

# The research in Scotland event in Edinburgh: reflections and key issues

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To celebrate World Parkinson's day, part of World Parkinson's Awareness Month, a day of talks, panel discussions and networking was organised at the Royal College of Physicians of Edinburgh in 2024 to bring everyone with an interest in Parkinson's disease (researchers, clinicians, people with Parkinson's and their loved ones) together. The aim of the event was to share knowledge, express concerns and frustrations, hear about new advances in the field and build collaborations. Several important points were raised: the requirement for better awareness and better support for those living with Parkinson's (including specialist care) and the need to invest in research and work together including the importance of Patient and Public Involvement to find better treatments and, hopefully, a cure.

We attended the Research in Scotland event that was jointly organised by Parkinson's UK, four Scotland Parkinson's Research Interest Groups, NHS Scotland Neuroprogressive and Dementia Network, and the universities of Dundee, Edinburgh, Robert Gordon Aberdeen. The aim of this hybrid meeting was to bring together everyone with an interest in Parkinson's disease (PD) to share expertise and provide updates on any advances in research, policy and support available for those living with PD (People with Parkinson's, PwP). Attendees included researchers, clinicians, research interest groups, policy makers, Parkinson's UK Local Advisers, campaigners, PwP and their loved ones. There were several key issues that were raised throughout the day.

## Better support for those with PD

For those with PD and their loved ones, a key issue was the need for better mental health support, better access to specialist PD support and regular consultations with medical professionals as outlined in the 'Parky Charter Petition' (see further reading section for link) that we urge people to sign. In regard to clinical support, people would like to see further investment in specialist PD nurses (since over 40% plan to retire by 2030), neuropsychologists, speech therapists, occupational therapists and specialist dietitians. We heard about the *Scotland Can't Wait* report and campaign (Tanith Muller from Parkinson's UK) who discussed the importance of better services for PwP and their families. She discussed the need for better

diagnosis, better medications and better mental health support, highlighting emotional support and better access to specialist care to help PwP who often have complex symptoms

## The importance of investing in research

Research was another key issue. In order to understand PD better, there is a need for more government funding for research. We need to investigate why incidences of PD are increasing, identify the causes of PD and how it might be prevented, and gain more knowledge about the molecular details and pathways involved. Working together and collaborating (e.g., with the Aligning Science Across Parkinson's, 'ASAP', pharmaceutical companies and Patient and Public Involvement, PPI) might speed this process up. The use of Artificial Intelligence (AI) could potentially help drive research forward with tools such as Deepmind.

We also discussed causes of PD such as the use of pesticides (e.g., Paraquat) and the need for better research into prevention. Also high on the agenda was a demand for new treatments to manage the condition and symptoms better. There have been no major breakthroughs in PD treatments since the 1960s (Levodopa) and we don't have a cure for PD yet. We discussed that scientific research takes a long time and the community needs to work together to drive this forward.

We heard about the advances being made in research. There were two talks about the role of leucine-rich repeat kinase 2 (LRRK2, or dardarin)

in PD from Professor Dario Alessi (Dundee University) and Professor Grzegorz Kudla (Edinburgh University). LRRK2 has been associated as a common genetic risk factor for PD. Overactivity and mutations in the LRRK2 gene have been associated with both early- and late-onset PD. Reducing LRRK2 kinase activity is an area of active research underway in clinical trials. Other genes such as Parkin and GBA1 have been associated with early-onset PD. Enhancing the activity of these enzymes is another promising therapeutic target, since PwP have decreased levels of these functional enzymes.

Professor Tilo Kunath (Edinburgh University) spoke about the role of the  $\alpha$ -synuclein protein in PD and how it can adopt different conformations that have been shown to be associated with PD (aggregates known as 'Lewy bodies'). His group is trying to recreate PD in the laboratory by making human stem cells containing disease-associated  $\alpha$ -synuclein, so that they can screen potential drugs with the ability to reduce or prevent  $\alpha$ -synuclein from forming these pathological conformations.

