PARKINSON'S<sup>UK</sup>
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# **DRAFT MINUTES**

# Parkinson's UK Annual General Meeting

10:15 am - 12:00 noon, Saturday 14 October 2023

## MEETING OPENING

## 1. Welcome and Chair's report from the Board

- 1.1. The start of the meeting was delayed 10.15 am as Gary Shaughnessy, Chair of the Board, had been delayed by his car breaking down. At 10.15 am, in the absence of Gary Shaughnessy, Elaine Evans, Trustee for Wales, was appointed as Chair of the meeting.
- 1.2. The meeting Chair welcomed everyone to the Annual General Meeting (AGM), the first held in-person as well as online since 2019, on account of the Coronavirus pandemic. She reported that there were at least 50 members present, either in person or by proxy, which satisfied the formal quorum requirement under the Articles of Association. The meeting was being video recorded.
- 1.3. The Chair paid tribute to David Allan, the former Scotland trustee, who had died since the 2022 AGM and was much missed.

#### Forward look

1.4. Caroline Rassell (CR), Chief Executive, reflected on 2022, when we were coming out of lockdown from the Coronavirus pandemic and people could meet again. At the end of her first year as Chief Executive CR took the opportunity to meet people from the Parkinson's community, people with Parkinson's and their carers, researchers, clinicians and the charity's volunteers and staff. She heard of the need for everyone connected with the charity to make sure that the charity stood for hope, control and care. These themes would be reflected in the meeting presentations. In addition to supporting people in the Parkinson's community, key to the charity's work was to raise awareness of Parkinson's within the wider community at every opportunity.

#### Our work in 2022: Better support, every day

- 1.5. Emma Cooper, Director of Community, reported that the charity's core purpose was to provide people living with Parkinson's with the right information and support at the right time in their journey.
- 1.6. Our adviser service was staffed by people with expert knowledge based in local communities and was also available on the telephone through our helpline. In 2022 our advisers had supported over 36,000 people, almost a 30% increase on the previous year. Our online forum provided a place for people with Parkinson's to support each other. In 2022 almost 15,000

- people had been involved in the Parkinson's UK Forum. The charity's hard copy information resources were highly valued and in demand with over 180,000 items to people distributed across the UK in 2022.
- 1.7. 2022 had been a year when many people had faced financial hardship as the cost of living crisis had deepened. We had listened to what people were telling us about their experiences and we responded quickly, increasing our support for financial assistance by over 50% and providing specialist information through our adviser service.
- 1.8. In order to be able to access the kind of information and support described, people needed to know about Parkinson's UK. Connecting with people soon after their diagnosis of Parkinson's was something that continued to be a priority. We had been moving forward our plans for Parkinson's Connect which saw us working with NHS services to provide a way for clinicians directly to refer patients to charity services using a digital process.
- 1.9. In order to achieve our aims for the Parkinson's community it was vital that we worked with health and care professionals. This happened through the Parkinson's Excellence Network. In 2022 the charity had been delighted to welcome new directors to the Excellence Network two co-clinical directors, Professor Camille Carroll and Professor Richard Walker, and a new Director of Engagement, Jonny Acheson. These individuals were leading professionals in the field of Parkinson's who brought learned and lived experience of the condition.
- 1.10. In 2022 the Excellence Network had confirmed funding for ten new NHS posts and five service improvement projects worth over £1 million. These new posts were spread across the UK. They included Parkinson's nurses, occupational therapists, physiotherapists and speech and language therapists. We had also awarded grants that would improve palliative care, bone health, medication management and group-based physical activity. Also in 2022 fifteen new learning courses had been added to our offer and we saw over 28,000 health and care professionals take them up, a 14% increase on the previous year.
- 1.11. In 2022 our audit had assessed over 500 health and care services and asked around 7,000 people with Parkinson's about their experiences. This work was guiding our work and driving our priorities going forward.
- 1.12. As well as health care and support we invested in supporting people to become and stay active, because of what we know about the importance of physical activity in living as well as possible with Parkinson's. Our support in this area had grown over the past two years, including more printed resources, workout videos and online courses for staff working in the leisure industry so that they understood Parkinson's. We also had a popular grants programme, which supported the start-up of new activities in local communities including Nordic walking, swimming, boxing and walking football. In 2022, £160,000 in grants had made a real difference to people's quality of life in their local community.
- 1.13. In conclusion, EC reported that we worked in local communities, where people accessed their support and services, supporting incredible volunteers and volunteer-run groups, branches and activities. The more than 300 local groups across the length and breadth of the UK provided over 90% of local activities for people living with Parkinson's, providing mutual support, friendship, physical activities and information. At the heart of our community development we worked to expand and increase our offer to all communities, starting up new local activities and encouraging people to get involved. In 2022 there had been over 220 such new activities. We were excited about increasing our support in all the areas EC had described as we went into 2024.

