

DRAFT MINUTES

Parkinson's UK Annual General Meeting

9.30am, 15 October 2022

MEETING OPENING

1. Welcome and Chair's report from the Board

- 1.1. Gary Shaughnessy, Chair of the charity's Board ('the Chair') welcomed everyone to the meeting. He reported that there were at least 50 members present which satisfied the formal quorum requirement under the Articles of Association. The meeting was being video recorded.
- 1.2. In the three years since Gary had been appointed Board Chair, he reported that 54,000 more people had been diagnosed with Parkinson's, impacting individuals with their families and friends. Parkinson's UK with its partners helped this community of nearly one million people in the UK, with its branches, cafes and networks acting as lifelines to many. The combination of 496 Parkinson's nurses, helplines, forums and local activity groups and a focus on support for daily living activities made a real difference to peoples' lives.
- 1.3. Since the country had emerged from the Covid pandemic, the community's activities were picking up and once again becoming more visible and vocal. Activities included pushing the Government as well as scientific and health communities to do more.
- 1.4. While recognising the things we do well, the charity was not afraid to recognise the things we did which were not successful. In this respect Parkinson's Connect had not delivered to its original vision. We needed to do more to support our communities in person. To this end we were increasingly driven by people with Parkinson's.
- 1.5. The charity was making funding services and research easier through initiatives. For example, the charity's innovation fund had given out £100k in grants in just 6 months. The charity was also working with partners such as The Parkinson's Foundation in the US, Cure Parkinson's in the UK and Sport Parkinson's, to build on our research and clinical expertise.
- 1.6. In this respect, in the week of the Annual General Meeting the charity had announced our investment in a phase 2 clinical trial around Parkinson's Dementia and our decision to move

forward towards a further clinical trial of GDNF by seeking out a major investor with a commitment from us to invest several million pounds alongside them.

- 1.7. The Chair invited members of the executive leadership team to share some of the highlights from 2021.

Access to services and support

- 1.8. Emma Cooper (EC), Interim Director of Community and Participation reported that the year had been one of rebuilding, making sure that people could access the help and support they needed. This followed the lifting of the social restrictions which had arisen from the Covid pandemic.
- 1.9. The charity's adviser and helpline services were the cornerstone of our help and support for individuals. We now had a specialist adviser focusing on fuel poverty and income issues which were impacting on people. All the charity's advisers and helpline teams had the knowledge to raise the subject and give the information and support people needed. The helpline had seen an 8% increase in people accessing our service. So far in 2022 we had supported over 17,000 people. In the first six months of the year nearly 365,000 people had accessed information relevant to them on the charity's website; the most popular topics being types of Parkinson's, Parkinson's symptoms, and information for people who had been newly diagnosed. The top three topics that people asked for in print were the charity's booklet for people newly diagnosed, information about drug treatments, and about driving.
- 1.10. Our Parkinson's Excellence Network was driving excellence and improvement across the professional and clinical Parkinson's community. Parkinson's UK had at some point funded two thirds of Parkinson's nurse positions across the UK. Our education offer had been extended with the introduction of a therapist induction programme, completed by 161 therapists. 83 NHS Trusts and Health Boards had now signed up to 'Get it on time' - a commitment to ensure that people in hospital got their Parkinson's medication on time.
- 1.11. The charity's physical activity offer had seen over 800 physical activity providers sign up for our online awareness course. We were currently providing grant funding to over 84 projects across the UK for activities like dance, boxing, hydrotherapy, and Nordic walking. Free on demand exercise videos were being developed with specialist Parkinson's providers as was our Being Active with Parkinson's guide, which will be available online and in print. We were also working with sporting national governing bodies and clubs, across the four nations, to train coaches and see how we could increase access to activities and sports.
- 1.12. Volunteers' great contribution to delivering the charity's programme of advice, support and activities across the nations was recognised.

