

Minutes of the Annual General Meeting

4 October 2018, 1.20pm to 3pm
Aston Conference Centre

Minute

1. Welcomes

- 1.1. MG opened the meeting, noting that the attendance in the room clearly met the quorate requirement of 50 members in person or proxy.
- 1.2. MG informed members that before moving into the resolutions on the agenda he would start with an overview of the strategic report found in the Annual Report (Chair's report from the Board of Trustees) and then open the meeting up to questions about the report, the report from the Nominations & Remuneration Committee and any questions on the tabled resolutions.
- 1.3. MG introduced the newly recruited trustees: Kyle Alexander (attending the Templepatrick event), Andrew Cavey (attending the Newcastle event), Gary Shaughnessy, Paresh Thakrar and Matthew Durdy.
- 1.4. MG introduced the top table: Mary Whyham (Vice Chair of the Board of Trustees), Margaret Chamberlain (Governance Trustee), Nadra Ahmed (trustee and Chair of the Nominations & Remuneration Committee), Steve Ford (CEO), Hanah Burgess (Director of Finance & Performance), Paul Mayhew-Archer (member of Parkinson's UK and host for the Members' Day).

2. Chair's report from the Board of Trustees

- 2.1. MG informed members that the strategic report in the Annual Report focussed on impact and achievements. He noted that 2017 had been a year of great progress for Parkinson's UK, with the charity reaching even more of the 145,000 people with Parkinson's. However, earlier diagnosis of the condition and an aging population will increase the number of people living with, and affected by, Parkinson's to approximately a quarter of a million, with every one of those people requiring some degree of support and help. The question is whether the charity is doing enough to support these people.
 - 2.2. The charity's increasing level of contact with the newly diagnosed is impressive (85% of newly diagnosed people are being referred to Parkinson's UK) and,
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- through the Excellent Network, the charity is driving improvements in NHS services to people with Parkinson's.
- 2.3. Members heard that the charity had recently started a new local group in the Shetland Islands and of the 60 or so people diagnosed with Parkinson's in that area two thirds were already part of this new Parkinson's UK group. This showed that the charity can reach out to even more people even in the more remote parts of the UK.
 - 2.4. Parkinson's UK is also championing new models of drug development and is very hopeful of early successes in this arena but MG acknowledged that there would be failures as well as successes within the drug development pipeline. This was the nature of working in the virtual biotech realm and the board would need to continue to balance the risks around these programmes of work.
 - 2.5. MG stated that members heard at the last AGM that membership would be re-launched. The board was of the view that membership was the heart of Parkinson's UK and he knew that members attending would have given valuable input to the membership stand in the marketplace, where staff were gathering feedback on the planned re-launch.
 - 2.6. MG thanked members, volunteers and local groups, who were the teams that made all the difference at Parkinson's UK.
 - 2.7. MG noted that the board was also saying goodbye to two of its trustees, Nadra Ahmed and Richard Raine, and thanked both for their contributions. He was pleased to note that both intended to keep in contact and continue to help and support the board. MG informed members that the board had also said farewell to Lucie Austin earlier in the year.
 - 2.8. Members were informed that in 2017 the charity's finances had grown impressively, with an increase of just over 20% in income. Legacies grew by 40%, in part because of some particularly large legacies but also due to the hard work of Paul Jackson-Clark, Director of Fundraising, and the fundraising team who continued to grow revenues.
 - 2.9. The 2018 forecast showed a levelling out and a small decline on 2017's achievement, but members should note that these were not final numbers. MG informed members that the board were aware that the charity was approaching a period where fundraising was likely to be more difficult, while the demands on the charity's money would continue to increase.
 - 2.10. In terms of local group revenue, in 2017 there were a number of local groups with very big legacies. Local groups were continuing to grow revenue and grow it effectively.
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- 2.11. As a result of increased income in 2017, the charity had grown its services and cost of those services in 2018, thereby increasing expenditure. Feedback from membership was that members wanted the charity to increase funding for research and finding a cure, and so this year the Virtual Biotech investment had been increased (funding for which is structured in fairly large two to three-year tranches).
- 2.12. MG assured members that the growth in Virtual Biotech had not been at the expense of university grants, which had been maintained.
- 2.13. One of the common questions received by charities is how much they have spent on raising funds and support costs. MG shared a chart showing a comparison between Parkinson's UK and other similar charities, stating that Parkinson's UK stood up well in comparison.
- 2.14. Members were informed that Parkinson's UK had a very strong reserves policy, which required reserves to be maintained at an amount equal to between three and five months expenditure. The charity had been maintaining this at the top end of this range but, in these turbulent times, the board believed this is the right thing to do. The board would continue to have to consider whether maintaining service delivery required dipping into reserves.
- 2.15. Looking forward, trust in charities is holding up but is under threat. A recent publication by the Charity Commission on trust in charities set out the factors which make charities most trustworthy, these are:
1. Transparent about where their money goes
 2. True to their values
 3. Efficient use of resources
 4. Demonstrating positive difference
- 2.16. MG informed members that these were the keystones that the Parkinson's UK board wished to hold to and would continue to work on. The board was also asking themselves whether the charity was sufficiently flexible, agile and able to meet local needs. And, if not, how do we make this happen? Part of the work Steve Ford and his team were now focussed on was about answering these questions and it was clear that working in partnership with other organisations would be key to making this happen.
- 2.17. Finally, MG stated it was beholden to the board to ensure accountability, transparency and ethical conduct. This would maintain the trust that members and the public place in the charity, ensuring that Parkinson's UK was a charity that people wanted to support.
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3. Questions from members with answers from board and executive

