The OPDC News

West Wing, John Radcliffe Hospital

The scoop of the year!

It has been a while since our last newsletter and as we enter the spring after what feels like a long cold winter, we thought it was about time for a little update on what has been happening within the Oxford Parkinson's Disease Centre (OPDC)!

There have been new publications, changes within the team, updates to our core Discovery study and lots of other exciting things happening, and so we hope you enjoy finding out all about it!

And as always a MASSIVE thank you for your continued support over the years!

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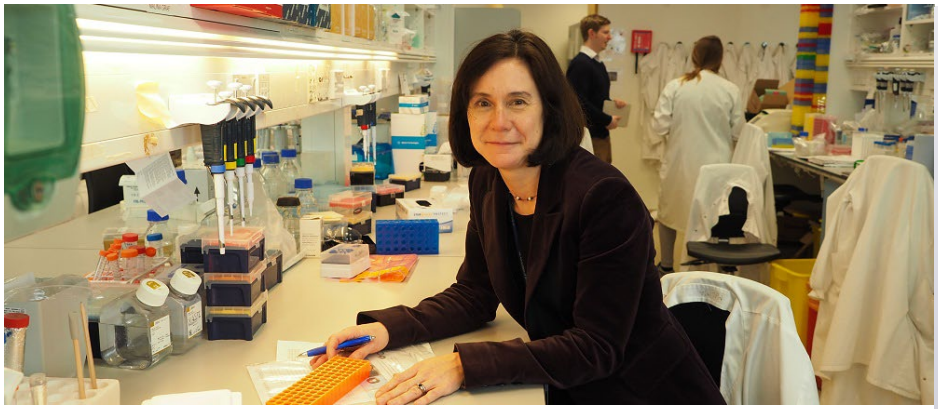
Oxford Parkinson's Disease Centre



Professor Michele Hu in the OPDC Lab

Professor Michele Hu:

'OPDC Discovery, also known as the Oxford Discovery Cohort, was set up in 2010 through a Parkinson's UK Award. This long-term observational study of diagnosed and prodromal Parkinson's is now listed as one of the leading biomarker cohorts worldwide.

I would like to thank all 1700 participants for generously supporting this study, giving their time to undergo clinic visits, brain scans, and donate precious bio samples. Your commitment has helped improve understanding on how Parkinson's starts and what drives later progression. We now have tools to measure baseline differences that will help improve future clinical trials and treatments for People with Parkinson's.

February 2026 will mark the end of a 15-year funding period by our funders Parkinson's UK whom I would also like to thank and acknowledge for their tireless support.

Thank you!'

The last (more than!) decade…

15 YEARS OF OPDC!

OPDC was set up in February 2010 by a group of scientists with the focus on understanding the earliest causes of Parkinson's Disease (PD). It was founded by the £5m Monument Trust Discovery award from Parkinson's UK, being the single largest research award funded by the charity. Since then, they have continued to support OPDC and the work we do.

The first clinical open day was held on 24th September 2010, where OPDC was officially launched, and participants were registered to be part of the Discovery cohort.

Since then, OPDC has become a world leading Parkinson's biomarker cohort, having recruited over 1100 people with PD, over 300 people with Rapid eye movement sleep behaviour disorder (RBD), over 300 healthy controls and over 100 relatives of people with PD.

Being a world class research Centre is something to be proud of and celebrate, and the fact that we were still able to keep going through a worldwide pandemic is something to commemorate.

The next and upcoming journey…

Researchers assessing a brain kindly donated for science

Everyone affiliated with OPDC works incredibly hard, and from the participants to the staff, we feel there is a real sense of community and camaraderie.

Discovery clinic follow-ups have ordinarily been every 12-18 months, and due to the Covid Pandemic we moved a lot to be done remotely, something we continue to offer to our cohort.

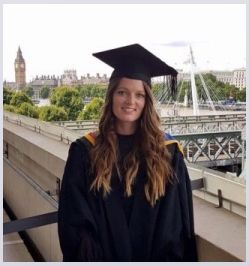
Since 2025, we will no longer be following up our control and PD relative arms. Having been followed up remotely for 10 years, we feel we have been able to obtain a wealth of data which we want to thank you for. We are also simplifying our PD remote follow ups so they are shorter, and will continue to follow up RBD in person where possible.

