body listed in Regulation 11(2) of the Charities Accounts (Scotland) Regulations 2006 (as amended). I confirm that I am qualified to undertake the examination because I am a member of The Institute of Chartered Accountants in England and Wales, which is one of the listed bodies.

Your attention is drawn to the fact that the charity has prepared financial statements in accordance with Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) in preference to the Accounting and Reporting by Charities: Statement of Recommended Practice issued on 1 April 2005 which is referred to in the extant regulations but has now been withdrawn.

I understand that this has been done in order for financial statements to provide a true and fair view in accordance with Generally Accepted Accounting Practice effective for reporting periods beginning on or after 1 January 2015.

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

- accounting records were not kept in respect of the charity as required by section 44 (1) (a) of the 2005 Act and Regulation 4 of the Charities Accounts (Scotland) Regulations 2006 (as amended) and section 130 of the 2011 Act; or
- 2 the financial statements do not accord with those records; or
- 3 the financial statements do not comply with the accounting requirements of Regulation 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended) and do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the financial statements to be reached.

N J Wharton FCA M J Read A4G Accountants Limited 1 Cobden Road Sevenoaks Kent

### INDEPENDENT EXAMINER'S REPORT (CONTINUED)

### TO THE TRUSTEES OF EUROPEAN PARKINSON'S DISEASE ASSOCIATION

TN13 3UB UK

Dated: 7 August 2019

### STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT

### FOR THE YEAR ENDED 31 DECEMBER 2018

,					
		Unrestricted	Restricted	Total	Total
		funds 2018	funds 2018	2018	2017
	Notes	2018 £	2018 £	2018 £	2017 £
Income and endowments from:	140103	~	~	~	~
Voluntary income	3	22,198	-	22,198	20,896
Charitable activities		,		10012001# 002028	60
Core income	4	260,492	132,995	393,487	577,176
Member organisation and board meetings	4	14,406	-	14,406	18,968
Publications	4	4,580	=	4,580	12,976
Investments	5	41		41	35
Other income	6	1,035	=	1,035	1,444
Total income		302,752	132,995	435,747	631,495
Expenditure on:			<del></del>	· <del>70/</del>	
Raising funds					
Charitable activities					
Grant funded projects	7	:	155,045	155,045	95,226
Member organisation and board meetings	7	56,146	-	56,146	53,849
Advocacy, communications and project					
development	7	278,544	-	278,544	252,115
Total charitable expenditure		334,690	155,045	489,735	401,190
Net (outgoing)/incoming resources before					
transfers		(31,938)	(22,050)	(53,988)	230,305
Gross transfers between funds		8,934	(8,934)	-	-
Net (expenditure)/income for the year/					
Net (outgoing)/incoming resources		(23,004)	(30,984)	(53,988)	230,305
Other recognised gains and losses					
Other gains or losses	12	(5,852)	· ·	(5,852)	(2,695)
Net movement in funds		(28,856)	(30,984)	(59,840)	227,610
Fund balances at 1 January 2018		124,165	217,138	341,303	113,693
Fund balances at 31 December 2018		95,309	186,154	281,463	341,303

The statement of financial activities includes all gains and losses recognised in the year.

All income and expenditure derive from continuing activities.

### **BALANCE SHEET**

### AS AT 31 DECEMBER 2018

	201	8	2017	
Notes	£	£	£	£
14	89,640		112,690	
	385,237		331,105	
	(1000)			
	474,877		443,795	
15	(193,414)		(102,492)	
	*	281 463		341,303
				0.17.100
16				217,138
		95,309		124,165
				0.44.000
		281,463		341,303
		Notes £  14 89,640 385,237 474,877  15 (193,414)	14 89,640 385,237 474,877 15 (193,414) 281,463	Notes £ £ £  14 89,640 112,690 385,237 331,105 443,795  15 (193,414) (102,492) 281,463 281,463

