

NEWSLETTER

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NIHR Oxford Biomedical Research Centre

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All Change Here for the Discovery Cohort!



A huge thanks to every single participant and person, who has donated their time to the Discovery study and OPDC as a whole. We are pleased to announce we have been awarded a further 5 years funding to continue the Discovery study. The study will change slightly to what you have become used to over the past few years and we hope to explain this here, if you have any questions please get in touch via parkinsons.discovery@nhs.net.

Unfortunately, changes mean many of our wonderful sites who have been hosting the study will be closing to follow up from the end of February 2021. We cannot thank them enough for their help supporting and meeting all of our participants. You (our study participants), will continue to be enrolled in the study but your follow ups will be organised and managed by the central team in Oxford. You have probably met some of the Oxford staff at your appointments or at research open days.

The new study phase, called OPDC3 includes the introduction of remote, tele-medicine follow ups. Instead of a clinic visit, you may be offered a videocall appointment instead (or telephone call if you do not have access to a suitable device). We have been piloting this in Oxford during 2020 and have had positive feedback from participants.

The videocalls take around 1 hour and will be offered to all people with Parkinson's from visit 4 onwards or, for anyone unable to attend the hospital for any reason. For all RBD participant visits and Parkinson's visits 1-3, we will still offer clinic visits unless you let us know you are unable to attend. RBD visits at Papworth Addenbrookes will move to the Cambridge Addenbrookes site 5 minutes away (Cambridge University Hospitals or Cambridge University Centre for Brain Repair). RBD clinics will be held either in Oxford, Cambridge or Sheffield (you can ask for more information when you are invited to your next follow up appointment). All of our relative and control participants will continue to be offered telephone follow ups as before.

There may be times where you will be invited to attend the clinic for an additional procedure, such as a memory test, a blood test, an MRI, lumbar puncture. At any time you can ask for more information or decline the visit. Most of the additional visits will be held in Oxford and we can reimburse or organise travel as necessary if you ask when being invited or booked in.

The study paperwork that we normally get you to complete at home can be sent by link to your email to save on paper and ensure the researcher (who may be working remotely) can see your responses at the time of the

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ABOUT OPDC

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call. You can complete the questionnaires on your smartphone, tablet or a computer ahead of the appointment. If you have not got access to any of these devices we are still able to send out paper copies and freepost envelopes.

Parkinson's UK are a fantastic source of information and can signpost you to some great support and/or help. There may be opportunity for someone from your local Parkinson's UK branch to help you set up a computer at home to facilitate you getting online for research assessments.

OPDC3 Summary:

- We will now move most clinic assessments to remote visits using video or telephone calls, similar to those used routinely across the NHS.
- Video calls take around 1 hour, and will be offered to all people with Parkinson's in active follow-up from visit 4 onwards, and anyone shielding or unable to attend hospital
- RBD participants will continue to be held face to face in Oxford, Sheffield or Cambridge.
- All relative and control participants will be offered telephone follow up as before.
- Visit co-ordination for the majority of sites will be led by the central team in Oxford.
- We may occasionally ask you to come to clinic for additional tests if you agree, including blood tests, examination, an MRI or lumbar puncture.
- The Oxford team will be in contact with you before your next follow-up is due.
- Help may be available through your local Parkinson's UK branch volunteers to set up your video call/computer or tablet.

Introducing your Central Oxford Cohort Team



Lorraine Johns,
Research Administrator



Jessica Welch,
Research Practitioner



Jamil Razzaque,
Research Practitioner



Prof Michele Hu,
Cohort Lead

Thank you again for all of your ongoing help, and we'll be in touch soon

New OPDC website to be launched!

We will be launching a new OPDC website in Spring 2021. Our new website address will be www.dpag.ox.ac.uk/opdc The website will continue to feature information about our unique multidisciplinary research centre of internationally-renowned scientists who work on the genetics of Parkinson's, the generation of cell and animal models, and the wiring of brain circuits which control movement, with clinical experts in the diagnosis and treatment of Parkinson's.

Update on the OPDC team



My name is **Jamil Razzaque**, and I joined the OPDC team in May 2020 having previously worked on the Discovery study at Buckinghamshire Healthcare Trust from February 2017, as a Clinical Research Practitioner.

