NEWSLETTER

Issue 10, Autumn 2019

Oxford Parkinson's Disease Centre

NHS National Institute for Health Research
Clinical Research Network Thames Valley and South Midlands

Oxford Biomedical Research Centre
Enabling translational research through partnership

Funded by PARKINSON'S UK
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Discovery Cohort Update from cohort director Michele Hu

Recruitment: Since 2010 we have recruited a total of 1093 participants with Parkinson's, 320 Controls, 111 Relatives and 258 participants with Rapid-eye movement Behaviour Disorder (RBD) into the OPDC Discovery cohort. We are continuing to invite all of our Parkinson's and RBD study participants for face-to-face follow-up appointments every 18 months. Our controls and relatives are being followed up over the telephone, as well as any participants who may have difficulties coming to the hospital for their appointments. Our participants with Parkinson's have attended between 3 and 6 visits in the research clinic, which equates to 4.5 to 9 years' worth of follow-up information. We are incredibly grateful to all of our participants for their ongoing dedication and commitment to the research.

Funding update: The second Monument Trust Award from Parkinson's UK which funds the OPDC Discovery cohort will expire at the end of January 2020. After a long application process for cohort renewal funding, we were recently informed that Parkinson's UK will not be funding any Parkinson's cohort studies this year due to lack of funds. However, we have secured ongoing cohort funding to the end of January 2021 through a no-cost extension with Parkinson's UK, and I am currently working on several alternative applications to fund this precious resource. My aim is to secure ongoing cohort funding to January 2025, so that people with Parkinson's can be followed up for a maximum 15 years, ensuring the cohort delivers its best possible research outcomes for patients.

Research strategy: We are gaining increasing international momentum and recognition of the cohort's unique strengths, including its integration of clinical data with digital wearable technology/brain imaging/patient-derived stem cells and blood-based biomarkers. Our contribution to data sharing for Parkinson's research was recently recognised through a Critical Path Institute Award (see https://c-path.org/programs/cpp/overview/people-with-parkinsons/) to help advance future Parkinson's treatments. We collaborate closely with the NIHR Oxford Biomedical Research Centre (https://oxfordbrc.nihr.ac.uk), the Michael J Fox Foundation (www.michaeljfox.org) and the Cure Parkinson's Trust (www.cureparkinsons.org.uk) among other funded initiatives. This year alone, the Oxford Discovery cohort has helped deliver 4 cutting-edge trials testing novel Parkinson's treatments, with further new 3 trials planned for 2019-2020.

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ABOUT OPDC

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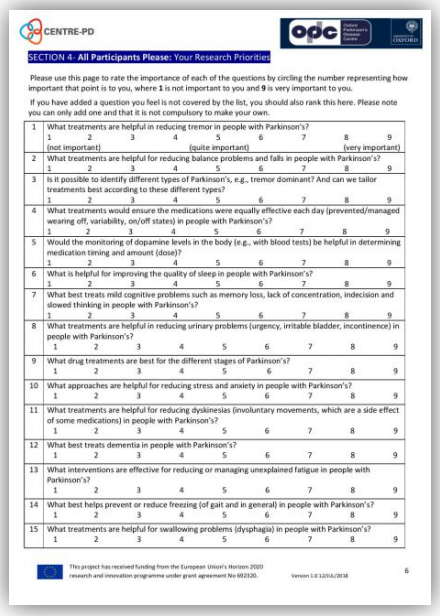
Hellos and Goodbyes from the OPDC team

It has been my pleasure and privilege to work as the OPDC administrator for the last 5 years. As someone without a background in medical sciences, I have learnt so much about Parkinson's, how it affects people's lives, and the many ways my colleagues here at OPDC and Parkinson's UK are working to improve things for people living with this condition. I have loved sharing the stories of our research with you via our newsletters, website and social media, as well as meeting many of you at the open days and Parkinson's UK events. I will not be going too far, and will be keeping a keen eye on the exciting developments to come from OPDC. *Melanie Witt, OPDC Administrator.*

In June we bid farewell to Katie Ahmed who joined OPDC in January 2018 as a research administrator. Over the past 18 months Katie has played a vital role in running and co-ordinating the OPDC cohort. Katie is going to be starting an MRC-funded PhD on statins and cardiovascular function at the University of Liverpool this September. We would like to congratulate her and wish her all the best on this new project. We thank her for all her hard work over the last 18 months and she will be dearly missed by all of us in the OPDC team.

My name is Jess Welch and I previously worked as a Research Assistant on surgical studies. I gained my MSc in Clinical Neuroscience, my project was comparing how the blood flows in the brain of Frontal Temporal Dementia (FTD) patients versus healthy controls. Prior to this I completed my BSc in Psychology. My dissertation was measuring certain brain waves using an electroencephalogram (EEG), and exploring the relationship between these waves and their anxiety scores and attentional control in healthy individuals. I have always had a huge interest in Neurological conditions, and so I am very excited to be working for OPDC! I will mainly be assisting with Discovery and the sleep wearables study, and will therefore be based at the John Radcliffe Hospital, but will also be travelling to other hospital sites to assist with the research.

Top 10 Research Priorities for the Management of Parkinson's - Francesca Bowring



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SECTION 4- All Participants Please: Your Research Priorities

Please use this page to rate the importance of each of the questions by circling the number representing how important that point is to you, where **1** is not important to you and **9** is very important to you.

If you have added a question you feel is not covered by the list, you should also rank this here. Please note you can only add one and that it is not compulsory to make your own.