3.1. MG opened the meeting to questions.

3.2. **Paul Mayhew-Archer, member:** What is the balance of money that Parkinson's UK spends on research to find a cure as compared to the balance of money that is spent on making life easier now for people with Parkinson's?

3.2.1. MG responded that spend on research on better treatments had grown. Steve Ford, Chief Executive (CEO), added that there was a further breakdown in relation to money spent on research in terms of the proportion of this spent on finding a cure as compared to finding relief for symptoms people are facing now. CEO noted that he did not have this data to hand but that it was information that was regularly tracked and reviewed by the board so that a balance between these was maintained. CEO added that within the Virtual Biotech some of funding was being directed towards trials next year to relieve psychosis symptoms.

3.3. **Valerie Letherin, Oxford branch:** How closely are we working with other countries and are we ahead or behind in terms of the amount of money we are spending to help find a cure?

3.3.1. CEO agreed that this was an international challenge and shared that he had recently chaired a phone call with the World Parkinson's Congress, a group that brought together Parkinson's organisations internationally to share best practice and learn from one another. In the week following the AGM he and the Director of Research would be going to the United States to attend a conference with the Michael J Fox Foundation. Working internationally was particularly strong around research, but also in terms of sharing best practice and new initiatives in healthcare. He believed that Parkinson's UK was leading the way in many areas and had a responsibility to share this knowledge.

3.4. **Kath Elkin, East Midlands Research Support Network:** Regarding Virtual Biotech, is there any financial payback in terms of intellectual property rights and future income streams on successful projects that Parkinson's UK has in part or in whole funded?

3.4.1. Arthur Roach, Director of Research (DR) responded that yes that was the case and was part of the essence of the Virtual Biotech programme: Parkinson's UK was working as a funder of projects and part of that meant that when the charity provided money, in exchange it was given rights to future revenues. There were some repurposing projects of old, inexpensive drugs which were supported through Virtual Biotech and in relation to these projects no revenue was expected.

3.5. **Madeleine Atkins, North West London:** I had a mother and two aunts with Parkinson's so the family have wondered about the genetic link, additionally because they were children at the time of the 1918 flu epidemic I wonder how much that might have played a part?

3.5.1. DR responded that there was no well understood link between the flu and Parkinson's but there was some inflammation that was part of the brain pathology and it is thought that peripheral inflammatory infections might be one of the many contributors. In most people that there would be a combination of genetic and environmental contributors and while it is thought that they all play a bit of a part it was very difficult to attribute to any one cause.

3.6. **Colin Cheesman, former trustee:** Firstly, it is great to see so many people here so congratulations for increasing the turnout. Also, the fundraising Paul and his team have carried out is a stunning success. The point I want to make is around how that success can really be demonstrated at a local level. This 'boom' has not been felt at a local level and we don't see much evidence of investment in branch network. If you look at the number of full-time employees, that also seems to be rising. My question for the board in relation to the budget is are they satisfied that they have got the balance right between what goes on in the centre and what goes on at a local level?