Research

- 1.13. Arthur Roach, Director of Research, reflected that priorities from the Parkinson's community - as conveyed through workshops, surveys, panels and one-to-one conversations - shaped the whole of Parkinson's UK's research programme. Anyone who wished to get more directly involved was encouraged to visit the Research Support Network section of our website or write to us. For example, research grants were prioritised by panels that included people with Parkinson's whose votes counted alongside research advisers in decision making. The Parkinson's Virtual Biotech programme was dedicated to developing specific new treatments; groups for each clinical trial included people with Parkinson's alongside scientific and clinical experts.
- 1.14. The charity was currently funding four pre-clinical projects, each of which aimed to discover a new drug that would stop or slow progression of Parkinson's. These were the "cure" type of
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treatment. In addition the charity was helping research projects to obtain support from other funders to move forward two such projects which the charity had previously funded.

- 1.15. Clinical trials were the closest to delivering new treatments. Many people with Parkinson's were interested in participating in clinical trials and where they did so the insights could be especially impactful. Of the four clinical trials currently supported by our funding, two were looking at hallucinations and psychosis in Parkinson's, one for dyskinesia, and one that could lead to prevention of Parkinson's. Three additional trials were at various stages under consideration. Of these, one - currently our most challenging research project - was GDNF, which involved an experimental drug and an experimental surgical procedure to pipe the drug directly and precisely to the critical areas deep in the brain. To make a new trial possible we would have to secure the commitments of others to do their parts. While this might be neither easy nor possible, the charity proposed to pursue it because the project had the potential to deliver a fundamentally new treatment for Parkinson's with unique benefits.
- 1.16. Currently there were more than a dozen new potential treatments reaching people through clinical trials. At this stage they were experiments rather than proven treatments. In the UK, hundreds of people were enrolled and receiving the new agents. More such trials would start in the future. If all went well, in the most optimistic case, they might start to become standard treatments in three years. This should be seen as good news in terms of progress.
- 1.17. The charity would continue to drive forward involving people with Parkinson's and supporters through the research programme and fundraising.

Finances

- 1.18. Stephen Hooper, Director of Finance, reported that our finances had remained stable in 2021 and throughout 2022 so far. The charity was maintaining good cost management as well as seeing our income hold up well despite numerous challenges. Our performance had been driven by legacy income. The latter part of 2022 could be challenging, affected by the cost of living crisis together with disruption from the new Government's fiscal policies.
- 1.19. The charity's reserves remained healthy. We expected to finish the year with a surplus of around £1 million, but our reserves would be higher due to the sale of the head office building in central London. Stephen Hooper was pleased to report a positive financial position for the charity given the current general economic outlook.

Forward look

- 1.20. Caroline Russell, Chief Executive, reported that she had spent much of the year gathering insights from people in the Parkinson's community to inform our work. Based upon this we would be revisiting the work we did and how we delivered it. One priority would be to help people newly diagnosed with Parkinson's and their families.
- 1.21. Under the banner 'Project 300', the charity was campaigning for more Parkinson's nurses to support a workload of 300 patients per nurse. Currently, some of the 496 Parkinson's nurses had a thousand patients, which was unsustainable.
- 1.22. We were also looking to support the Parkinson's community to meet the growing interest in Parkinson's to ensure that people could access our digital and physical services to help people with Parkinson's lead active lives.
- 1.23. Finally we were looking to build on the research work. We were committed to virtual biotech but we also recognised that there was an increasing interest in non-drug based research such as
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nutrition, activity and complementary therapies. We wanted to share our knowledge more widely making sure that the Parkinson's community owned and supported the charity.

- 1.24. The Chair thanked the speakers for their presentations and moved to the formal part of the meeting.

AGM BUSINESS

2. Resolutions

- 2.1. The Chair reported that there were no resolutions to put to the meeting.

3. Receipt of the annual report and accounts

- 3.1. The Chair reported that the annual report and financial statements for the year ended 31 December 2021 had been published on the charity's website at the end of September following review by the Audit and Risk Committee and approval by the Board of Trustees. He recorded the annual report and accounts as having been received.

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

- 4.1. The Chair reported that the report from the Chair of the People Committee had also been published on the website and made available to members. He recorded this report as having been received.

5. Minutes of the 2021 Annual General Meeting

- 5.1. In the absence of points of accuracy raised or questions asked, the Chair took the draft minutes of the 2021 Annual General meeting as having been approved.

