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🌷 Tulip Fun Run 2025 Information 🌷

The whole group of runners, walkers and volunteers from the 2024 Tulip Fun Run!

🚶 **4-mile circular route from Scotsdales Garden Centre along the scenic DNA Trail**

🌞 **Everyone welcome – walk, run, or cheer! Launched by Cllr Dinah Pounds, Mayor of Cambridge!**

💷 **All funds raised support local Parkinson's programmes and vital research**

🧑‍⚕️ **Route fully marshalled and supported by professional first aiders**

👨‍👩‍👧 **Family-friendly – make a day of it with lunch at Scotsdales after**

🗓️ **Registration opens Monday 14th July at parkinsonscambridge.org**

✅ **Can't take part? Ask a friend, family member or gym buddy to walk on your behalf!**

Put the date in your diary and help us beat last year's total – over £4,000 raised!

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The Tulip Fun Run (although usually walked by the majority!) has been the Branch's major fundraising event since its inception in 2014. The money raised, through registration and sponsorship, helps to underpin the Branch's finances, ensuring that it can continue to run both social and exercise programmes in support of all people living with Parkinson's in the Cambridge Area. It has also allowed the Branch to make substantial donations each year towards the ongoing research into a cure for PD; and more recently has made it possible for young research students to attend important Parkinson's- focused conferences worldwide.

We need everyone living with Parkinson's to consider how they might support the event, happening on the morning of Sunday 31 August this year. Those who feel unable to take part are encouraged to persuade family members, sympathetic friends, gym buddies, to register and garner sponsorship from their friends. But many PwPs DO walk the route which is safely overseen by professional first aiders and marshalled by volunteers at six points on the route. The TFR is along a safe circular 4-mile run or walk from the Scotsdales Garden Centre (CB22 5JT), along the DNA trail to the outskirts of the Biomedical Campus and back to Scotsdales. The years have repeatedly demonstrated that family groups have a great day out – often repairing to Scotsdales for a well-deserved lunch.

We are also pleased to announce that Cllr. Dinah Pounds, the Current Mayor of Cambridge will be launching the event this year!

Registration will begin in mid-July. Details of how to register, how to solicit sponsorship, what preparations you need to make, and the details of the day's schedule will all be available on the website parkinsonscambridge.org from Monday 14 th July.

Please put the date in your diary, start to discuss it with friends and family, and do your bit to support the work of the Cambridge Branch of Parkinson's.

BRANCH MEETINGS

May Branch Meeting: Professor Roger Barker

In May, we were delighted to welcome our honorary president, Professor Roger Barker, who gave an engaging talk covering three key areas: redefining Parkinson's disease (PD), the impact of technological advances in research, and updates on clinical trials.

Roger began by discussing efforts to redefine PD based on biological rather than clinical markers. He highlighted Professor Maria Spillantini's discovery of the protein alpha-synuclein, which becomes misshapen in PD

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and is believed to play a central role in its development. Although PD is currently diagnosed based on clinical symptoms, Roger noted that a definitive diagnosis often isn't possible without post-mortem brain examination. He joked that "the only way to be sure is to look at your brain under a microscope."

By the time symptoms appear, around half of the brain's dopamine-producing cells are already lost. Catching PD earlier, in its "prodromal" stage, could be key to better treatments. However, early signs—like constipation, mood changes, and sleep issues—are non-specific. One strong clue is that 80% of people with REM sleep behaviour disorder go on to develop PD or a related condition within 15 years.

There's ongoing debate about renaming PD to "Neuronal Alpha-synuclein Disease" to reflect its biological basis, but Roger cautioned that this could be misleading and potentially confusing for patients and the public. Though alpha-synuclein is important, other proteins and mechanisms are involved.

Promising lab techniques like the alpha-synuclein seeding assay may help predict PD before symptoms arise, but screening people without symptoms raises ethical issues, especially since there are currently no disease-modifying treatments.

