

## DRAFT MINUTES

# Parkinson's UK Annual General Meeting

10am, 24 October 2020

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### MEETING OPENING

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

- 1.1. Gary Shaughnessy, Chair of the Board (the Chair), welcomed everyone to the AGM.
- 1.2. Owing to the Covid-19 pandemic restrictions, the AGM was taking place via the internet and not with members meeting in person. In these circumstances he was pleased to confirm that he had been appointed as proxy by the minimum 50 members required under the articles of association for the quorum necessary to conduct the meeting.<sup>1</sup>
- 1.3. When the charity had met at the previous year's AGM, no one had any expectations of the scale of change that lay ahead. It had been a hugely challenging year for people across the world. For many people with Parkinsons it had been a year of change, fear and often isolation.
- 1.4. As the COVID 19 numbers were now rising again, concerns were increasing for everyone; individual members of the Parkinson's community had lost their lives and others their livelihoods. There would also be long-term impacts of Covid for many , including impacts directly or through delays in treating other conditions or delays to diagnosis of Parkinson's.
- 1.5. However, the pandemic had also shown the tremendous spirit and resolve of the Parkinson's community - volunteers , friends, family and employees of Parkinson's UK and specialists in the health service - supporting the community through this difficult time.

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<sup>1</sup> For formal purposes those present at the meeting were Gary Shaughnessy (Chair and member), Kate Monro (Company Secretary and Member) and Steve Ford (Chief Executive)

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- 1.6. During the past year the environment in which the charity operated had become more polarised: the number of people diagnosed with Parkinson's continued to rise, as had pressure on NHS services. In addition there were the challenges of mental health issues in lockdown and shielding and the isolation which was the reality for many of our members. On the other hand research opportunities had progressed and the charity had embraced technology to support exercise and sharing experiences across the community. Beyond the technology, the Chair believed that society was once again remembering the importance of community and connection. The challenges of 2020 had inspired and brought out the best in people.
- 1.7. The Chair congratulated the members and volunteers who had recently received Queen's Birthday Honours. Those the charity was aware of were:
- Paul Mayhew-Archer, MBE, for services to people with Parkinson's & cancer
  - Jack Glenn, BEM, services to the community in Londonderry
  - Bert Baillie, BEM, services to people with disabilities and older people in Northern Ireland
  - Shirley Clegg, MBE, services for prison visiting.
- 1.8. The Chair then outlined the proceedings for the meeting. He asked anyone who had attended the previous year's AGM who wished to raise any points with regard to the accuracy of the minutes, which had been circulated for approval, to raise them in the Q&A box in advance of the agenda item being dealt with at the formal AGM.
- 1.9. As members were not gathered in one place, voting on formal resolutions would only be by proxy. The Chair would cast the proxy votes received in order to vote on the resolutions.
- 1.10. Following the formal business of the AGM there would be a Q&A session which would be facilitated by Clare Addison and Jane Rideout, two of the charity members who had been instrumental in designing and delivering members' events, to ensure that the questions most on members' minds were responded to. The panel of people responding to the questions would comprise trustees and members of the senior management team.
- 1.11. The Chair invited Steve Ford (SF), Chief Executive, to address the meeting in relation to the charity's activities in 2019 and 2020.
- 1.12. SF said he would spend some time reporting on the charity's activities in 2020. The restrictions which the Government had brought in to counter the Covid-19 pandemic had made it a particularly tough year for people with Parkinson's and their families: the isolation and anxiety, the lack of access to healthcare and to local group activities for exercise and social support had had a significant impact on people's mental and physical wellbeing.
- 1.13. The charity had responded quickly to rapidly changing circumstances but its strategy priorities were just as relevant and the charity remained committed to these priorities:
- Better support every day
- 1.14. Parkinson's Direct was an ambitious project to provide people with personalised information and support offering a proactive service both on and off-line. During the year it had rapidly adapted the way it delivered information and support, using new tools and resources to keep people up-to-date.
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- 1.15. Many groups had moved their activities online. SF had joined a number of these sessions in recent weeks. Feedback had shown that the loss of the ability to exercise had been a challenge for people with Parkinson's. To address this, the charity's physios had provided classes through our YouTube online channel. The First Steps programme for people newly diagnosed with Parkinson's had gone online and would be rolled out over the rest of the year. However, the charity was very aware that a significant proportion of the Parkinson's community were not online, so the charity was looking at how to serve them.
  - 1.16. One of the charity's priorities was to work with colleagues in the NHS providing services and advice to people with Parkinson's. Parkinson's UK's Excellence Network was achieving this by supporting people in rebuilding their services to meet added demand during the pandemic. The charity was determined that all People affected by Parkinson's would receive the support they required through this difficult time.