1	What treatments are helpful in reducing tremor in people with Parkinson's?	1 2 3 4 5 6 7 8 9 (not important) (quite important) (very important)
2	What treatments are helpful for reducing balance problems and falls in people with Parkinson's?	1 2 3 4 5 6 7 8 9
3	Is it possible to identify different types of Parkinson's, e.g., tremor dominant? And can we tailor treatments best according to these different types?	1 2 3 4 5 6 7 8 9
4	What treatments would ensure the medications were equally effective each day (prevented/managed wearing off, variability, on/off states) in people with Parkinson's?	1 2 3 4 5 6 7 8 9
5	Would the monitoring of dopamine levels in the body (e.g., with blood tests) be helpful in determining medication timing and amount (dose)?	1 2 3 4 5 6 7 8 9
6	What is helpful for improving the quality of sleep in people with Parkinson's?	1 2 3 4 5 6 7 8 9
7	What best treats mild cognitive problems such as memory loss, lack of concentration, indecision and slowed thinking in people with Parkinson's?	1 2 3 4 5 6 7 8 9
8	What treatments are helpful in reducing urinary problems (urgency, irritable bladder, incontinence) in people with Parkinson's?	1 2 3 4 5 6 7 8 9
9	What drug treatments are best for the different stages of Parkinson's?	1 2 3 4 5 6 7 8 9
10	What approaches are helpful for reducing stress and anxiety in people with Parkinson's?	1 2 3 4 5 6 7 8 9
11	What treatments are helpful for reducing dyskinesias (involuntary movements, which are a side effect of some medications) in people with Parkinson's?	1 2 3 4 5 6 7 8 9
12	What best treats dementia in people with Parkinson's?	1 2 3 4 5 6 7 8 9
13	What interventions are effective for reducing or managing unexplained fatigue in people with Parkinson's?	1 2 3 4 5 6 7 8 9
14	What best helps prevent or reduce freezing (of gait and in general) in people with Parkinson's?	1 2 3 4 5 6 7 8 9
15	What treatments are helpful for swallowing problems (dysphagia) in people with Parkinson's?	1 2 3 4 5 6 7 8 9

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 692320. Version 1.0 12/JUL/2018

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A big thank you to all those who participated in the top 10 survey, Delphi panel and focus groups. The results are in and will be headed for publication very soon.

For this project, we wanted to update the research priorities to reflect what our cohort, and also the members of two similar cohorts with whom we collaborate we collaborate with, wanted to see addressed by research. We used the list of research questions identified by the previous group in 2014[1], allowing responders to add a question they felt was not represented. We asked people to rate each question rather than requiring people to remember all of the choices when selecting their favourite 10.

A fantastic 879 responses were pooled to form the top 10 priority list. Two priorities came out joint first: "**What is the best form of exercise (physiotherapy) for improving muscle strength, flexibility, fitness, balance and function?**" and **"What drug treatments are best for the different stages of Parkinson's?**". Interestingly, when we separated the results by responder type, healthcare professionals had not placed the question on physiotherapy in their top 10 at all, highlighting an important difference in perceptions.

The Delphi panel went on to rank the questions four times to see if they could reach consensus on the top 10. That means we wanted at least 80% of the group to agree it was important. Unfortunately, only on two of the top 10 questions did more than 80% agree it was a high priority! The panel voted physiotherapy as the 8th most important priority, and drug treatments for different stages came 5th. Instead, "What helps improve the dexterity…?" was the number one in this group. However, over 50% of the group had dropped out by the end.

The focus group without healthcare professionals also had the question on physiotherapy as their number one priority. As well as this, they chose to rate some of the questions which were created during our survey round in the top 10. The focus group with healthcare professionals had "What treatments are helpful in reducing balance problems and falls…?" as their number one priority. However, the question on physiotherapy did not make it into their top 10. This indicates a possible influence that healthcare professionals might have in these types of settings. The full results will be distributed and available as open access once published. Thanks again!

[1]**Deane KHO, Flaherty H, Daley DJ, et al., Priority setting partnership to identify the top 10 research priorities for the management of Parkinson's disease. BMJ Open 2014;4:e006434.**

New OPDC study aims to predict Levodopa side effects

Non-motor features of Parkinson's such as low mood and anxiety increase the risk of motor complications of levodopa, according to a recent study from OPDC Discovery. Recently published online in Movement Disorders, this is the largest study of its type to assess predictors of dyskinesia and motor complications, common side effects of levodopa, in early Parkinson's.

Levodopa treatment in Parkinson's is a constant balance between the symptomatic relief and adverse effects. Dyskinesia and 'on-off' fluctuations are among the most common and problematic of these effects. While most people with Parkinson's will eventually experience these effects in some shape or form, they can occur early in the treatment course. Identifying those at greatest risk of these complications can help to direct treatment decisions and tailor medications to the individual.

This study used an innovative longitudinal analysis technique and applied it to almost ten years' worth of data from 734 Discovery study participants. We show that motor complications occur most commonly in people with earlier-onset Parkinson's, with lower BMI, who take higher levodopa doses and experience greater symptomatic relief from treatment. The most interesting and novel finding is that people who experience more non-motor symptoms, particularly anxiety and low mood, are at greater risk of these complications.

Dr Beckie Port, Research Manager at Parkinson's UK, said: *"There are more than 40 different symptoms that affect people with Parkinson's and everyone's experience with the condition will be very different, which makes treating and studying the condition very difficult.*

"These recent results offer hope we may be able to predict what symptoms people with Parkinson's may develop, and also help identify who may be more at risk of developing side effects. Being able to predict how Parkinson's may progress in an individual could help with earlier interventions and better management of symptoms, ultimately improving quality of life."

In future, we hope these findings can be applied to clinical practice, helping optimise and individualise symptomatic treatments for people with Parkinson's.