Roger then turned to advances in lab-based research. One potential treatment involves creating antibodies against alpha-synuclein. While promising in theory, challenges include identifying the right form of the protein and delivering treatments across the blood-brain barrier.

Because no animal naturally develops PD, researchers rely on stem cells made from patients' skin cells, turned into dopamine-producing brain cells. However, these are "young" cells, lacking age-related traits that influence the disease. Future personalised medicine could involve modifying a patient's own cells and reimplanting them, although this remains experimental.

Post-mortem brain donations also remain vital. Cutting-edge methods like single-cell and spatial transcriptomics now allow researchers to study gene expression across individual brain cells. One area of interest is **Transposable Elements**—ancient viral remnants in our DNA that may become active in ageing brains. Their activation could trigger immune responses and inflammation, potentially contributing to PD. Drugs originally developed for HIV, which target similar viral elements, may have therapeutic potential.

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Our local research efforts include Clotilde's work in Prof Caroline Williams-Gray's lab on inflammation in PD, and research by Prof Jo Jones, Roger, and myself investigating these Transposable Elements and inflammation using transcriptomics!

Finally, Roger gave an overview of current clinical trials. Many trials focus on repurposing existing drugs with known safety profiles. Notable examples include:

- **Exenatide (GLP-1 agonist)** – trial led by Tom Fulton
- **Ambroxol** – cough medicine trial led by Anthony Schapira
- **Ozempic** – typically used for diabetes/weight loss
- **Felodipine** – a blood pressure drug being studied in Huntington's disease by Roger's group

Roger introduced an innovative "rolling" trial design starting this summer in Cambridge. It allows for multiple drugs to be tested continuously across different trial arms, reducing costs and increasing flexibility. Drugs can be swapped in or out depending on effectiveness, akin to successful prostate cancer research models.

He also spoke about efforts to use growth factors like **GDNF** (a sort of "fertiliser" for dopamine cells) via gene therapy, as well as **cell replacement therapies**. A recent trial transplanted foetal-derived dopamine cells into the brain, and a new wave of trials is now using stem cells. The **STEM-PD** trial, led by Roger's team, has already treated eight patients, with results expected next year. A follow-up trial, **Transcend**, is being developed in partnership with Novo Nordisk.

Roger concluded by emphasizing that the next five years will be pivotal in determining whether dopamine cell replacement therapy can deliver real benefits to people with PD.

June Branch Meeting: Welcoming Future Doctors

Our 27th June meeting was a special one, as we welcomed six second-year medical students from the University of Cambridge: Rohan, Evangeline, Aditi, Sophia, Perpetual, and Keshav. As a course requirement, these students came to meet members of our branch to learn more about Parkinson's from the people who live with it every day. They've completed two pre-clinical years focused on scientific foundations, including a lecture series on the neurobiology of motor symptoms, and were eager to hear directly from those with lived experience of Parkinson's.

Before the student conversations began, Caroline updated the group on upcoming events and announcements. She shared that the Committee will be subsidising BeechBands for those who missed out on the country-wide offer of 500 free devices, and

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that Maddy Brown has kindly offered various items that helped her late mother with Parkinson's. There are several dates for the diary: Pam Holt's open garden in Haslingfield for Cream Teas on 7th September, the Serenata "Taking Flight" concert in Fulbourn on 26th July, the Tulip Fun Run on 31st August, and a Tombola and information stall at the Shelford Feast on Sunday 6th July (12–4pm). Members also brought along items for the tombola and were reminded to collect donation cans for pubs and local venues. Tesco has also generously offered us a collection slot in Ely on Friday 15th August, from 8am to 6pm.

Mark introduced the visiting students and explained that this session is designed to give them insight into how Parkinson's affects individuals beyond what textbooks can offer. The students shared their curiosity about how people are diagnosed, how care is managed, and how charities like Parkinson's UK make a difference.

