PARKINSON'S UK
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.

DRAFT MINUTES

Parkinson's UK Annual General Meeting

11.10am, 12 October 2019

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

PRESENT: please see Appendix 1.

Meeting Opening

1. Welcome and apologies for absence

1.1. Mark Goodridge, Chair of the Board, (MG) opened the meeting welcoming those attending at the venue and those accessing the meeting electronically at different venues in Newcastle, Stirling and Templepatrick and from home via the internet.

1.2. He confirmed that the attendance in the room of more than 50 members in person or by proxy met the requirement for the meeting to be quorate. He declared the formal part of the AGM open to transact the business required by the charity's Articles of Association.

1.3. Members had received notice of the business in advance of the meeting and copies the agenda were available in the room. Unless there were any objections, MG proposed to take the notice of the meeting as read.

2. Chair's Report from the Board

2.1. MG said that normally the Chair's report would review the year to date. However, as 2019 was the fifth year of the charity's five-year strategy, he would reflect upon the charity's achievements during the past five years.

2.2. In 2015 the charity had consulted people with Parkinson's, their partners, families and friends, obtaining the views of over 700 people on what would make the biggest difference to their experience of Parkinson's. The outcome of this consultation formed the basis of the five-year strategy, which comprised three pillars: finding 'Better Treatments and a Cure', providing 'Quality Services' and empowering people affected by Parkinson's, 'Taking Control'.

2.3. Consequently, the charity had invested more in research than previously to achieve better results and a cure, as well as pioneering a radical new approach through the Virtual Biotech programme designed to fill critical funding gaps preventing promising research discoveries quickly turning into real drugs on the market.

2.4. The charity had also co-funded and co-led the Critical Path for Parkinson's consortium with nine of the largest pharmaceutical companies in the world and with the European Medicines Agency (EMA) and the US Federal Drugs Agency. This had transformed the way influential regulatory authorities worked with the pharmaceutical industry to make clinical trials more cost-effective and likely to succeed. It led, in 2018, to the EMA backing a special brain scan for use in Parkinson's trials, which was now widely used, helping to select the right people to reduce the chance of trials failing.

2.5. The pioneering GDNF clinical trial delivered an experimental treatment directly to the brain and was reported on two BBC television programmes. While the results of the trial had not met the trial's stated target outcome, they were still encouraging. As a result the partners in the original trial were now seeking to establish the viability of a further trial.

2.6. In pursuit of the second strategic pillar, quality services, we set up the UK Parkinson's Excellence Network in 2015 to help address the 'postcode lottery' of clinical and social care. The Network involved more than 9,000 people affected by Parkinson's, had trained 15,000 professionals and had given 20,000 professionals access to tools and support to improve their treatment and care of people with Parkinson's. This had resulted in a 16 per cent increase in quality of care to date and an 11 per cent reduction in the gap between the highest- and lowest-rated services.

2.7. Via the Excellence Network the charity had worked with professionals to improve the diagnosis experience; within two years clinicians were signposting 84 percent of people to Parkinson's UK at diagnosis, an increase from barely 15 per cent in 2015.

2.8. The third pillar of the strategy was to empower people with Parkinson's to take control. The charity had introduced local peer support, providing opportunities to meet others living with Parkinson's. And, following a volunteer starting a 'Parkinson's Cafe' in Cardiff in 2015, the charity had supported the creation of 170 local cafes across the UK, providing informal support at evenings and weekends to hundreds of people with Parkinson's and their family and friends.

2.9. Financial security was a key element of feeling in control and so the charity had improved its UK-wide benefits and employment support. The specialist advice team, advocating on behalf of people with Parkinson's, had helped win 95 per cent of appeals and supported people affected by Parkinson's in accessing over £1m of benefits they were entitled to.

2.10. In addition, in 2018 the charity had launched a programme to offer grants to people with Parkinson's and their carers. The grants were partly funded by local groups and in 2018 trained volunteer panel members had awarded a total of £100,000 in grants to those in greatest need.

2.11. The three pillars of the strategy depended on two further things: membership and technology. The charity had developed Team Parkinson's to envirogate the charity's membership offer and, after a period of stagnation and decline in membership, had now seen 3,000 new members join the charity in the past year.

2.12. As a campaigning organisation, the charity campaigned to influence policymakers and since 2015 it had achieved 63 positive policy changes. In 2017 almost 34,000 people had petitioned the government to stop making people with Parkinson's go through a stressful and unnecessary process in order to receive essential benefits payments. As a result, people on the highest rate of Personal Independence Payments no longer had to go through an annual reassessment.

2.13. On the financial side of the charity's performance, there had been a dip in income in 2018, but 2017 had been an exceptional year in terms of income. MG acknowledged that these were economically and politically uncertain times and therefore the charity was adopting a cautious approach, preparing for volatility in income in the foreseeable future.

2.14. MG noted that while local group income had fallen in 2018 contributions to national programmes had remained stable. He thanked local groups for their ongoing contributions.

2.15. In 2018 the charity had maintained its spend on services, notwithstanding the drop in income. It had increased its spend on activities by £4.9m, the largest proportion being on activities aimed at Taking Control and these included local and helpline support, volunteer-led support programmes and raising awareness. The charity had increased spending on Better Treatments and a Cure by £2.5m to £10.5m and on Quality Services by £600k to £5.2m.

2.16. Fundraising activities had cost £7.5m. Support costs had accounted for 15 per cent of the charity's spend, which was around the average for the sector.

2.17. In summary, the accounts for the year showed that the charity was in a strong position and, while there was still much more to do, during the last five-year period the charity had become better at learning how it could improve: learning fast, failing fast and moving forward.

2.18. MG asked Steve Ford (SF), CEO, to speak to the charity's future ambitions. SF shared that the charity's ambitions for the next five years would build on its achievements in the previous five years. The 2020 strategy had been shaped by over 600 people affected by Parkinson's, Parkinson's UK staff, health professionals and donors. The overriding aim for the strategy was how the charity could make the biggest impact on the lives of people living with Parkinson's. Strategy objectives would be to accelerate breakthroughs in research, provide better support and get Parkinson's understood.

2.19. The charity's Virtual Biotech programme was owned and shaped every step of the way by people with Parkinson's. It provided a speedier, more agile approach to research, investing only in the best ideas to deliver life-changing new treatments, partnering with leading researchers and innovators worldwide to get results faster.

2.20. To date the Virtual Biotech programme had funded one major new treatment which was now available in the UK and the charity's research grants had generate three new Virtual Biotech projects. 2,000 supporters and groups had made restricted donations totalling £2.5m to the Virtual Biotech portfolio, the commercial value of which had increased by 300 per cent. The charity's leadership had brought £10m in funding from other organisations to support research priorities, and influenced others to involve people living with Parkinson's.

2.21. By 2024 the charity would provide personalised information, services and opportunities to many more people affected by the condition. And the strengthened UK Parkinson's Excellence Network would enable the NHS to significantly improve the expert care and support on offer.