Talks by the study's lead author Dr Mark Kelly can be viewed at www.opdc.ox.ac.uk/videos

Kelly MJ, Lawton MA, Baig F, Ruffmann C, Barber TR, Lo C, Klein JC, Ben-Shlomo Y, Hu MT. (2019) Predictors of motor complications in early Parkinson's disease: A prospective cohort study. Movement Disorders. PMID: 31283854.

Smartphone test predicts how symptoms develop in Parkinson's

Our researchers have found that a simple test carried out on a smartphone can help to predict future change in people in the early stages of Parkinson's.

This OPDC study, supported by the NIHR Oxford Biomedical Research Centre (BRC) and Parkinson's UK, has the potential to foster a more personalised approach to the treatment of Parkinson's and allow clinicians to target interventions to those individuals most likely to benefit. All of the participants were part of our Discovery Cohort.

The smartphone test guides users through seven tasks assessing voice, balance, walking, reaction time, finger tapping, rest tremor and postural tremor.

The test, which takes around seven minutes in total to perform, makes use of the sensors in smartphones to measure different kinds of movement consistently and accurately. The test was carried out in clinic and at home on a range of regular consumer smartphones and was matched to standard motor, cognitive and functional assessments and questionnaires that were conducted in clinic. Almost 1,000 different statistical features were extracted from each test and fed into machine learning algorithms, which were taught to make the predictions.

*"**The main driver for this study was to improve clinical care by finding better ways of predicting how Parkinson's is likely to progress over time on an individual basis, as its course can vary greatly from person to person,***

"In this study, we've been able to show that, using a fairly simple smartphone test, we can accurately predict key future clinical outcomes, 18 months before they occur, potentially making it easier to tailor treatment to individuals with Parkinson's,

***"Future avenues of research may include looking at whether such knowledge may help direct interventions such as lifestyle changes or therapy input, with the aim of benefitting patients and their families**." Christine Lo, Clinical Research Fellow at OPDC*

"Parkinson's is a hugely varied condition with over 40 symptoms that affect each individual differently. Today, there is currently no assessment that can predict what type of symptoms someone may experience or when they may appear, which means it is hard to plan for the future and ensure that each individual is given access to the treatments and therapies they need to improve their quality of life.

"This research study, for the first time, shows that a 7-minute smartphone test could help predict how Parkinson's may affect someone 18-months later. By leaning on technology, including machine learning algorithms, this ingenious project could one day help with the delivery of better care for everyone with Parkinson's."
Dr Beckie Port, Research Manager at Parkinson's UK

Watch Dr Christine Lo talk about her research at www.opdc.ox.ac.uk/videos and see a video from Oxford University on our artificial intelligence work at www.youtu.be/qw6Nqjt2a7w

Lo C, Arora S, Baig F, Lawton MA, El Mouden C, Barber TR, Ruffmann C, Klein JC, Brown P, Ben-Shlomo Y, Vos M, Hu MT. (2019) Predicting motor, cognitive & functional impairment in Parkinson's. Annals of Clinical and Translational Neurology. DOI 10.1002/acn3.50853

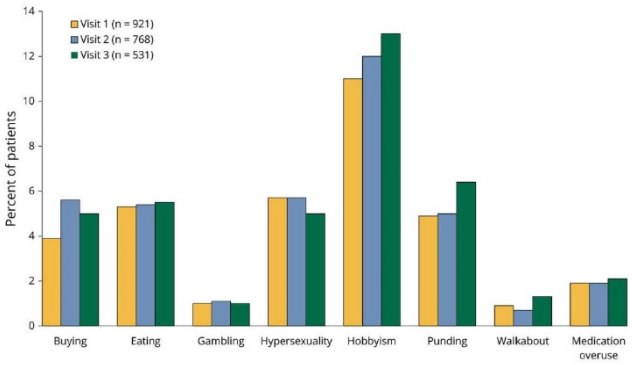
New paper from OPDC cohort on Impulse control disorders in Parkinson's and REM sleep behaviour disorder (RBD)

Our new paper on Impulse control disorders in Parkinson's and REM sleep behaviour disorder (RBD) is out now in the journal Neurology. Impulse control disorders are a possible side effect of some Parkinson's drugs and can have a big impact on the person affected and those around them.