#### Accelerating breakthroughs in research

- 1.14. Arthur Roach (AR), Director of Virtual Biotech, reported that Parkinson's UK's research was unique in that unlike other organisations undertaking research, including charities and universities, Parkinson's UK was driven entirely by the priorities of the Parkinson's community, we were not run by scientists or investors.
- 1.15. Parkinson's Virtual Biotech was a unique programme enabled by the size of the charity's research budget. This was the charity's flagship programme for discovering and developing new treatments for Parkinson's. It acted like a seed investment fund, working with biotech companies, other funders and scientists, taking its priorities from the Parkinson's community.
- 1.16. In 2022, Parkinson's Virtual Biotech had awarded £2.68 million to NRG Therapeutics to develop treatments that could slow Parkinson's; Parkinson's UK and the Parkinson's Foundation in the USA had collaborated to speed up the search for new treatments, In future, Parkinson's UK would look for similar collaborations with other organisations around the world to make the research a truly global, patient-led programme. In addition, Parkinson's UK was looking to fund research into a drug that slowed the effects of Parkinson's in its early stages. In addition, he highlighted that Parkinson's UK would be co-funding a phase 3 clinical trial with Cure Parkinson's.
- 1.17. David Dexter, Director of Research, reported that we had funded £8.7 million research in 2022, up from £6.1 million the previous year. Our project grants were funding pioneering research to better our understanding of the causes of Parkinson's and pump-prime new drug development. In 2022 we had funded four new projects with a value of £1.33 million.
- 1.18. One project aimed at better understanding of how astrocytes, the support cells in the brain, helped maintain nerve cells and how this broke down in Parkinson's. In Parkinson's, nerve cells started dying at the nerve endings or synapses. One project would investigate how dysfunction in the nerve cells' waste disposal system affected the integrity of the synapses.
- 1.19. Knowledge of why cognitive decline occurred in Parkinson's was poor, but one research project aimed to identify the key cellular mechanism that led to cognitive decline in some people. A groundbreaking research project would investigate how alterations in a protein called alpha-synuclein in the gut could transmogrify to the brain to potentially cause Parkinson's.
- 1.20. In 2022, the charity had funded research into non-drug based methods to improve the lives of people with Parkinson's without delay. These included physical activity programmes to improve balance and prevent falls and the design of a novel training programme so that more healthcare professionals could provide vital mental health support to people with Parkinson's.
- 1.21. In 2022, we had promoted fifty-five new opportunities to take part in research through our web-based Take Part Hub, reaching more people than ever before. We had welcomed fifty new volunteers to our network who had helped shape fifty new research projects. We now had 440 people help us review research. Thus, people with Parkinson's were having a real impact on helping us design research. The number of regional Research Interest groups, currently twelve across the UK; in 2022 they had delivered 20 research events designed by people with Parkinson's and delivered for people with Parkinson's.
- 1.22. To find better treatments and a cure for Parkinson's, we needed as many people as possible to get involved in research especially people from communities who had traditionally been under-represented in research. In 2021, the charity launched the Race Equality in Research project to work with people from black, Asian and other minority racial and ethnic groups, to help make research accessible and inclusive to everyone and encourage people to get involved. Our steering group met monthly and, in 2022, had started our in-person community engagement