3.6.1. MG responded that the board was satisfied that significant progress had been made but acknowledged that the board were not completely satisfied that they had got the balance right going forward. The board were putting a degree of challenge on the assumptions that had previously served the charity well in terms of growth generally but had not delivered that balance between the centre and local networks.

3.6.2. CEO added that he had spoken earlier in the day about the three themes around which the strategy would develop and how the existing theme of 'taking control' could be combined with the existing theme of 'quality services'. The vision here was to support better alignment of resources and ways of working around everyone diagnosed with Parkinson's, so that when someone was diagnosed they were very clearly signposted into a series of services that really make a difference.

3.6.3. There was an opportunity here for the charity to really streamline this process, thinking about how these services were positioned locally. Following on from this the charity needed to think about how it is devolving some of those decisions and resources around local communities.

3.7. **Sally, Oxford branch:** The word partnership has come up, which is refreshing. I hope we have more partnerships between branches because I feel as though we're working in isolation. My main question relates to how refreshing it's been to have Paul give such a good example of what living with Parkinson's is all about and when are we going to have more members of staff with Parkinson's, and on the board? It makes such a difference having people at the top with the condition.

3.7.1. MG responded that the board were very aware of this and there was now had four people on the board with Parkinson's. It was something very much on the board's mind. The board was looking for the best possible people in terms of skills to ensure the board would steer the charity in the best possible way. Of course, one of the ways to ensure this was by having that day-to-day understanding of what it means to have Parkinson's.

3.8. **Ken Culley:** I was diagnosed three years ago and since then I have had nothing but help and support from the charity and I hold it in the highest possible regard. I decided I wanted to give something back and, with a background working in building societies, I knew the value of membership to any organisation. Membership is the engine that drives the activity, that generates the funds, that are needed to finance the research, that will hopefully one day find a cure. I was horrified to see that for the past six years Parkinson's UK membership has been in decline, today it is approximately 35,000, whereas six years ago it was 38,000. Our annual subscription is £4 and that has not been revised for almost twenty years. It is a loss leader for the services that we get and the support that we get. I've been delighted to learn we have a major project underway to grow the membership but I would like some assurance that:

1. Membership will continue to be a major part of the ongoing strategy of the charity and not allowed to fall into decline.
2. The membership project will be allocated the appropriate resource in terms of skills and money so it can be delivered in a timely manner.
3. Progress against your agreed target will be reported regularly at the AGM and in The Parkinson magazine.
4. Trustees will consider embedding membership in its entirety into the objectives for the CEO and his executive leadership team.

3.8.1. MG offered immediate reassurance on the point that membership was part of the objectives set for the CEO, and therefore of the senior leadership team as well. The board was strongly committed to the membership project and agreed that membership was the foundation of

both the charity's past success and future success. As far as resources go, the board had agreed the resource envelope for the project and it and the senior leadership team was determined to see this delivered successfully, with transparency to members about the progress.

3.9. **Submitted remotely via sli.do:** Why did we change from a Parkinson's awareness week to a Parkinson's awareness day?

3.9.1. CEO noted that the reality was that the focus had always been on one particular day. In 2018 there was media coverage in every single hour of the 24 hours of Parkinson's Awareness Day. Local groups were still encouraged to undertake activities during that week.

3.10. **Submitted remotely via sli.do:** How much is spent on awareness raising?

3.10.1. CEO responded that the charity did not spend enough on awareness raising and this would be 'dialled up' in the next strategy.

3.11. **Submitted remotely via sli.do:** Can healthy people get involved in research?

3.11.1. CEO responded yes, and encouraged people to join the Research Support Network. Most research projects needed 'controls', people who did not have the condition who would be suitably age matched against people who had Parkinson's.

3.12. **Submitted remotely via sli.do:** Are we doing research on the digestive system?

3.12.1. CEO confirmed that Parkinson's UK was funding research that was focused on the digestive system.

3.13. **Submitted remotely via sli.do:** How far away are we from early detection?

3.13.1. CEO informed members that there was a project that Parkinson's UK was funding looking to identify those early changes that take place in someone with Parkinson's that would help improve understanding of when the process of Parkinson's really started. Generally, it was probably seven or eight years before someone went to the doctor with symptoms.

