

Parkinson's UK funded research

Better treatments:

At Parkinson's UK (PUK), the research is driven by PWPs, striving for new and better treatments in years, rather than decades. People with the condition and their families are setting the research agenda, making decisions about the projects they fund and working in partnership with researchers at every stage.



<http://www.parkinsons.org.uk/content/about-our-research>

Contact rsn@parkinsons.org.uk to find out more about how you can get involved with Parkinson's research.

<http://www.parkinsons.org.uk/news/26-january-2016/patient-and-public-involvement-resource-researchers>

10 research areas for improving everyday life:

PUK's number 1 priority is to develop better treatments and a cure for [Parkinson's](#), and that is what the majority of their [research](#) is working towards. But finding a cure will take time so they also champion research to improve quality of life for people with the condition and their families. To help researchers focus on the most important issues, they asked people affected by Parkinson's, [carers](#) and health and social care professionals to come up with 10 priority areas for improving everyday life with Parkinson's.

The findings were published in December 2014 in The British Medical Journal: [read the full open access paper](#).

<http://www.parkinsons.org.uk/content/our-top-10-research-areas-improving-everyday-life>

PUK Research Support Network (RSN):

The RSN is an online network for people driven to help find a cure and better treatments for [Parkinson's](#). Through their network, anyone can get involved in [research](#). You don't need a scientific or research background and it's free to join. [Join the Research Support Network](#)

The RSN sends their members regular updates including:

- [news about research](#)
- information about [research events](#)
- opportunities to participate in research
- opportunities to work with PUK and researchers to help shape research



The aim of the RSN is to increase involvement and participation in research amongst the Parkinson's community. At the moment they have three priority areas: increasing involvement, increasing participation and development of regional structures to help achieve these aims. All RSN

members are encouraged to join in, give comments, share experiences on the ParkyRSN website. You can do this by making a post (don't worry – it is easy), by leaving comments, or by contributing to occasional features. This site is by and for us, people with Parkinson's, their carers, partners and even their pets. If there is something you want to see here, or you would like to get more involved, let them know.

www.parkyrsn.org.uk

Research News sources

Some good sources of Parkinson's research news are as follows:

- Parkinson's UK:
<https://www.parkinsons.org.uk/news/news-topics/research>
- Oxford Parkinson's Disease Centre (OPDC):
<http://www.opdc.ox.ac.uk/news>
- Viartis:
<http://www.viartis.net/parkinsons.disease/news.htm>
- Michael J Fox Foundation:
<https://www.michaeljfox.org/foundation/news.html?tagid=50>
- MJFF Third Thursday webinars
<https://www.michaeljfox.org/page.html?hot-topics-webinar-series&navid=webinar-series>
- US National Institute of Neurological Disorders and Strokes:
<http://www.ninds.nih.gov/research/parkinsonsweb/>
- European Parkinson's Disease Association:
<http://www.epda.eu.com/en/news/>
- US National Parkinson Foundation
<http://www.parkinson.org>
- The Science of Parkinson's
<https://scienceofparkinsons.com>

For those of you who use Twitter, searching for #parkinson's can bring a lot of information, but the quality and reliability is more mixed than the sources above, so caution is advised.

4th World Parkinson Congress, Portland, Oregon 20-23 Sept 2016

The World Parkinson Congresses provide an international forum for dialogue on the latest scientific discoveries, medical practices, and caregiver initiatives related to Parkinson's. Each Congress brings together physicians, neuroscientists, a broad range of other health professionals, care partners, and people with Parkinson's (PwPs) for a unique and inspiring experience. Cross pollinating members of the community is important in the effort to expedite the discovery of a cure and cultivate best treatment practices. You can access speaker's slides through the following link:

<https://wpc2016.quickmobile.center/#/event/4c8f9b66a9a829867de478f7b3fa69b3/123474/Schedule>

A series of webinars was featured as a prelude to WPC16, you can find them at <http://www.worldpdcoalition.org/?page=PortlandCountdown>

Finding Research Papers

PUK Completed research:

Completed research that has been funded by PUK is reported on the web site as a [series of lay summaries](#). If you need further information it requires more digging.

Searching for Research Papers

- The general method of finding papers is to use a search engine to, for instance, find a list of publications for an author and/or University; or to search by key words, for example, Parkinson's Disease and balance
- Google Scholar can also be useful
- PubMed comprises more than 25 million citations for biomedical literature from MEDLINE, life science journals, and online books. Citations may include links to full-text content from PubMed Central and publisher websites
www.ncbi.nlm.nih.gov/pubmed/
- For further search options try Medical Subject Headings (MeSH)
www.ncbi.nlm.nih.gov/mesh/
- Europe PMC is a useful source of papers: you can search for publications connected to particular grants using the grant look up tool
<http://europepmc.org/GrantLookup/>.
- ScienceDirect is a leading full-text scientific database offering journal articles and book chapters from over 3,500 journals and more than 34,000 books
www.sciencedirect.com

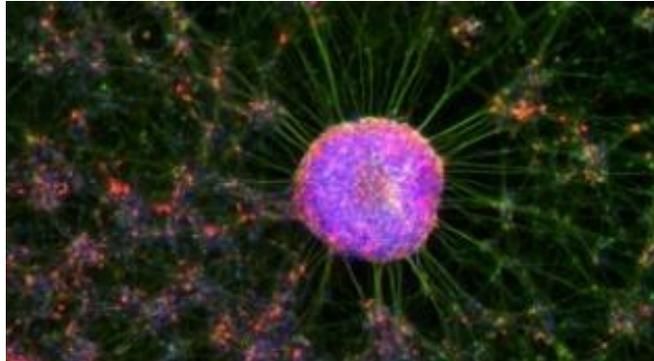
Open Access Research Publications

- Journal of Parkinson's Disease - <http://www.journalofparkinsonsdisease.com/>
- Journal of Neurological Disorders -
<http://www.esciencecentral.org/journals/neurological-disorders.php>
- Movement Disorders-
[http://onlinelibrary.wiley.com/journal/10.1002/\(ISSN\)1531-8257](http://onlinelibrary.wiley.com/journal/10.1002/(ISSN)1531-8257)

Parkinson's Research in Oxford

Oxford Parkinson's Disease Centre (OPDC) research

The OPDC Discovery Project is worthy of special mention as it is Parkinson's UK's largest ever research project - £11million over 10 years - made possible by their funding partners [The Monument Trust](#).