- events with a meeting in Hounslow aimed at engaging with the South Asian community: 60% of the attendees had not interacted with the charity before. Subsequently, two events in London and one in Bradford had been held, to connect with local communities.
- 1.23. The best way to stay up-to-date on what was happening in research was to join our research support network to which almost 9,000 people interested in research had signed up. Research opportunities were shown on the Take-Part Hub, with the address on the charity website.

#### **Finances**

- 1.24. Sue Hall, Interim Chief Finance and Operating Officer, reported that the charity continued to be in good financial health. Our overall income for 2022 was £53.5m, which included the £14 million proceeds from the sale of the London headquarters in April 2022. Excluding this, the charity was £2m ahead of the 2021 position despite 2022 challenges: the ongoing cost of living pressures for the Parkinson's community and staff and the impact on face-to-face fundraising activities.
- 1.25. Legacies made up the majority of the charity's income: £19.6 million in 2022. Fundraising activities had generated an increase of £0.5 million over 2021. This highlighted the resilience of the team and our donors in the face of the cost-of-living crisis and pandemic impact.
- 1.26. Our expenditure on charitable activity also increased as we bounced back from the pandemic. In line with the strategy we had increased our total spend by £8m from 2021. The charity had invested more in research, helplines, volunteer support programmes and campaigns to raise awareness of Parkinson's and its impact. The strong financial position had been maintained into 2023 and enabled the charity to designate £14.7 million of our reserves for the strategic investments as outlined.
- 1.27. Branches and groups collectively held £7 million of funds that they could use to support activities and causes on a local level on top of the central investments we made.
- 1.28. Our investment policy objective was to generate a total return of inflation plus 2-3% pa. This had been more challenging with rising inflation rate but also meant that we received a good return on our cash holdings. Our current 5 year strategy would see our reserves reduced to around £20m to £27m in 2027, which would cover our ongoing running costs.

#### Pushing for Excellent Health and Care

- 1.29. Juliet Tizzard, Director of External Relations, reported that in 2022 the charity had started expanding our grants to fund nursing and, for the first time, therapist posts in the NHS. We had funded Parkinson's specialist nurses for 35 years now, pump-priming funding. We were proud that the NHS had always continued the funding after the charity's initial two-year grant. We funded around three new posts each year but this rate would be insufficient for addressing the current shortfall of a hundred nurses across the UK. Over the next three years, the charity would fund twenty new nursing posts, benefitting 6,000 people with Parkinson's across the UK.
- 1.30. In 2022, we had expanded our pump priming grants to other posts in the Parkinson's team physiotherapists, speech and language therapists and occupational therapists but we needed to increase this if we were to address the real service provision gap. Over the next three years, we would also fund 20 new therapist posts across the NHS, which should help increase access to health professionals so important to people living well with Parkinson's.
- 1.31. In partnership with the Association of British Neurologists, 2023 funding would be invested in clinical fellowships to support specialist doctors wanting to specialise in Parkinson's care. This would assist the shortage of neurology consultants and develop future practitioners.

- 1.32. The charity was giving greater voice to the issue of people getting their medication on time when in hospital. Our recent report, *Every minute counts*, had highlighted to politicians and NHS leaders the situation was: only 42% of people getting their medication on time, causing people to become distressed and symptomatic and to stay longer in hospital. Progress had been seen in some hospitals where NHS staff, often through a PUK grant, had turned the situation around. For example, in Argyle & Arran the service had driven the rate up from 41% to 75% hospital in-patients getting their medications on time
- 1.33. This one healthcare issue illustrated how we could improve things. It took people, money and determination. With the investment that the Board of Trustees has made, we now had more people and money and we had the determination to take things forward.

