

## MINUTES

(approved by Board of Trustees 5 February 2025)

### Parkinson's UK Annual General Meeting

11:30 am - 13:30 pm Saturday 12 October 2024

#### PARKINSON'S UK 2024 ANNUAL GENERAL MEETING MINUTES

##### MEETING OPENING

##### 1. Introductions and welcome

- 1.1. Introductions and welcomes were given by presenter Paul Jackson-Clark, Director of Fundraising and Experience, and Gary Shaughnessy, Chair of the Board of Trustees, who was joining the Annual General Meeting remotely and would be co-chairing the meeting with Matthew Durdy, Vice Chair of the Board of Trustees.
- 1.2. Gary Shaughnessy delivered an introduction to the charity, which had reported significant progress in expanding the range of skills and services available to the Parkinson's community, both through partnerships and directly from Parkinson's UK. Notable growth had been seen in the provision of therapies, exercise, diet, and other services, with many now accessible online or in groups. Despite these advances, it was acknowledged that more work remained to ensure comprehensive support for all individuals affected by Parkinson's. The organisation continued to advocate for the Parkinson's community, highlighted by ongoing campaigns and the Movers and Shakers podcast.
- 1.3. The focus remained on people living with Parkinson's, with a strong commitment to supporting their determination in managing the condition. The Chair expressed heartfelt thanks to the Parkinson's UK volunteers, colleagues, partners, trustees, and fundraisers whose contributions are vital to our success.
- 1.4. A video message from Sir Bob Geldof was presented, in which Sir Bob delivered Gary's mantra: "live life, love life, stop Parkinson's".
- 1.5. Gary handed over to Matthew Durdy to introduce the running order of the 2024 Annual General Meeting agenda.

## 2. Our impact

### 2.1. Pushing for Excellent Health and care

- 2.1.1. Juliet Tizzard, Director of External Relations, and Elaine Evans, Trustee for Wales, provided an update on the charity's impact in 2023 under our Pushing for excellent health and care strategic objective. The ongoing pressures on the NHS across all four nations were highlighted, and it was reiterated the charity's commitment to addressing these challenges.
- 2.1.2. Juliet Tizzard described work in 2023 to provide learning about Parkinson's for health care professionals, support innovative approaches and fund posts in the NHS. The importance of resources for healthcare professionals was emphasised, noting that educational materials had been accessed over 33,000 times - an increase of 15% from subsequent years. These resources had significantly improved care quality, with a focus on bite-sized learning tools for NHS staff.
- 2.1.3. The charity had invested in crucial healthcare roles by funding 10 new positions across the NHS, including nurses, physiotherapists, speech and language specialists, occupational therapists, and pharmacists. This was part of the broader strategy to enhance care delivery.
- 2.1.4. Elaine Evans discussed efforts to influence political decision-makers, particularly through participation in political party conferences where the charity demonstrated the realities of living with Parkinson's and advocated for practical solutions. The 2024 UK Parkinson's audits revealed that only 42% of people with Parkinson's received their medication on time. In response, the charity successfully persuaded NHS England to launch a quality improvement programme, providing hospitals with proven methods to address this issue. Local efforts continued as the charity worked with NHS bodies to expand and improve care services for Parkinson's patients at a regional level.

### 2.2. Community update

- 2.2.1. David Newbold, Director of Community, and Brian Carson, Trustee for Scotland, shared an update on the progress made in building our community of support in 2023. The key message was clear: no one is alone in their Parkinson's journey.

2.2.2. In 2023, the Parkinson's UK helpline received 27,000 calls, offering a broad range of advice and support from information on symptoms and treatments, through to benefits, local activities and support. Further, our 80 local advisors across all four nations assisted 13,000 individuals with more in depth support such as accessing local care. Services for those newly diagnosed expanded to include online courses and new welcome webinars, attended by over 300 people, this number has already more than doubled in 2024, with expectations to expand support to thousands of people newly diagnosed in future years. 12,500 people accessed local groups for support, social activities and physical activity, with over £190,000 invested in 90 new physical activity grants.

2.2.3. Over 5,000 copies of 'Being Active with Parkinson's' were shared to promote physical activity, while 10 new partnerships were built with sporting organisations to further expand opportunities to be active. Brian shared his personal experience, noting how increasing sports and activity levels had positively impacted his Parkinson's symptoms.

### 2.3. Research update

2.3.1. David Dexter, Director of Research, and Sally Bromley, Trustee, reported that Parkinson's Virtual Biotech had invested £4.3 million into new projects.

2.3.2. Neurolix had announced positive results for NLX, which had been shown to alleviate symptoms of dyskinesia. There was optimism that NLX could eliminate side effects for most patients, and efforts would be made to promote its use.