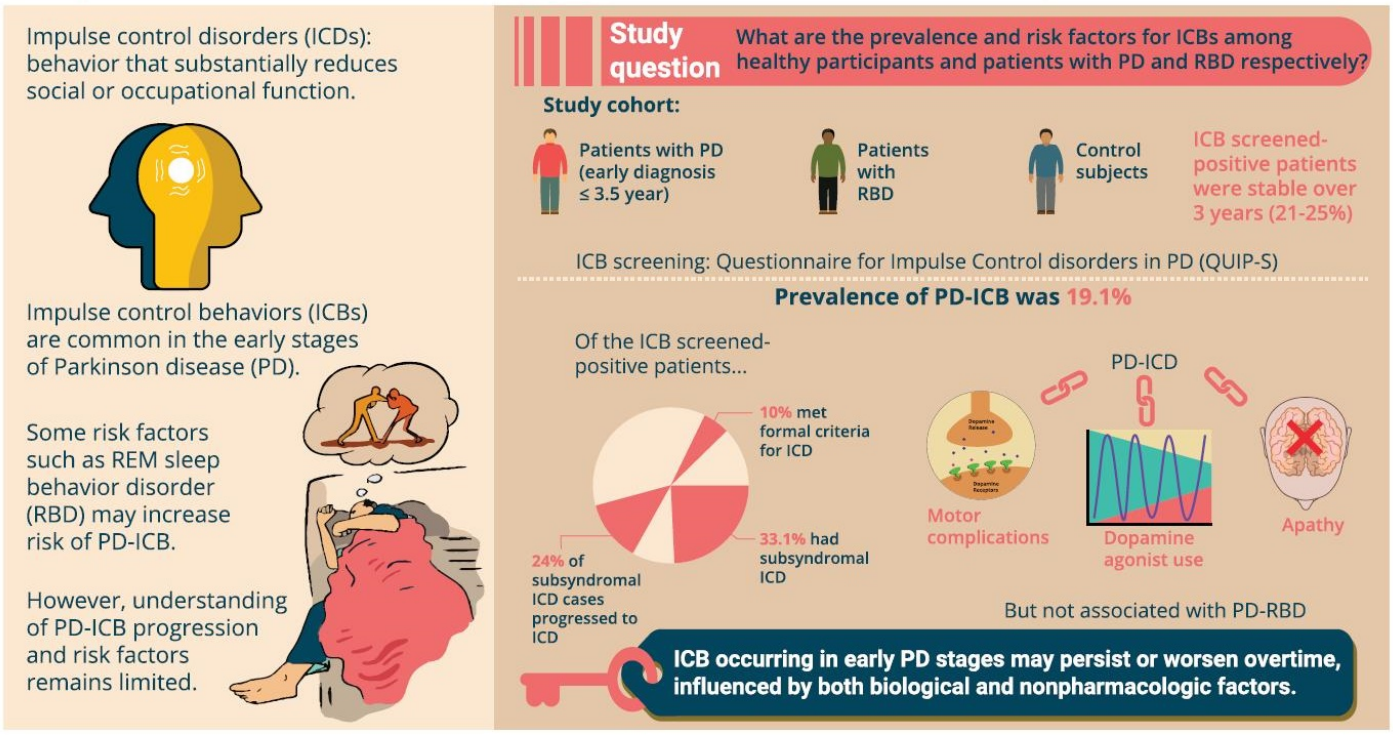
Our research included people in the cohort who were within 3.5 years of diagnosis at the start of the study, those with diagnosed RBD and controls, with follow up visits every 18 months. The interview element of the study allowed us to accurately diagnose impulse control disorders to validated criteria, characterise the severity of the behaviours and collect information about each case.

Impulse control behaviours occurred in 19% of people with early Parkinson's, associated with the use of dopamine agonists, apathy and motor complications. Participants with RBD did not have an increased risk of Impulse Control Disorders (ICD).

We also found that 24% who were found to have cases of impulse control behaviours not severe enough for an ICD diagnosis in their initial interview were found to have impulse control disorder in follow-up interviews.



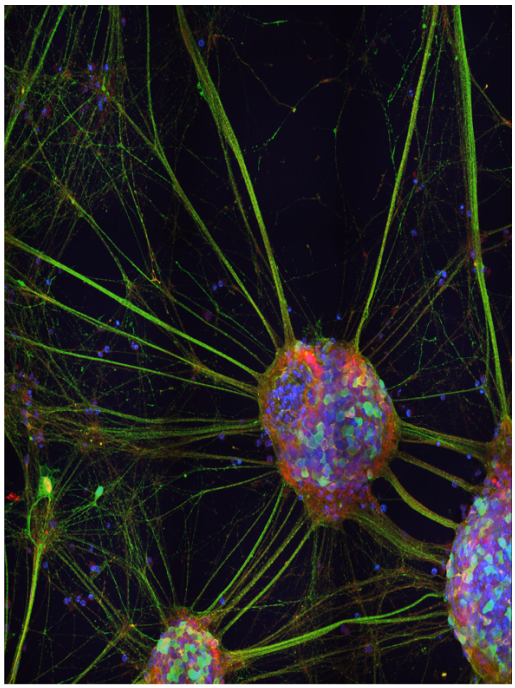
We found that mood and support networks can affect the severity of impulse control behaviours experienced. Given the well-known difficulty in withdrawing dopamine agonists in a number of people, it encourages clinicians to promote activities with other people and address social needs.



Authors on this study Michele Hu and David Okai have recorded a podcast to accompany the paper which can be heard at https://tinyurl.com/y29lug7g. Fahd Baig and Mark Kelly spoke about their work on impulsivity in Parkinson's at our previous open days. Talks available at www.opdc.ox.ac.uk/videos.

Baig F, Kelly MJ, Lawton MA, Ruffmann C, Rolinski M, Klein JC, Barber T, Lo C, Ben-Shlomo Y, Okai D, Hu MT. (2019) Impulse control disorders in Parkinson and RBD: A longitudinal study of severity. Neurology. PMID: 31311842

Experimental cancer drug shows promise for Parkinson's



A drug originally developed for prostate cancer may have exciting potential for treating Parkinson's, according to our new research published in the journal Cell Stem Cell.

The study, funded by Parkinson's UK, suggests that the drug, tasquinimod, which is not yet on the market, works by controlling genes that may cause Parkinson's. This happens when the drug interacts with a protein inside brain cells.

Our team at the Oxford Parkinson's Disease Centre, used cutting-edge stem cell techniques to grow brain cells from skin cell samples donated by people with a rare genetic form of Parkinson's, and from healthy people without the condition. We followed the progression of the condition in brain cells made from the patients' stem cells and saw that a number of important genes became inactive when problems first started to occur inside the Parkinson's-inflicted cells. The "switching off" of these genes early in the process brought the condition on later.

"**This is the first time researchers have followed the progression of the condition over time in brain cells in the lab, something we simply cannot do in cells inside the living brain.**" *Professor Caleb Webber, study co-lead*

"**We think that switching off these genes in brain cells may play a vital role in the cell damage and death that occurs in Parkinson's. Finding a way to 'turn them back on' with a drug could be a promising, unexplored way to develop new treatments**." *Professor Richard Wade-Martins, study co-lead*

"This study has opened up a new avenue of research and is a fantastic example of where cutting-edge technology is enabling the use of stem cells to show what may be causing Parkinson's.