Dr Kathryn Bowles (Edinburgh University) spoke about a new and exciting area of research looking at the role of LRRK37A2 in PD. This protein co-localises with pathological conformations of  $\alpha$ -synuclein in the brains of PwP. The precise function and mechanism of this new gene is the focus of her research and could be a promising new therapeutic target.

Prof Miratul Muquit (Dundee University) spoke about the link between the functioning of the mitochondria (the powerhouse of the cell needed for cell survival) and its link to neurodegeneration in PD. He is interested in decoding the mechanisms behind mitochondrial dysfunction and PD especially understanding how the enzymes PINK1 and Parkin are involved (both are associated with early-onset PD), and he highlighted their promise as a therapeutic target for PD.

Dr Angus Macleod (University of Aberdeen) talked about prognostic models for PD, since PD is a degenerative disorder. Depending on when PD is diagnosed, it can affect people's lifespan (people with early-onset PD are thought to have shorter life spans than those with late-onset PD).

Dr Tom Gilbertson (Dundee University) spoke about the development of a new non-invasive focussed ultrasound technology (magnetic resonance-guided focused ultrasound) that uses sound waves to destroy tissue that prompts unwanted movements in people with essential tremor (a chronic neurological condition with faulty circuits in the thalamus that prompts involuntary movements in the hands and arms).



Scientific talks in the main hall.

## Raising awareness and campaigning

Raising awareness of PD was another key issue. Suggestions included improving communication with the public by involving inclusive groups of PwP who represent the wider community and offer positive role models.

Other ideas were to hold more fundraising events and communicate with parliament to bring about change for PwP. The panel discussed having better advocates for Parkinson's campaigns and the need for more awareness across the general public. Suggestions included broadening the appeal of campaigns by representing a more inclusive selection of people from the wider community, since Parkinson's does not discriminate. It can affect people of all ages, gender and cultural heritage, and so our communications should reflect that. We discussed the success of other charity campaigns (e.g., the 'ice bucket challenge' that raised awareness and money for amyotrophic lateral sclerosis) and the need for better campaigning and fundraising events to help fund research.



Panel discussions. From left to right: Marc van Grieken (Dundee Research Interest Group), Lorna Fraser (Parkinson's UK Local Adviser), Joy Milne (Dundee Research Interest

Group and famous for being 'the woman who can smell Parkinson's), Dr Esther Sammler (University of Dundee), Tanith Muller (Parkinson's UK Scotland Policy and Campaigns Manager), and us, Dr Cassie Terry from London Metropolitan University and Neil Morrison, representing the North of Scotland Research Interest Group. Chaired by John Minhinick (far right).

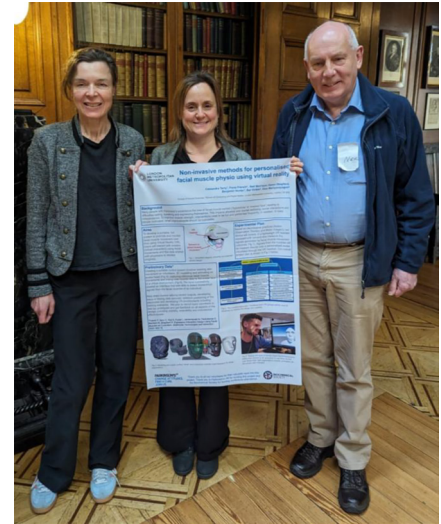
## Networking and knowledge exchange

Networking is particularly important when considering medical conditions such as PD, because a multidisciplinary approach is recommended for optimising the treatment and support given to patients.

Dr Francesca Tonelli (Dundee University) spoke about funding multidisciplinary research initiatives using an open science approach, to accelerate finding a cure for PD. She introduced ASAP that aims to do this through collaborations, data sharing and research-enabling resources.

There were several information stands and poster presentations at the event that facilitated discussions and establishing new collaborations.