The financial statements were approved by the Trustees on 11 July 2019

Mr K J Onarheim **Trustee** 

Ms S G M Lindvall Trustee

### STATEMENT OF CASH FLOWS

### FOR THE YEAR ENDED 31 DECEMBER 2018

	Notes	2018 £	£	2017 £	£
Cash flows from operating activities Cash generated from operations	19		54,091		176,817
Investing activities Interest received		41		35	
Net cash generated from investing activities			41		35
Net cash used in financing activities			"E"		=
Net increase in cash and cash equival	ents		54,132		176,852
Cash and cash equivalents at beginning	of year		331,105		154,253
Cash and cash equivalents at end of y	ear		385,237		331,105
Relating to: Cash at bank and in hand			385,237		331,105

### NOTES TO THE FINANCIAL STATEMENTS

### FOR THE YEAR ENDED 31 DECEMBER 2018

### 1 Accounting policies

### **Charity information**

European Parkinson's Disease Association is a Charitable Incorporated Organisation registered in the UK on 19 August 2015.

### 1.1 Accounting convention

The accounts have been prepared in accordance with the charity's trust deed, the Charities Act 2011, the Charities and Trustee Investment (Scotland) Act 2005, the Charities Accounts (Scotland) Regulations 2006 (as amended) and "Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)" (as amended for accounting periods commencing from 1 January 2016). The charity is a Public Benefit Entity as defined by FRS 102.

The financial statements have departed from the Charities (Accounts and Reports) Regulations 2008 only to the extent required to provide a true and fair view. This departure has involved following the Statement of Recommended Practice for charities applying FRS 102 rather than the version of the Statement of Recommended Practice which is referred to in the Regulations but which has since been withdrawn.

The financial statements are prepared in sterling, which is the functional currency of the charity. Monetary amounts in these financial statements are rounded to the nearest £.

The financial statements have been prepared under the historical cost convention, modified to include the revaluation of freehold properties and to include investment properties and certain financial instruments at fair value. The principal accounting policies adopted are set out below.

### 1.2 Going concern

At the time of approving the financial statements, the Trustees have a reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future. Thus the Trustees continue to adopt the going concern basis of accounting in preparing the financial statements.

### 1.3 Charitable funds

Unrestricted funds are available for use at the discretion of the Trustees in furtherance of their charitable objectives unless the funds have been designated for other purposes.

Restricted funds are subject to specific conditions by donors as to how they may be used. The purposes and uses of the restricted funds are set out in the notes to the financial statements.

Endowment funds are subject to specific conditions by donors that the capital must be maintained by the charity.

### 1.4 Incoming resources

Income is recognised when the charity is legally entitled to it after any performance conditions have been met, the amounts can be measured reliably, and it is probable that income will be received.

Cash donations are recognised on receipt. Other donations are recognised once the charity has been notified of the donation, unless performance conditions require deferral of the amount. Income tax recoverable in relation to donations received under Gift Aid or deeds of covenant is recognised at the time of the donation.

Legacies are recognised on receipt or otherwise if the charity has been notified of an impending distribution, the amount is known, and receipt is expected. If the amount is not known, the legacy is treated as a contingent asset.

### NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

### FOR THE YEAR ENDED 31 DECEMBER 2018

### 1 Accounting policies

Turnover is measured at the fair value of the consideration received or receivable and represents amounts receivable for goods and services provided in the normal course of business, net of discounts, VAT and other sales related taxes.

### 1.5 Resources expended

All expenditure is accounted for on an accruals basis. All expenses including support costs and governance costs are allocated or apportioned to the applicable expenditure headings.

### 1.6 Cash and cash equivalents

Cash and cash equivalents include cash in hand, deposits held at call with banks, other short-term liquid investments with original maturities of three months or less, and bank overdrafts. Bank overdrafts are shown within borrowings in current liabilities.