#### FORMAL BUSINESS

## 2. Results of the Trustee elections in England, Northern Ireland and Scotland

- 2.1. Results from the 2023 trustee election ballots were received. Trustees were elected for four year terms starting from the end of this meeting. Three trustees were re-elected: Jane Burston for England; Kyle Alexander for Northern Ireland (unopposed); and Brian Carson for Scotland. Kate Platts was elected as a new trustee for England. Elected trustees were congratulated and the many people who had expressed an interest in standing as trustees and engaged with the charity about the role thanked. The charity would look forward to continued work with these many supporters.
- 2.2. The meeting Chair also thanked Peter Miller, who was standing down at the end of this AGM, for his service as a trustee and committee member during the past four years.

#### **AGM BUSINESS**

#### 3. Receipt of the annual report and accounts

3.1. The annual report and financial statements for the year ended 31 December 2022 had been published on the charity's website on 11 September following review by the Audit and Risk Committee and approval by the Board of Trustees. The report and financial statements had been produced in accordance with the charity Statement of Recommended Practice and received an unqualified audit opinion from our external auditors, BDO LLP. The meeting received the annual report and accounts 2022.

#### 4. Receipt of the report of the Chair of the People Committee

4.1. The report from the Chair of the People Committee had also been published on the website and made available to members. This report was received.

#### 5. Resolutions

#### Proposed amendments to the Articles of Association

5.1. The meeting Chair invited the meeting to consider and, if thought fit, approve the following resolution, which was being proposed as a special resolution which required a 75% majority vote to be approved. The proposed changes to the Articles of Association had been set out in the Notice of Meeting for the 2023 AGM and the accompanying Explanatory Notes.

- 5.2. THAT the Articles of Association of the Charity be amended as follows:
- 5.3. (a) By the deletion of the existing Article 7 and the insertion of a replacement Article 7 (in substitution for and to the exclusion of the existing Article 7) in the form of the document initialled by the Chair for the purposes of identification; and
- 5.4. (b) By the deletion or amendment of the following definitions set out in Article 17:
- 5.5. (i) the deletion of the definition of 'Co-opted Trustee';
- 5.6. (ii) the deletion of the definition of 'criteria for selection' and the insertion of a replacement definition (in substitution for and to the exclusion of the existing definition) as follows:
- 5.7. "'criteria for selection': means the specific professional, managerial and specialist skills, competencies and expertise and the mix of experience, knowledge and backgrounds needed to balance the Board and contribute to effective leadership and decision-making, having regard to the need to ensure a diversity and balance of perspectives and the need to recognise the importance of having persons on the Board with a connection to Parkinson's;";
- 5.8. (iii) the amendment of the definition of 'Elected Trustee' by the deletion of 'either England, Wales, Scotland or Northern Ireland' and its replacement by 'any of England, Wales, Scotland or Northern Ireland'; and
- 5.9. (iv) the amendment of the definition of 'Trustee' by the deletion of the words 'Appointed Trustees, Elected Trustees and Co-opted Trustees' and the insertion of the words 'Appointed Trustees and Elected Trustees'.
- 5.10. Following the close of the poll, the meeting Chair declared that the resolution had been carried by 1098 votes in favour of the resolution and 14 against, a 98.74% majority of the votes cast in favour.

## 6. Minutes of the 2022 Annual General Meeting

6.1. In the absence of points of accuracy raised or questions asked, the meeting took the draft minutes of the 2022 Annual General meeting as having been approved.

## 7. Provisional date of the 2024 Annual General Meeting

7.1. The provisional date of the 2024 AGM was reported as Saturday 12 October 2024.

#### MEMBER ENGAGEMENT

## 8. Member engagement

The Chair of the meeting encouraged members to take this opportunity to ask questions and have members' voices heard. If time ran out the charity would endeavour to answer unanswered questions.