Members split into smaller discussion groups with the students, which gave rise to an engaging and often eye-opening exchange. Topics included:

- **Diagnosis**: Members described the frustration of having no definitive test for Parkinson's — diagnosis often relies on symptoms alone. Experiences with doctors varied widely; some were compassionate, others gave the news in a blunt and clinical way.
- **Healthcare Challenges**: Many felt that care was generalised rather than personalised. Five-minute assessments, inconsistent contact with PD nurses and consultants, and long waiting times were recurring themes. In-person care especially home visits, which are extremely rare, were strongly preferred.
- **Lack of Information**: Members expressed a desire for more education from clinicians about new treatments. Many people learned about local support from groups like ours not through their doctors but via friends, podcasts, or their own research.
- **Support and Community**: The group reflected on how helpful it is to talk with others in similar situations. Carers especially shared how isolating the experience can be and how important the branch's carers meetings are for support. One member noted, "You can't care for someone else if you're not looked after yourself."
- **Living Well With Parkinson's**: Conversations touched on the benefits of exercise, maintaining social connections, and sharing humour — including the suggestion that we *can* shake collection cans thanks to tremors, unlike other charities!

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- **Public Misconceptions**: Members were keen to highlight that dementia is not synonymous with Parkinson's, and that the condition is often invisible to others. The "Movers and Shakers" podcast was widely praised for its honest and supportive content, offering more relatable insight than many medical consultations.

The students were clearly moved by the conversations and expressed their appreciation for the honesty and openness of the group. One commented on the striking differences in care experiences and how these perspectives would stay with them as future doctors.

After the meeting we received comments on the students experience meeting with the group. They described the visit as valuable and inspiring, with one student saying, "This experience has made me very excited to start my clinical work", while another wrote "A key takeaway for me was that Parkinson's affects everyone differently". They also said that they felt that it was extremely useful for them, and that future cohorts of medical students should be offered such experiences.

SCIENCE AND RESEARCH

Researcher Spotlight: Dr Alex Peattie

I'm a Postdoctoral Researcher in the Williams-Gray/Barker lab at the John Van Geest Centre for Brain Repair. I work with a team to better understand and treat Parkinson's disease (PD) and the dementia that sometimes comes with it (PDD), with the goal of spotting both earlier and improving outcomes.

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One of the main studies I work on is called **NET-PDD**. It follows people with Parkinson's over time to track how the disease progresses and how dementia may develop. We use brain scans to look at two key signs in the brain: a protein called **tau**, and signs of **inflammation** caused by immune cells in the brain. We also look at brain structure with MRI scans, check for inflammation markers in blood and spinal fluid, and study how these biological changes relate to memory, thinking, and behaviour.

Another project, **AZA-PD**, is a clinical trial testing whether a common anti-inflammatory drug called **Azathioprine** can slow down Parkinson's. We measure its effects using brain scans, blood and spinal fluid samples, and assessments of symptoms and behaviour.

A newer trial, **DAPA-PD**, is testing a different anti-inflammatory drug called **Dapansutrile**. Like the AZA study, we're checking whether reducing inflammation helps slow Parkinson's by looking at brain scans, biological markers, and symptoms.

Overall, our research is trying to understand whether **inflammation in the body and brain plays a key role in Parkinson's and dementia**, and whether we can slow or stop disease progression by targeting that inflammation.

To find out more about Dr Alex Peattie's Work please go to:

Cambridge Neuroscience: Dr Alex Peattie

UPCOMING BRANCH EVENTS

25 July: 10:30 -12:30, Branch Meeting; speaker Peter Moore from Wiltshire Farm Foods.

26 July: 7pm, "Taking Flight: a programme of uplifting songs and words" performed by **Serenata** (the all-female choir that raised £2,000+ for us last Christmas, and will try to do the same on 21 Dec this year). St Vigor's Church, Fulbourn, CB21 5EP: Click Here To Book Tickets!

22 August: 10:30-12:30, Branch Meeting, Speaker Dr Alistair Mackett, Consultant Geriatrician specialising in Parkinson's Disease.

