

APPROVED MINUTES

Parkinson's UK Annual General Meeting

11.10am, 12 October 2019

etc. venues, County Hall, Riverside Building, Belvedere Road, London, SE1 7PB

PRESENT: please see Appendix 1.

Meeting Opening

1. Welcome and apologies for absence

- 1.1. Mark Goodridge, Chair of the Board, (MG) opened the meeting welcoming those attending at the venue and those accessing the meeting electronically at different venues in Newcastle, Stirling and Templepatrick and from home via the internet.
- 1.2. He confirmed that the attendance in the room of more than 50 members in person or by proxy met the requirement for the meeting to be quorate. He declared the formal part of the AGM open to transact the business required by the charity's Articles of Association.
- 1.3. Members had received notice of the business in advance of the meeting and copies of the agenda were available in the room. Unless there were any objections, MG proposed to take the notice of the meeting as read.

2. Chair's Report from the Board

- 2.1. MG said that normally the Chair's report would review the year to date. However, as 2019 was the fifth year of the charity's five-year strategy, he would reflect upon the charity's achievements during the past five years.
 - 2.2. In 2015 the charity had consulted people with Parkinson's, their partners, families and friends, obtaining the views of over 700 people on what would make the biggest difference to their experience of Parkinson's. The outcome of this consultation formed the basis of the five-year strategy, which comprised three pillars: finding 'Better Treatments
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and a Cure', providing 'Quality Services' and empowering people affected by Parkinson's, 'Taking Control'.

- 2.3. Consequently, the charity had invested more in research than previously to achieve better results and a cure, as well as pioneering a radical new approach through the Virtual Biotech programme designed to fill critical funding gaps preventing promising research discoveries quickly turning into real drugs on the market.
- 2.4. The charity had also co-funded and co-led the Critical Path for Parkinson's consortium with nine of the largest pharmaceutical companies in the world and with the European Medicines Agency (EMA) and the US Federal Drugs Agency. This had transformed the way influential regulatory authorities worked with the pharmaceutical industry to make clinical trials more cost-effective and likely to succeed. It led, in 2018, to the EMA backing a special brain scan for use in Parkinson's trials, which was now widely used, helping to select the right people to reduce the chance of trials failing.
- 2.5. The pioneering GDNF clinical trial delivered an experimental treatment directly to the brain and was reported on two BBC television programmes. While the results of the trial had not met the trial's stated target outcome, they were still encouraging. As a result the partners in the original trial were now seeking to establish the viability of a further trial.
- 2.6. In pursuit of the second strategic pillar, quality services, we set up the UK Parkinson's Excellence Network in 2015 to help address the 'postcode lottery' of clinical and social care. The Network involved more than 9,000 people affected by Parkinson's, had trained 15,000 professionals and had given 20,000 professionals access to tools and support to improve their treatment and care of people with Parkinson's. This had resulted in a 16 per cent increase in quality of care to date and an 11 per cent reduction in the gap between the highest- and lowest-rated services.
- 2.7. Via the Excellence Network the charity had worked with professionals to improve the diagnosis experience; within two years clinicians were signposting 84 percent of people to Parkinson's UK at diagnosis, an increase from barely 15 per cent in 2015.
- 2.8. The third pillar of the strategy was to empower people with Parkinson's to take control. The charity had introduced local peer support, providing opportunities to meet others living with Parkinson's. And, following a volunteer starting a 'Parkinson's Cafe' in Cardiff in 2015, the charity had supported the creation of 170 local cafes across the UK, providing informal support at evenings and weekends to hundreds of people with Parkinson's and their family and friends.
- 2.9. Financial security was a key element of feeling in control and so the charity had improved its UK-wide benefits and employment support. The specialist advice team, advocating on behalf of people with Parkinson's, had helped win 95 per cent of appeals and supported people affected by Parkinson's in accessing over £1m of benefits they were entitled to.
- 2.10. In addition, in 2018 the charity had launched a programme to offer grants to people with Parkinson's and their carers. The grants were partly funded by local groups and in 2018

trained volunteer panel members had awarded a total of £100,000 in grants to those in greatest need.