2.22. SF stated that the charity knew that the lack of awareness and understanding of Parkinson's made living with the condition that much harder. For this reason part of the new strategy was aimed at significantly increasing the public's understanding of Parkinson's, challenging myths about who got Parkinson's and educating the public, politicians and policymakers about its 40-plus symptoms and their impacts.

2.23. SF acknowledged that the number of people with Parkinson's would grow significantly in the next few years and more efficient ways of delivering support would have to be found, including better use of technology. The charity was helping to develop a new pathway to deliver services more efficiently and intended to pilot it in three areas in the next six months, another ten areas in 2020 and going nationwide in 2021.

2.24. Finally, in order to break down the disconnect between work centrally and locally, the charity would be exploring different ways to undertake its work. It would provide more support for local activities, seeking to establish vibrant local communities with cafes, researchers and fundraisers supporting people locally.

2.25. MG opened the meeting to questions.

2.26. **Paul Mayhew-Archer, member:** Could we have an update on the Live Loud speech programme presentation which was made at the previous Members' Day.

2.26.1. **Katherine Crawford, Director of Support and Local Networks, responded:** The project had been initiated in Wales by a speech language therapist to help people with Parkinson's speak louder. The initial pilot had worked well so funding had been provided to roll the project out in six other areas in Wales. The project team, evaluating the impact of the project, intended to compile a guide book on how to 'live loud'. The project would be rolled out nationally in the spring of 2020.

2.27. **John:** Everything had been presented in a positive way, but what were the charity's failings and weaknesses?

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

2.35.1. **Julie Dodd, Director of Digital Transformation responded:** The charity provided a diverse range of support, locally and nationally, with a variety of ways of accessing information, including in person, by telephone, on-line and printed copy. In recent years technology had enabled the charity to expand its services. The charity will retain its off-line services but wants to increase the services it provides and would look at how it can do so most effectively, including looking at how technology can support this. In many cases the role of technology to support the charity's delivery of services would be behind-the-scenes and not necessarily visible to the end user of the charity's services.

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

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

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

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

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

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

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

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

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

3. Approval of the draft minutes of the 2018 AGM

3.1. MG drew members' attention to an amendment to the heading of draft minutes 7, which had been circulated. The title of the minute should have read 'Reappointment and remuneration of auditors'.

3.2. He then invited the meeting to approve the minutes of the 2018 AGM, which the Board had agreed at its July meeting. Voting would be by a show of hands, unless a poll was demanded. Only members present in person at the venue in London and those who had already voted by proxy could vote. Members who were eligible to vote had been given white voting cards.

3.3. **Resolution:** members approved the minutes of the AGM held Saturday 12 October 2018.

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

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

4.2. Members noted the receipt of the charity's annual accounts for the financial year ended 31 December 2018 together with the trustees' report and auditors report on these.

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

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

5.2. The members noted the receipt of the report of the Chair of the Nominations & Remuneration Committee.

6. Declaration of the results of the Trustee elections

6.1. MG announced the results of the trustee elections in England and Scotland: Jane Burston and Peter Miller were elected as Trustees in England and David Allan in Scotland.

6.2. MG congratulated the newly elected trustees and thanked all the candidates for making such a big commitment in standing for election.

7. Appointment of the auditor: members' resolution

7.1. MG reminded the meeting that the previous year he had reported that the charity would be required to change auditors. In 2019, the Board had conducted a re-tender exercise and were recommending the appointment of BDO LLP as auditors.

7.2. He propose the resolution: that BDO LLP be appointed as auditors of the charity and the Board of Trustees authorised to agree their remuneration.

7.3. A majority voted in favour of the tabled resolution and the resolution was carried.

7.4. **Resolution:** Members resolved that BDO LLP be appointed as auditors of the charity and the Board of Trustees authorised to agree their remuneration.

8. Thank you and close

8.1. In closing, MG thanked everyone for attending. He was pleased to confirm that the charity was on track to raise a record £175m in the five years from 2015 to fund its life-changing services and groundbreaking research programmes.

8.2. Voluntary donations and support funded over 97 per cent of the charity's work . He thanked the supporters, members and volunteers who had driven this. The charity did not take this for granted and as it moved into more uncertain times it would be even more dependent on their fundraising and support to continue its work.

8.3. In stepping down from the chair, he thanked the trustees staff for their determination and hard work to help the charity achieve its mission. In the past year, Anne MacColl and Richard Raine had left the Board and Mary Whyham, the current Vice Chair, was stepping down. He thanked her for her support and valuable contribution, in particular during the past year as Chair of the Nominations & Remuneration Committee.

8.4. He thanked David Allan, who had replaced Anne MacColl in Scotland and who had now been elected to continue the work he had started.

8.5. He thanked Steve Ford and the senior leadership team for bringing about the charity's successes of the past five years. He was confident in their ability to further raise the level of charity's work in future. He thanked the staff and volunteers without whom the charity would not have been able to achieve what it had done and for aiding him in his work of ten years as a volunteer and four years as chair.

8.6. In closing the meeting, MG introduced Gary Shaughnessy, the new Chair.

Date of next meeting: Saturday 24 October 2020

Appendix 1: Present

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

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

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

Appendix 2 Q&A on slido - Members’ Day & AGM 2019

In advance of and during the Members’ Day & AGM we received numerous questions from members, most of which were answered before or during the event, but a few of which we needed to provide more information after the event. The following is the list of questions asked by our members and answered by staff.

Susan Awareness. Ever since my husband was diagnosed with Parkinson’s, nearly 10 years ago, I’ve noticed the lack of awareness in the media to this condition. When we were told my husband had Parkinson’s, we were in shock. What is Parkinson’s? Will I die from it? We had no idea. This scenario has been echoed by many of my branch members. Since I became the Lady Chairman of the local branch it has been my goal to make people aware of Parkinson’s. My Secretary and I attend as many meetings as possible in our area in order that we can educate people what it is like to either have (my secretary has Parkinson’s) or care for people with this condition. These meetings are not necessarily to do with us but we attend. It’s working: we’re getting recognised and get lots of feedback. We’re getting sponsorship from local companies and members of the public are taking on challenges for us. We see on the TV adverts asking for donation for all different charities including dogs, cats even birds. Do we see anything for Parkinson’s – No! I’ve asked the question numerous times	Answer by email: We know there is a lack of awareness and more specifically proper understanding of what it's like to really live with Parkinson's - people like yourself have shared this with us and we have heard it from the public too. We are committed to changing this. Our new corporate strategy, which will launch early 2020, will look at how we can ensure our work aims to increase the understanding of Parkinson’s. Although our budgets can't stretch to TV ads at the moment, our use of digital channels is proving cost effective and reached more than 4.2 million people through our *Parkinson's Is* campaign alone (launched in April 2019). To reach more people and increase their understanding of Parkinson’s, we realised we needed to widen the charity’s appeal so people who aren't directly affected by Parkinson's would consider supporting us. This wasn't a rebrand as it carried through lots of great things that we already had in place (such as our cyan blue and stencil font) and added elements like a stronger personality, secondary colours and different photography styles - all of which we successfully tested with people living with and without Parkinson’s.