Prior to starting my research posts, I completed my undergraduate degree in Medical Genetics, which led me to undertake further postgraduate studies in Clinical Neuroscience. I will mainly be working on the Discovery study and also helping with the running of our other studies under the OPDC portfolio, such as the Exenatide randomised controlled clinical trial and the Sleep wearables study. I am also helping with the management of the OPDC laboratory and biobank, working with our various international collaborators and academics.

I look forward to meeting many more of our trial participants as we open up face to face clinics and to be working alongside the fantastic team at OPDC!

Hi, I would like to introduce myself. My name is **Lorraine Johns**, and I joined the OPDC Team at the end of June after working in Neurology for the past five years as a Medical Secretary. I have a wealth of NHS experience, having worked in the NHS for over twenty years. I felt I needed a change in my career, but I wanted to carry on working with Professor Michele Hu in the area of Parkinson's disease as I have learnt a lot about the disease over the years and working in Parkinson's research would be the perfect opportunity for me to learn more and further develop my career. Commencing a new role during the Covid pandemic has been a challenge at times with many changes occurring on a regular basis and trying to learn a new role. However, I have been able to do remote learning which has proved very beneficial.



Unfortunately, due to the pandemic this has meant we haven't been able to conduct our face to face clinics, so instead we are offering remote telephone and video appointments. This has proven to be a huge success with about 80% of patients happy with a remote appointment. This means that participants do not need to attend the hospital and can have their follow up appointment in the comfort of their own homes. I am currently focusing on calling participants to arrange their follow up appointment, so you will be receiving a telephone call from in the next few weeks. Thank you very much to those who have already participated.



My name is **Falah Al Hajraf**. I am a medical doctor from Kuwait and I graduated from the Royal College of Surgeons in Ireland. I hold a master's degree in Clinical Neurology from University College London. My MSc dissertation was about the plasma biomarkers of dementia in Down syndrome population. I worked for two years in Al Amiri Hospital as a senior house officer before coming to Oxford. My research interests are in cognition and Parkinson's disease. That includes assessing the efficacy of the current cognitive treatments and also testing the use of online cognitive assessments to detect and monitor cognitive changes in PD and RBD patients.

I'm **Navin Cooray** and I've been hired as a post-doctoral researcher taking over from Dr Christine Lo. I recently completed my PhD at the University of Oxford in biomedical engineering where I developed automated diagnostic tools to identify REM sleep behaviour disorder through wearable sleep devices and machine learning techniques. I am now working with Professor Michele Hu on a project to compare the efficacy of smartphone motor test and free-living gait monitoring to detect clinically relevant changes. This work has the potential to revolutionise the approach to measure Parkinson's disease symptoms and the response to clinical trials through frequent and objective data through home-based smartphones.



My name is **Tharuka Herath**. I graduated from Faculty of Medicine, University of Peradeniya with first class honors and nine distinctions, achieving first place in the all Island Merit List in MBBS in 2012. I completed an internship at the National Hospital of Sri Lanka and obtained MD in Neurology from the Post Graduate Institute of Medicine, University of Colombo. I have conducted several presentations in international congresses, and have several publications in international journals. I have been an active member in International Parkinson and Movement Disorder Society since 2014, International League Against Epilepsy, The Young Epilepsy Section and International Headache society. My main clinical interest is in Movement disorders and Parkinson's disease. I am eager to offer quality medical care and contribute to its advancement at primary, tertiary and policy levels, and to expertise in deep brain stimulation to be able to establish this procedure in Sri Lanka.

Hello everyone, I am Cristina Campos and I come from Seville, a beautiful city in the South of Spain. It is there where I graduated from medical school and completed my neurology residency in one of the reference centers in Andalusia. Since I started my training in neurology almost five years ago, I became passionate for Movement and Sleep Disorders, devoting further time to the attention of these patients. Besides, during this period I have attended clinical and technical training programmes and courses in national and foreign institutions and participated in several research projects. I look forward to working in OPDC and, hopefully, making a positive contribution.



With a sad goodbye...

It is with a heavy heart that after 5 years working in Discovery, that I say good bye to you all. I have absolutely adored working with every single person working on and with OPDC. Most of all, I will miss the clinics and seeing you regularly, some of you I would consider good friends I have got to know you so well!
I want to thank every single person who has helped and supported me with my various emails and projects over the years. You will be most welcome to contact me on francescabowring@aol.co.uk to keep in touch.



And a couple more...