2.3.3. In 2023, the organisation had awarded over £3.3 million towards research grants. The grants programme was funding technology improvements for individuals with Parkinson's while drug development continued, in partnership with Cure Parkinson's.

2.3.4. Currently, 70 Parkinson's research studies were seeking participants, with over 450 research volunteers already recruited. This had expanded the research support network to almost 9,000 members and facilitated more than 20 research events with volunteer-led research interest groups. Sally shared her personal experience with discovery projects, highlighting her role in providing samples to advance research.

### 3. Q&A session

- 3.1. **This AGM had been scheduled on the Jewish Sabbath, and Yom Kippur, the holiest Jewish festival of the year. Holding the AGM on this date had resulted in the disenfranchisement of observant Jewish people in the AGM and raised issues about what is said and done to support inclusion. The Senior Leadership Team were asked what lessons had been learned and how these lessons would impact on the inclusion work of Parkinson's UK?**

Caroline Russell, CEO, issued an apology to the affected members, emphasising that there had been no intention to exclude specific groups. This incident underscored the importance of a more inclusive approach moving forward. A provisional date had been set for the 2025 AGM, which would remain tentative until inclusivity considerations were fully reviewed, ensuring that all members felt represented and included in future events.

- 3.2. **How are Parkinson's UK working with the health service across the UK, specifically in Northern Ireland, to improve access to consultants?**

Juliet Tizzard, Director of External Relations, acknowledged that current wait times to see specialists such as neurologists were unacceptably long. After attending a recent event, Juliet gained further insight into the challenges within the NHS. While new tech systems in Northern Ireland had caused additional delays, these changes had also created an opportunity to review neurology services across the region. Parkinson's UK would aim to actively engage in this review to advocate for the inclusion of Parkinson's services. Parkinson's UK would continue to promote the importance of multidisciplinary teams and integrated care, striving to establish this as the standard. The organisation was committed to addressing barriers to accessing care in both hospital and community settings.

- 3.3. **Should Parkinson's UK adopt a more targeted, short-term focus to drive success in one specific area rather than pursuing broad aims?**

Caroline explained that all pillars of the Parkinson's UK strategy were interrelated. For example, focusing exclusively on health and care would reveal the need for appropriate diagnoses, which require motivated clinicians interested in supporting the Parkinson's community. These clinicians are essential in directing individuals toward research, building a supportive community network, and empowering individuals to lead fulfilling lives and participate in vital research efforts.

Whilst Parkinson's UK collaborates with others in the pursuit of treatments and a cure, concentrating solely on one area, such as research, does not guarantee accelerated breakthroughs. A balanced approach across all pillars is essential to inspire clinicians and encourage those affected by Parkinson's to live as they choose.

Parkinson's UK believes its balanced priorities are optimal but commits to an annual

strategy review to ensure alignment with community needs and priorities.

- 3.4. **Could there be further encouragement for the Parkinson's community to engage in campaigning and advocating for Parkinson's rights to influence public and political opinion? Would providing the community with facts and statistics empower them to reach out to political figures, especially in a new, economically-driven government?**

Caroline agreed that highlighting the economic impact of those with Parkinson's who are unable to work could resonate with political leaders. Moreover, the wealth of expertise in the UK's life sciences shows that investing in research is beneficial in boosting the economy, and at the centre of this is those with lived experience. Juliet Tizzard emphasised the value of both local community action and strategic conversations with policy makers. It was noted that engaging directly with ministers, where possible, can be just as effective as public campaigns. Successes have shown that these targeted discussions can drive real progress. Despite this, there was a need for the organisation to proactively share political achievements with the community and ensure they had access to key data which would allow them to advocate independently.

- 3.5. **Is there any future for ultrasound thalamotomy treatment for Parkinson's sufferers?**

David Dexter replied that many Parkinson's patients who considered deep brain stimulation (DBS) were assessed and deemed not suitable for treatment. This situation presents an opportunity to explore ultrasound thalamotomy as an effective alternative for treating Parkinson's tremors when DBS is not viable. Research indicates that ultrasound thalamotomy has a promising outlook.

- 3.6. **At the 2023 AGM the organisation was in the process of recruiting more staff, how has this helped progress at Parkinson's UK?**

David Newbold reported that an additional £1.4 million had been invested in the organisation in the past year, with most growth being in staffing within the Community directorate. The organisation had welcomed over 100 new staff members, including an expanded helpline team, enhancing local volunteer officer numbers to better support local groups and growing our Local Adviser service. In 2024, Parkinson's UK experienced a 30% growth in the number of individuals supported, with expectations for an additional 15-20% growth in 2025. Recruitment was ongoing, and so the full impact on community support was still unfolding, however, the results thus far had been positive.