We are currently applying for a new OPDC funding from February 2026, with a focus on delivery of new treatment trials for people with Parkinson's. Although years have passed, our aim is the same and we will continue to work towards preventing PD onset and delaying PD progression.

OPDC STAFF!

(Because it's always nice to put a face to the name!)

Michele Hu
Professor of Clinical Neuroscience &
Consultant Neurologist



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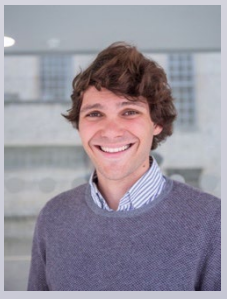
Research Practitioner

Karolien Groenewald
Clinical Research Fellow/DPhil Student

Ludo van Hillegondsberg
Clinical Research Fellow/DPhil Student



Timothee Aubourg
Postdoctoral Scientist

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Core Research Scientist

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Senior Clinical Research Fellow &
Honorary Consultant Neurologist

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Neurologist

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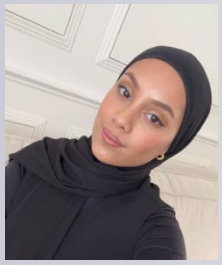
Research Administrator



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Senior Research associate in Medical Statistics

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Professor of Clinical Epidemiology

Tamir Eisenstein
Postdoctoral Researcher

Laura Parkkinen
Professor of Translational Neuropathology

Katarina Gunter
DPhil student

Olivia Morris
Research Nurse

World first iRBD drug trial - Syntara

Karolien Groenewald

It was with great excitement that we welcomed the first OPDC participant to screening for the much awaited, world first iRBD drug trial on 5 March 2025!

Isolated REM Sleep Behaviour Disorder (iRBD) is a condition where people physically act out their dreams during REM sleep, without yet having developed PD or another related condition. It's considered an early warning sign that a person might develop a synucleinopathy- a brain disease involving abnormal alpha synuclein protein deposits-such as PD or DLB.

This trial is in collaboration with the University of Sydney and sponsored by Australian pharmaceutical company, Syntara, and Parkinson's UK, as part of their Virtual Biotech initiative to push new treatments forward.

The OPDC aims to recruit 20 participants to this trial investigating the reversibility of neuro-inflammation as a driver of neurodegeneration in synucleinopathies, including iRBD.

First UK iRBD drug trial participant during his trial visit. When asked why he is taking part in the trial, the participant states:

'To help find a cure!'

High-throughput Proteomics

Ludo van Hillegondsberg

Proteomics is a way to study lots of proteins all at once, and it's opening an exciting new path to learn more about PD.

We have teamed up with experts at the Oxford-GSK Institute of Molecular and Computational Medicine to use this advanced technology in our OPDC Discovery Cohort.

We are looking at blood and spinal fluid to spot changes in proteins that might tell us when and why Parkinson's Disease starts and helps us figure out why Parkinson's Disease can look so different from one person to the next.

Through doing this work we hope to deepen our understanding of Parkinson's Disease and improve our ability to develop treatments and design better clinical trials.

Fast vs. Slow Parkinson's Progression in the Exenatide Trial digital substudy

Timothee Aubourg

Predicting how quickly Parkinson's will progress in an individual remains a major challenge, as the disease varies widely from person to person.

One of the key findings from the Exenatide-PD3 trial digital sub study was that Parkinson's progression occurs at different rates, which can be modelled-some people experience faster motor declines, while others remain relatively stable over the 96-week study period. Researchers explored this by analysing clinical assessments and using machine learning to identify two broad groups among 98 participants: 'fast progressors' (22%) and 'slow progressors' (78%).

While traditional clinical scores are commonly used, the sub study showed that they alone weren't reliable in predicting who would progress quickly at baseline visit. However, when digital motor data from smartphone assessments was combined with clinical measures using a machine learning approach, predication accuracy improved significantly.

In the future, these digital tools could help doctors better understand a person's likely progression from the outset, allowing for more precise grouping in research studies and ultimately paving the way for more personalized treatment approaches.

Patient conducting the smartphone assessment during a study visit.