6. Provisional date of the 2023 Annual General Meeting

- 6.1. The Chair reported the provisional date of the 2022 AGM as Saturday 14 October 2023.

MEMBER ENGAGEMENT

7. Member engagement

The Chair encouraged members to take this opportunity to ask questions and have members' voices heard.

- 7.1. **Charlie Crossley (Member):** How is the research progressing to find a cure for Parkinson's? A lot of money has been spent but there has been no apparent progress over the years since my diagnosis.
- 7.1.1. Arthur Roach (AR), Director of Research, responded that finding treatments that have a real impact on Parkinson's is difficult. Parkinson's was one of the most difficult conditions with which to make progress but progress was being made. Significant investment was being made by charities such as Parkinson's UK, pharma companies and Government. AR believed that there was progress and pointed to evidence that research was finding a new wave of genetic and biological approaches from discoveries 10 - 20 years ago which were starting to reach clinics. In another few years it would be clear what experimental treatments would be successful and reach clinical care. The charity's goal was to support and accelerate this

work, Paul Jackson-Clark (PJC), Director of Fundraising and Experience, reminded everyone that people could join the Research Support Network to get involved in the research agenda and debate with the Research Team. Details were available through the charity website.

7.2. **John Kane (Member):** As a Parkinson's UK volunteer educator, I have delivered over 600 face-to-face courses in over 14 years. During the Covid pandemic online training had replaced face-to-face training. When is Parkinson's UK going to support volunteers committed to face-to-face training? And, how many educational courses other than mine have Parkinson's UK delivered over the past three years?

7.2.1. Emma Cooper (EC), Interim Director of Community and Participation, thanked John for his support and great volunteer educator achievement. The online training programme had started when the pandemic restrictions had stopped trainers from going, for example, into care homes hence the shift to online training. The programme had proved very successful because it had allowed care home staff and volunteers to participate at the same time and benefited less mobile participants in particular. This year 135 sessions have been delivered to nearly 1500 participants, a massive increase since 2020. The charity saw the value of face-to-face training in the community, while at the same time it saw the pressures that professionals were under and so the online training offer met a need.

7.3. **Kevin D S Towler (Member):** The MS Society has broadened its mission to include other conditions. What are the risks and opportunities to Parkinson's UK of the MS Society offering services in relation to other conditions? Amersham and High Wycombe branch work closely with the Chiltern MS Centre and see some positive benefits. How does our experience with our local MS Centre compare? Could Parkinson's UK formalise support for this to benefit our branches around the country?

7.3.1. PJC recognised local partnership working between local branches and the MS Society. Chester Branch had been an early adopter. EC observed that MS therapy centres are independent local organisations, without UK-wide coverage. The charity had a good relationship with these therapy centres, signposting people to them and collaborating with them, and was keen to build upon and encourage this local access for people with various neurological conditions. Local development managers look at ways to work with MS centres. The Chair added that we are looking at how we share things across the charity, to transfer awareness of what works well from one group to another, such as collaborating with the MS Society. Caroline Russell (CR), Chief Executive reflected that the charity supported the benefits of collaboration at every level from local to national to give people a choice. The Neurological Alliance brought together relevant interest groups together to campaign with a single voice in relation to neurological conditions, particularly dementia and Alzheimer's groups.

7.4. **Karen Bown (Member):** Are there any plans to re-establish community support workers across the country? Doing away with them has caused hardship for people with Parkinson's because they had no idea what was available to them.

7.4.1. EC pointed to the organisation's different staff working across different areas, development managers, advisers and helpline services, to deliver our services. All these staff have a local presence. There has been an increase in the number of people who access our adviser and helpline services. We need to ensure that these services are sufficiently resourced. The helpline now provides access to local services previously accessed by through the local contact. While we no longer have the community support worker title, other staff now deliver the same support, putting people in touch with a local person where necessary.