3.14. **Submitted remotely via sli.do:** Locally we're dealing with six complex forms, does anyone have an overview of what local group are asked to do?

3.14.1. CEO noted that later on the afternoon members would be hearing about the Bridging the Gap project on strengthening the work between local networks and the centre.

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- 3.15. **Submitted remotely via sli.do:** The AGM audience has insignificant black and ethnic minority representation and we have the same challenge in our branch. We need to address this together.
- 3.15.1. CEO agreed that this was something the charity and its members needed to work together on.
- 3.16. MG asked DR to address questions regarding cannabidiol (CBD oil). DR clarified that CBD was extracted from cannabis but was not cannabis. It was thought to have a number of health benefits but not enough was known about these. Parkinson's UK was funding research into this and the results would be announced in a few months.
- 3.17. PMA asked to put a couple of questions to DR that members had asked over lunch.
- 3.18. **Submitted to PMA:** What is the current situation with reference to the brain bank? Do you still want brains with Parkinson's and without Parkinson's?
- 3.18.1. DR responded that the brain bank was still open and that Parkinson's UK was negotiating another term of funding for it. Members heard that the brain bank was one of the best in the world, used by researchers from all over the world, and there was a programme in place to increase this use even further. The bank needed both Parkinson's brains and healthy brains as a control.
- 3.19. **Submitted to PMA:** Is there any success with using older, licensed drugs for Parkinson's treatment?
- 3.19.1. DR replied that this was called repurposing and was a very active area for not only Parkinson's UK but other charities and organisations who also invested heavily in repurposing research and development. Parkinson's UK was considering funding a couple of projects they hoped to announce in the next year that involved repurposing of drugs for Parkinson's treatments, these should save years and millions in the drug development process.
- 3.20. **Submitted to PMA:** Are there any crossovers with treatments for other conditions?
- 3.20.1. DR informed members that yes, there were crossovers with treatments for other conditions. One of the Virtual Biotech projects is aimed at producing a new drug which would be effective at treating Parkinson's but also ALS and possibly other neurological conditions.
- 3.21. **Submitted to PMA:** Is there any research into change of diet?
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- 3.21.1. DR stated that there was relatively little evidence that diet itself would change Parkinson's and Parkinson's UK did not believe this was a major place to look.
- 3.22. **Roger Elkin, East Midlands Research Network:** I think Virtual Biotech is absolutely the right way to speed up the development process, but in doing this it moves away from the traditional model of funding and changes the risk reward balance to make it attractive to commercial partners. This puts Parkinson's UK in the position of underwriting new projects which is new territory. £2m has already been spent with a further £4m committed and any commercial company will operate a formal programme management methodology that serves their best interests. Is the board confident that from the Parkinson's UK perspective there is adequate management of financial, development and delivery risks within the Virtual Biotech projects or is it a case of Parkinson's UK needing to become more involved?
- 3.22.1. MG responded that from the board's perspective they undertook a skills audit about twelve months ago which concluded that more expertise was required on the board to address these questions. The recent recruitment of new trustees had very much changed the balance of skills and the board now had a number of trustees who added more value in terms of better addressing those questions.
- 3.22.2. Parkinson's UK research was in many ways catalytic. MG stated that Parkinson's UK would not be able to fund full trials in his lifetime and therefore the charity needed to work with big and mid-sized pharma companies if it was going to get some of those drugs and therapies to market.
- 3.22.3. DR added that Parkinson's UK had also hired a small number of staff who had worked in pharma or biotech for 20-30 years who were able to provide in-house experience and advice. Parkinson's UK had also created a Biotech Business Group formed of staff, trustees and external experts to advise the charity.
- 3.23. **Unknown:** It's only four and a half months until our world changes, can you reassure us that we will still get our medication after Brexit?
- 3.23.1. MG stated that he could not give that assurance, although he wished he could, but that it was something the charity was involved in lobbying for. CEO added that Parkinson's UK was a member of the Association of Medical Research Charities and was working together with other charities to make sure the charity's voice was heard as part of those conversations, in regular dialogue with MHRA and other key bodies. He noted that a lot of the noises had been quite reassuring but as soon as
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the charity received any indication of concerns, it would give very good advice to the Parkinson's community and the clinical community.