regarding media awareness to Head Office and have been told it costs too much £100,000.00. I’m told it would be money Ill spent as Parkinson’s is a small charity. However, you have decided to rebrand. My question is how much did the rebranding cost and WHY did you decide to rebrand? You are not trying to sell something! It’s a medical condition. Surely promoting Parkinson’s through awareness is more important. There is an advert on the TV called ‘That’s Life’ where Parkinson’s UK is included but unless you know what to look for it’s pointless. With more and more people being diagnosed surely we have a duty to educate people to the possible early signs. I appreciate that Parkinson’s UK is working hard on research for new drugs but none of us have any idea when and if we will see new medication on the market so, we must look at the present and try and get earlier diagnosis and help by awareness and through awareness you get more support and hopefully monetary gains to help in much needed research. I would appreciate your comments.	As part of the effort to grow our appeal and make people sit up and take notice of Parkinson’s, we worked with some specialists who helped us define how we communicate the brand. This cost of this was approx £50k. This is an investment in our long term future and a very small investment in comparison to other charities who have done the same thing.
Kay “We also launched a new campaign on Parkinson’s symptoms like anxiety and freezing, which helped increase brand awareness. We kept public awareness of the condition (94%) and brand awareness (66%) above the 50% target. " I know that, like myself, very many people with Parkinson's feel that increased public understanding of the condition would have a massive impact on their daily lives but the statement above seems to suggest that public understanding is high at 94%. This doesn't correlate with my own experiences or any feedback from other people with Parkinson's that I hear or read so I must be misunderstanding the 94%. Could I ask what it relates to and	Answer by email: Increasing public understanding of Parkinson's is absolutely seen as something that would improve the lives of those living with the condition. Here, the 94% figure refers to public awareness of Parkinson's, i.e. the amount of people in the UK who are aware of the condition, rather than the amount of people who understand the condition, i.e. how its diagnosed, its symptoms, its impact, etc. With that in mind, the purpose of the 'Parkinson's Is' campaign was to increase condition understanding, by showing the realities of living with Parkinson's via stories of real people. The campaign was primarily aimed at a new audience that was identified as having great potential value: those who are emotionally open and highly empathetic, willing to support charitable causes and also relatively young. The campaign has now moved into a second phase, where we aim to further strengthen the relationship between ourselves and those who engaged with us for the first time through the campaign's initial phase. We believe that fostering deeper, more

where the figure comes from? What happened to the 'Parkinson's is' campaign? I think I understand from the information that I have gleaned that it was primarily a marketing campaign but I thought it was also a raising awareness campaign that was going to continue beyond the initial release and yet it seems to have disappeared. Only one person in my life actually saw any information regarding it and their main comment was that I should feel lucky that I was diagnosed in my 40s and not my 20s or 30s! Are there plans to continue with this campaign and expand it to represent all people living with Parkinson's and to actually focus on really raising public awareness rather than the key aim being to increase membership and fundraising amongst target audiences?	meaningful connections with this audience will provide Parkinson's UK with greater opportunities for longer-term support, growing our appeal and making more people sit up and take notice of Parkinson’s.
Kay I don't really understand all the financial information. I struggle to interpret the tables so I do apologise if the information I'm asking for is actually already in the report but is there a breakdown of spending on: research that is intended to improve life for people living with Parkinson's today, research focused on supporting the NHS in reducing expenditure on managing people living with Parkinson's (for example, digital and virtual healthcare and exercise programs: people with Parkinson's really don't want to be trapped in their homes forever in order to be managed as cost effectively as possible) and research aimed at finding a cure or improving treatments which will not provide people living with Parkinson's improved treatment options within the next 5 years?	Answer by email: In a recent review of studies we are supporting financially, 34 were aimed at new treatments and cures, and 14 were aiming at improving living with Parkinson’s. The size (£££) of grants in the “treatments and cures” category is generally higher so the differential in costs is higher (very roughly, 10:1). Please recall that Parkinson’s UK supports many programmes in the ”living with Parkinson’s” area that are not under our Research programmes.
Kay The report states that the Self Management program was dropped	Answer by email: The charity is committed to delivering a significant range of information and support

in part because it was not impacting on enough people. I think I read that 741 people were supported in 2018 and yet the personal grants initiative only supported 53 people and this is considered viable. I don't understand this and I don't really understand from the report whether or not the charity intends to increase provision in terms of support for people living with Parkinson's today. I also have absolutely no idea what Parkinson's Links are. The report states that the aim is to maintain the Links created but doesn't mention increasing them so if there is very little available in any given area does this mean that this status quo will continue to be the situation in the coming year? In actual fact, provision in my area has improved but this is only because somebody with real drive has taken over the local group. This provision will cease if the person in question becomes too ill to continue or chooses to stand down for any other reason. If local support is to be the main offer for people living with Parkinson's today, what is Parkinson's UK doing to support local groups and what financial assistance do they get?	for people living with Parkinson's. This support is provided in a range of formats: from an information leaflet. our online community forum, our Helpline and our face to face support offer. The Self Management Programme formed part of that information and support offer, and we recognise and appreciate that people found it beneficial. However, there were some challenges in how the programme was operating and on balancing up the way that we should distribute our resources as equitably as possible, we took the difficult decision to stop that specific programme. Our Financial Assistance Programme began in 2018, and distributed small grants of up to £1500 to those families living with Parkinson's who are in the greatest need. With the support of local groups, we are proud to say that we are on track to deliver £100k worth of grants to more than families in 2019. The charity has been working to increase people living with Parkinson's opportunities to access key activities like mutual support, exercise or creative and therapeutic activities in this strategy. We have called these activities "Parkinson's Links". Activities provided by local groups have played a really significant part in delivering these activities, which is really powerful, and we have increased the opportunities available to people from just under 900 to over 4000 during the life of this strategy. We have done this in a range of ways- either by directly funding opportunities, working in partnership with other organisations - eg British Nordic Walking or simply by directing people to other organisations who provide those opportunities. We've also supported volunteers who're now running 170 Parkinson's cafes across the UK. We plan to continue to support these activities in the next strategy, and will be working even more closely with local groups and others to sustain and continue to develop from this position. Local groups continue to form an important part of the charity's work and we are very grateful to all of the volunteers who support that work. Our groups are financially self sustaining, and provide a fantastic resource for people in local areas. The charity provides assistance through volunteer support staff and by ensuring that our groups are confident that they are following charity governance rules. This support will continue as the charity moves forward.