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- 7.4.2. CR said that while some people might feel a sense of loss not being able to see people face to face, post lockdown our phone line service and digital offer are delivering all the services we delivered before the Covid pandemic lockdown. Our staff undertake the key support roles but one of our main priorities is to increase our face-to-face communications with the Parkinson's community.
- 7.5. **Alan Dunwell (Member):** Has Parkinson's UK placed enough emphasis on promoting exercise such as boxing, to help alleviate Parkinson's symptoms, as well as its research investment into drug treatment and cure? From looking at Parkinson's UK's accounts, the member questioned whether sufficient resources had been placed in their area. Mr Dunwell's drug regime had benefited greatly from exercise. If Parkinson's UK shifted its priorities to exercise it would reduce the cost of care in future.
- 7.5.1. CR recognised Mr Dunwell's points. The charity was committed to promoting activities, spending money on promoting them and working with other bodies, to promote them. Plans included a significant increase in the range of activities the charity offered to widen the appeal of activities to people with Parkinson's. Over the next year the charity would be taking a more strategic view of the importance of exercise to ensure that everyone affected by Parkinson's could find their activity.
- 7.5.2. The Chair agreed on the importance of exercise for people with Parkinson's. The charity already allocated significant funding for support services and would do more to enhance the focus on specific exercise activities and the availability of information about them in future. The research programme was not just about funding drugs-related research, as the Director of Research had set out. A proportion of the charity's donors wanted their donations to be placed in research areas, while others were pleased to donate to support our work helping people to live with Parkinson's, contributing to an increasing focus on diet, mindfulness and exercise.
- 7.6. **Neil Morrison (Member):** What are Parkinson's UK doing to help people with outreach to communities with help to access the charity's services, for example people who feel uncomfortable about going out and doing exercise with others or even admitting that they had Parkinson's?
- 7.6.1. EC acknowledged that the pandemic has hit people's confidence about going out and about in addition to which there exists a group of people who did not feel able to go out to meet other people. Parkinson's UK was building a community offer to provide activities, support and friendship either face-to-face or through a Connect Online forum where people can talk with each other. People who could not get out were encouraged to contact the charity's helpline and advisers' services for support and signposting.
- 7.6.2. CR referenced that the charity was in contact with around 40,000 of the 145,000 people with Parkinson's in the UK. It was a challenge for the organisation to connect with everyone with Parkinson's. Some people with Parkinson's might not feel that the charity is relevant to them, but there was a huge proportion of people who would benefit from our services and contact. This contact might be digital, by phone, or through volunteers and networks. Parkinson's nurses were one point of contact for people with Parkinson's. Working through the Excellence Network and a linked exercise hub, the charity was working to signpost people to exercise through clinical support and exercise providers to help individuals to stay healthy. To provide individuals with the most helpful information, the organisation was learning how different parts of the Parkinson's community interact with us and sought to hear from people about the best ways to communicate and create links.
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7.7. Phil Bungay (Member): What is Parkinson's UK's offer to people newly diagnosed with Parkinson's?

7.7.1. CR pointed to the First Steps programme and guidance to give support to people newly diagnosed with Parkinson's. While website-held information could be hard to find, going beyond website-held information, CR also appreciated that information for people newly diagnosed should touch upon the emotional support which people newly diagnosed with Parkinson's might want. Shared examples from people who have had similar lived experience to create dialogue around the point of diagnosis could be beneficial, so long as data protection rules could be met. We have an enthusiastic community who can offer this support to people newly diagnosed with Parkinson's. The charity was seeking feedback from people regarding what they found helpful and what they did not find helpful when they had been newly diagnosed, and was seeking to listen and learn, including carers in the listening exercise.

7.8. Linda Bishop (Member): Why do people at Parkinson's not reply to emails or telephone in many cases. The person trying to get an answer gets very frustrated and it can turn into a nasty exchange of words. By not replying you cause extra anxiety

7.8.1. PJC recognised that we need to improve our customer care and feedback to respond positively and to avoid missed opportunities. CR referred to the charity's work which was addressing the importance of leaving individuals who make contact feeling that they had been heard and had received a quick response. The organisation was working to instil working practices which ensured a prompt and transparent reply reached each person waiting for an answer, even if the answer might disappoint.