We presented our poster entitled *Non-invasive methods for personalised facial muscle physiotherapy using virtual reality*. Our research is focused on developing a portable device offering people the opportunity to interact with a virtual reality environment to undertake exercises or tasks that promote movement of their facial muscles. This movement will be tracked through personalised sensors so we can see whether muscle movement improves over time after using the device. Many PwP can experience reduced muscle movement in their face, resulting in 'masked face' or 'hypomimia'. This can be frustrating if it impacts speech, swallowing or non-verbal communication, potentially limiting facial expression. Our research aims to improve people's physical and mental wellbeing. The project received funding from Parkinson's UK ('Non-Drug Approaches') and is a multidisciplinary collaboration between scientists, engineers and digital media experts from London Metropolitan University and PwP. As a result of attending this event, Dr Julie Jones (Robert Gordon University) invited us to do a podcast to talk about our work (<https://nosprigpod.podbean.com/e/facial-physio-dr-c-terry-dr-f-french-london-met-university-and-patient-participant-neil-morrison/>).



Our poster presentation. Non-invasive methods for personalised facial muscle physio using virtual reality. From left to right: Fiona French, Cassandra Terry, Neil Morrison.

Other posters included *Neuronal basis of perception of PD-associated odours by Caenorhabditis elegans* by Dr Varsha Singh (Dundee University), *Permission to Contact – A recruitment tool for the Neuroprogressive & Dementia Network* and *Neuroprogressive & Dementia Network (NDN): Partners in Research* (both by Neuroprogressive & Dementia Network). There were also numerous information stands (NHS, Parkinson's UK, Parkinson's Research Interest groups, Parkinson's UK Research Team, Neuroprogressive and Dementia Network) providing information and support for researchers, PwP and their loved ones, including how to become involved in community fundraising and events, and how to join research interest groups and find out about relevant research opportunities.



Information stalls being set up.



## The importance of PPI

Dr Tom Russ (Neuroprogressive & Dementia Network) gave an update on the ongoing clinical trials across Scotland and encouraged people to become involved as ‘partners in research’ to speed up research. He encouraged people to sign up with the Permission To Contact (PTC) register so that they can be contacted about current and future clinical trials, and we discussed the importance of donating our brains to the brain bank so we can continue research into PD.

Marc van Grieken (chair of the Dundee Research Interest Group) gave an honest and insightful talk about living with PD and explained how, instead of being passive, he has become an activist who won’t let PD define who he is. He described how he uses his PD diagnosis as a positive, working as an advocate and campaigner for the PD community, explaining how people can get involved in PPI (e.g., joining their local Research Interest Group), clinical trials and how PwP can help ‘shake out’ Parkinson’s.

It was pointed out that researchers desperately need PwP to help them in their research and that with online platforms such as Zoom, collaboration is easy (Neil reflected on his own experience living in the North of Scotland working with Cassie and Fiona who work in London). PPI has played a key role in the success of our research, with Neil Morrison and Karen Shepherd involved from the start. In addition to supporting the design of the device and associated activities, they are also co-applicants on our grant application and our proof of concept publication.

Here, we introduce Neil’s PPI experience and reflections of the event:

*“I live in the far North of Scotland with Jennifer and our two dogs Meg and Pippa. I enjoy walking my dogs, good food and supporting my football team St Johnstone”.*

*“I was diagnosed with Parkinson’s over 6 years ago. After getting over the initial shock, I thought – what can I do to help myself and others with this terrible condition? I joined the Parkinson’s UK Research Support Network. Through the Research Network I learned that there was a need for people to help researchers in the role of PPI. I*

*applied to become a PPI Volunteer and after an online training course, I started helping researchers in a variety of ways. The role has involved editing plain English summaries in funding applications, being a member of focus groups for projects and taking part in workshops to help design medication routes or devices. I am also a member of the Parkinson’s Involvement Steering Group which works to promote best practice for implementing PPI in the research community. Even prior to Covid, Parkinson’s UK encouraged the use of communication tools like Zoom to allow people from across the UK to be involved in supporting research. As a result, I have been in meetings with people from across the world discussing future research”.*