We also say goodbye to our research fellows, Dr Christine Lo and Dr Agustin Querejeta-Coma. The time and work they contributed to OPDC was huge and they will both be so greatly missed! We wish them luck in all of their future endeavours.



New trials, publications & useful links

Active clinical trials

Discovery cohort and other Parkinson's volunteers have taken part in **4 PD trials at Oxford**: Exenatide PD-3, Ketone drink (ΔG°) to alleviate the symptoms of Parkinson's, Biogen SPARK and MOVES-PD (Sanofi Genzyme). We are actively recruiting for Exenatide PD-3 with the Ketone trial due to restart soon.



Exenatide PD-3

October 2020 was the month we recruited our first patient onto the Exenatide-PD3 trial! After months of being on pause due to the Covid-19 pandemic, it was great to finally get the go ahead to start recruitment.

The drug trials aim is to see if Exenatide (a drug already approved for the use in diabetes) can help slow down progression in Parkinson's Disease. A pilot trial and a phase 2 trial have already been conducted, with some encouraging results, and so it is very exciting that Oxford is being used as a site for the phase 3 trial. This trial has two treatment groups (drug vs. placebo) which participants are randomly allocated to, and involves self-injection once a week, with follow ups every 12 weeks.

Dr Yaping Liu

One of OPDC's research fellows who has sadly now gone back to work in Hong Kong also gave us an update on his current work:

'I am investigating the longitudinal change in motor and non-motor symptoms of PD and further to determine the effect of presence of REM sleep behavior disorder on the progression of these symptoms of PD in OPDC discovery cohort. In addition, I am also exploring the potential neuroimaging biomarker relating to the brain structural connectome using diffusion tensor imaging data to differentiate PD and REM sleep behavior disorder from controls in the OPDC discovery cohort.'



Sleep issues in Parkinson's

A webinar took place at the end of January, 'Night Fight with Parkinson's: Acting Out Dreams, Insomnia and Other Sleep Issues', A group of panellists including OPDC's Michele Hu discussed the range of sleep issues that may come with Parkinson's disease, sometimes occurring before any motor symptoms show. Treatment approaches are covered. To view these talks, please go to the link below and register. This will then take you directly to these talks:

<https://www.michaeljfox.org/webinar/night-fight-parkinsons-acting-out-dreams-insomnia-and-other-sleep-issues>



Recent publications

There have been a number of recent publications that OPDC have been involved in, with many more coming up! Below is a snapshot of some of these, with information on how to access the full paper too.

Sites of early dysfunction in Parkinson's identified

A new study led by Prof Stephanie Cragg and Dr Bradley Roberts has seen evidence of a new site in the brain involved in early dysfunction in Parkinsonism. This study reveals that Astrocytes support Dopamine release in the brain, which is something that is seen to be dysregulated in people with Parkinson's. These findings not only support growing literature about the involvement of Astrocytes in neurodegenerative diseases, but could also provide new therapeutic targets for Parkinson's.

For more information on this study and to read the full paper, go to:
<https://www.dpag.ox.ac.uk/news/sites-of-early-dysfunction-in-parkinsons-identified>

Tiny brain 'tweezers' could hold the key to treat Parkinsons

A collaborative study led by Dr Nora Bengoa-Vergniory has shown that compounds known as molecular tweezers could become a promising disease modifying therapy for Parkinson's.

It is thought that a new kind of drug works by pulling apart toxic clumps of protein that form in the brain of people with Parkinsons, acting as 'tweezers'. This study highlights a potentially new route in Parkinson's therapy, and something to look at in future research.

For more information on this study and to read the full paper, go to:
<https://www.dpag.ox.ac.uk/news/tiny-brain-tweezers-could-hold-the-key-to-treat-parkinsons>

Predicting the onset of meaningful change in Parkinson's

Work using the OPDC smartphone app in 237 Discovery Parkinson's volunteers found the 8 minute smartphone test can predict the onset of meaningful outcomes including falls, gait freezing and needing more help at home, 18 months **before** onset. This work has the potential to target interventions including physiotherapy to those most likely to benefit, improving delivery of personalised care for People with Parkinson's.

For more information on this study and to read the full paper, go to:
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6689691>



Jim Sheridan, Research participant



I was diagnosed with Parkinson's disease in 2010 and I'm happy - and, yes, proud - to call myself a Parkinson's research advocate. I am one of the ~1000 participants in the Discovery trial and have also participated in PDSTAT (Simvastatin drug repurposing trial), OxQUIP (instrumented measurement) and numerous single day and online trials.