- 2.11. The three pillars of the strategy depended on two further things: membership and technology. The charity had developed Team Parkinson's to envirogate the charity's membership offer and, after a period of stagnation and decline in membership, had now seen 3,000 new members join the charity in the past year.
- 2.12. As a campaigning organisation, the charity campaigned to influence policymakers and since 2015 it had achieved 63 positive policy changes. In 2017 almost 34,000 people had petitioned the government to stop making people with Parkinson's go through a stressful and unnecessary process in order to receive essential benefits payments. As a result, people on the highest rate of Personal Independence Payments no longer had to go through an annual reassessment.
- 2.13. On the financial side of the charity's performance, there had been a dip in income in 2018, but 2017 had been an exceptional year in terms of income. MG acknowledged that these were economically and politically uncertain times and therefore the charity was adopting a cautious approach, preparing for volatility in income in the foreseeable future.
- 2.14. MG noted that while local group income had fallen in 2018 contributions to national programmes had remained stable. He thanked local groups for their ongoing contributions.
- 2.15. In 2018 the charity had maintained its spend on services, notwithstanding the drop in income. It had increased its spend on activities by £4.9m, the largest proportion being on activities aimed at Taking Control and these included local and helpline support, volunteer-led support programmes and raising awareness. The charity had increased spending on Better Treatments and a Cure by £2.5m to £10.5m and on Quality Services by £600k to £5.2m.
- 2.16. Fundraising activities had cost £7.5m. Support costs had accounted for 15 per cent of the charity's spend, which was around the average for the sector.
- 2.17. In summary, the accounts for the year showed that the charity was in a strong position and, while there was still much more to do, during the last five-year period the charity had become better at learning how it could improve: learning fast, failing fast and moving forward.
- 2.18. MG asked Steve Ford (SF), CEO, to speak to the charity's future ambitions. SF shared that the charity's ambitions for the next five years would build on its achievements in the previous five years. The 2020 strategy had been shaped by over 600 people affected by Parkinson's, Parkinson's UK staff, health professionals and donors. The overriding aim for the strategy was how the charity could make the biggest impact on the lives of people living with Parkinson's. Strategy objectives would be to accelerate breakthroughs in research, provide better support and get Parkinson's understood.

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- 2.19. The charity's Virtual Biotech programme was owned and shaped every step of the way by people with Parkinson's. It provided a speedier, more agile approach to research, investing only in the best ideas to deliver life-changing new treatments, partnering with leading researchers and innovators worldwide to get results faster.
- 2.20. To date the Virtual Biotech programme had funded one major new treatment which was now available in the UK and the charity's research grants had generate three new Virtual Biotech projects. 2,000 supporters and groups had made restricted donations totalling £2.5m to the Virtual Biotech portfolio, the commercial value of which had increased by 300 per cent. The charity's leadership had brought £10m in funding from other organisations to support research priorities, and influenced others to involve people living with Parkinson's.
- 2.21. By 2024 the charity would provide personalised information, services and opportunities to many more people affected by the condition. And the strengthened UK Parkinson's Excellence Network would enable the NHS to significantly improve the expert care and support on offer.
- 2.22. SF stated that the charity knew that the lack of awareness and understanding of Parkinson's made living with the condition that much harder. For this reason part of the new strategy was aimed at significantly increasing the public's understanding of Parkinson's, challenging myths about who got Parkinson's and educating the public, politicians and policymakers about its 40-plus symptoms and their impacts.
- 2.23. SF acknowledged that the number of people with Parkinson's would grow significantly in the next few years and more efficient ways of delivering support would have to be found, including better use of technology. The charity was helping to develop a new pathway to deliver services more efficiently and intended to pilot it in three areas in the next six months, another ten areas in 2020 and going nationwide in 2021.
- 2.24. Finally, in order to break down the disconnect between work centrally and locally, the charity would be exploring different ways to undertake its work. It would provide more support for local activities, seeking to establish vibrant local communities with cafes, researchers and fundraisers supporting people locally.
- 2.25. MG opened the meeting to questions.
- 2.26. **Paul Mayhew-Archer, member:** Could we have an update on the Live Loud speech programme presentation which was made at the previous Members' Day.
- 2.26.1. **Katherine Crawford, Director of Support and Local Networks, responded:** The project had been initiated in Wales by a speech language therapist to help people with Parkinson's speak louder. The initial pilot had worked well so funding had been provided to roll the project out in six other areas in Wales. The project team, evaluating the impact of the project, intended to compile a guide book on how to 'live loud'. The project would be rolled out nationally in the spring of 2020.
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2.27. John: Everything had been presented in a positive way, but what were the charity's failings and weaknesses?