- 3.24. **Phil Bungay:** Next year can we please have a breakdown of those figures relating into money spent on finding a cure vs treatments for now. Additionally, it seems that the organisation is run on a very top-down basis. While there are Working Together events, there are no mechanisms to support grassroots up innovation. Finally, it would be helpful to have local support to help local groups identify what grants they can apply for.

3.24.1. MG asked for the points in 3.24 to be noted.

- 3.25. **Valerie Rossiter, Hampshire:** I would like to continue that thought and ask the board how they see local finances in local branches. I'm sure my branch isn't the only one finding it more and more difficult to raise funds. One of our local events has been a huge summer fete since 1985 and I have watched our income on it plummet. I had a team of six people working on it very hard this year and we raised £200 which will not even pay a month's room hire for us. Are there funds at national level to help us start new projects because at the moment we are at a complete standstill?

3.25.1. Katherine Crawford, Director of Support and Local Networks (DSLN) agreed that these were important points and questions. She stated that after the break there would be a session called 'Strengthening our Local Work' which would look at how the charity could work together better; from the centre to local networks and between local networks.

3.25.2. She acknowledged that local networks had been spending money very effectively on delivering the kinds of activities the charity wanted everyone to have access to, e.g. exercise, creative and therapeutic activities. Coming back to CEO's earlier point, the strategy discussions now taking place would have a focus on working with and supporting local networks more effectively. There is a backstop, if a local group is really struggling we do try to help from central funds and have done so once this year. She offered to speak to the questioner after the meeting.

3.25.3. MG agreed that the board were aware that the organisation was essentially running two economies and there would be more work done to improve this.

- 3.26. **Reenie, Central London Branch:** Have we ever thought of amalgamating with Cure Parkinson's Trust?

3.26.1. MG stated that the charity maintained close relationships with the Cure Parkinson's Trust and would continue to do so. DR's team was working

closely with them to ensure there was no duplication of work in relation to research activities.

3.27. MG thanked members for their questions.

4. Approval of the minutes of the Saturday 14 October 2017 AGM

- 4.1. MG moved to the formal voting and reminded attendees that only members could vote and, of attending members, only those who had not already voted by proxy could vote. Those who were eligible to vote were given white voting cards at registration.
- 4.2. MG asked for members to approve the minutes of the 2017 AGM. A clear majority of white voting cards were displayed by members.
- 4.3. **Resolution:** members approved the minutes of the AGM held Saturday 14 October 2017.

5. Receipt of the charity's annual accounts for the financial year ended 31 December 2017 together with the trustees' report and auditors report on these accounts.

- 5.1. MG noted receipt of the report by the members.

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

- 6.1. MG reiterated his thanks to Nadra Ahmed (NA) for her chairing of that committee and asked for questions on the report.
 - 6.2. **Colin Cheesman, former trustee:** You will recall at last year's AGM I asked a question about how the new flexibility for appointment of trustees was to be managed. My concern was that we would start to lose the link between elected trustees and the membership of the organisation if there was overuse of the power of co-option. We seem to be in a situation whereby co-option or appointment is a route to becoming an elected trustee and boards tend to appoint people in their own image.
 - 6.2.1. MG stated that the board was in full agreement on the principles behind having elected trustees on the board. However there had been particular challenges with finding individuals to stand for the Northern Ireland role and the board were very pleased to have appointed Kyle Alexander to this role.
 - 6.2.2. There was no desire from the board to use co-option as a route to the elected trustee role. There had been a number of co-options in 2018 and this was to address particular skills needed by the board. Two of those
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trustees co-opted would become appointed (rather than co-opted) trustees immediately after the AGM.

- 6.3. **Unknown:** Can we not have in the constitution that there should be a minimum number of people with Parkinson's on the board?

6.3.1. MG responded that this would be difficult to create a hard and fast rule on and that the board needed to consider the broad needs of the charity and get the best people to help them to meet these.

- 6.4. MG noted receipt of the report by the members.