31 August: TULIP FUN RUN 2025 — SAVE THE DATE. Registration from 14 July. This is our major fundraising event of the year; please join in. Details on the Homepage and front page of this newsletter!.

7 September: from 2pm, Cream Teas in the lovely garden of The Dovecote, 29 High Street, Haslingfield, CB23 1JW; in aid of Parkinson's and the Little Owls playgroup. Entrance £5 (and worth every penny!).

26 September: 10:30-12:30, Branch Meeting, Speaker Clotilde Tournerie, PhD student: "*The AD/PD 2025 International Conference on Alzheimer's and Parkinson's Diseases and related neurological disorders in Vienna*"

3 October: Museum Encounters Autumn Term begins, details later.

24 October: Branch meeting; Parkinson's nurses Preethi Biju, Claire, and Rachel, and Local Advisor, Becky Linnell, will be present.

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21 December: CHRISTMAS CONCERT IN TRINITY COLLEGE CHAPEL (by kind permission of the Master and Fellows of the College) **SAVE THE DATE**

6 February 2026: Museum Encounters Winter Term begins, details later.

This page on the Movers and Shakers website gives more details.

Here are some FAQs about the competition, and also the flyer about the petition to print and use at events. The petition is open until 10 September.

CHARITY NETWORK NEWS

Join the 'Parky Petition Challenge'

The Movers and Shakers are a group of public figures who all have Parkinson's and are not afraid to say what they think. And they have been saying it in their podcast about Parkinson's. Movers and Shakers.

They've been listening too, and have reached the unfortunate conclusion (their words) that the NHS and other public services are failing people with the condition.

They have published a charter, 'The Parky Charter', describing 5 things that people with Parkinson's need from the government but are not getting. Parkinson's UK, Cure Parkinson's and Spotlight YOPD support the principles of the Charter and are partnering with the Movers and Shakers to bring it to the attention of politicians.

They have a petition on the Parliament website and they need 100,000 signatures to trigger a debate in the Commons. To encourage local groups to help them, the Movers & Shakers have decided to launch a competition with themselves as the prize. They have promised to turn up in the area with the most signatures, and record a podcast with the group there.

Parkinson's UK Nurse Appeal

It's been just over a month since Parkinsons UK publicly launched the Parkinson's UK nurse appeal and they've had an incredible response. They've received hundreds of messages of support for nurses via email and socials, had over a thousand people sign up to Walk for Parkinson's events and have now raised over £4million of our £9 million target.

This is the equivalent of paying for around 33 new specialist roles to be pump-primed for two years. If you have already shared the appeal with your network - a big thank you.

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Opportunity to get involved in reviewing tech, for our Tech Guide.

What is the Tech Guide?

The Tech Guide is somewhere to discover and understand the devices and apps aimed at people with Parkinson's. It's somewhere you can come to work out what to trust with your time, your money and your health. And it's somewhere you can share your own experiences and discoveries with others.

The Tech Guide lists devices and apps aimed at people with Parkinson's, reviewing these products based on the real-world experience of people with Parkinson's. Connecting you to the information and support you need to make the right decisions for yourself about this technology.

Parkinson's UK created the Tech Guide so that people with Parkinson's can make the right decisions for themselves about all the devices and apps that claim to be able to help improve their quality of life.

- They can't recommend any product as being right for you, but can hopefully help you make more-confident decisions for your own needs.
- To connect you to the information and support you need to make the right decisions for yourself about technology.

When Parkinsons UK review a product, they give it to 6 people with Parkinson's. These reviewers are picked from a pool of volunteers based on their match to the particular product. These reviewers then live with the product for 4 weeks, taking notes of their experiences. At the end of this time, they answer a detailed questionnaire to gather all the information needed. Could you be one of the reviewers? Here is where you apply to be involved with this project.