2.27.1. **Steve Ford, Chief Executive, replied:** The SLT talked about this at every meeting. They asked how the charity could accelerate research. The Excellence Network was working well but how could it improve, particularly in areas where it was not so successful? The change to the membership scheme had taken longer than had been anticipated. This year the SLT had addressed fundraising and reducing the charity's costs. The Board rightly challenged the SLT on matters which could be improved, so there was no complacency in dealing with failings and weaknesses.

2.28. Charlotte, from Newcastle, asked: what was the charity doing to educate and advise employers?

2.28.1. **Val Buxton, Director of Strategic Intelligence and Excellence, replied:** The charity's five-year strategy had focussed on different employing bodies and worked with different businesses to help them understand the requirements of people with Parkinson's. The charity had developed resources to aid this work and its expert team advised employers. The team would continue to develop this work.

2.29. Kevin, from Northern Ireland: Could we have uncomplicated procedure for obtaining fundraising materials and should we charge for this?

2.29.1. **Paul Jackson-Clark, Director of Fundraising replied:** Yes, was the obvious answer: anything which made things less complicated was good. The charity was not complacent and would always look at how to improve the services it provided.

2.30. Question: Recently there had been publicity linking prostate cancer drugs and Parkinson's. Has this been followed up?

2.30.1. **Claire Bale, Head of Research Communications and Engagement:** We published a [story on our website](#) highlighting the potential that the prostate drug, terazosin, can protect brain cells to slow the progression of Parkinson's. We are actively investigating the potential of repurposing drugs for other conditions to help people with Parkinson's. One way we are doing this is through our partnership work with Benevolent AI. There are many potentially repurposable drugs being identified through this and other initiatives. It's important that these drugs are evaluated closely and the most promising are taken forward.

2.31. Mark Jennings from Oxford asked: What political lobbying was the charity doing? By way of example, he cited exemption for prescriptions.

2.31.1. **Val Buxton, Director of Strategic Intelligence and Excellence, responded:** The Labour party conference had adopted a policy of free prescriptions in England.

The charity was lobbying for changes to welfare benefits and reassessment of people for Personal Independence Payments (PIP). Lobbying can be particularly effective when everyone in the Parkinson's community was involved.

2.32. **Question:** In 2017 staff costs had been 40 percent of income. In 2018 it was 50 percent. In 2017 11 staff were earning over £60,000 pa, this had gone up to 14 in 2018. During the same period there had been a reduction in the staff supporting branches. Were the increases justified?

2.32.1. **Mark Goodridge, the chair, responded:** The charity's costs was a constant priority for the board. This year the number of staff had been reduced but high costs might be incurred to provide staffing flexibility during what was anticipated might be a volatile period for income.

2.32.2. **Hanah Burgess, Director of Finance & Performance, added:** This year the charity had reduced staff across the organisation. As a result, spending on staff should be lower in 2019, bringing staff salaries down in line with the 2017 level. The SLT was to be reduced, thereby reducing higher salary band payments. The charity did not pay London staff a London weighting.

2.33. **Question:** How would the charity roll out multi-disciplinary teams?

2.33.1. **Steve Ford, Chief Executive, responded:** There were 380 Parkinson's nurses across the UK. A priority for the charity over the next five years was to develop people with skills to provide local multidisciplinary teams nationally with the aim that at least 80 percent of people with Parkinson's would see all the members of their local multidisciplinary team. In addition the charity was developing new models to make the case to local healthcare managers and commissioners to provide services for people with Parkinson's. Finally, the Excellence Network was about people sharing among themselves and inspiring other communities to do this.

2.34. **Question:** Why was there no money for exercise?

2.34.1. **Katherine Crawford, Director of Support and Local Networks, replied:** If anyone felt that they could not afford to join a health programme they could phone the Parkinson's UK helpline for advice on how they might access programmes of physical activity for people with Parkinson's. The charity funded local exercise programmes at low or no cost for participants. In addition, the charity had introduced a financial assistance programme to help people living with Parkinson's who had the greatest financial need.

2.35. **Question:** What was the charity doing to help older people who were not technically literate?

2.35.1. **Julie Dodd, Director of Digital Transformation responded:** The charity provided a diverse range of support, locally and nationally, with a variety of ways of accessing information, including in person, by telephone, on-line and printed

copy. In recent years technology had enabled the charity to expand its services. The charity will retain its off-line services but wants to increase the services it provides and would look at how it can do so most effectively, including looking at how technology can support this. In many cases the role of technology to support the charity's delivery of services would be behind-the-scenes and not necessarily visible to the end user of the charity's services.