8.1. Laurel Miller): The popularity of recently launched podcasts since Covid, in particular '2 Parkies in a Pod' and 'Movers and Shakers', and webinars like 'No Silver Bullet', has demonstrated a desire amongst your beneficiaries for more open and accessible discussion about Parkinson's, and the provision of expert information on topics of importance or interest to them. Some of the content of these is not well informed by what PUK is actually doing already to support PwP in the UK. To address this, why don't you initiate your own regular webinar/podcast, with topical news, views and information about the excellent work PUK does to help PwP, including the

support of the NHS through the Parkinson's Excellence Network, and practical initiatives to support both daily living with Parkinson's and research?

- 8.1.1. JT, Director of External Relations, responded that existing podcasts provided an insight into the experience of living with Parkinson's: they were intimate and personal. The charity had links to some producers and lobbied them on their content. The Director of Research had appeared in a recent podcast and the charity would continue with this approach. There were no plans to introduce our own podcasts or webinars at this time. However, JT would welcome people's thoughts on this. The charity's focus was on people living with Parkinson's, providing services and opportunities for people to get involved in our activities. The charity was undertaking research to understand how people in the community consume media the publications they read, the podcasts they listen to in order to have them become involved with our services and activities.
- 8.2. **Ian Brooks**: Diet appears to have significant potential to combat Parkinson's. What percentage of Parkinson's UK's research spending is currently funding diet-related research?
  - 8.2.1. David Dexter (DD), Director of Research, responded that in 2022 we had highlighted the connection between gut bacteria and the brain in relation to Parkinson's. The charity was supporting research into this, but DD was not aware of the percentage spent on this target.
- 8.3. **Member, Solihull branch**: What is our advertising expenditure to gain support for Parkinson's UK? Would it be worth spending more?
  - 8.3.1. JT responded that spending on advertising was a balance relating to other expenditure. Historically we had focussed our spending on the general population, recently spending around £500k on this. We now want to attract people who have no relationship with Parkinson's UK. We would probably see advertising expenditure increase.
- 8.4. **Mr M Wheelan**: Having sold our building at 215 Vauxhall Bridge Road for £14 million, what will be the net gain or loss on moving to new premises?
  - 8.4.1. Sue Hall (SH), Interim Chief and Operating Officer, responded: 215 needed around £250,000 work done to maintain it with ongoing costs of £100,000 annually. The building sold for a good price. The sum would be invested over the next three to five years..
  - 8.4.2. The trustees then looked for the accommodation we needed and found a building with good access not far from the current premises. We were still in the process of negotiating the contract. We were negotiating a rent-free period, which would allow us to maximise the investment from selling 215. The rent would be the market rent. The proceeds from the sale of 215 should cover the rent for the next twenty years.
- 8.5. **Jonathan Bromley**: While it is good news that we're looking to get twenty new Parkinson's nurses, but is there an issue about getting them trained?
  - 8.5.1. JT responded that our focus is on recruitment and retention. We would provide funding to make Parkinson's a specialty that people would want to join, funding that would support healthcare professionals retrain.
- 8.6. Jo Caldicott: Is it OK for a Parkinson's nurse not to have the prescribing qualification?