Kay Is there hard medical evidence to substantiate the many claims PUK is making regarding the benefits of exercise? I know from personal experience that exercise does help with motor symptoms but I can't find any hard evidence to back up the claims being made for its impact on mood, anxiety and the longer term impact on symptom progression. I can't actually find any evidence that unequivocally backs up the statement relating to exercising for 2.5 hours a week either. The research that I have read all seems to be far more cautious than PUK in making bold claims for the benefits of exercise and I worry that with the main aim of care and support agencies seemingly being to manage people living with Parkinson's as cost effectively as possible until a cure is found, excessive claims are being made for treatment options which don't cost. The impact of this will be to raise unrealistic expectations both within in the community of people living with Parkinson's and the expectations placed upon them by people affected by the condition and the outcome will not be positive for anybody.	Answer by email: Research into the benefits of exercise for Parkinson's is an evolving field. The results showed that motor symptoms improved more in those doing the aerobic exercise programme than the control group. However, no difference was seen in non-motor symptoms such as sleep and memory. This study added to growing evidence of the importance of exercise in Parkinson's and highlights that more vigorous aerobic activity may be more beneficial to improve motor symptoms in those in early stages of Parkinson's. https://www.parkinsons.org.uk/news/research-shows-home-exercise-improves-movement-symptoms
Lisa Are we any further in finding out whether CBD oil is effective for Parkinson's symptoms? As a Parkinson's nurse we are being asked this question more frequently in clinic. Newcastle.	Answer on slido platform: Hi Lisa! Great question and one we get asked a lot. At the moment there is not enough research evidence to fully understand the benefits and risks of CBD oil or other cannabis-based treatments for Parkinson's. This research is coming though so do watch this space! And we have put together a comprehensive article that rounds up what we know so far which you can read here:https://medium.com/parkinsons-uk/the-case-for-and-against-cannabis-6c6dbd232ac5
Charlotte, Newcastle As a person with Parkinson's - living with it for over 16 years - we	Answer on slido platform: Hi Charlotte, Val our director of strategic intelligence and excellence has answered this for you:

need to concentrate on improving the quality of life of PwP, educating GPs, retailers, airports, transport systems, ask the people who live with it about their real life experiences?	As far as GPs go, we have had success in working with the online info system that GPs use, so Parkinson's info is easily accessible to them when they see someone affected. We're also working to make access to parkinson's uk even easier so that medical professionals can refer to us at point of diagnosis. We also have a GP training programme, alongside the Brittish medical journal, and we've been working with a medic who has Parkinson's on further training. On the other part of your question, we have training for businesses, like airports, and have had some success with gatwick airport in training their staff: https://www.parkinsons.org.uk/get-involved/parkinsons-your-workplace-ocs-gatwick-airport People with Parkinson's were involved in developing the training, but we absolutely want to do more about bringing experiences into our training too, so it's feedback we absolutely recognise For example https://www.newcastleairport.com/passenger-assistance/hidden-disabilities/ people need to be aware of this - it's for the whole of the party
Anon As PD is in general an older persons illness and they as not as tec. literate how is this to be addressed	Answer on slido platform: Whilst I agree that we remain inclusive for the less tech savvy generation, interestingly, the age at diagnosis is falling. We need to ensure people don't continue to see it as an old person's condition.
Anon As someone new to PUK could you inform me the progress made in clinical research in the last 5 years and your hopes for the next 5 years.	Answer on slido platform: Hello there, I'll put this one live as I'm sure everyone in the room and online will be keen to hear more. But, I've also flagged this one for Claire Bale, our Head of Research Communications who is joining us from 11.30, and who might also reply on here. Thanks so much for the question. Lucy (moderator for today!) Hello, Claire from Research here. There has been some huge progress in clinical research in the last five years. The completion of the complex and ambitious GDNF trial was a major achievement. While the results fell frustratingly short of providing scientific proof that the treatment was slowing the course of Parkinson's, there were

	encouraging signs that it may have been helping damaged brain cells to recover and regrow. There are currently many more promising new treatments and therapies entering clinical trials in the UK. These range from repurposed drugs such as exenatide, a type 2 diabetes treatment through to new therapies based on the latest genetic insights. And we will be introducing two new clinical trials of new treatments funded through our Virtual Biotech programme in the next few months. All these new trials and other studies need participants. We know many people with Parkinson's are interested in taking part but it can be difficult to find trustworthy and up-to-date information. That's why we developed the Take Part Hub on our website - a simple, searchable system that helps people to find opportunities to participate in research at the click of a button:www.parkinsons.org.uk/takepartresearch
Anon Can you look at making people more aware of what Parkinson's UK offers regarding supporting people staying in work., reasonable adjustments etc?	Answer on slido platform: Hello, we've run out of time in this particular section to get an answer from the panel, I'm really sorry. I wondered if you've been in touch with the helpline on this? we have dedicated employment and benefit advisors there who may be able to help. Our policy advisor Michael is also doing work in this area, and I am sure would be happy to hear from you. If you'd be happy to be connected with Michael, can you drop us an email at agm@parkinsons.org.uk? In terms of making people more aware of the support we offer on this - absolutely, it's something we are keen to do through our marketing efforts over the coming year, so that more people can take advantage of this. Thanks so much for the question. Answer on similar question live (see minutes): The charity's five-year strategy has focussed on different employing bodies and worked with different businesses to help them understand the requirements of people with Parkinson's. The charity has developed resources to aid this work and its expert team advised employers. The team would continue to develop this work.
Anon connection with Parkinson's and gut - celiac?	Answer on slido platform: Hello, Claire Bale published this blog last year which answers this: https://medium.com/parkinsons-uk/diets-for-parkinsons-research-explained-edfc17a9

	9d12 Hello, thanks for your question. Yes, there is a growing body of evidence that the gut may play a role in the development of Parkinson's. Digestive problems can appear before movement difficulties, and scientists are investigating differences in gut bacteria that may lie at the root of this connection. Hope that helps, Claire
Kevin Could we have an uncomplicated procedure for obtaining fundraising material. Should we be charged for this	Answer on slido platform: Hello Kevin - if you can email us via agm@parkinsons.org.uk with any ideas it would be so great! Any detail provided would really help come up with ideas in this area. Thanks Kevin. Answer on this question live (see minutes): Yes, was the obvious answer: anything which makes things less complicated was good. The charity was not complacent and would always look at how to improve the services it provided.
John Everything is being put over in a positive way and yes whilst there is progress we are a long way from reaching our target. Please share the failings and weaknesses it's the only way we can improve.	Answer on slido platform: Hi John, it's Lucy here, helping send questions live and answer some too. Could you give me a little more info so I can pop this one live and make sure we're answering correctly? i.e is this overall income targets or for local groups? Answer on this question live (see minutes): Steve Ford, Chief Executive, replied: The SLT talked about this at every meeting. They asked how the charity could accelerate research. The Excellence Network was working well but how could it improve, particularly in areas where it was not so successful? The change to the membership scheme had taken longer than had been anticipated. This year the SLT had addressed fundraising and reducing the charity's costs. The Board rightly challenged the SLT on matters which could be improved, so there was no complacency in dealing with failings and weaknesses.
Anon From N/cle. A shortage of sinemet left me for about 6 weeks	Answer on slido platform: Hello, we recently published this article on Sinemet: https://www.parkinsons.org.uk/news/sinemet-availability