2.36. **Question:** Could the charity form an alliance with other neurological charities?

2.36.1. **Steve Ford, Chief Executive, replied:** The charity is a member of [The Neurological Alliance](#). The common goals of the charities in the alliance provided an excellent basis to help take some of the charity's work forward.

2.37. **Bruce Blain, Newbury and District Branch chair, asked:** People needed to know that there was a branch in their area from which they could get immediate and personal support. Membership application forms (on-line and on postcards) did not refer applicants to their local branch for immediate help and it could take three or four months before someone contacted them.

2.37.1. **Julie Dodd, Director of Digital Transformation responded:** Parkinson's Direct would solve this. The charity was aware that getting referred to a local group was important and was making improvements to raise the profile of local groups with applicants. These would be rolled out before the end of 2019.

2.38. **Question:** Why did the charity still have a London head office?

2.38.1. **Steve Ford, Chief Executive, responded:** This was an important question, which the Board had considered. The charity relied upon being able to recruit good quality staff. In respect of this, being in London provided an advantage by having more people to draw upon within a one-hour radius. Developments in technology allowing for working from home meant that less office space might be required in future. However, as a UK-wide charity, we had lots of people visiting the head office, many of them with Parkinson's, and it was important for the office to be accessible, which the current London office was.

2.39. **Question:** What research has been done into accessible technology for people with Parkinson's?

2.39.1. **Julie Dodd, Director of Digital Transformation responded:** Research was being undertaken and the charity would keep it under review and inform members accordingly. In the meantime, other organisations, such as ability net could provide advice on accessible technology.

2.40. MG concluded the question and answer session. Answers had been given to questions from the meeting room in London and external venues on-line and written questions which had been submitted on-line. Written questions which had been submitted on-line but which had not been answered at the meeting would be answered outside of the meeting.

3. Approval of the draft minutes of the 2018 AGM

- 3.1. MG drew members' attention to an amendment to the heading of draft minutes 7, which had been circulated. The title of the minute should have read 'Reappointment and remuneration of auditors'.
- 3.2. He then invited the meeting to approve the minutes of the 2018 AGM, which the Board had agreed at its July meeting. Voting would be by a show of hands, unless a poll was demanded. Only members present in person at the venue in London and those who had already voted by proxy could vote. Members who were eligible to vote had been given white voting cards.
- 3.3. **Resolution:** members approved the minutes of the AGM held Saturday 20 October 2018.

4. Receipt of the charity's annual accounts for the financial year ended 31 December 2018 together with the trustees' report and auditors report on these accounts.

- 4.1. MG invited the meeting to note the receipt of the charity's accounts for the financial year ended 31 December 2018 together with the trustees' and auditors' reports on the accounts. The accounts had been audited by the charity's auditors Crowe UK in accordance with the SORP charities' recommended practice, endorsed by the Audit and Risk Committee, and approved by the Board at its July 2019 meeting.
- 4.2. Members noted the receipt of the charity's annual accounts for the financial year ended 31 December 2018 together with the trustees' report and auditors report on these.

5. Receipt of the report of the Chair of the Nominations & Remuneration Committee

- 5.1. MG invited the members to note the receipt of the report of the Chair of the Nominations & Remuneration Committee.
- 5.2. The members noted the receipt of the report of the Chair of the Nominations & Remuneration Committee.

6. Declaration of the results of the Trustee elections

- 6.1. MG announced the results of the trustee elections in England and Scotland: Jane Burston and Peter Miller were elected as Trustees in England and David Allan in Scotland.
 - 6.2. MG congratulated the newly elected trustees and thanked all the candidates for making such a big commitment in standing for election.
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7. Appointment of the auditor: members' resolution

- 7.1. MG reminded the meeting that the previous year he had reported that the charity would be required to change auditors. In 2019, the Board had conducted a re-tender exercise and were recommending the appointment of BDO LLP as auditors.
- 7.2. He proposed the resolution: that BDO LLP be appointed as auditors of the charity and the Board of Trustees authorised to agree their remuneration.
- 7.3. A majority voted in favour of the tabled resolution and the resolution was carried.
- 7.4. **Resolution:** Members resolved that BDO LLP be appointed as auditors of the charity and the Board of Trustees authorised to agree their remuneration.