"The study also highlights the growing number of drugs which can be repurposed from their original medical use to treat Parkinson's. Developing a drug from scratch is a long, slow and expensive process. By finding existing drugs and moving them rapidly into clinical trials, we can make them available for people with Parkinson's much more quickly, easily and cheaply." *Professor David Dexter, Deputy Director of Research at Parkinson's UK*

The team showed that turning the genes back on corrected cell changes in the Parkinson's brain cells. The study was conducted using cells grown from people with a relatively rare form of Parkinson's. To find out whether the results apply to all people with Parkinson's, the team next studied brain cells grown from people with the more common, non-genetic form of the condition.

"We've only studied brain cells from eight individuals with 'regular' Parkinson's so far so it's early days, but initial findings indicate that the brain cells that share the same pattern of inactive genes and might also benefit from the same treatment. Others, however, don't. This may mean that tasquinimod may work for some people with Parkinson's and not for others, and we are working on how to tell who will benefit." *Professor Richard Wade-Martins*

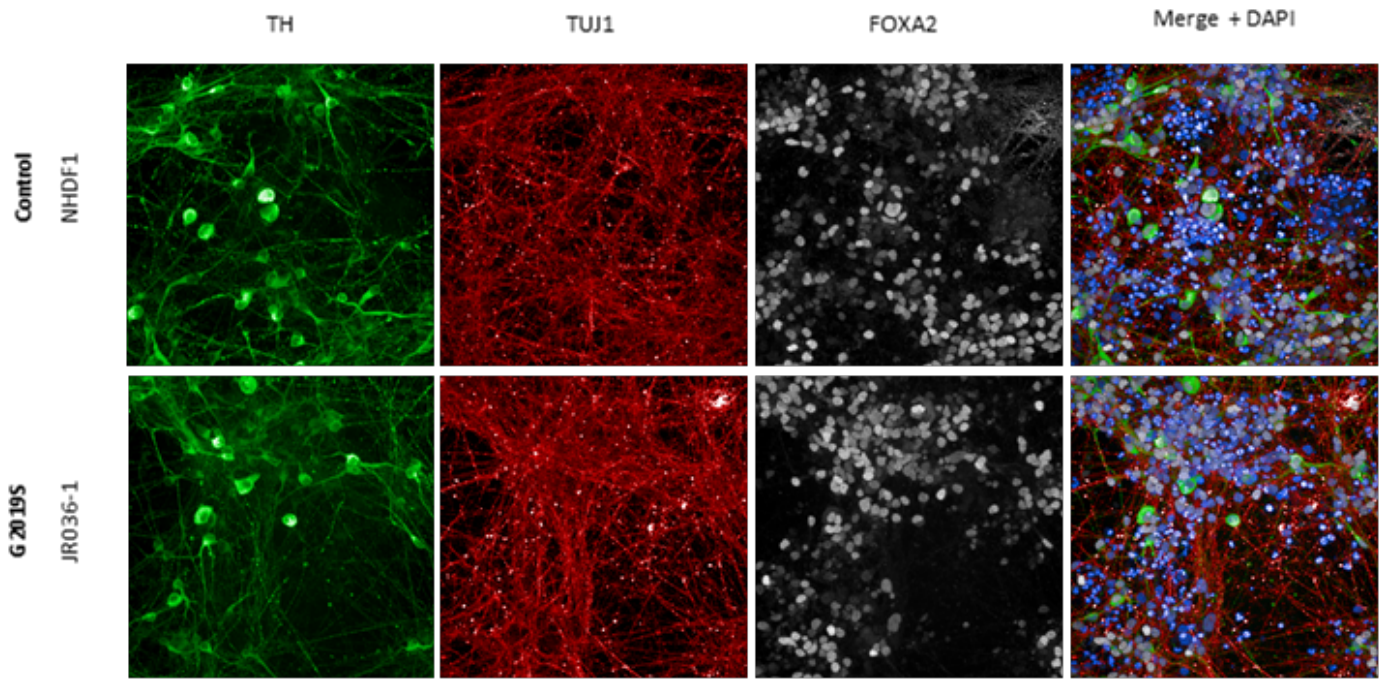
Read more from Parkinson's UK on this paper at http://tinyurl.com/yx8q9h4p

Lang C, Campbell KR, Ryan BJ, Carling P, Attar M, Vowles J, Perestenko OV, Bowden R, Baig F, Kasten M, Hu MT, Cowley SA, Webber C, Wade-Martins, R. (2019) Single-Cell Sequencing of iPSC-Dopamine Neurons Reconstructs Disease Progression and Identifies HDAC4 as a Regulator of Parkinson Cell Phenotypes. Cell Stem Cell. 24, 1–14.

Understanding the role of LRRK2 in Parkinson's

It is essential that our brain cells are kept healthy and free of waste in order for them to function properly. One way cells are kept 'clean' is through their very own recycling system, made up of structures called lysosomes. These are acidic sacks filled with digestive enzymes capable of breaking down waste material within the cell. When the recycling process is not working efficiently, waste can quickly build up. This can alter the cells' behaviour and ultimately lead to the cell death.

Changes in the LRRK2 gene are linked to an increased risk of developing Parkinson's. This gene holds the instructions for the LRRK2 protein that controls many processes within the cell, including recycling. Parkinson's-associated changes in the LRRK2 gene are thought to cause a problem with the recycling system, leading to unwanted proteins building up inside brain cells. In a suite of recently published papers from OPDC we are getting a better understanding of the role of LRRK2 in Parkinson's.