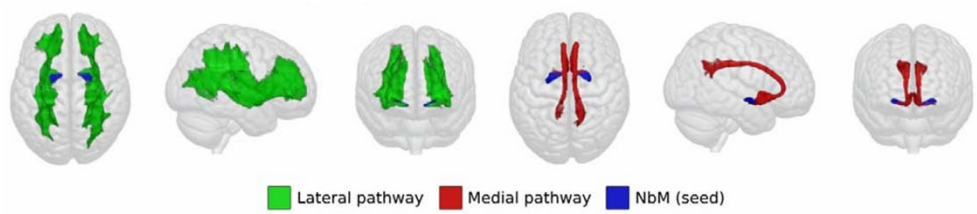
Brain Imaging in Parkinson's Disease

Tamir Eisenstein

We are currently using neuroimaging methods to investigate neurotransmitter systems in the brain.

The aim is to try identify imaging derived markers which may help in assessing future risk, disease manifestation and clinical progression in prodromal and manifest Lewy bodies disorders with and without dementia.

The neurotransmitter systems of interest are dopamine and acetylcholine, which are particularly involved in motor control and reward pathways.



MRI-based reconstruction and evaluation of central cholinergic white matter pathways in Lewy body disorders

Recent Publications

THE GUT-BRAIN AXIS IN EARLY PD: FROM PRODROME TO PREVENTION

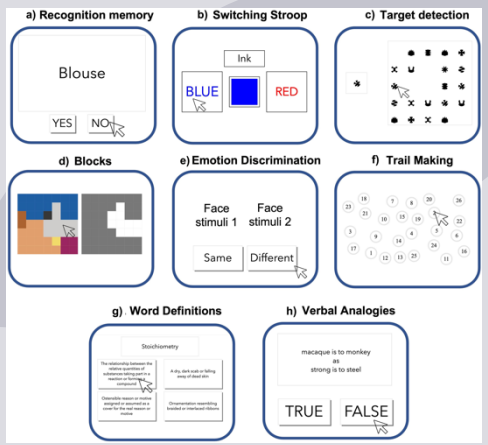
A review of studies investigating gut microbiota and the gut-first model in Parkinson's Disease, and whether the evidence available could be considered in RBD, representing a prototypical gut-first subtype in PD. The pivotal question for the review being could a gut-based understanding of PD support earlier identification and treatment through gut based-interventions.

The review concluded that PD could be mediated by gut microbia dysbiosis in prodromal states before motor symptoms are present. It could be that this is due to a combination of gastrointestinal constipation, inflammation, impaired luminal integrity and distributed fatty-acid metabolism. Utilizing the gut-brain axis could enable early intervention to alleviate potential conversion to PD from RBD.

ONLINE COGNITIVE MONITORING TECHNOLOGY FOR PEOPLE WITH PARKINSON'S DISEASE AND REM SLEEP BEHAVIOUR DISORDER

https://doi.org/10.1038/s41746-024-01124-6

Developed an online 20-minute battery to measure early cognitive changes in PD and RBD. The tasks were driven by memory language, attention and executive underperformance, and global reaction time deficits in PD.



Tasks from the cognitive assessment battery

It was concluded the battery was more sensitive to early-stage and prodromal deficits than the supervised neuropsychological scales and that this technology could offer an economical and scalable method of assessing these populations where appropriate.

SMARTPHONE-BASED REMOTE DIGITAL MONITORING FOR PARKINSON'S DISEASE AND DEMENTIA

https://doi.org/10.1212/WNL.0000000000204980

The aim to develop an objective and multi-modal digital platform to remotely measure changes and hopefully predict clinical outcomes in PD and dementia patients. This is done through a smartphone application and interactive dashboard.

It was concluded that the use of the remote smartphone assessments can estimate clinical scores and risk outcomes if they are clinically interpretable. Integrating assessment and the predictive capabilities with the reliable digital platform could improve management of neurodegenerative conditions.

Recent Publications

PRESYNAPTIC DOPAMINERGIC IMAGING IN PATIENTS WITH RBD

Https://doi.org.10.1002/ana.26902

The study looked at 173 patients who initially had iRBD (without Parkinson's or dementia) and then developed either PD or DLB. The study involved a DaT-SPECT scan alongside other clinical assessments of motor function, cognition, smell, and digestive symptoms.