*“I found the event very exciting and stimulating, getting the chance to meet my heroes (that’s what I call everyone involved in treating and researching Parkinson’s). It is always strange to meet people you may have been talking to on Zoom for years in real life. The lectures were intellectually challenging, which just shows how complex and difficult a condition Parkinson’s is. Most importantly, the chance to network and point people in the right direction, for example, to the UK Brain bank or to learn where the best contacts are to help with research problems. Finally, it was wonderful to meet up with Fiona and Cassie in real life in such a wonderful building!”*

In conclusion, this was a wonderful meeting and we got to meet so many inspirational people. The meeting highlighted that we still have a long way to go to cure Parkinson’s disease due to the complexity of this condition; however, if we work together and share our expertise at meetings such as this, we can hopefully improve our understanding of the condition and speed up the development of better treatments. Investment in research and specialist care is essential for supporting those with Parkinson’s and their support networks and should be a priority moving forward. If you want to hear more about our work on ‘Non-invasive methods for personalised facial muscle physiotherapy using virtual reality’ or be involved, please email us. If you want to learn more about Parkinson’s disease, you might be interested in attending the International BNA2025 Festival of Neuroscience event in April (link below). ■

### Further Reading

- Parkinson’s UK website: <https://www.parkinsons.org.uk>
- Research Interest Groups - <https://www.parkinsons.org.uk/research/local-parkinsons-research-interest-groups>
- London Metropolitan University research: <https://www.londonmet.ac.uk/research/>
- The North of Scotland Parkinson’s Research Podcast Series- <https://nosprigpod.podbean.com>
- ASAP- <https://parkinsonsroadmap.org/open-science-champions/#>
- Joy Milne who can detect PD through smell <https://www.bbc.co.uk/news/uk-scotland-47627179>

(Continued)

### Further Reading (Continued)

- French F, Terry C, Huq S, Furieri I, Jareminski M, Pauliukenas S, Morrison N, Shepherd K et al (2022). *Expressive Interaction Design Using Facial Muscles as Controllers*. *Multimodal Technol. Interact.* 6, 78. <https://doi.org/10.3390/mti6090078>
- Scotland can't wait campaign: <https://www.parkinsons.org.uk/get-involved/cant-wait>
- Neuroprogressive and dementia Network: <https://services.nhslothian.scot/neuroprogressiveanddementianetwork/>
- Brain bank: <https://www.parkinsons.org.uk/research/parkinsons-uk-brain-bank>
- Parky Charter: <https://www.moversandshakerspodcast.com/post/sign-the-petition-here-to-support-our-parky-charter>
- <https://meetings.bna.org.uk/bna2025/bna2025/programme/>

### Author information



*Dr Cassandra Terry is a scientist at London Metropolitan University researching how the body's own proteins misfold and cause protein misfolding disorders such as Parkinson's disease and type 2 diabetes. Cassandra received a general travel grant from The Biochemical Society to fund attendance at the event. Email [c.terry@londonmet.ac.uk](mailto:c.terry@londonmet.ac.uk) Twitter/X @CassieJTerry. Email: [c.terry@londonmet.ac.uk](mailto:c.terry@londonmet.ac.uk)*



*Dr Fiona French works in the School of Computing and Digital Media at London Metropolitan University, teaching game development and researching how technology can support the welfare and enrichment of all species. Email [f.french@londonmet.ac.uk](mailto:f.french@londonmet.ac.uk) Twitter/X @FionaFrench Email: [f.french@londonmet.ac.uk](mailto:f.french@londonmet.ac.uk)*



*Neil Morrison is a retired chemist having specialised in analytical and radio chemistry. He currently volunteers for Parkinson's UK as a PPI volunteer and is on the Research Involvement Support Group. Email [neil.s.morrison@icloud.com](mailto:neil.s.morrison@icloud.com) Twitter/X @Cagerf Email: [neil.s.morrison@icloud.com](mailto:neil.s.morrison@icloud.com)*