worrying whether I would get any more. Is this going to be the norm for the future?	We're trying hard today to answer as many questions as we can, but can't put all of them live. So, I hope that might help answer the question? If not, please let me know and I will get some more info in the next break. Lucy.
Anon From N/cle. Should we have a separate strand/ organisation for younger people.	Answer on slido platform: Hello, we have the Younger Person's Alliance, which whilst not separate entirely is very much aimed at younger people! So, if anyone is keen to be involved this story from Mark is worth a read, https://www.parkinsons.org.uk/information-and-support/marks-story or email involvement@parkinsons.org.uk
Anon From N/cle. Thank you for this event today. Very informative. Enjoying it and very helpful.	Answer on slido platform: Thanks very much!
Anon From N/cle. We need more campaigning regarding prescription charges for people with Parkinson's. Will this be something that P.UK will consider as part of their plans? There has been no progress since 1960's	Answer on slido platform: Hello, we ran out of time to answer this one in the main room, but this is still an active area of campaigning for Parkinson's UK for sure! Parkinson's UK is the co-chair of the Prescription Charges Coalition and last year we had a petition to end the charges for people with long term conditions. Over 22,000 signed and we presented the petition to Number 10. Since then we've been lobbying the political parties and recently Labour pledged to end prescription charges. We've been lobbying the other parties to join this call too when they announce their manifestos. You can find out more about Parkinson's UK's work and sign up to here more: https://www.parkinsons.org.uk/get-involved/prescription-charges
Anon From N/cle.GIOT needs to be delivered to all care staff. Residential and home care is delivered to people 365 days a year. Hospital	Answer on slido platform: Hello, we've run out of time to get to this one in the main room, but we are planning to scale GIOT up to cover care homes as the next phase of the campaign. We're starting with hospitals because of the findings in our report about the experience of people with Parkinson's. There is lots more info than I can give here on the website about this:

care may only be for short periods when someone is admitted.	https://www.parkinsons.org.uk/get-involved/get-it-time
Anon GP's don't understand Park's so why do they certify if I have a severe Mental Impairment to qualify for Council Tax Reduction. I feel this should be certified by my Parkinson's Dr who has dealt with my condition since diagnosis. Will Parkinson's UK look at this as part of their campaigning?	Answer on slido platform: Hello, sorry for the delay in coming back to you on this, we've had questions thick and fast! The first port of call on this would certainly be to give our helpline a call; in terms of eligibility they can give some guidance. We're also keen to look into this a little more, so if you are able to email agm@parkinsons.org.uk we can get back to you on Monday? Thanks so much, Lucy.
Anon Has there been any thought given to going into schools to tell young people about Parkinson's to help remove the stigma that some people feel?	Answer on slido platform: Hello, we ran out of time to get this one answered in the main room, but I can help with an answer: we do have volunteer speakers, who go into schools (among other venues) to speak about Parkinson's, I'm (Lucy!) actually working with some of our volunteer speakers at the moment to re-jig the presentation given, so hoping to have something concrete to share soon. Does that help? Lucy.
Anon I have been a volunteer educator for 12 years delivering Parkinson's awareness and understanding training to residential care homes, home care providers and the NHS (600 courses to date) I bring an all new audience into the Parkinson's arena and in turn brings us more funding. Support needed.	Answer on slido platform: Hi John, Lucy here. Val, our director of strategic intelligence and excellence, and Katherine, our director of support and Local networks (who I know you have spoken to) are both here today. We absolutely know support is needed for the education programme, and are looking into this - you should be hearing more soon. And, if you have any feedback as to what that support might look like please do let us know - volunteering@parkinsons.org.uk is a good place to start, or via Rose in your area. Thanks too for all you do as a volunteer educator; volunteers - both in the excellence network locally, and as volunteer educators, have made a significant contribution to Parkinson's UK by educating more than 15,000 professionals, so this is a hugely important area for us
Anon	Answer on slido platform: Multi-disciplinary teams (Kate here) through an MDT we want people to have access to a range of specialists

MDT?	to support their different needs - e.g. clinician, Parkinson's nurse, physiotherapist, etc.
Anon Money drives research. PUK sits behind the donkey sanctuary and 5 dog and cat charities in a recent study of money raised. Is it not time to change the message to be more severe to bring reality to the lives we have to live. This was an emotional topic at the WPC recently. Does PUK have any plans	Answer on slido platform: Absolutely agree that a more punchy message about Parkinson's is part of how we'll get more people to notice and care about our cause. We have already started to change the language we use in this year's campaigns - for example using the line "Parkinson's is brutal" and that has worked well. It is always a fine line between what is seen by some as scaremongering for those living with the condition, and telling the plain facts about how tough Parkinson's is, but I think we're making good progress on this front, and will continue to test language that is bolder in 2020.
Anon My husband was diagnosed at 42, 22 years ago. Lots more awareness can help, try to be an educator. Talk to GP, surgeries, hospitals and workplaces and encourage them to understand more about this.	Answer on slido platform: Hello, thanks very much for sharing your thoughts on this - apologies it's taken a while to get back to you! As far as GPs go, we have had success in working with the online info system that GPs use, so Parkinson's info is easily accessible to them when they see someone affected. We're also working to make access to Parkinson's uk even easier so that medical professionals can refer to us at point of diagnosis. We also have a GP training programme, alongside the Brittish medical journal, and we've been working with a medic who has Parkinson's on further training.We also have training for businesses, like airports, and have had some success with gatwick airport in training their staff: https://www.parkinsons.org.uk/get-involved/parkinsons-your-workplace-ocs-gatwick-airport If you're also interested in sharing your experience a little more, it would be brilliant to have you on board as a volunteer? If you're interested please do let us know at volunteering@parkinsons.org.uk? Thank you so much
Anon N/cle -People with Parkinson's can request their GP's to have	Answer on slido platform: Hello, sorry for the delay in coming back to you, we've had lots to get through here. To answer your question, we'd absolutely support asking your GP for a named drug, and we suggest this when working with professionals as

named medications and not the generic drug, if this is detrimental to the person's symptom management. Government states the cheapest option should be dispensed. Will PUK campaign to ensure that the appropriate drugs can be given?	medication can be so personal. We also try to make people aware of the yellow card scheme where they can raise adverse reactions to medication.
Charlotte, Newcastle Newcastle, exercise is important, we need more activity on prescription, is this something the charity can look at?	Answer on slido platform: Hello, I'm answering this one as we ran out of time, and have chatted to those in the room; also thank you Charlotte as we know you've been involved! Because we know physical activity can be as effective as medication in dealing with Parkinson's symptoms, the exercise framework is just one of many resources we have shared with professionals to encourage them to refer Parkinson's patients to local exercise opportunities. The local support tool is also a key way we refer people directly to exercise locally.
Anon Newcastle, what effect will Brexit have on working with our European partners?	Answer on slido platform: Hello. Sorry for the delay on replying to this, Steve has just stopped by and says: Brexit doesn't feel like a threat to working with partners on research as it's so international (the way we work) we have partners in Europe, but also in the US and elsewhere, and Brexit won't stop us working with them
Anon Newcastle. Steve, your speech about uniting people with Parkinson's to campaign for PIP, ESA etc... why are you so against including people with Parkinson's???	Answer on slido platform: Hello, Steve has just been with me (Lucy - the moderator) and says: Sorry to hear you feel that way - it would be good to understand why? We put people with Parkinson's at the centre of all our work, for example in developing the recent strategy: https://www.parkinsons.org.uk/news/how-youve-shaped-our-new-strategy Any feedback on how we could improve this, we're always keen to know - if you're able to email us on agm@parkinsons.org.uk
Anon Our group is desperate for more help. Many of the helpers we do have are doing more than one job. What should staff do to help	Answer on slido platform: Hello, thanks for the question. We're trying hard today to answer as many questions as we can, but can't put all of them live. Mark is answering something similar to your question now, but I can also help answer this too, and will do ASAP! Please let us know on agm@parkinsons.org.uk if you have anything you'd like us to follow up! We'll also keep a record of all questions asked today too. Thank