Key findings found that clinical data alone wasn't accurate at predicting which iRBD patients would later develop PD or DLB, and that a DaT-SPECT brain scan was better at predicting which iRBD patients would develop PD or DLB, as well as that the pattern of brain changes helped predict whether someone would develop PD or DLB. This

This research could help identify which iRBD patients should be prioritized for future disease-modifying treatment studies.

MOTOR COMPLICATIONS IN PARKINSON'S DISEASE: RESULTS FROM 3343 PATIENTS FOLLOWED FOR UP TO 12 YEARS

https://doi.org/10.1002/mdc3.14044

Aim to quantify the presence, impact, severity and associated factors with motor complications in PD.

Three large prospective cohort studies of recent-onset PD patients who were followed up for up to 12 years were analysed.

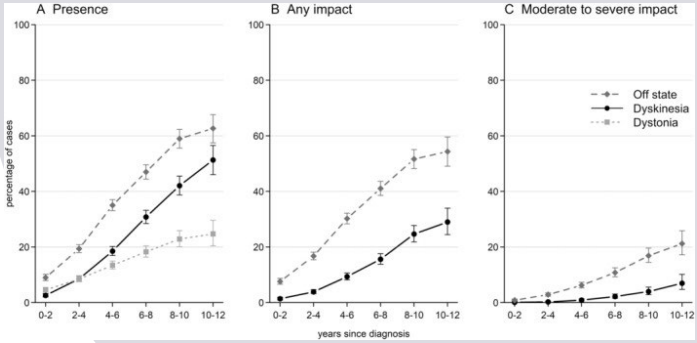
It was concluded that compared with dyskinesia, 'off' periods are more common and cause greater functional impairment. It was also concluded that a higher genetic risk score and greater dopaminergic responsiveness are significant independent risk factors for the development of motor complications.

CENTRAL CHOLINERGIC WHITE MATTER PATHWAYS IN PRODROMAL AND EARLY MANIFEST LEWY BODY DISEASE

https://doi.org/10.1101/2025.03.06.25323482

Using diffusion MRI data from the OPDC cohort to examine if there are differences in the microstructural integrity of certain white matter pathways in the brain are already evident in isolated RBD and early PD compared to matched controls.

Findings suggest that the examined white matter system may serve as a non-invasive biomarker, indicating the risk for clinical conversion, and so may be a useful tool to screen potential patients for clinical trials of disease-modifying and neuroprotective therapies.



Graphs to show presence and functional impact of motor complications over time in people with Parkinson's Disease

'The Open Day was enjoyable, informative and helpful as ever!'

'Thank you for the hospitality arrangement-the refreshments and the lunch, delicious!!'

OPDC Open Day 2024

'A really interesting and informative day-it was really appreciated'

'I hope to be able to contribute a little by continuing to assist in any relevant research projects'

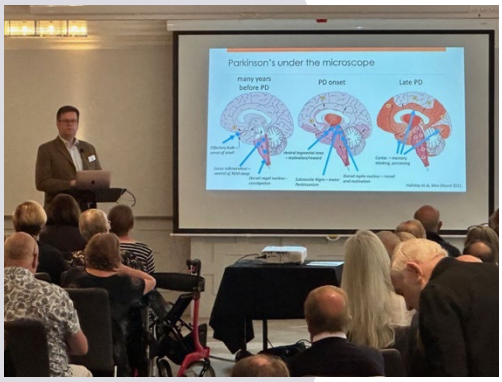
OPDC Open Days!

Since our last newsletter, we have hosted two OPDC Open days! These open days are designed to be fun, inciteful and engaging for everyone, whilst also emphasizing how grateful and thankful we are for all our participants, and really showcase what we do. It is also a really great way for participants to see just how helpful their participation is, and for them to see what their participation has resulted in.

We also use the day for guest speakers to give talks on their current research so that participants can gain an insight into the research and can find out where the research is heading!

As well as talks, we also use the opportunity to have poster presentations, great Q & A sessions, and of course a lovely lunch and refreshments!

We are currently in the middle of organising our 2025 one, so stay tuned for an update on that, but keep the 22nd of **September 2025** free....