The [Oxford Parkinson's Disease Centre](#) (OPDC) is a unique, collaborative initiative that brings the best scientific minds together to speed up the search for better treatments and a cure for Parkinson's. The team is looking at Parkinson's from every angle and by 2020 they hope to:

- **Identify targets for new and better treatments for Parkinson's with fewer side effects.** Using the knowledge and insights they gain in the lab and the clinic the team will identify promising targets for new therapies that can slow or stop the development of Parkinson's.
- **Develop simple ways to diagnose and monitor Parkinson's much more accurately.** The team are exploring innovative new approaches diagnosis including looking at brain scans, blood samples and using new technologies – such as smartphone applications – to monitor Parkinson's symptoms remotely.

OPDC are very pleased to be able to share the videos of the talks about their exciting research from the May 2016 Participants' Day. These highlight some of the advances they have been making and how they are improving our understanding of Parkinson's. Includes talks from Dr Michele Hu, Prof Richard Wade-Martins, Dr Fahd Baig, Dr Claudio Ruffmann and Dr Tom Barber.

<http://www.opdc.ox.ac.uk/2016-open-day-podcasts-now-online>

OxQUIP Trial to Quantify Parkinson's

Prof Chrystalina Antoniades and Dr James FitzGerald, who are close friends of the Oxford Branch, have set up a new research trial to quantify Parkinson's. The Oxford study of Quantification in Parkinsonism (OxQUIP) is recruiting subjects with Parkinson's and Progressive Supranuclear Palsy (PSP). The study is directed at the use of technology to develop new ways of measuring symptoms as precisely as possible so that, when new drugs are ready to test, researchers will be able to very accurately measure their effectiveness in clinical trials. Hopefully, once the value of the tests has



been assessed, we may even see some of them being used in routine clinical consultations to assess patient response to established medication.

The team was interviewed on 31 October 2016 by BBC South, Jack FM and Oxford Mail. Oxford University Hospitals Communications Manager, Oliver Evans, has provided the following links:

<http://www.ouh.nhs.uk/news/article.aspx?id=553>

<https://www.youtube.com/watch?v=dHTJu9xvcFk>

For further information or to volunteer to participate see the link:

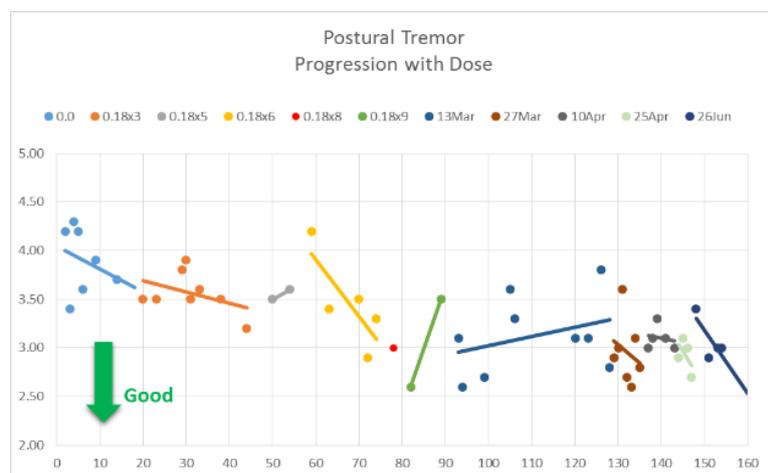
<https://www.ndcn.ox.ac.uk/research/neurometrology-lab>

Oxford Brookes University Research on Exercise

At the April 2015 Oxford Branch meeting, Marloes Franssen of Oxford Brookes University presented the findings of her research into the effects of physical exercise and handwriting on Parkinson's. Over 100 PwP participated in the trial, which involved a 6 month engagement in either exercise or handwriting and 12 months monitoring of symptoms. The key outcomes were that exercise can reduce the symptoms of Parkinson's., increase leg strength and reduce self-reported fatigue. The handwriting also reduced self-reported fatigue

PUK Oxford Branch member's DIY Research on Self-Monitoring

Jim Sheridan, an Oxford Branch member, was the speaker at the July 2016 meeting of the Oxford and District Branch, and gave an overview of his own research on himself – measuring symptoms to monitor his response to changes in medication. If anyone wants to find out more about self-monitoring, please go to the link:



<http://www.parkyrnsn.org.uk/category/self-monitoring/>

The full Parkinson's Self-Monitoring Protocol has been criticised by PUK London office as too scientific, and Jim has tried to respond to this by producing a Short Test Plan (included as the last Annex of the protocol). The aim is to develop something simple that we can all make use of, if we wish to, in the spirit of 'taking control.' To achieve ultimate suitability for anyone, Jim needs comments from a broad spectrum of people with Parkinson's – as well as those that care for us. Please join the discussion online or contact Jim directly.