us? We have asked for help.	you, Lucy. Hi Katherine Crawford here. Please let us know where you are, and we can work out what we can do to support you at a local level. We will shortly be working with you on your "annual review". It's a good opportunity to consider what support you need as a group to enable you to deliver your plans. Our staff will be able to support you with recruiting volunteers for your group too. Having said that, we do know it's not always easy to recruit volunteers, so I hope you'll feel able to sit down and have open discussions with staff in your local area to think about creative solutions to your challenges. Always happy to hear from you too. And thank you for all that you do to support people locally too.
John Parkinson's is massively on the increase (10 years ago it was 1 in 500 people, changed to 1 in 350 a few years ago, now I believe it is around 1 in 200 people). Why don't we launch a national Parkinson's U.K. day?	Answer on slido platform: Hello John, thanks for the question. I'm trying hard today to get answers to as many questions as possible, but can't put all of them live. So, I'm going to answer this one rather than putting it to the room - please let us know on agm@parkinsons.org.uk if you have anything you'd like us to follow up! We'll also keep a record of all questions asked today too. Lucy. April 11 is World Parkinson's Day (as I'm sure you know!). each WPD we see an increase in community fundraising activity, a significant increase in people talking about Parkinson's and engaging with Parkinson's UK on social media - so this is in effect the 'national' day for us, as it is the rest of the Parkinson's community
Anon Previously, lots of members were concerned àt how low the membership fee of £4 was compared to other charities. Most people were willing to pay more. The response was to switch from fee to donation. Have more people joined as a result and what is the current impact on income from this source?	Answer on slido platform: Hello, thanks for the question. We're trying hard today to answer as many questions as we can, but can't put all of them live. So, I'm going to answer this one rather than putting it to the room - please let us know on agm@parkinsons.org.uk if you have anything you'd like us to follow up! We'll also keep a record of all questions asked today too. Lucy. As of 17th Sep our membership figures were at 36,972, with 3,372 new members since February. In terms of the change from fee to donation, we have seen an increase in donations as a result of taking away the £4 membership fee - with an average of £12 to £18 where people have opted to donate. Just 31% of our new members have

	chosen not to donate, and of our current members over 200 people have increased their debit debit donations as a result of taking away the £4.
Anon Quality is in the North East!! This attitude of staying in London invites the divide of discrimination. A passport is not required to pass Watford Gap en-route to the North East.	Answer on slido platform: Hello, I'm trying hard today to answer as many questions as I can, but can't put all of them live. So, I'm going to answer this one rather than putting it to the room - Steve also mentioned this earlier, so to recap, what he mentioned was - we own the UK office building in London, a hugely important asset it would be costly to purchase elsewhere. Our location also means we're within commutable distance for a large proportion of the country, and with 50% of our staff home based, we can make best use of skills from across the UK too. Please do let us know on agm@parkinsons.org.uk if you have any follow up questions. Thank you, Lucy.
John Anon We are fortunate in the North good committed staff (low turnover) totally different in London why is our headquarters there?	Answer on slido platform: Hi John, hopefully you'll see that a similar question has been asked - so I have popped that one live and won't put yours up. trying hard to get as many questions answered as we can, whilst not duplicating too much! thanks, Lucy.
Anon Re the point about the wages going up.... they fail to realise that people they employ as specialists could be from the charities own volunteer "brain bank".. utilising their skills and employment assets , who would love the opportunity to work for the charity they have in common with themselves	Answer on slido platform: Hello, apologies for the delay in getting back to you, we've had lots of questions through and just haven't managed to answer all of them in the Q&A! I'm Lucy, moderating questions and can also help answer this one as I work in our volunteering team. When we surveyed volunteers in 2017 and 18, one of the biggest motivations people shared with us for volunteering was to use or gain skills. So, I completely appreciate we haven't necessarily been making the most of this at Parkinson's UK and are trying hard to do better. One of the ways we're trying to do this is with the launch of a new online tool later this year which will enable volunteers to list their skills, and for these to be visible across the organisation to make better use as you rightly say. If you'd like to hear more about this, please do let us know on volunteering@parkinsons.org.uk

Anon Sheila North (London event) Long Eaton branch - v disappointed at termination of the self management programme and I note that the 7 people involved in Mark Goodridge's video were all graduates of the self management programme. Can you please explain how the cost benefit analysis was conducted?	Answer on slido platform: HI Sheila, Katherine Crawford here. We considered several factors before coming to the very tough decision to close the self management programme. We know that people really did benefit from the programme and from the expert input of our volunteer facilitators such as yourself- Thank you. However, we struggled to recruit enough volunteers and indeed participants to roll out the programme UK wide in the way that we'd envisaged, so when we did analysis, we came to the difficult conclusion that continuing to fund the programme with the aim of rolling out from the centre was not effective or efficient, and that when we were having to make some choices about how to use our resources to support as many people as well as possible, we decided we had to close the programme. However, we don't want to lose the valuable learnings from the programme, or indeed the high quality of the programme itself. So we have been "repackaging" the programme so that it can be used again as the charity moves into its next strategy, and as we move to building the Team Parkinson's community
Anon There has been no mention about Education, especially care staff in residential care home care and NHS. This is vitally important, and this would be beneficial to be delivered by people with Parkinson's.	Answer on slido platform: Hello, it may have been yourself, but a similar question has been asked and I have popped it live. So, hopefully our speakers will answer but I will also share some more info with you after the Q&A. Thanks so much for the question, Lucy. Great, thank you. Just to say too, that the get it on time campaign aims to focus on care homes next year - but I can give a bit more info after the Q&A on this. Lucy Hello, to follow up on this, we do currently have volunteer educators across the UK who have educated more than 2000 professionals this year. We absolutely know that these volunteers need more support, and are focusing on this - any ideas would be incredibly welcome. Please email agm@parkinsons.org.uk From Val Buxton, our Director of Strategic Intelligence and Excellence.
Anon What are you doing to educate, & advise employers on employing people with Parkinson's? The DWP? Particularly for YOPD, we are	Answer on slido platform: Hello, I've put your question live as I know it's something others will be keen to hear more on. I can also connect you with Michael, our policy advisor working (with those including the DWP) on this issue, if you were happy to