### 1.7 Financial instruments

The charity has elected to apply the provisions of Section 11 'Basic Financial Instruments' and Section 12 'Other Financial Instruments Issues' of FRS 102 to all of its financial instruments.

Financial instruments are recognised in the charity's balance sheet when the charity becomes party to the contractual provisions of the instrument.

Financial assets and liabilities are offset, with the net amounts presented in the financial statements, when there is a legally enforceable right to set off the recognised amounts and there is an intention to settle on a net basis or to realise the asset and settle the liability simultaneously.

### Basic financial assets

Basic financial assets, which include debtors and cash and bank balances, are initially measured at transaction price including transaction costs and are subsequently carried at amortised cost using the effective interest method unless the arrangement constitutes a financing transaction, where the transaction is measured at the present value of the future receipts discounted at a market rate of interest. Financial assets classified as receivable within one year are not amortised.

### Basic financial liabilities

Basic financial liabilities, including creditors and bank loans are initially recognised at transaction price unless the arrangement constitutes a financing transaction, where the debt instrument is measured at the present value of the future payments discounted at a market rate of interest. Financial liabilities classified as payable within one year are not amortised.

Debt instruments are subsequently carried at amortised cost, using the effective interest rate method.

Trade creditors are obligations to pay for goods or services that have been acquired in the ordinary course of operations from suppliers. Amounts payable are classified as current liabilities if payment is due within one year or less. If not, they are presented as non-current liabilities. Trade creditors are recognised initially at transaction price and subsequently measured at amortised cost using the effective interest method.

### Derecognition of financial liabilities

Financial liabilities are derecognised when the charity's contractual obligations expire or are discharged or cancelled.

### NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

### FOR THE YEAR ENDED 31 DECEMBER 2018

### 1 Accounting policies

### 1.8 Employee benefits

The cost of any unused holiday entitlement is recognised in the period in which the employee's services are received

Termination benefits are recognised immediately as an expense when the charity is demonstrably committed to terminate the employment of an employee or to provide termination benefits.

### 1.9 Retirement benefits

Payments to defined contribution retirement benefit schemes are charged as an expense as they fall due.

### 1.10 Leases

Rentals payable under operating leases, including any lease incentives received, are charged as an expense on a straight line basis over the term of the relevant lease.

### 1.11 Foreign exchange

Transactions in currencies other than pounds sterling are recorded at the rates of exchange prevailing at the dates of the transactions. At each reporting end date, monetary assets and liabilities that are denominated in foreign currencies are retranslated at the rates prevailing on the reporting end date. Gains and losses arising on translation are included in net income/(expenditure for the period.

### 1.12 Irrecoverable VAT

Irrecoverable VAT is charged against the expenditure heading for which is was incurred.

### 2 Critical accounting estimates and judgements

In the application of the charity's accounting policies, the Trustees are required to make judgements, estimates and assumptions about the carrying amount of assets and liabilities that are not readily apparent from other sources. The estimates and associated assumptions are based on historical experience and other factors that are considered to be relevant. Actual results may differ from these estimates.

The estimates and underlying assumptions are reviewed on an ongoing basis. Revisions to accounting estimates are recognised in the period in which the estimate is revised where the revision affects only that period, or in the period of the revision and future periods where the revision affects both current and future periods.

### 3 Voluntary income

Unrestricted funds	Total
2018 £	2017 £
Donations and gifts 3,644 Membership fees 18,554	3,260 17,636

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

## FOR THE YEAR ENDED 31 DECEMBER 2018

### 4 Charitable activities

Total 2017	ćų	31,944 577,176 609,120	397,302 211,818 609,120	397,302 211,818 609,120
Total 2018	сų	18,986 393,487 412,473	279,478 132,995 412,473	
Publications	2018 £	4,580	4,580	12,976
Member organisation and board meetings	2018 £	14,406	14,406	18,968
Core income	2018 £	393,487	260,492 132,995 393,487	365,358 211,818 577,176
		Income within charitable activities Grants received	Analysis by fund Unrestricted funds Restricted funds	For the year ended 31 December 2017 Unrestricted funds Restricted funds

### NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

### FOR THE YEAR ENDED 31 DECEMBER 2018

5	Investments		
		Unrestricted funds	Total
		2018 £	2017 £
	Interest receivable	<u>41</u>	<u>35</u>
6	Other income		
		2018	2017
		£	£
	Costs recharged	1,035	1,444

### NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

### FOR THE YEAR ENDED 31 DECEMBER 2018

7	Charitable activities					
		Grant funded projects	Member organisation and board meetings	Advocacy, ommunications and project development	Total 2018	Total 2017
		2018 £	2018 £	2018 £	£	£
	Members meeting Administration board Project costs PDG think tank Website Publications Exhibitions External affairs Communications Social media Digital strategy Webinars Member organisation outreach GDPR	155,045	25,657 24,390 - 6,099 - - - - - - - - - - - - - - - - - -	15,660 58,241 1,795 94,535 8,430 9,244 17,702 - 6,885 8,733	25,657 24,390 155,045 6,099 15,660 58,241 1,795 94,535 8,430 9,244 17,702 - 6,885 8,733 	25,291 22,351 95,226 6,207 20,077 55,236 832 37,979 10,978 6,860 51,308 2,651 8,560
	Share of support costs (see note 9) Share of governance costs (see note 9)	- - - - - - - - - - - - - - - - - - -	- - - 56,146	49,663 7,656 ———————————————————————————————————	49,663 7,656 ———————————————————————————————————	52,018 5,616 
	Analysis by fund Unrestricted funds Restricted funds	155,045	56,146	278,544	334,690 155,045 489,735	305,964 95,226 401,190
	For the year ended 31 December 2017 Unrestricted funds Restricted funds	95,226 95,226	53,849	252,115 - 252,115		305,964 95,226 401,190

### NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

### FOR THE YEAR ENDED 31 DECEMBER 2018

### 8 Description of charitable activities

### Grant funded projects

Project costs for healthcare systems where people with Parkinson's receive early and appropriate treatment and individualised care.

### Member organisation and board meetings

Expenditure on the annual members organisation meeting to share good practices from around Europe and the world, particularly high-quality Parkinson's-specific initiatives, resources and information, re-appoint its administration board and other matters relating to the running of the organisation.

### Advocacy, communications and project development

To advocate for people with Parkinson's and their families to get the right information at the right time throughout their Parkinson's journey. Raising awareness of the complexities of Parkinson's and the impact it has on people's quality of life. This includes the website and online resources, Parkinson's Life online magazine, use of social media and the general running of the organisation.

### 9 Support costs

	Support Go costs	Support Governance 2018 2017 costs costs		Basis of allocation	
	£	£	£	£	
Staff costs	6,644	-	6,644	_	Time spent
Fundraising	5,351	12	5,351	8,564	Administration
Financial administration	13,679	-	13,679	16,338	Administration
General expenditure	12,649	-	12,649	5,855	Administration
Administration costs	10,587	-	10,587	20,904	Administration
Bank charges and interest	753	-	753	357	Administration
Independent examiners fee for external scrutiny	-	1,872	1,872	1,872	Governance
Independent examiners					Governance
fee for other services	<b>=</b> 2	5,784	5,784	3,744	
	49,663	7,656	57,319	57,634	
Analysed between					
Charitable activities	49,663	7,656	57,319	57,634	

### 10 Trustees

None of the Trustees (or any persons connected with them) received any remuneration during the year for their services as Trustees, but five of them were reimbursed a total of £23,877 travelling and other expenses (2017- three were reimbursed £16,821).

Ms M E Graham received fees totalling £33,852 in connection with her role as Executive Director and reimbursement of the organisations expenses of £21,162 (included above). The payments have been made in accordance with the charity's constitution and approved by the other trustees.

### NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

### FOR THE YEAR ENDED 31 DECEMBER 2018

11	Employees		
	Number of employees The average monthly number of employees during the year was:		
	The average monthly humber of employees during the year was.	2018 Number	2017 Number
		1	; <del>-</del>
		·····	
	Employment costs	2018 £	2017 £
	Wages and salaries	14,442	-
	Other pension costs	160	-
		14,602	-
		<u> </u>	
12	Other gains or losses	2018	2017
		£	£
	Foreign exchange losses	5,852	2,695
13	Financial instruments	2018 £	2017 £
	Carrying amount of financial assets	£	L
	Debt instruments measured at amortised cost	88,888	112,474
	Carrying amount of financial liabilities		
	Measured at amortised cost	193,414	102,492
14	Debtors		Windows (2000) 2007
	Amounts falling due within one year:	2018 £	2017 £
	Trade debtors	88,888	112,474
	Prepayments and accrued income	752 	216
		89,640	112,690

### NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

### FOR THE YEAR ENDED 31 DECEMBER 2018

15	Creditors: amounts falling due within one year		
	orounder announce ranning and retain one your	2018	2017
		£	£
	Trade creditors	185,378	96,876
	Other creditors	2,276	
	Accruals and deferred income	5,760	5,616
		193,414	102,492

### 16 Restricted funds

The income funds of the charity include restricted funds comprising the following unexpended balances of donations and grants held on trust for specific purposes:

	Movement in funds						
	Balance at 1 January 2018	Incoming Resources	Resources Expended	Transfer between funds	Balance at 31 December 2018		
	£	£	£	£	£		
My PD Journey	107,813	39,001	(95,699)	_	51,115		
Medtronic Information	6,853	450	(334)	(6,969)			
Parkinson's Information	2,823	9,244	(10,899)	-	1,168		
Global Campaign	3,951	29,450	(30,966)	(2,435)	-		
Herantis	(469)	-	=	469	_		
Data Collection	15,353	-	(2,855)	2=3	12,498		
Treat ER Herantis	80,814	12,636	(1,698)	_	91,752		
European Young Onset PD	-	42,215	(12,594)	-	29,621		
	217,138	132,996	(155,045)	(8,935)	186,154		
The Restricted fund project - My PD Journey, has been independently							

The Restricted fund project - My PD Journey, has been independently funded by the following donees:-

	2010	2017
	£	£
Abbvie Biopharmaceuticals Sarl	8,752	43,444
Boston Scientific International SA	4,584	2,704
UCB Biopharma SPRL	8,764	4,222
TEVA		8,962
Britannia Pharmaceuticals Ltd	=	4,222
Acorda Therapeutics	16,026	16,025
Others	875	1,695

2019

2017

### NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

### FOR THE YEAR ENDED 31 DECEMBER 2018

	Analysis of net assets between funds	Unrestricted	Restricted	Total	Total
		2018	2018	2018	2017
		£	£	£	£
	Fund balances at 31 December 2018 are represented by:				
	Current assets/(liabilities)	95,309	186,154	281,463	341,303
		95,309	186,154	281,463	341,303
18	Related party transactions				
	There were no disclosable related party transaction	tions during the year	(2017 - none).		
19					
19	Cash generated from operations			2018 £	2017 £
19	Cash generated from operations  (Deficit)/surplus for the year				1000 E 100
19	(Deficit)/surplus for the year Adjustments for:			£ (53,988)	£ 230,305
19	(Deficit)/surplus for the year  Adjustments for: Investment income recognised in statement of f	inancial activities		£ (53,988)	£ 230,305
19	(Deficit)/surplus for the year Adjustments for:	inancial activities		£ (53,988)	£ 230,305
19	(Deficit)/surplus for the year  Adjustments for: Investment income recognised in statement of f	inancial activities		£ (53,988)	£ 230,305
19	(Deficit)/surplus for the year  Adjustments for: Investment income recognised in statement of foreign exchange differences	inancial activities		£ (53,988)	£ 230,305
19	(Deficit)/surplus for the year  Adjustments for: Investment income recognised in statement of foreign exchange differences  Movements in working capital:	inancial activities		£ (53,988) (41) (5,852)	£ 230,305 (35) (2,695)