#### Accelerating breakthroughs in research.

- 1.17. The charity had not paused its research ambitions. It was determined to maintain its research spend in spite of the uncertainty over income. It had expanded the Virtual Biotech portfolio. New clinical trials were starting, having been redesigned to enable more remote monitoring, and the charity would shortly announce an exciting partnership with the Michael J Fox Foundation.
- 1.18. The charity was determined to support the research community to share and learn from each other. This year the research conference had been held online, achieving its highest attendance to date, with 467 people attending.
- 1.19. The Research Support Network had continued to shape and support the charity's research programme in many ways. The charity was determined to find a new treatment by 2024, which would only be achieved through working with partners
- 1.20. Members were reminded to use the Take Part Hub to see the opportunities for people to join a research study or trial, locally or from home.

#### Getting Parkinson's understood

- 1.21. Now, more than ever, the charity needed to increase awareness and understanding of Parkinson's and the charity's work. Its campaign priorities survey had ascertained the Parkinson's community's priorities.
  - 1.22. The Get It On time campaign had resulted in a 20,000-signature petition being presented at an online event supported by politicians from all over the UK and the international Parkinson's community had worked together to promote World Parkinson's Day.
  - 1.23. The challenge for the year ahead was how to raise money and ensure that people understood the needs of people with Parkinson's and the charity's support for them. To this end, the charity's emergency appeal had met with a very good response in raising £1.3 million. Similarly, the 2.6 challenge had met with a good response; this fundraiser had replaced the London Marathon, which had been cancelled due to the restrictions imposed in response to the Covid pandemic.
  - 1.24. The charity was determined that many more people should understand what Parkinson's was and should care about those affected and be inspired to take action. To aid this, a TV advertising campaign, Time for Can, would be launched on Channel 4 in November. It was an
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integrated campaign aimed at increasing the understanding of Parkinson's among an unaffected audience. A target of 43 million views had been set.

- 1.25. SF concluded by saying how proud he was of the charity's staff and volunteers in the way they had met the difficulties of the past year through living the charity's values: People First, Pioneering, Driven and Uniting. He believed it was this attitude and these values which would see the charity through the months ahead.
- 1.26. SF introduced Stephen Hooper (SH), Director of Finance to talk members through the charity's financial position.

#### Charity financial update

- 1.27. The charity's income had grown over the past five years and 2019 had been a good year for the charity financially: income had risen by 35% (£8m) from 2018, mainly as a result of a change in the legacy policy and a large gift (£4m) from an anonymous trust. So, on a like-for-like basis, income had remained stable from 2018 to 2019.
- 1.28. The charity's spending in 2019 was similar to 2018 but during the year action had been taken to reduce the cost base, which had stood the charity in good stead to manage the challenges in 2020.
- 1.29. The charity's reserves had grown by £2.5m in 2019, as a result of its investments performing well and the £4m gift.
- 1.30. During the year the board and management team had worked together more closely than ever to protect the charity's financial sustainability. When lockdown started, a Crisis Team of trustees and management was formed to scrutinise finances on a weekly basis.
- 1.31. The charity's reserves remained stable and the charity would end 2020 close to a break even position which was a remarkable achievement in the circumstances
- 1.32. Predicted income for 2020 was £31.6m, which was £3.2m lower than the budgeted figure but much better than that anticipated at the start of the pandemic. Most income channels had held up well in 2020, with legacies and major gifts being ahead of budget. The regional events programme had borne the brunt of the impact of the pandemic giving rise to a substantial loss of income through this channel.
- 1.33. To put this in context, the charity sector stood to lose £12.4bn (24%) of income in 2020. This showed the scale of the challenge the charity was facing and how well it was doing in the circumstances.
- 1.34. In the light of the pandemic's impact on local groups' ability to fundraise and provide important local services for the Parkinson's Community, SH thanked the local groups for their generous financial support in response to the pandemic, which had seen them transfer over £630k to bolster the charity's finances.
- 1.35. The charity would continue to support groups during the crisis through its cash-pooling platform, tackling the challenges which lay ahead, together.
- 1.36. The charity's spending in 2020 had been carefully managed and costs had been managed, saving £4.4m on the budgeted figure, while protecting research spending of over £8 million. It was noted that some cost-savings had resulted from the cessation of face-to-face activities and fundraising events.