7. Reappointment and remuneration of auditors

- 7.1. MG noted that members had asked at the 2017 AGM whether there would be a re-tender for audit services during 2018. This had not happened to do internal reasons but this was very much on the agenda of the new Director for Finance and Performance and the re-tender was planned for 2019. However, for audit of the 2018 accounts the board was proposing reappointment of Crowe UK LLP.
- 7.2. MG put the tabled resolution to vote. A clear majority voted in favour of the tabled resolution and the resolution set out at 7.3 below was carried.
- 7.3. **Resolution:** Members resolved that Crowe UK LLP be re-appointed as auditors of the charity and the Board of Trustees authorised to agree their remuneration.

8. Date of the 2019 AGM.

- 8.1. MG informed members that the date of the 2019 Members' Day and AGM would be Saturday 12 October 2019.
- 8.2. MG called the 2018 AGM to a close.
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APPENDIX 1: AGM attendance list (Birmingham, Aston Conference Centre)

David Adams	Alison Heath	David Ridley
Pam Archer	Alan Highway	Tony Robbs
Maurice Archer	Maureen Highway	Karen Rose
Anne Askins	Jan Hirons	Michael Rose
David Baldwin	Cynthia Ho	Valerie Rossiter
Paul Barker	Andrew Hobbs	Bill Rutt
John Stanley Bethell	David Hudson	Ian Scarrett
Joan Bethell	Carol Hudson	Pauline Schofield
John Bewley	Keith Hughes	Byron Scott
Graham Bloore	Lionel Humphries	David Scrivens
Howard Bridge	Christopher Jones	Diane Scrivens
Sally Bromley	Gill Jones	Stephen Searle
Jonathan Bromley	Tony Jones	Pamela Ann Searle
Dorothy Brooks	Alison Jordan	Gary Shaughnessy
Graham Brown	Sheila Knapman	Kay Slawson
Philip Bungay	Paul Knapman	Paresh Thakrar
Mary Burnell	John Lawton	David Thomas
Mark Butler	Pat Lee	Patricia Thomas
Richard Button	Valerie Letheren	Jean Turnbull
Robin Bywater	Mr Letheren	William Turnbull
Margaret Chamberlain	Anne MacColl	Jean-Louis Turpin
Colin Cheesman	Ian Mackintosh	Symon Vegro
Briony Cooke	Timothy Mason	Margaret Walpole
Ken Culley	Janet Mason	Paul Warner
Pam Culley	Paul Mayhew-Archer	William White
Helen Deane	Julie Mayhew-Archer	Alison Williams
Nigel Deane	Keith Mcavan	Ivor Williams
Mary Dejevsky	Avril Mcavan	David Wilson
Matthew Durdy	Douglas McNeill	Philip Wylie
Roger Elkin	Peter Miller	Ben Wylie
Kath Elkin	Laurel Miller	Sue Wylie
Joyce Elliott	Alison Miller	Madeline Lauder-Atkins
Kathy Espin	Barbara Molyneux	Rene Peel-Woloshyn
David Espin	Sheila North	Rick Morris
Anne Ferrett	Barry North	Aravind Bhadri
Roger Foulds	Joan O' Doherty	Bill Cox
Jonathan Mark	Bill O'Brien	Nigel Hamilton
Goodridge	Anne O'Brien	Kate Howard
Anne Goodridge	Margaret Owen	Andrew Cherry
Paul Gostick	Keith Palastanga	Diana Cherry
John Gregory	Rosemary Palastanga	Ishverbhai Patel
Rose Gregory	Elaine Payne	Gillian Howard de
Austin Griffiths	Eric Powell	Walden
Yvonne Hancocks	June Powell	Chris Wade
Mary Hansford	Sylvia Prankard	Mary Whyham
Sharon Harris	Anthony Pyne	
Andrea Harvey	Patricia Reed	
Robert Harvey	Terry Reed	

Staff:

Chris Holmes
Tyna Brych
Christopher Brodrick
Hanah Burgess
Jo Burrill
Val Buxton
Henry Cooke
Emma Cooper
Katherine Crawford
Aleksandra Di Fato
Steve Ford
Benali Hamdache
Emma Hypher
Gemma Instrall
Paul Jackson-Clark
Colleen Keck
Gayle Kelly
Sue Mills
Kate Monro
Liz Nash
Jade Oorthuysen-Dunne
Luis Perpetuo
Arthur Roach
Julia Selby
David Swindells
Dianne Stradling
Suzanne Merchant
Mina Dhillon
Jo Burrill
Steven King
Ana Palazon