OPDC Open Day 2023

BRC event 2023, Westgate, Oxford

Other Events

Alongside our OPDC open day, we also like to host and participate in other events over the year, especially where the public is involved!

From team barbecues to events hosted by the Biomedical Research Centre (BRC), we like to engage as much as possible to maintain and build relationships as much as possible, but they are also great opportunities to help involve the public who may not know how to get involved and show them what we do!

Another key thing we do to engage with the public is through organizing volunteer groups, patient and public involvement and engagement groups and doing guest talks at events, such as branch meetings, other universities and conferences. If there are any talks or events you feel would be beneficial for us to attend, then please do get in touch on 01865 226778!

Cream Tea Branch Meeting

OPDC Team Summer BBQ

OPDC Volunteer Group Meeting

OPDC take NYC!

OPDC is a site for the Parkinson's Progression Markers Initiative (PPMI) study, which was launched by the Michael J. Fox Foundation in 2010. It is a landmark study to gather information over time to learn more about how brain disease starts and changes and how to stop it.

As a site, Oxford is heavily involved and puts in a huge amount of work into running the study, and over the last few years there has been an annual conference in New York to give research updates, discuss the study and any current findings, and the study projections (and what better place than New York to go to!).

Michele, Karolien, Ludo, Luca and Jamil flew out for a couple days in April 2025 to attend and had an amazing time discussing all things PPMI!

The main conference was focusing on study updates and Data Blitz's, including topics on alpha-synuclein seed amplification assays, innovation in molecular imaging and DAT scans, and a vison on expanding international PPMI to include more remote data acquisition. There was also a presentation on the new path to prevention where the new initiative for interventional studies for prodromal participants was discussed, with a hope to include multiple arms and multiple interventions for participants.

A full on 3 days, but extremely informative and a great way to thank everyone included for all their hard work.

A special mention should be made here to Jamil Razzaque, who puts an outstanding amount of work into running PPMI at Oxford and received awards at the conference for both PPMI outstanding mentor, and legacy coordinator, so well done Jamil!

A note to our Discovery Participants!

We could not be prouder that the Discovery cohort has grown to the size it has, producing some amazing research publications, and with that has become a multidisciplinary world class research centre.

We would not have gotten to the size we have without our valued participants, and we are beyond grateful! Having said this, we are now in a position where we are going to make some changes to our follow-ups, and so want to reiterate the changes mentioned earlier.

Controls & Relatives

Having managed to collect 15 years' worth of longitudinal data, we now believe we have reached an endpoint for these groups, and so we will no longer be following-up our controls and relatives' arms.

We want to emphasise our gratitude and say a MASSIVE thank you for all your time and effort and valued participation in our research.

Although we will not be following you up, there may still be the opportunity to participate in other aspects of our research and so we may potentially get in touch in the future!

PD Follow-ups

We have been fortunate enough to have moved a lot of our visits remotely (*thank you covid!!*) which has enabled us to still gather our study data, but also enable participants to still participate in the research without having to come into the John Radcliffe. Having started to review our remote data, we have decided to make a few changes, ultimately resulting in the remote visit being shorter!

We hope that this will encourage participant retention, whilst still enabling us to gather vital data!

If anyone has any questions or queries about these changes, please do not hesitate to get in touch, and as always, **THANK YOU** for your ongoing participation and support!

Want to be part of research?

There are so many ways to be involved!

Research and medicine would not move forward without research and clinical trials, and these of course can't be done without devoted and selfless participants who are willing to give up their time and energy to take part.

If you want to see if there is a research study you can be involved with, please do get in touch and we will either send over potentially relevant studies or keep your information on our database for future research!

Please do contact us if you have any questions or queries!

Giving to OPDC

Any support is appreciated

Research and medicine would not move forward without research and clinical trials, and these of course can't be done without devoted and selfless participants who are willing to give up their time and energy to take part, or without funding!

If you would like to donate there are different ways to do this, whether it be a legacy gift, a one-off donation or a regular payment.

Any donation we are truly thankful for!

Please do get in touch through the details on this page if you would like to know more!

Join the RBD Registry:

Use the QR code below

or visit:
https://www.dpag.ox.ac.uk/opdc/opdc-rapid-eye-movement-sleep-behaviour-disorder-rbd-registration

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