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1.37. In conclusion, the charity's finances had remained stable in 2019 and in 2020 the charity had performed better than the sector as a whole. However, 2021 would be a challenging year, with fundraising continuing to be vital in order to fund the provision of services, support for everyone with Parkinson's, and the charity's important research programme.

Chair's summary

1.38. In conclusion, before the formal business of the meeting, the Chair summarised a few points.

1.39. The Virtual Biotech programme was showing real success and potential by accelerating the funding of research which the charity believed would make a critical difference.

1.40. The Parkinson's Connect programme was well positioned to make a real difference, for example, by linking newly diagnosed people in a more coherent way to the services that Parkinson's UK offered, including putting people in touch with local branches and community networks. Its work to date had been funded by institutional donors and the next phase had been underpinned by a £600k matched fund established by the Frank Brake Charitable Trust.

1.41. Financially the charity had weathered the first part of the Covid-19 pandemic storm exceptionally well, reducing costs and managing to limit the reductions in income which all charities were seeing.

1.42. The Chair thanked everyone who had delivered support to the Parkinson's community during this difficult period in countless ways, including locally, through the helpline and website.

1.43. The community's innovation in supporting exercise and social activity and continuing to push forward programs like First Steps and Live Loud had been critical during this period when continuing face-to-face activity had been limited. This was even more important in the face of the pressures on the NHS where core services around hospitals, care homes and medication supplies were creaking. Parkinson's UK would continue to engage government and NHS management to ensure that the needs of the Parkinson's community were not put aside because of Covid-19 or Brexit.

1.44. At the previous AGM, when he had become chairman, the Chair had raised his concern that at times the Parkinson's community was fragmented. It was clear that some progress had been made and while the current environment had limited this in some ways, it had also opened up opportunities. The charity's clear priority had to be to reflect the community it served and be driven by the needs of all people with Parkinson's. This had to be more than an intention, to achieve this the charity had to build on the progress it had made.

1.45. The Chair concluded the informal presentations and turned to the formal business of the meeting, for which purpose the documents to be considered had been circulated to members in advance of the meeting and resolutions had been circulated for members to vote on in advance of the meeting.

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## 2. Receipt of the annual report and accounts

2.1. The Chair invited the meeting to note the receipt of the charity's accounts for the financial year ended 31 December 2019 together with the trustees' and auditors' reports on the accounts. The accounts had received an unqualified audit opinion from external auditors, BDO LLP, in accordance with the SORP charities' recommended practice and had been endorsed by the Audit and Risk Committee at its June 2020 meeting, and approved by the Board at its July 2020 meeting.

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- 2.2. Members noted the receipt of the charity's annual accounts for the financial year ended 31 December 2019 together with the trustees' report and auditors' report on these.
  - 2.3. The Chair recorded the annual report and accounts as received.
  - 2.4. Any questions on the annual report and accounts would be taken during the Q&A session.

### **3. Receipt of the report of the Chair of the People Committee**

- 3.1. The Chair reported that the report from the Chair of the People Committee (formerly the Nominations & Remuneration Committee) had been circulated to members.
- 3.2. There had been three developments to bring to members' attention:
- 3.3. David Burn was stepping down as a trustee at the end of the AGM, due to work commitments. The board was very sorry to be losing him. On behalf of the board and members, the Chair thanked David for his long-standing commitment to the charity.
- 3.4. The board had appointed Katrina Green as Finance Trustee for a term of four years. Katrina had previously been co-opted.
- 3.5. The board had co-opted Tim Tamblyn for up to one further year. The charity had been under considerable financial pressure in 2020 and the board had felt that it would be detrimental to the charity to lose Tim's specific expertise at present.
- 3.6. The Chair invited the members to note the receipt of the report of the Chair of the People Committee.
- 3.7. The members noted the receipt of the report.
- 3.8. Any questions on the report would be taken during the Q&A session.

### **4. Resolution (R1): re-appointment and remuneration of the auditors**

- 4.1. The Chair proposed the resolution: that BDO LLP be re-appointed as auditors of the charity and the Board of Trustees be authorised to agree their remuneration.
- 4.2. The Chair reported that he had received 1,110 non-discretionary votes in favour of the resolution and 16 against. He had also received 666 discretionary votes, which he had cast in favour of the resolution. He confirmed that the resolution had been carried by 1,776 votes to 16.