7.9. Margaret Chamberlain (Member): Would the board consider for a future AGM the model of an in-person event with in-person gatherings at different locations feeding in remotely, with inspiring, practical content that incentivised members to attend because it was more than a formal session? This had happened previously, for instance at a gathering in Birmingham. This was not to denigrate the value of the formal proceedings, but to make the time and journey worthwhile.

7.9.1. The Chair and PJC were pleased to agree that this would be the plan, looking forward to a valuable in-person and remote combined future event which offered members full value from activities wrapped around the formal meeting.

7.10. Colin Rickards (Member): I've run a cafe for 4½ years. Attendance numbers are down following the Covid pandemic. How can we make ourselves visible to people who need our support to get people with Parkinson's to return to us and how can we get people newly diagnosed with Parkinson's to come to us? I find that people are travelling long distances to attend meetings, they need to know where there are cafes closer to them.

7.10.1. Elaine Evans as Trustee for Wales responded that her experience of the Llandudno Group had been very positive, perhaps thanks to active follow up and reaching out to new people.

7.10.2. EC agreed that cafes were a great way of bringing people together though some people remained anxious about going out and about following the Covid pandemic. Some cafes have not restarted following the pandemic but things were picking up. The charity was raising awareness of local activities, including cafes: people could access local groups and activities on the charity website by typing in their postcode or by making contact through our helpline. CR suggested that the charity's local adviser might be able to help with spreading the message about the availability of the cafe and local activities through GP surgeries.

7.11. Andrew Logan (Member): How is Parkinson's UK raising the general awareness of Parkinson's in the community? People diagnosed with Parkinson's, their families, friends and healthcare professionals knew about the condition, but wider awareness seemed low. Could the charity raise greater awareness through, for example, education in colleges and schools?

7.11.1. CR pointed to raising awareness as top of the charity's campaigning agenda, building on established work that the charity had carried out. Decision-makers were key, to ensure the right services - such as benefits - were available to people with Parkinson's. Work to influence employers to continue to employ people with Parkinson's was in place: for example an initiative with Next, where a person with Parkinson's was raising awareness about what it is like to have Parkinson's. The charity's new advertisement featured people stating that their Parkinson's would not define them. Peter Miller, a Trustee for England pointed to recent television programmes and interviews with well known presenters such as Jeremy Paxman, Rory Cellan Jones and Mark Mardell, all raising awareness of their lives since diagnosis. The Chair highlighted plans for a November webinar on Parkinson's and what it means for a bank with Barclays. This webinar had been instigated by a charity supporter, the partner of a person with Parkinson's: this was a good illustration of a person's connection helping raise awareness.

7.12. Noel Robertson (Member): Why doesn't Parkinson's UK have charity shops?

7.12.1. PJC responded: In his in directing fundraising experience, charity shops could be a complicated business with poor margins relative to other fundraising channels, given the infrastructure and overhead costs, warehousing, people, leases and the competition on the high street. The charity had no plans for a high street presence for the foreseeable future. The online shop continued to sell living aids, greetings cards, gifts and branded merchandise.

7.13. John Buckley (Member): Could we do more to promote the Parkinson's Professionals organisation working with the walking football team which does a lot for people with Parkinson's? Also, how many people working for the charity have Parkinson's? I contacted the charity with an idea for a T-shirt to make people aware of people who have Parkinson's. When I fell down, someone recognised my problem because of my T-shirt. I suggested a competition to promote this T-shirt but received no reply from Parkinson's UK. How many people do you employ who have Parkinson's who understand the issues we have, because if you did I think I might have received a response.

7.13.1. Kerrie O'Connor (KO'C), Director of People and Operational Services knew of three charity staff members with Parkinson's who were willing to share their diagnosis with the charity. The organisation recognised that there was more to do and actively tried to recruit as many empl. Recruitment practices had been changed recently to try to get as many applications with people as possible with Parkinson's, but we could do better. We have recently changed our policies to increase the number of job applicants with Parkinson's. Elaine Evans, Trustee for Wales added that a number of trustees have got Parkinson's so decisions about Parkinson's are at the forefront of our decision-making process. PJC would follow up with Mr Buckley regarding walking football, of which CR was also a fan.