8. Thank you and close

- 8.1. In closing, MG thanked everyone for attending. He was pleased to confirm that the charity was on track to raise a record £175m in the five years from 2015 to fund its life-changing services and groundbreaking research programmes.
- 8.2. Voluntary donations and support funded over 97 per cent of the charity's work . He thanked the supporters, members and volunteers who had driven this. The charity did not take this for granted and as it moved into more uncertain times it would be even more dependent on their fundraising and support to continue its work.
- 8.3. In stepping down from the chair, he thanked the trustees staff for their determination and hard work to help the charity achieve its mission. In the past year, Anne MacColl and Richard Raine had left the Board and Mary Whyham, the current Vice Chair, was stepping down. He thanked her for her support and valuable contribution, in particular during the past year as Chair of the Nominations & Remuneration Committee.
- 8.4. He thanked David Allan, who had replaced Anne MacColl in Scotland and who had now been elected to continue the work he had started.
- 8.5. He thanked Steve Ford and the senior leadership team for bringing about the charity's successes of the past five years. He was confident in their ability to further raise the level of charity's work in future. He thanked the staff and volunteers without whom the charity would not have been able to achieve what it had done and for aiding him in his work of ten years as a volunteer and four years as chair.
- 8.6. In closing the meeting, MG introduced Gary Shaughnessy, the new Chair.

Date of next meeting: Saturday 24 October 2020

Appendix 1: Present

Total member attendance: 130 (including 32 staff*, 9 trustees)

John Clark	Terence Curran	Joe Lacy
Paul Smith	Marilyn Curran	Pauline Lacy
David Adby	Alexandra Curtis*	Theresa Lai
Roger Axtell	Leonard Dickens	Nella (Ann) Lake
Claire Bale*	Julie Dodd*	David Lee
Lydia Barnett O'Regan*	Paul Dodd	Freda Lewis (trustee)
Barbara Bates	Matthew Durdy (trustee)	Keith Lewthwaite
Jason Batup	Liberty Duvall	Susan Lewthwaite
Lucy Bell-Reeves*	Richard Evans*	Dil Limbu
Faye Benfield*	Anne Ferrett	Brian Lowe
Bruce Blaine	Steve Ford*	Geraldine Marks
James Bole	Melanie Fortescue	Gerald Mcenery
Neil Bonner	Satpal Ghatora	Michelle McPhail
Nigel Borrett	Katie Goates*	Barry Melton
Veronica Borrett	Mark Goodridge (trustee)	Sue Mills*
Sally Bromley	Jack Grant	Kate Monro*
Jonathan Bromley	Austin Griffiths	Liz Nash
Tyna Brych*	Mary Hansford	Sheila North
Philip Bungay	Peter Harling	Barry North
Elinor Burniston*	Sharon Harris	Carolyn Nutkins*
Lizbeth Burr	Naudette Harvey*	Kerrie O'Connor*
Dave Butterworth	David Haydon	Laura Payton*
Val Buxton*	Anthony Hewitt	Irene Peel-Woloshyn
Paula Carey*	Gina Hill*	Tony Robbs
Margaret Chamberlain (trustee)	Martha Holley	Simon Russell
Christopher Church*	Chris Holmes*	Julia Selby*
Simon Cran-McGreehin	David Hughes	Gary Shaughnessy (trustee)
Katherine Crawford*	Mark Hughes	Janet Shaughnessy
Mark Jennings	Alastair Jack	Stuart Shelbourn
Steven King*	Paul Jackson-Clark*	Tony Jones

Amanda Slawson	Philip Watt
Ivan Sloboda	Ivor Williams
Simona Southgate	Richard Windle
Carolyn Spice	Peter Weigall
Janine Starling*	Leslie Bailey
Emily Sturdy*	Marion Bailey
John Sweeney	Polly Cook*
Tim Tamblyn (trustee)	Anne Edwards
Robert Taylor	Malcolm Forster
Elizabeth Anne Taylor	Benali Hamdache*
Rick Telford	Melanie Hargreaves
Lynn Telford	Janet Jobber
Paresh Thakrar (trustee)	Sandra Jones
Andrew Thomson	Martin Miller
David Thomson	Tim Morton*
Diana Townsend	Paul Smith*
Richard Tyner	
Cheryl Tyner	
Michael Vanek	
Clive Walker	
Paulene Ann Walker	
Paul Warner (trustee)	
Jane Warner	
Mary Watt (trustee)	