### **5. Special resolution (R2); changes to the Articles**

- 5.1. The Chair reported that several proposed changes to the charity's Articles of Association had been circulated in advance of the meeting. The purpose of the changes was to reduce barriers which might deter members with Parkinson's from standing for election and to allow the use of electronic facilities and attendance at satellite meetings as part of the AGM.
  - 5.2. The Chair reported that he had received 1,080 non-discretionary votes in favour of the resolution and 12 against. He had also received 699 discretionary votes, which he had cast in favour of the resolution. He confirmed that the resolution had been carried by 1,779 votes to 12.
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## 6. Minutes of the 2019 AGM

- 6.1. The Chair asked the Company Secretary if any points had been received regarding the accuracy of the draft minutes. The Company Secretary confirmed that no points had been received.
- 6.2. The Chair confirmed the meeting's approval of the minutes.

## 7. Provisional date of the 2021 AGM

- 7.1. The Chair reported that the provisional date for the next AGM was Saturday 25 September 2021.

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## MEMBER Q&A

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### 8. Member Q&A

- 8.1. **Member's name (unknown)<sup>2</sup>**: what would be the financial challenges to the charity over the next year or two? How might they impact on the charity's resilience?
  - 8.1.1. The Chair responded that the charity's reserves were robust. This would allow the charity to choose how to respond to our priorities in the immediate future.
  - 8.1.2. Steve Ford (SF), Chief Executive said that in the present climate no one could see far ahead nor knew how far into the pandemic we were. There would be an economic downturn and the charity would have to consider its impact on its work. In planning for 2021 a conservative approach was being adopted maintaining similar levels of expenditure as in 2020, but finances would be closely tracked and changes to the way of working would be made quickly as necessary to meet the changing conditions.
- 8.2. **David (member)**: in a pie chart for research spending, how big would the slices in the pie be between support for everyday living and research? How might this division change and why?
  - 8.2.1. SF responded that the balance of funding for research and day-to-day support was a question he was dealing with all the time. In recent years the aim had been to protect and increase the share of research spending but, in the environment which the Covid-19 pandemic had created, the charity needed to increase our support for the day-to-day needs of people with Parkinson's. This might require some tough choices, but the solution was to continue to grow income to fund the best possible research and support.
- 8.3. **Anil Vaghmaria (member)**: following George Floyd's death on 25 May, Parkinson's UK issued a statement on 5 June regarding its response to the black lives matter campaign. It later acknowledged that it had been wrong not to issue its response at the time of Floyd's death. There was a general acknowledgement of racism in the charity sector. What was Parkinson's UK doing to address the matter in the charity and was it treating this as a priority?
  - 8.3.1. **Julie Dodd (JD), Director of Transformation, responded**: initially we had decided not to put out a response so that we would not be seen as another organisation jumping on the bandwagon. Feedback on the statement that was issued later was both positive and negative and we know this is an emotive issue. Reflecting on the position we saw that

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<sup>2</sup> Names of members have been recorded in the minutes where verbally stated, or visible via the recording or where questions were submitted in advance.

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involvement in our research and other areas of our work was not representative of the community, and this was a pattern across a large part of the charity sector.

- 8.3.2. Diversity is an organisational priority. If the charity wants to be there for everyone with Parkinson's then it needs to work particularly hard to reach under-represented groups, and that is not just about racial diversity, it is also about disability and gender and other aspects of diversity. This is also relevant to the charity's responsibilities as an employer.
- 8.3.3. All staff, and some priority groups of volunteers, had undertaken diversity awareness training. Diversity which would raise diversity issues as part of the work people undertook rather than as a separate diversity project.
- 8.3.4. Diversity action plans were being introduced for all major programmes of work so that all of the charity's team are thinking about how they can better reach under-represented groups through their work; this will help to embed diversity into the charity's work. Diversity in medical research is a challenge and the charity is looking at the influence it can have in this sphere.
- 8.3.5. The charity is also changing its recruitment and selection processes to ensure that these enabled the recruitment of a broader range of people.
- 8.3.6. The Chair confirmed the charity's absolute commitment to ensure that it represented and was accessible to all members of the Parkinson's community. This means expanding the charity's existing reach beyond those to whom it currently provides services and advice to.