all different and capable of different things? Should we be constantly judged and reassessed?	share your email address privately with me? I'm Lucy, moderating questions today. We also have information for anyone who employs, manages or is responsible for a member of staff who either has Parkinson's or cares for someone with the condition, which we are working to share more widely: https://www.parkinsons.org.uk/information-and-support/information-employers-about-parkinsons Apologies, if you did want to be connected with Michael, please can you email agm@parkinsons.org.uk? Thanks so much again for the question - Lucy. Answer live during Q&A session: Val Buxton, Director of Strategic Intelligence and Excellence, replied: The charity's five-year strategy had focussed on different employing bodies and worked with different businesses to help them understand the requirements of people with Parkinson's. The charity had developed resources to aid this work and its expert team advised employers. The team would continue to develop this work.
Anon What happened to the 'Parkinson's is' campaign? I know it was a marketing campaign but I thought it was also a raising awareness campaign & yet it seems to have disappeared. Are there plans to continue & expand it to focus on raising public awareness instead of increasing membership & fundraising?	Answer on slido platform: Thanks for the question. We ran the first wave of the Parkinson's Is campaign in April to a range of different target audiences (we're particularly targeting people with low understanding of the condition but whom we've identified as people who will get behind our cause when they learn more). We are currently running a follow up to the campaign but it is focused on going back to those who engaged well with the first wave to deepen their knowledge and engage them in more of our work. That's why it probably feels invisible - we're trying to do the most we can and deliver best value for money by very specific targeting. We'd love to have the funds to do a bigger, more visible campaign but right now that would mean taking money out of our research or services or other crucial spend.
Anon What is the "official" number of people with Parkinson's in the UK?	Answer on slido platform: Hello, thanks for the question. We're trying hard today to answer as many questions as we can, but can't put all of them live. So, I'm going to answer this one rather than putting it to the room - please let us know on agm@parkinsons.org.uk if you have anything you'd like us to follow up! We'll also

	keep a record of all questions asked today too. Lucy. It's estimated there are currently 145,000 people with Parkinson's in the uk You can see more statistics here: https://www.parkinsons.org.uk/about-us/statistics-journalists
Anon [In follow up to the above question] Estimated??? So the figure has not increased since last year.	Answer on slido platform: The estimates were derived from an analysis of records of over 2.5 million patients over the age of 20 from the Clinical Practice Research Datalink (CPRD) database. Following advice from clinical experts, we estimated the number of patients with a definite diagnosis of Parkinson’s in their records and adjusted these in terms of age and gender to ensure they were representative of the UK population. Using projected population figures from the Office of National Statistics, we then estimated prevalence and incidence for 2018 and potential growth up to 2025 and beyond.
Colin What proportion of income goes directly into research, what is the tangible benefits of that investment and who monitors investment schemes for outcomes? Importantly how does this investment benefit PwPs?	Answer on slido platform: Hello Colin, thanks for the question. I'll put it live from 2pm this afternoon, as our deputy director of finance Stephen Hooper will be logging on to answer all your finance questions. I've also flagged it for Claire, our head of research comms. If you won't be on the livestream then, please do let me know your email and I can send a response directly to you. Thanks, Lucy. Hi Colin, thanks for your question. Claire from research here. Monitoring the results and impacts of the research we fund is a major part of what the research team do. Every project we fund is required to report on progress on a regular basis and we share this through the results section of Progress magazine. These outcomes range from building knowledge and understanding of Parkinson's as a condition, to scientific breakthroughs in genetics or molecular biology, through to discoveries that identify potential new treatments and therapies.I'll let my colleagues get back to you on the financial aspects of your question but I hope that's helpful. Hi Colin. Stephen from Finance here. To follow on from Claire’s response, throughout the current strategy we have increased the % spent on Research. In 2018 it was 27% of total expenditure of which 76% went directly on research grants/investment in our

	virtual biotech programme.
Anon What will be the role of Local Development Teams in the next five years?	Hello, sorry for the delay in coming back to you - we've had more questions than we can get through in the Q&A! Throughout 2020, if you're in an LDT you'll be involved in deciding with staff, volunteers and others affected by Parkinson's how you want to work together in your area. There will be invitations on this coming early next year, so please look out! if you have any follow up q's please do email us agm@parkisnons.org.uk
Kevin Where is the multi discipline team seen in the video, I want to move there?	Hello Kevin, so sorry for addressing you by the wrong name! The video about the multidisciplinary team is from Derby teaching hospital… so if you fancy a relocation that's the place! On a serious note, using examples of best practice like this is how we're working with professionals to try and get this consistency of service UK wide
John Why not change the logo from "Find a Cure " to " Fund a cure " which to me living with Parkinson's is far more positive?	Hi John. Completely understand your logic here, but there's a couple of important reasons why sticking with 'Find' feels most true to our cause 1) the crucial role of involvement in clinical research - so much of the progress we're making is because we champion and encourage people to get involved in the whole research process, from taking part in trials, to shaping how trials are structured and measured. That really is important and we don't want people to feel that the only way to help is to give money. 2) We did test our brand messaging quite extensively when it was first developed and whilst there's never a perfect set of words, most people do still really like it From Julie, our Director of Transformation
Anon Wouldn't it be great if there was a PUK rep (paid or volunteer) in attendance at every Parkinson's outpatients clinic in the country.	It's an interesting idea for sure, and one we'll feed into Katie, who works in our excellence network. Please do email into agm@parkinsons.org.uk if you'd like her to get in touch? Thank you so much. Lucy (moderating)

Anon Your video praises your work...pat on the back to yourselves - re stopping unnecessary assessments. As someone who has just undergone dbs surgery 1 week ago, i was just demanded to attend an assessment or face being sanctioned. Where is the help here,???? Follow up replies from other members: ● They are not here to help "fill out forms".. as i have been told. ● I'm well aware of the people in head office.. im a member of the young Parkinson's Alliance... but I'm told time and time again that it's not something that you offer. ● The excellent PLAs are spread thinly. I cannot say how thankful we were for the one who helped with my partner's claim for PIP. It was initially rejected but with the help of our PLA and friends who had made a successful claim we got it through. ● I can appreciate why PLAs don't help with initial PIP etc claim. If it fails at this point, where can you go for support. ● Im also annoyed that the "medical professional" who assessed me, openly admitted his knowledge of Parkinson's was very little. Being that he was a physiotherapist. ● Your mentioning a campaign get it in time as if it's a new campaign...... it was a campaign from about years ago.??	Hello, I'm Lucy, helping answer questions and send them live too. Sorry to hear you've had this experience - I'd absolutely suggest getting in contact with our helpline on 0808 800 0303 where we have our benefits and employment advisors. I'll put your question to the room, but I'd also really like to connect you with Katherine, our Director of Support and Local Networks who is around from 13:00, and who can give a more detailed reply - is that ok? Thank you, Lucy. Hello, sorry for the delay in coming back to you, we've questions thick and fast here so doing our best to get back to people. Katherine will be with us soon, and I'll ask her to hop on to answer your questions. As far as Get it On Time goes, you're right that this isn't a new campaign, of course - but, we're giving it a significant push this year with a new report and findings Hi Katherine Crawford here. Thank you for your questions about accessing welfare benefits. And sharing your frustrations. We DO have a specialist Benefits and Employments Advice team who you can access through the Helpline on 0808 800 0303. Their role is to support you both with applications and appeals should that be necessary. We also have a partnership with DWP, who should be able to support you with writing applications- but if you find that is not working well in your area, PLEASE TELL US and we will do our best to support you both with the form, and with any subsequent challenges you may have The Welfare benefits medical assessments have given people living with a range of conditions real challenges in recent years. We can absolutely understand your frustration if you found that the person assessing you did not have an understanding of Parkinson's. Sharing your experience with our campaigns team really helps us when we're pressuring government to change their policies and processes. We work with other charities through the Disabilities Consortium to try to make this happen. Member's reply: *Thank you for your reply. I am, and have always been very keen to share the experience of dealing with the DWP for my esa and PIP.* Thank you! We'd be very grateful. If you're in London- Benali and Jack from our campaigns team are here. If you're in Scotland or Northern Ireland- please contact Tanith Muller (Scotland) or Caroline McEvoy (Northern Ireland. If in Newcastle, please