- 3.7. **What was being done to help those with advanced Parkinson's so that they did not feel forgotten?**

Caroline acknowledged that the organisation had not made significant progress in

supporting those with advanced Parkinson's. However, ongoing engagement with the community highlighted the critical need to talk to and support caregivers and families affected. It was agreed that more efforts should be made in this area. Given the complexity of the issue, it was essential to manage this support effectively as part of the Parkinson's journey, ensuring that it is meaningful for both individuals affected and their families.

- 3.8. **How can members promote the educational resources and information from Parkinson's UK to GPs and healthcare professionals to enhance their knowledge and care? Additionally, many newly diagnosed individuals are not receiving their newly diagnosed packs from specialist nurses - what steps can we take to ensure that Parkinson's nurses distribute these essential packs to those who need them?**  
David Newbold reported that 13,000 newly diagnosed packs were distributed this year, emphasising that timely access to information is key. Plans were underway to meet with the Director of England to ensure that access to the newly diagnosed packs is consistent across different regions.  
Sally Bromley noted that the initial steps in diagnosis are crucial. Parkinson's UK will review the content of the newly diagnosed packs, to ensure they contain an appropriate level of information.
- 3.9. **What is being done to improve outreach in Sub-Saharan Africa?**  
Juliet Tizzard stated that, although our work is focussed in the UK, we do also, as part of a global network, assist other organisations by sharing our extensive professional information on Parkinson's, including medications, support, and care. At the World Parkinson's Congress, smaller organisations frequently seek our assistance. However, it was noted that we should take a more proactive approach to ensure a balance between funding and resources.
- 3.10. **Is there a gym space specifically tailored towards those with Parkinson's? If not, would Parkinson's UK support this initiative?**  
Caroline responded that Parkinson's UK has partnerships with Anyone Active and PureGym, offering free memberships to individuals with Parkinson's. There was also potential to advocate for a dedicated, Parkinson's-friendly space. Brian Carson added that there are active teams in Scotland training gym instructors to better assist those with Parkinson's.

#### 4. Forward view

- 4.1. Caroline thanked the members for their ongoing support and urged them to continue spreading awareness of Parkinson's UK to reach potential new members who could benefit from Parkinson's services.

- 4.2. Recent data analysis from the NHS was discussed, in which 16 million anonymised records related to Parkinson's were reviewed. The analysis examined age of onset, particularly noting a potential increase in diagnoses for people aged under 50. It also highlighted differences in diagnosis rates between males and females across all age groups, suggesting the need to study the effects of Parkinson's in women further. Additionally, correlations with other health conditions, such as diabetes, were identified, opening the possibility of links between Parkinson's and other conditions.
- 4.3. The organisation had committed £500,000 to fund clinical fellowships, aimed at training top specialists in fields critical to Parkinson's diagnosis and treatment.
- 4.4. Caroline informed members that we will roll out a new brand in 2024 and thanked members for helping the charity choosing the approach which will be engaging, accessible and recognisable.
- 4.5. There was ongoing consideration of how to enhance support for the Parkinson's community, ideas included creating discussion groups within the civil service and NHS across the UK, focused on managing and living with Parkinson's.
- 4.6. Caroline had met with the Michael J. Fox Foundation to discuss collaboration on technology for Parkinson's. Parkinson's UK had received funding to test new applications, with trials set to begin in November. Members were encouraged to review available tech guides and consider participating in testing to provide valuable feedback.

## 5. Formal business

- 5.1. The minutes of the 2023 Annual General Meeting were approved.
- 5.2. Elaine Evans was re-elected as Trustee for Wales due to no contest.
- 5.3. The charity's annual report and financial statements were received for the year ending 31 December 2023.
  - 5.3.1. A member queried whether fundraising should be more central to the charity's strategy, noting its effectiveness in supporting initiatives such as student programmes. Ben Clarkson, Chief Finance and Operating Officer, highlighted the annual report and accounts which showed that a large portion of the charity's reserves came from fundraising. It was also noted that events organised by the charity were regularly oversubscribed, indicating the continued success of fundraising efforts.
- 5.4. The 2025 Annual General Meeting had been provisionally scheduled for Saturday 11

October 2025, and would be confirmed in due course.

## 6. Contingency & closing remarks

- 6.1. Closing remarks were delivered by Matthew Durdy and thanks were given to all volunteers and members for their continued support. Over 3700 volunteers supported the charity in 2023: they play a vital role in helping us to achieve our strategic objectives. Matthew also thanked the Senior Leadership Team and all those who had attended this year's AGM. Special thanks were given to Sam Ward, Fiona Day, Valerie Cadoret, Charlotte Boyd, and Nisha Patel who had worked hard to deliver the Par-Con and AGM successfully.

Minutes: C Rix, Governance Officer  
12 October 2024