8.4. **Julie Adby (Member), on behalf of the York, Harrogate and Scarborough groups:** this morning attendees had heard how the charity valued its volunteers, but what did this mean on the ground? How can the charity value volunteers more? If the people on the ground didn't feel valued, they could not sell the charity to other people to get them involved. Sometimes volunteers did not feel as valued as they might and this could be improved by:

- (1) The language used in relation to volunteers: it should be 'working with volunteers' rather than 'providing things to volunteers', and asking not telling.
- (2) Involving volunteers at the start of initiatives to allow volunteers to contribute from the beginning.
- (3) Allowing volunteers ideas and views to be heard more, including by trustees. Responses from trustees would help volunteers and members to feel valued.
- (4) A volunteers' skills-map to make better use of volunteers' skills.
- (5) Exploring volunteers' representation within the charity and feeding back to volunteers about how their voice was heard within the charity.

8.4.1. **Katherine Crawford (KC), Director of Services, responded:** she thanked volunteers in North Yorkshire, with whom she had worked closely, along with all of the charity's volunteers, for the work they did on behalf of the charity and the Parkinson's community. The questions from the North Yorkshire groups had been submitted before the meeting and had been responded to in the written Q&As.

8.4.2. People living with Parkinson's were at the heart of what the charity does and there were many aspects of its work in which this could be demonstrated, where volunteers and

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people with Parkinson's taking important decisions for everyone living with Parkinson's. helping in our work and making important contributions to improving the information, services and conditions for people with Parkinson's - such as the research grants programme, the financial assistance programme and the development of World Parkinson's Day 2021.

- 8.4.3. In local communities the charity is working to pull together members of the Parkinson's community to inform the charity's priorities for the next year. Members can get involved via their area development managers.
- 8.4.4. Volunteers were involved in this big journey, which was part of the charity's cultural transformation which, as JD had touched upon, would involve recognising volunteers' skills as part of the work we would be undertaking on our culture during 2021.
- 8.4.5. Margaret Chamberlain (MC) introduced herself as Chair of the People Committee, which had been set up this year to build upon and broaden the work of the former Nominations and Remuneration Committee. The committee's remit included volunteers and it had already held a meeting focussed on volunteers: the committee recognised the issues which had been raised. She would ensure that the committee followed them up at future meetings.

8.5. **Harry (Member):** There had been an issue in the area regarding the local adviser, what had been going on?

- 8.5.1. The Chair suggested that as it was a specific local issue, Katherine Crawford would pick it up outside the meeting.
- 8.5.2. Clare Addison noted that there were differences in the way different local groups were run and asked whether the charity had thoughts on that should be more standardised.
- 8.5.3. With regard to changes which had been made in respect of local advisers, KC acknowledged that some big changes had been made to information and support services during the past year. Local advisers had not disappeared, but there were fewer people in those roles. However the charity had improved the way people could access this advice either by phoning the helpline (callers could book a call, if they wished) or contacting the charity through the website. This approach helped channel the service and provide the support which was needed.
- 8.5.4. Parkinson's UK had a fantastic range of over 300 local groups across the UK, with thousands of volunteers running some substantial programmes. Groups varied with regard to volunteer capacity, their location and what was needed locally. Groups had local rules and governance which set minimum standards regarding how they were run and what volunteers did. It would be difficult setting one standard what groups should deliver., so the running of groups was for local volunteers to do. However, it was important for the charity to be able to co-ordinate the work which local groups did. People could contact KC through their local group or by emailing her directly. She invited people to do this to help shape plans for 2021.
- 8.5.5. Jane Rideout suggested that with more groups now using zoom, people could always join another group online if they felt they were not getting what they needed from their own local group.