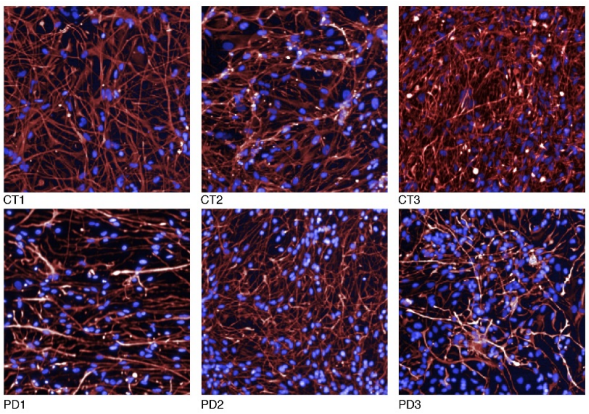


We generated dopaminergic neurons, the cells that are affected in Parkinson's, from stem cells reprogrammed using skin samples donated by people with Parkinson's who carry LRRK2 mutations. These neurons were used for in depth analysis which showed the most altered pathway in these cells was endocytosis. Endocytosis is a pathway essential to neurons for their normal function. This pathway is important to recycling in the cells. We also observed endocytosis was disturbed when we looked at human post-mortem brain tissue from people who had LRRK2 and in aged rats carrying the same LRRK2 mutations found in people with Parkinson's.

The rats with a LRRK2 mutation had decreased levels of recycling in brain cells, due to the lysosomes becoming less functional. However, we found the malaria drug clioquinol was shown to improve the function of the lysosomes back to normal levels, and this restored effective recycling in the cells. These new results reaffirm the potential of targeting the recycling system in brain cells for therapeutic use.

"***We urgently need a better understanding of the causes of Parkinson's and then apply that knowledge to develop new therapies, and that is what our work has done. Our work identifies for the first time the very important role of LRRK2 in regulating the acidity and the normal function of the protein recycling centre, the lysosome, and identifies a new way to target this therapeutically in Parkinson's***". *Professor Richard Wade-Martins*

We have also been working to understand the role of astrocytes in Parkinson's. Astrocytes are the most common type of cell in the central nervous system. They play a crucial role in the development and maintenance of the neurons that they support and growing evidence suggests they may contribute to how Parkinson's develops.



We have developed a method to produce astrocytes from stem cells reprogrammed using skin samples donated by people with Parkinson's who carry LRRK2 mutations to compare to heathy controls. We studied the expression levels of genes in LRRK2 and control astrocytes and found key differences in genes involved in the extracellular matrix, which is the space between cells that is essential for their communication. We think that astrocytes of people with this common LRRK2 mutation have a reduced ability to support and protect the vulnerable dopaminergic neurons from critical damage.

Watch Professor Richard Wade-Martins discuss these papers at https://tinyurl.com/y54z35tp

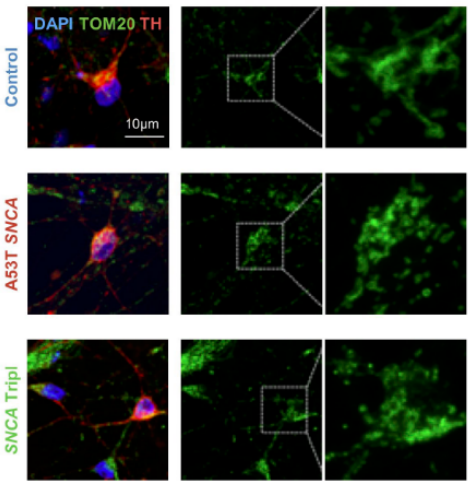
Wallings R, Connor-Robson N, Wade-Martins R. (2019) LRRK2 interacts with the vacuolar-type H+-ATPase pump a1 subunit to regulate lysosomal function. Hum Mol Genet. PMID: 31039583.

Connor-Robson N, Booth H, Martin JG, Gao B, Li K, Doig N, Vowles J, Browne C, Klinger L, Juhasz P, Klein C, Cowley SA, Bolam P, Hirst W, Wade-Martins R. (2019) An integrated transcriptomics and proteomics analysis reveals functional endocytic dysregulation caused by mutations in LRRK2. Neurobiol Dis. 127:512-526. PMID:30954703

Booth HDE, Wessely F, Connor-Robson N, Rinaldi F, Vowles J, Browne C, Evetts SG, Hu MT, Cowley SA, Webber C, Wade-Martins R. (2019) RNA sequencing reveals MMP2 and TGFB1 downregulation in LRRK2 G2019S Parkinson's iPSC-derived astrocytes. Neurobiol Dis. 129:56-66. PMID:31085228

New OPDC study on neurons grown from skin samples reveals key molecular changes in people with Parkinson's

In a new study from OPDC researchers we generated dopaminergic neurons, the cells that are affected in Parkinson's, from stem cells reprogrammed using skin samples donated by people with Parkinson's who have changes in the alpha-synuclein gene (alpha-synuclein mutation and triplication).



Alpha-synuclein is a protein which is abundant in the human brain, and in Parkinson's, the alpha-synuclein protein misfolds forming a toxic clump or aggregate. We observed that cells produced from people with Parkinson's accumulated detrimental alpha-synuclein species in the cells. The cells also showed problems in how their mitochondria produced energy. These findings were accompanied by evidence of cell stress as well as impairments in cholesterol and other lipids. Together, the changes we have found suggest new avenues to investigate potential therapies for people with Parkinson's who have changes in alpha-synuclein.