- 8.6.1. JT responded that in getting Parkinson's nurses we look at a balance to get a range of skills. In some cases this might mean appointing Parkinson's nurses who did not have the prescribing qualification. This is acceptable, but we do want prescribing nurses to be available.
- 8.7. **Anonymous**: What more can be done to eliminate the financial inequalities of people living with Parkinson's, remembering that families may also be impacted by living with other diseases too?
  - 8.7.1. Emma Cooper (EC), (Director of Community) responded that, in responding to people's requests, we brought in cost of living and fuel poverty advisers to the advice service, as part of our provision to reduce financial inequality. The service also provided benefits and employment advice to help people maximise their income.
  - 8.7.2. JT added that we are also campaigning to influence the government. Last year we focused on energy costs, this year the focus might be on food costs. To strengthen our impact on decision-makers, we were doing this in alliance with other charities.
- 8.8. **Sam Williams**: Can you simplify the Parkinson's UK website to simplify and improve the search process and results?
  - 8.8.1. JT responded that the charity would be addressing this over the next six to twelve months.
- 8.9. **Anonymous**: Where is the transparency in deciding upon research projects and ensuring that they represent as many views as possible?
  - 8.9.1. David Dexter (DD), Director of Research, responded that we involve people with Parkinson's in every decision we make. Lay reviewers sat on the Virtual Biotech board making decisions about what we got involved with. We wanted lay reviewers and scientific reviewers to ensure that the research projects were appropriate for the Parkinson's community.
  - 8.9.2. Arthur Roach (AR), Director of Virtual Biotech, added that our Patient Involvement Strategy Group oversees how we bring patient involvement into our research. You can join the Research Support Network to find out more about this.
- 8.10. **Bruce Blaine**: Could we offer a holistic needs assessment service like those offered by Macmillan or Cancer Research to support people's emotional, spiritual, social, practical, physical, financial and family issues? Such an assessment could provide a useful personalised document for people living with Parkinson's.
  - 8.10.1. EC responded that our advisor service provides a holistic service. We seek to ascertain people's needs to help them live with Parkinson's. It would also help people if the NHS could adopt this broader approach.
- 8.11. **Alison**: The NHS does not understand the needs of people with advanced Parkinson's leading to inadequate support and wasting resources. How can people with advanced Parkinson's, particularly the elderly, get better support from the NHS to meet their needs?

- 8.11.1. EC responded that this was an important matter. The charity was increasing support in this area, creating a team of specialist advisers on advanced care planning to advise on social care. We would then want to influence the government around social care.
- 8.11.2. In response to EC, Alison said that she found care for advanced Parkinson's was often labelled by hospitals as a social care issue. This had financial and care sector and NHS implications. If you had advanced Parkinson's, the care was not social care and shouldn't be labelled as such.
- 8.12. **Anonymous**: In future, could we take World Parkinson's Day (11 April) beyond poetry and blue lights by putting forward a charter for Parkinson's?
  - 8.12.1. JT would respond outside of the meeting.
- 8.13. **Anonymous:** What new treatments have come out of research undertaken in the last few years?
  - 8.13.1. AR responded that treatments for Parkinson's might arise from any research, not just the research we undertook. Duodopa had been made available a couple of years previously to smooth out L-Dopa delivery for mid- and later-stage Parkinson's. There was also a treatment approved outside of the UK for cognitive symptoms in Parkinson's.
  - 8.13.2. DD added that there were currently 175 clinical trials in respect of Parkinson's. These trials were both for slowing Parkinson's and treating every symptom, like movement, anxiety and depression. These trials were open for people to join.
- 8.14. **Nigel Willis**: Durham University have found a cure for Parkinson's in mice. They were not producing it commercially. How could they approach Parkinson's UK for funding for human trials?
  - 8.14.1. AR responded that there was a huge gap between treatments which proved successful in animals and developing them to achieve successful results in humans. Parkinson's had been cured in mice many hundreds of time. But we'd be glad to speak with the Durham University team.
- 8.15. **Jagdeep**: Is there a teaching course to provide qualified trainers to coach people with Parkinson's in sports such as boxing?
  - 8.15.1. Caroline Rassell (CR), Chief Executive, responded that we were exploring with sports' governing bodies how we could provide sports training and facilities for their members, so we can highlight for the Parkinson's community the activities that are Parkinson's-friendly, because trainers have been trained to allow them to adapt the needs of people with Parkinson's.
  - 8.15.2. Some people may have applied to us for grants and been refused. We are keen to support people locally but we have to ensure that what is being delivered is safe for the Parkinson's community. If you don't get a grant, we want you to understand why.
- 8.16. **Dr Shipton**: How can Parkinson's UK support more left-field, alternative fundraising?
  - 8.16.1. PJC would directly respond to the questioner after the meeting.