### INCOME AND EXPENDITURE ACCOUNT for the year ended 31 December 2018

	2018		2017	
	£	$\epsilon$	£	$\epsilon$
Income:				
Members fees	18,554	21,030	17,636	20,214
Donations	3,644	4,130	3,260	3,736
Core income	260,492	295,257	365,358	418,755
Project funding	132,995	150,744	211,818	242,775
Member Organisation Meeting	14,406	16,329	18,968	21,740
Costs recharged	1,035	1,173	1,444	1,655
Publications	4,580	5,191	12,976	14,872
Interest received	41	46	35	40
	435,747	493,900	631,495	723,787
Expenditure:				
Web site	15,660	17,750	20,077	23,011
Publications	58,241	66,014	55,236	63,309
Administration Board meetings	24,390	27,645	22,351	25,618
Member Organisation Meeting	25,657	29,081	25,291	28,987
Exhibition costs	1,795	2,035	832	954
External affairs	94,535	107,151	37,979	43,530
Communications	8,430	9,555	10,978	12,582
Social media	9,244	10,478	6,860	7,863
Digital strategy	17,702	20,064	51,308	58,807
Webinars	-	_	2,651	3,038
Member organisation outreach	6,885	7,804	8,560	9,811
PDG think tank	6,099	6,913	6,207	7,114
GDPR	8,733	9,898	-	-
General expenditure	12,649	14,337	5,855	6,711
Fundraising	5,351	6,065	8,564	9,816
Financial administration	13,679	15,505	16,338	18,726
My PD Journey	95,699	108,471	46,393	53,173
Medtronic Information	334	379	823	943
Parkinson's Information	10,899	12,354	9,554	10,950
Global campaign	30,966	35,099	27,205	31,181
Herantis		-	476	546
Data collection	2,855	3,236	1,250	1,433
Treat ER Herantis	1,698	1,925	9,525	10,917
European Young Onset PD	12,594	14,275		-
External examiner/Auditors' remuneration	7,656	8,678	5,616	6,437
Staff costs - support	6,644	7,531	10.50	-
Administration costs	10,587	12,000	20,904	23,959
(Profit)/Loss on foreign exchange	5,852	6,633	2,695	3,089
Bank charges and interest	753	853	357_	409
	495,587	561,729	403,885	462,914
NET CUDDI UC//DEFICITY	(50.940)	(67.920)	227.610	260,873
NET SURPLUS/(DEFICIT)	(59,840)	(67,829)	227,610	200,873
			F	

Conversion to  $\ensuremath{\varepsilon}$  at the average rate of exchange of

1.133458

1.1461502

### BALANCE SHEET for the year ended 31 December 2018

	2018		2017	
	£	€	£	$\epsilon$
Fixed assets:				
Tangible assets	10.	-		-
Current assets:				
Debtors	89,640	99,850	112,690	126,818
Cash at bank	385,237	429,114	331,105	372,616
	474,877	528,964	443,795	499,434
Creditors: amounts falling due within one year				
Creditors and accruals	193,414	215,443	102,492	115,342
Net assets	281,463	313,521	341,303	384,092
Reserves:				
Balance brought forward	341,303	384,092	113,693	134,638
Surplus/(deficit) for year	(59,840)	(67,829)	227,610	260,873
Exchange adjustment	45000000000000000000000000000000000000	(2,742)	·	(11,419)
Balance carried forward	281,463	313,521	341,303	384,092

Conversion to  $\ensuremath{\varepsilon}$  at the closing rate of exchange of

1.113896

1.1253721