7.14. Kay (Member): What is Parkinson's Connect and what is it going to look like in practice for people who have been diagnosed for a while? Is Parkinson's UK planning to increase digital services and freeze or reduce adviser and helpline services as an integral part of Parkinson's Connect? What is the process of selection for people who manage to get involved in major

projects such as Parkinson's Connect? I have tried and tried to be involved but get no further than nice words and vague offers that never materialise.

- 7.14.1. KO'C set out Parkinson's Connect as the charity's adviser service and helpline and our online and digital support offer. We recognise that some people might be confused by this. We need to look at how we talk about our information and support services, taking on board the feedback that face to face contact is important to people. The charity was reviewing our online digital support and other ways we provide help and support looking to increase our in-person and digital services. The in person and adviser services were essential and the charity was not planning to freeze or reduce them.
- 7.14.2. EC apologised for Kay's experience of not hearing from the charity when trying to get involved. Volunteering opportunities are advertised on our website, with volunteering opportunities advertised through the volunteering platform, although there are limitations to that approach. We are looking at a variety of ways in which to connect more in the future with people in local communities and for people with Parkinson's to have their voice heard.
- 7.15. **A Villamil (Member):** At our local working-age group meetings, people would like to have a greater connection with Parkinson's UK. How can we get people from the charity to speak at our meetings? These groups are a great success but there is a lack of connection with the charity. This is our opportunity and a recruiting ground for volunteers.
 - 7.15.1. EC reflected that the charity was very supportive of this opportunity to connect with the Parkinson's community and encouraged further discussion outside the meeting.
- 7.16. **Kevin D S Towler (Member):** During the lockdown period, people embraced online meetings. Following the lockdown people would like a combination of online, e.g. Zoom, and face-to-face meetings but many local groups do not have the technical expertise to provide this and they have problems recruiting people. Branches are struggling. Could Parkinson's UK formalise support for a broader mission (like the MS Society) to benefit our branches around the country?
 - 7.16.1. Elaine Evans, Wales Trustee, responded that one way of overcoming the problem of recruitment was to form a support group, rather than a branch. A support group only required a treasurer.
 - 7.16.2. CR regularly visited local groups to ensure that we are engaging with our volunteers across the country, and reinforced the point that local groups are fundamental to the Parkinson's community. Without branches, people with Parkinson's would not have the support they need. Ways forward needed to be found to offer technical skills not available in some of our branches to our groups. CR was keen to hear how we can remove our bureaucracy, so people will not be intimidated about volunteering. Local groups inform the organisations where they seek help, and CR encouraged more to do so in order that local needs could be met.

8. Thank you and close

- 8.1. The Chair closed the meeting by thanking, on behalf of the board and the executive team, everyone for attending a stimulating and thought-provoking session. While no cure for Parkinson's had been found since it was first described over 200 years ago, Parkinson's UK collaborated globally in the search for a cure. The charity was assisting the Parkinson's community during a challenging economic period with its effect on services and the uncertainties caused by the Covid virus. The charity's expertise and resources saw us continuing to support people with Parkinson's to manage their symptoms and continue to live well in daily life with the condition.

8.2. The Chair declared the meeting closed, ending the session by sharing with its participants a viewing of the recent TV advertisement celebrating the diversity of the Parkinson's community.

Provisional date of next meeting: Saturday 14 October 2023

Panellists

Gary Shaughnessy (Trustee and Chair)
Matthew Durdy (Trustee and Vice Chair)
Kyle Alexander (Trustee)
Jane Burston (Trustee)
Andrew Cavey (Trustee)
Elaine Evans (Trustee)
Katrina Green (Trustee)
Annie McCallum (Trustee)
Peter Miller (Trustee)

Caroline Russell (Chief Executive)
Emma Cooper (Interim Director of Community and Participation)
Stephen Hooper (Director of Finance and Planning)
Paul Jackson-Clark (Director of Fundraising and Experience)
Kerrie O'Connor (Director of People and Operations)
Arthur Roach (Director of Research)
Oliver Wareham (General Counsel)
Lydia Barnett O'Regan (Webinar coordination)

Membership attendance: 163 members joined the meeting
The charity's External Auditor was in attendance