Last October I started on the Exenatide drug repurposing trial. Stating the obvious, I know that people like me are needed to participate in research to help scientists and clinicians to better understand Parkinson's – from the biochemistry to the measurement of how we behave – to test new drugs and therapies and, eventually, come up with a cure. But what is less obvious is participating in trials actually makes me feel good. I find the enthusiasm of the researchers is infectious and they always make me feel relaxed. They also have a wealth of knowledge and can answer many of my questions. Sure, most of the trials involve testing my mental and physical performance under various conditions,

but, unlike school and university, 'they are tests that I can't fail' – I just have to be myself and I've done everything expected of me.

In what can often be an atmosphere of play, the researchers learn so much about Parkinson's and I have learned a lot about my own unique set of symptoms. One of the big things I've learned – and I hope I'm not giving away a 'Parky' secret here – is that when I feel good my Parkinson's symptoms can be massively reduced and my performance enhanced. So, the trials appointments bring out the best in me and make me realise what I could achieve if I was able to maintain that elevated mood. I do, however, have to admit, it's not all rosy – on the current Exenatide trial I had a miserable first couple of months and the low mood, combined with anxiety, made my Parkinson's symptoms worse. Either I suffered many of the side effects to the active drug, or I experienced a nocebo response to the placebo. I recognise the power of the mind, so I genuinely don't know which. As Christmas approached, my anxiety grew and I toyed with the idea of giving up. But Jess Welch, one of the researchers, kept checking on me and reassuring me that I was engaged in something exciting – the possibility that the progression of Parkinson's could be slowed or even halted. Fortunately, the side effects abated just in time for Christmas.

Parkinson's is an awful condition and we desperately need a cure. To do this we need the scientists - but they need us to test their theories and generate data. There is a wide range of Parkinson's research trials opportunities and every one is a step closer to a cure. So, I highly recommend getting involved. You may benefit more than you might think.

Giving to OPDC

At the OPDC we are working hard to understand Parkinson's and to develop new treatments. As we look to the future, we want to ensure that our work is sustainable, and that it can continue for years to come.

If you would like to specifically support our research projects working on Parkinson's at the University of Oxford, you can make a one-off **donation** or set up a regular payment to OPDC via www.opdc.ox.ac.uk/donate.

The OPDC is funded by the Monument Discovery award from Parkinson's UK. If you would like to support the work done nationally by Parkinson's UK, please visit www.parkinsons.org.uk/donate.

A **Legacy gift** will help the OPDC to continue vital research programmes, to find a cure and to improve the lives of everyone affected by Parkinson's. Large or small, your support will really make a difference to our work. If you would like to know more about leaving a gift to the OPDC Cohort in your will, please contact us on **01865 223166** or parkinsons.discovery@nhs.net. www.opdc.ox.ac.uk/giving.

New laboratory space for the OPDC Researchers

A major building in the centre of Oxford has been constructed to create a new research centre bringing together cellular neuroscience and physical sciences.

Known as the new Kavli Institute for NanoScience Discovery (Kavli INSD), the building will uniquely combine structural biology with world-leading biochemistry, pathology, chemistry, physics, physiology and engineering.

It will also be home to many research staff including a strong presence of OPDC researchers. They will relocate to exciting new laboratory facilities with a focus on stem cell modelling for Parkinson's Disease. The new building located at the heart of the South Parks Road Discovery Science Campus is nearing completion with research groups expected to move in Spring 2021.



Work in progress. The above photo shows OPDC researchers taking a tour around their new laboratory space in February 2020. The new space will bring together the Wade-Martins and Cowley laboratories to create a major new effort for generating and studying stem cell models of Parkinson's Disease.



Professor Richard Wade-Martins, Head of the OPDC:

"I am delighted that the Oxford Parkinson's Disease Centre will be moving into new state of the art laboratory facilities as part of the new Kavli Institute on the South Parks Road campus. The Institute will offer outstanding opportunities to work with other cell biologists working in similar areas as well as to initiate new cross-disciplinary programs with physical sciences, chemists and advanced microscopy. We are all very excited!"

Artists' impression of the external view of the Kavli Institute for NanoScience Discovery (Kavli, INSD), which will accommodate OPDC researchers at the University of Oxford.



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Information on all our current research activities can be found on our website

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Enabling translational research through partnership



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