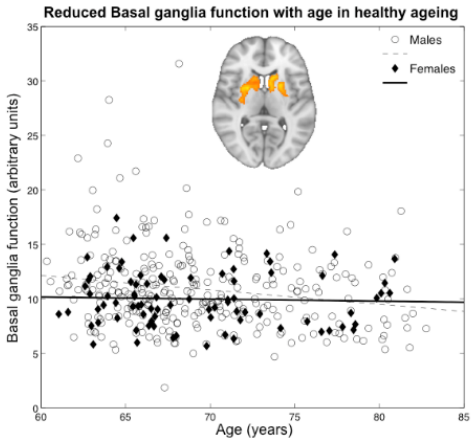
Without the constant contributions towards OPDC of people with Parkinson's, careers and every single supporter none of this work would have been possible.

Zambon F, Cherubini M, Fernandes HJR, Lang C, Ryan BJ, Volpato V, Bengoa-Vergniory N, Vingill S, Attar M, Booth HDE, Haenseler W, Vowles J, Bowden R, Webber C, Cowley SA, Wade-Martins R. (2019) Cellular α-synuclein pathology is associated with bioenergetic dysfunction in Parkinson's iPSC-derived dopamine neurons. Hum Mol Genet. 28(12):2001-2013. PMID: 30753527

Exploring variability in basal ganglia connectivity with functional MRI in healthy ageing

The basal ganglia is a group of structures in the base of the brain, which is associated with several functions, including control of voluntary motor movements.

Changes in brain function in the basal ganglia have been observed in Parkinson's and other conditions with altered dopaminergic function. However, less is known about factors affecting brain function in these areas in healthy ageing.



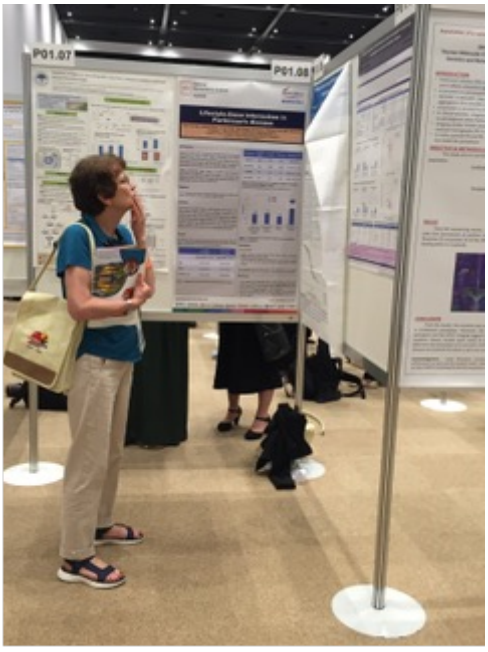
We recently carried out a study imaging brain activity in 486 healthy older adults. This was done with an MRI technique, called resting-state fMRI, in which people are simply required to stay still in the scanner. We used the MRI data to look at the 'connectivity', or strength of brain networks, in the basal ganglia by looking at changes in blood flow to different areas of the brain: the greater the blood flow in a certain area of the brain, the greater the amount of brain activity in that area. We observed reduced activity in the basal ganglia with increasing age in male participants but we didn't see this in females. Given the greater risk for Parkinson's in males this is an interesting result.

None of the other dopamine-related factors that we tested such as impulsive behaviour, self-paced tasks, mood, and motor control seemed to have a clear link with basal ganglia function. This is probably due to the amount and complexity of functions that involve the basal ganglia. However, this study confirms that age is a very important factor to take into account for the development of imaging biomarkers.

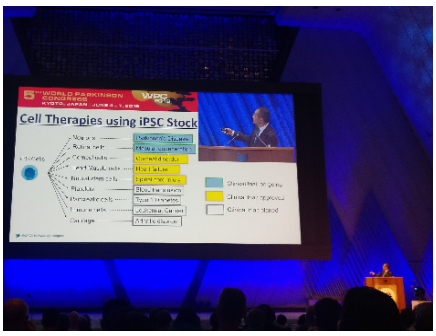
Griffanti L, Stratmann P, Rolinski M, Filippini N, Zsoldos E, Mahmood A, Zamboni G, Douaud G, Klein JC, Kivimäki M, Singh-Manoux A, Hu MT, Ebmeier KP, Mackay CE. (2018) Exploring variability in basal ganglia connectivity with functional MRI in healthy aging. Brain Imaging Behav. 12(6):1822-1827. PMID: 29442271

The 5th World Parkinson's Congress in Kyoto 4-7 July 2019 – Nigel Hamilton, Parkinson's UK Oxford Branch

Travelling almost half way around the globe seemed a long way to go to find out more about what is happening in the world of Parkinson's research and treatment. However, after an eleven hour flight to Japan, we found ourselves taking part in an extraordinary event involving 2,600 delegates, lasting three and a half days and set in a most impressive venue. There was a very ambitious programme faultlessly delivered by the staff of the World Parkinson's Congress (WPC) based in Canada. This was the 5th WPC and it all took place in the lovely city of Kyoto.



The extensive programme included 27 themed sessions (each one made up of 3 or 4 individual talks), 54 workshops, 72 round table discussions, 12 hot topics, 600 posters and numerous other activities. There were more than 140 talks given by expert clinicians, neurological researchers, health professionals, and many by people with Parkinson's (PwP). Speakers, PwP and other delegates had gathered from all over the world and the central role awarded to PwP was evident throughout. The official language was English with simultaneous Japanese translation.