The Parkinsons UK team then takes all this feedback and turns it into a single article to publish in the Tech Guide. Every review is checked by our Steering Group (members of the Parkinson's community who've volunteered their time to help the Tech Guide) and by a group of Parkinson's specialists (doctors, nurses, physiotherapists, speech therapists, academic etc.) so that the charity can be confident that it's correct and useful.

The tech guide is available free of charge in hard copy from our online shop or on virtually our website here

Catch Up on Our Webinar: Tackling Hallucinations and Delusions in Parkinson's

On 14 May, a webinar was hosted, *"Tackling Hallucinations and Delusions in Parkinson's,"* featuring a panel of experts and people with Parkinson's. The session covered why hallucinations and delusions happen, practical tips for managing these symptoms, and the latest research we're funding to develop new treatments.

The webinar recording is now available on YouTube.

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Contacting your Parkinson's Local Adviser

You will have met your Parkinson's Local Adviser now. I just wanted to remind you that they can be reached via the helpline (freephone) 0808 800 0303 or emails to adviser.east@parkinsons.org.uk. Any member of our community is welcome to self-refer through the helpline or by email. If you refer on their behalf we do need to know that you have their consent for us to contact them directly.

The Parkinsons UK helpline can support you with information and advice about all aspects of living with Parkinson's, such as:

- Medical issues
- Employment and benefits
- Health and social care
- Emotional support
- Local activities
- Signposting to other sources of information

They can put you in touch with your Local Adviser if you need more local or in depth support, including Blue Badges.

Watch out for fake QR codes!

QR codes (Quick Response codes) are square barcodes that can be scanned by the camera of a phone or tablet to quickly access information, such as websites or apps. Parkinson's UK uses them on some forms and posters. Unfortunately, scammers can also create harmful QR codes and share them online or stick them up in real places. These direct people to fake websites designed to get bank account, credit card or other personal information. This may be referred to as 'quishing'

Here are our top tips for being careful when you scan a QR code:

- Action Fraud recommends that you use the QR-scanner that comes with your phone, rather than using an app downloaded from an app store.
- Scanning QR codes in open spaces (like stations and car parks) might pose a greater risk. Check for signs that codes may have been tampered with (usually by a sticker placed over the legitimate QR code). If in doubt, do not scan them: use a search engine such as Google to find the official website or app for the organisation you need to make a payment to.
- If you receive an email with a QR code in it, and you're asked to scan it, you should be cautious due to an increase in these types of 'quishing' attacks.

Find out more about how to protect yourself from fraud on the Stop! Think Fraud site - https://stopthinkfraud.campaign.gov.uk

Grants for Marginalised Communities

Parkinson's UK has launched a new grants programme for marginalised groups and communities who are delivering physical activity classes for people with Parkinson's.

They are encouraging all our volunteers to share this amongst your networks, so if you

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currently work with groups or individuals from marginalised communities then please let them know. If you have any questions about the new pilot grants programme, visit our website or contact physicalactivity@parkinsons.org.uk.

Interested in finding out more about research?

Sign up to our Research Support network!

Interested in finding out more about campaigning?

Sign up to our Campaigns network!

All Branch Enquiries: pukcambridge@gmail.com

CAMBRIDGE BRANCH COMMITTEE MEMBERS

Chair: Mark Goodridge markgoodridge@gmail.com

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USEFUL CONTACTS

Branch Website: https://www.parkinsonscambridge.org

Parkinson's UK: www.parkinsons.org.uk 020-7931-8080 enquiries@parkinsons.org.uk

Helpline: A free, confidential helpline is available from Mon-Fri: 9am-7pm and Saturday 10am-2pm. Call 0808-800-0303, or email hello@parkinsons.org.uk

Facebook: www.facebook.com/parkinsonsukcambridge/

Parkinson's Nurses locally; for help and information:

- Parkinson's Nurse Team 0330-726-0077
- Addenbrooke's Hospital Parkinson's Nurses 01223-349814

Thank you for reading this issue of the Cambridge Branch newsletter and for supporting Parkinson's UK