- 8.17. **Roger Mortimer**: A patients' charter would benefit people with Parkinson's, particularly at the start of the Parkinson's journey, pointing people where to find services and local groups to find out about how to deal with your Parkinson's.
  - 8.17.1. CR responded to this by saying that the answer might come up later in the day.

## 9. Thank you and close

- 9.1. Gary Shaughnessy (GS, Chair of the Board of Trustees) had arrived after his car break-down and addressed the meeting, reflecting that currently there were 158,000 people with Parkinson's in the UK and 10 million worldwide. Parkinson's did not just affect the individual, it affected family and friends too and the government must recognise that the condition had this wider impact.
- 9.2. GSapologised for his late arrival and thanked Elaine Evans for chairing the meeting and colleagues for ensuring the smooth-running of the meeting in his unexpected absence.
- 9.3. The previous Sunday he had attended an event near Henley with 350 people who had participated in a walk-for-Parkinson's event, providing a wonderful example of the community that was Parkinson's. He thanked everyone who had been involved over the years in raising funds for Parkinson's. As Caroline had said, Parkinson's UK was about hope, control and care. To this end, Parkinson's UK was a core part of the Parkinson's community. We needed to ensure that the Parkinson's community felt that Parkinson's UK was their charity. He called on the members to ensure that the charity did what was right for people with Parkinson's and people affected by Parkinson's.
- 9.4. GS spoke of hearing the experience of people saying that some doctors told them there was no cure for Parkinson's and no drugs to slow its progression which could create a very negative view of the condition at the point of diagnosis. GS pointed to the lot that people could do to alleviate their condition. This was the message for us to give to our community, the medical profession, government and people who may influence investment in our condition in future. GS' view was that individual mindsets made the greatest difference to how they dealt with living Parkinson's and the charity's role was to have a positive impact on people. We needed to think about our communications and how we might run podcasts, for example.
- 9.5. GS thanked members of the NHS Professionals Living and Working with Parkinson's Group who, in collaboration with the Parkinson's Excellence Network had won the Patient Involvement in Safety Award at the HSJ Patient Safety Awards 2023: Tincy Jones, Clare Addison and Jonny Acheson.. He thanked all the people in the NHS who were working under difficult conditions supporting people with Parkinson's. He also thanked the people who continued to support us recently while the charity had gone through significant change. In looking around the room with the people who had joined the meeting virtually, GS saw a number of people who were inspirational for people with Parkinson's. Inspiration did not have to come from undertaking challenging activities, it came from the knowledge people had and the role models they could be and the belief people could give to others in the community. He thanked people who had given him support since he had been diagnosed with Parkinson's. These were demonstrations of the help that the community gave and could give to make a real difference to people who had Parkinson's and were living with it. We could make a difference if we kept doing this every day.
- 9.6. The meeting Chair declared the Annual General Meeting closed.

## Provisional date of next meeting: Saturday 12 October 2024

## **Board of Trustees and Executive Leadership Team members present**

Gary Shaughnessy (Trustee and Chair)

Kyle Alexander (Trustee)

Sally Bromley (Trustee)

Jane Burston (Trustee; online)

Brian Carson (Trustee)

Andrew Cavey (Trustee; online)

Elaine Evans (Trustee)

Katrina Green (Trustee; online)

Annie McCallum (Trustee)

Peter Miller (Trustee)

Paresh Thakrar (Trustee; online)

Caroline Rassell (Chief Executive)

Emma Cooper (Director of Community)

Paul Jackson-Clark (Director of Fundraising and

Experience)

Sue Hall (Interim Chief Finance and Operating

Officer)

Arthur Roach (Director of Virtual Biotech)

Juliet Tizzard (Director of External Relations)

Oliver Wareham (General Counsel)

Membership attendance: 181 voting members recorded as present

The charity's External Auditor was in attendance