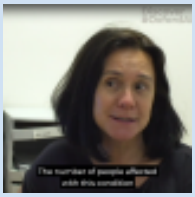


To go to more than a handful of sessions would not have been possible but we chose wisely and came away with an experience that was both informative and inspirational. Highlights for us were included the opening event featuring which featured Lyndsey Isaacs talking so movingly about her husband Tom, who died in 2017 and a special lecture given by the Japanese Nobel prize winner, Shinya Yamanaka. Shinya who Yamanaka was the first to discover that iPS cells can be produced from skin or blood cells. He described how these cells can then be converted into other types of cells which can potentially be used to treat disease. There has already been some success with treating Macular Degeneration and trials have already begun with PwP.

The first plenary session was about alpha-synuclein and the first of four speakers - Ronald Melki from France - gave a very clear explanation of the role of that protein and how problems begin when it becomes misfolded forming fibrils. These aggregate into Lewy bodies which then disrupt dopamine-producing neurons in a number of ways. Talks, workshops and parallel sessions covered developments in many aspects of Parkinson's research and treatment including symptom-relief, early diagnosis, the role of the gut in Parkinson's and living well with Parkinson's. A number of OPDC researchers were presenting at the conference including career development fellow Dayne Beccano-Kelly who spoke in the hot topics session about his work trying to better understand the mechanisms of Parkinson's by studying the electrophysiology of iPS cells derived from OPDC participants.

We came away inspired and with a broad overview of the extent of research going on worldwide. The date and venue of the 6th Congress were announced at the last session on the final day and unless the secrets of Parkinson's have been unlocked in the meantime, the date will be 7-10 June 2022 and the venue Barcelona. Maybe see you there?

New videos highlighting OPDC research



We have recently been working with Oxford University to produce videos explaining some of the work being carried out at OPDC. Our smartphone and sleep study have been selected by the University to feature in their #OxfordAI series celebrating machine learning innovations. www.opdc.ox.ac.uk/opdc-research-featured-in-oxfordai-videos

Richard Wade-Martin's lab also worked with the University to produce a video to mark World Parkinson's Day 2019 highlighting research being carried out by the team. www.opdc.ox.ac.uk/inside-the-wade-martins-lab

2019 OPDC Open Day

We invite cohort members to join us at the 2019 OPDC cohort open day on Monday 16th September at Jurys Inn, Oxford. We will have an afternoon of talks and discussions updating on our research including a talk from Michele Hu on Proactive symptom management to make the most of living with Parkinson's. We will also have some canine guests with a talk on the use of Medical Detection Dogs in Parkinson's. To learn more, including how to register, visit www.opdc.ox.ac.uk/openday2019.

All talks will be filmed and will be available to view after the event at www.opdc.ox.ac.uk/videos, where you can also find talks from previous years.

Spit in His Eye

I wrote this poem after spending 2 weeks at the ReGen Centre for Parkinson's patients in Boario, Italy.

It was an amazing place dedicated to slowing down the progression of the Disease and improving our posture, energy levels, speech, cognitive brain function and growing new pathways, all simple exercises and therapies that work (Maggie Lines, Diagnosed 2006).

Mr. Parkinson's aim in life is to try
To make you live sadly with a tear and a sigh
To encourage pessimism, to encourage fear,
I can't, I won't, are what he wants to hear.

So do something new and exciting each day,
Confirm out loud that you won't live his way
Make sure you tell him, your aim is to try,
To get up each morning and spit in his eye

Take care of yourself, Mr. P will hate that!!
Eat well, lots of water, fresh fruit, fish and veg
Make sure to push him right to the edge,
He mustn't define you, so don't let him try,

You really are NOT ill, though you take the odd pill,
Think of your Parkinson's as climbing a hill
Straighten your shoulders and reach for the sky
And when you get there you can spit in his eye.

Parkinson's UK Milton Keynes Branch News

Our group, in its current format started in 2005. The main group meets on the last Wednesday of the month (Except December) at Centrecom in the city centre. The programme we offer is varied, some serious topics relating to Parkinson's including research. Tess Adams, the Parkinson's Clinical Specialist comes when possible and talks about medication and the problems of living with Parkinson's, and we have had visits from OPDC's Michele Hu to update on research. But we try to cover a wide range of interests including the renovation of a local listed building, musical entertainment and quizzes. Also, there is the 'Saturday Group' which caters for people who are still working and in many cases, recently diagnosed. It is so important when first diagnosed that you can meet up with people in a similar situation, just to chat.

As a Group we run various activities – all are based on the fact that they must be enjoyable, therapeutic and help with well-being. Tai Chi has been running for several years, and in addition we have walking, keep fit and lunch outings. We also support a local singing group as there is nothing like singing to bring a feeling of joy. This group also fund raises about twice a year by singing in the city centre.

We try to reach out to all affected by Parkinson's, including carers. We have posters in surgeries and information stalls at public events. We man a stand several times a year at the hospital when the Parkinson's clinic is being held. Our future intentions are to help anyone with Parkinson's, including their carers. We try to be aware of information on local services and we encourage people to join in activities.

No-one ever needs to be alone.

Further information available from: Barbara Baker 01908 562738 Baker-b5@sky.com

Walk for Parkinson's

Walks for Parkinson's take part around the country raising vital funds for Parkinson's UK. Team OPDC have been proud to take part in these excellent events and have thoroughly enjoyed the beautiful walks and the chance to chat with other walkers. There is a choice of 1.5, 4.5 and 8 mile walks around beautiful parts of Oxford. To learn more, including how to sign up for the event visit www.parkinsons.org.uk/events/walk-parkinsons-oxford. We will have a team at the 2019 walk in Oxford on 22nd September where we hope many of you will say hello.



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 in your will, please contact us on **01865 282358** or opdc.administrator@dpag.ox.ac.uk.

www.opdc.ox.ac.uk/giving

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www.opdc.ox.ac.uk

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