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- 8.6. Jane Rideout noted there had been a number of questions in the chat function about what Parkinson's Connect was offering.
- 8.6.1. SF, Chief Executive, responded: Parkinson's Connect was an ambitious programme aimed at standardising the charity's information and support offer for everyone. Currently, people living with Parkinson's had to navigate a range of channels to find the support that was suitable for them. Parkinson's Connect will pull together the support and information available - e.g. the helpline, the local adviser service, the website - to provide people with information that is relevant to where they are at that point in time.
- 8.6.2. The starting point of Parkinson's Connect would be ensuring that professionals diagnosing Parkinson's put their patients, and those supporting them, in touch with the charity as soon as they had been diagnosed; this contact with the charity would continue as someone's Parkinson's progressed. The charity was currently undertaking this work with three hospitals across the UK and would shortly roll it out to a further ten hospitals.
- 8.6.3. Parkinson's Connect was innovative and ground-breaking work for the charity - the ambition was to use the model to contact everyone with Parkinson's and provide them with personalised support.
- 8.7. **Kay (Member):** when high quality healthcare is mentioned does the charity think that a move towards increased digitisation and taking control / self-care and rationing of access to specialists is what people living with Parkinson's want? People living with Parkinson's should be listened to as independent people.
- 8.7.1. Katherine Crawford (KC), Director of Services, responded: people living with Parkinson's should have access to the right care and support to live as well as possible at all stages of the condition. Parkinson's affects different people differently and therefore people will have differing expectations and needs from NHS services, but everyone must have access to the appropriate specialist support. This was an important factor in the charity's work campaigning and influencing to get the support people needed.
- 8.7.2. In the matter of access to specialist nurses, this was patchy in areas and there was more work for the charity to do. The NHS was currently under considerable pressure and known workforce issues had been exacerbated by the demands imposed by the present Covid-19 pandemic. Access to appointments via phone or videoconference had accelerated and while this suited some people well it was not for everyone. There was a role for the charity to play in influencing the NHS to ensure that people could access appointments in a way that suits them best.
- 8.7.3. People with Parkinson's should be first and centre in influencing their care and how that was delivered.
- 8.7.4. KC said that if people felt that they were not getting the care they wished, they were strongly encouraged to contact the charity's helpline so that the charity could support them in getting the best possible care.
- 8.8. Colin Cheesman, member: (1) Parkinson's Connect needed to ensure that people with Parkinson's had access to the information they required in a way which was sensitive to the individual's needs, as each individual diagnosed with Parkinson's responded to the diagnosis in different ways. (2) He agreed with everything that had been said in response to the question from the North Yorkshire groups (paragraph 9.4, above): the charity must be open to hear from
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its grass roots. (3) Regarding the special resolution which had been passed to remove the barriers which people with Parkinson's might have in getting elected to the Board, people with Parkinson's needed a strong voice on the Board of Trustees. What were the barriers which had been referred to?

8.8.1. **The Chair responded to the third point:** prior to the passing of the resolution, the rules set a four-year term of office for elected trustees. This was a long commitment but people with Parkinson's did not know how their condition would have progressed in four years time. The change in the rules would allow people with Parkinson's to feel comfortable in putting themselves forward for election to the board and not feel restricted in doing so by the four-year term of office. While the change in the rules should allow greater representation on the board among people with Parkinson's, they were already strongly represented on the board to the extent that more than half the trustees had Parkinson's or had a family connection to someone with Parkinson's. The Chair noted that the trustees had a huge breadth of skill and experience more generally, and took the opportunity to thank the trustees for their work and support over the past year.

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## 9. Thank you and close

- 9.1. The Chair thanked Clare Addison and Jane Rideout for managing the Q&A session and thanked everyone who asked questions. He thanked those who provided the technological support and thanked people for their patience on the one or two occasions when it had not run smoothly. Answers to the topics which had not been covered during the Q&A session would be posted in writing and, where appropriate, we would respond to people in person.
- 9.2. The Chair stated that the Q&A session had emphasised the importance of communication, open listening and working together.
- 9.3. 2020 had been a strange year for everyone across the Parkinson's community. He thanked all Parkinson's UK volunteers, employees, trustees, management team, fundraisers, donors and others for all they had done for the charity during the year.
- 9.4. It was easy to get disheartened in the face of the challenges which the year had presented, but Covid-19 could also be the catalyst to accelerate the technology, research and innovation through which the charity would support the Parkinson's community and, in doing so, bring it closer together. But Parkinson's was also a global disease and the charity's voice must be heard globally. To this end the charity was working with the Michael J Fox Foundation for Parkinson's Research and other organisations around the world.
- 9.5. Parkinson's UK must continue to be supportive of all of the Parkinson's community, leaving no-one behind. Technology must be harnessed to help, not exclude.
- 9.6. In recent years Parkinson's UK had taken steps to bring other voices to the table, including those of people working with local groups and the The Younger Parkinson's Alliance. The charity was moving from a model of participation to one in which the charity was driven by the community, listening when the charity did not get things right and acting accordingly.
- 9.7. The Chair announced that the charity would like to create a small group to help the charity understand how to use the website to reflect the community's work. The Chair invited people who thought they could bring a different perspective to this work to get in touch.

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- 9.8. The Chair shared that he felt energised and inspired by the incredible Parkinson's community. Parkinson's UK was the Parkinson's community's charity. It was crucial that everyone worked together going forward, with an urgency to make a real difference over this year and the coming years.
- 9.9. In conclusion, the Chair said that he hoped that the Parkinson's community would be able to meet in person as well as through technology at the next AGM.
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**Date of next meeting: Saturday 25 September 2021 (provisional).**

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