	email lcockram@parkinsons.org.uk Getting Medication On Time, Every Time is a long running campaign for the charity. But we make no apology for re- launching that campaign now. Despite the fact that we have almost 100% Parkinson's Nurse Specialist coverage across the UK, time and again people have a very poor experience in hospital because they do not get their medication on time, every time. It remains a key campaigning issue for us. We are determined that this will change, and that people living with Parkinson's can stay in hospital feeling confident that they will receive their medication on time, every time. Hi- Katherine Crawford here. I hope your recovery is going well from your surgery- and that you're starting to see improvements. I'm assuming you meant that you've been asked to attend a benefits assessment- I'd urge you to contact our Helpline as soon as possible, explain the situation, and we will put you in touch with a specialist adviser to support you with this. The number is 0808 800 0303. I hope that this helps and that your recovery goes well.
Anon When are they going to improve the waiting time for a person to see a neurologist for a diagnosis in NI?	Answer on slido platform: Hello NI team! Are you able to pick this up in the room? Thanks so very much. Lucy. *Note: direct contact was made with this individual following the event and our Northern Ireland team has provided the following statement:* On 19 December 2018, in light of pressures within the neurology service, the Department of Health published terms of reference for a Regional Review of Neurology Services with a Neurology Review Team to be established to take the review forward. An interim report showed that the number of people waiting for a first neurology outpatient appointment has more than doubled in Northern Ireland in the past four years. To tackle waiting list figures and modernise services, the review is expected to identify an optimal service configuration of neurology services through to 2035 and we are working closely with the Department of Health on a number of key work streams.

Anon What has happened to the Keeping in Touch project?	Answer on slido platform: Hello, really happy to send you some more information on this Monday, once I am back in the office (Lucy) - would you be happy to email agm@parkinsons.org.uk so I can contact you? Thank you! Answer by email after the event: There were a number of findings from the pilot that led to the decision to not roll it out more widely as a visiting project, but to instead focus on it as a telephone project only (where there is demand). In summary, the findings included: ● the perception of need for the project was greater than the reality of need on the ground, as demonstrated by the take up of the pilot project ● it was difficult to recruit volunteers to coordinate and manage the project ● it required resource intensive support and training for the volunteers ● it required a high level of coordination to ensure it was run safely These findings made the future sustainability of the project unlikely, and instead the option of telephone keeping in touch support is being offered as an alternative where there is demand. We have also trialled branch volunteers doing visits to care homes which worked more successfully when it was piloted.
Anon from N/cle event. Are GP's made aware of Parkinson's symptoms above and beyond a tremor and stride length. eg. eyes, writing, smell etc..	Not answered on the day, answer follows: Parkinson's UK produced a new 1 hour online course for GPs called Parkinson's from a GP and patient perspective: supporting initial assessment and referral. This course focuses on the following areas: ● An overview of Parkinson's ● Interview with a GP - case studies, signs and symptoms ● Patient's ideas, concerns and expectations ● Examination - GP consultation, examination videos and referrals The aim of this course is to give GPs information about suspecting and recognising Parkinson's for referral. It focuses on the experiences of people with Parkinson's and a GP. There is an additional focus on recognising that younger people may also be diagnosed with Parkinson's.It makes GPs aware of the wide range of symptoms that

	could present prior to diagnosis. The course is now available from the learning hub in the professionals area of our website (20 Nov 2019). We will be launching this course with publicity in the new year.
Anon Is there a time frame for the roll out of MDT teams across Scotland and the UK?	Answer on slido platform: Hello, hopefully we can refer you to Annie Macleod for this one if she is in the room? If the q's are about a specific area hoping you guys can pick up as you're the experts :) Thanks! Not answered on the day, answer follows: Using our Excellence network as a vehicle to share and spread best practice we have set out an ambition that by the end of our 2020 - 2024 strategy 80% of people living with Parkinson's have access to a multi-disciplinary teams across the whole of the UK. Access to multi-disciplinary teams is also a recommendation within the Scotland Services Report. Although embedding this type of approach will be a challenge within NHS structure, we are currently working with a number of health boards and NHS Trusts to implement this model of care for people with Parkinsons
Colin, Glasgow PUK and health professionals advocate keeping active. Most notices about activities require entry fee plus pledge to raise sponsorship. One cannot reap from the same sources and therefore entering events is discouraged. If PUK is serious then PwPs should be encouraged to take part regardless. Follow up clarification: Hi Lucy, its generally postings on FB from partners of PUK, Parkinson's Trust. For example, Deloitte is currently running a UK cycle event in Sept 2020. Cost £1,599 or £499 but pledge £2.2k to eg Parkinsons. Having just raised £2k+ I was hoping for some	Answer on slido platform: Hi Colin, thanks for the question. Really keen to raise this with Katy, our head of events - so can I clarify if you mean Parkinson's UK run events? Thanks in advance for any extra info. Lucy. Not answered on the day, answer follows: Parkinson's UK promotes and supports approximately 180 fundraising events a year with an income target of over £3.5million. This money funds the work that we do across the charity - including local support groups, research and our helpline. Events naturally have overheads and as such will also incur a cost to run, aside any additional income raised through personal fundraising. We specifically choose and promote a variety of fundraising activities to try and ensure we deliver as much income as possible to support people affected by Parkisnon's at a variety of price points.There will always be some events which have large costs attached to them - the Deloitte Ride Across Britain event for example includes full accommodation and

discretion. Events want fee + sponsorship. The fee + sponsorship demand on every event is a discouragement. If we are serious about getting people moving there shouldn't be a financial barrier. Taking part is key to delaying advancement. Over the last 2 years since diagnosis there have been so many events Id like to have participated but the financial demands on top of cost of attending is restrictive and a discouragement. So much activity missed.	support for 9 days and as a charity we are invoiced per place for this event so we therefore need participants to cover this cost to ensure we deliver some return for the charity to support our work. However there are also some events we promote - such as our walks series or our virtual activity which have low entry points - £3-10 and no minimum target to hit. The virtual activity in particular is aimed at encouraging people to build exercise into their daily routine and participate at their own pace, and although we are always delighted if people use the opportunity to fundraise some individuals choose not to and there is no obligation. Ultimately our fundraising event portfolio is there primarily to deliver income. This income then supports the work we do around the country including delivering exercise opportunities to people living with the condition which is accessible to all. We have to ensure a balance between supporting individuals with keeping active - which we do through our exercise programme and support services - and raising money to deliver all of our work through event fundraising.