

## Thames Valley Regional Meeting Update: June 2016

### What is the Thames Valley Excellence Network (TVEN)?

Formed in Summer 2015, when our first regional network meeting was launched, the TVEN is part of a wider nationwide initiative led by Parkinson's UK to improve the quality of care for people with Parkinson's (PwP), address regional inequalities and empower both patients and Health Professionals managing Parkinson's to proactively manage this condition. The network will:

- Enable professionals to work together for change
- Build an expert workforce
- Equip professionals to influence services
- Strengthen the voice of people affected

Further details can be found on the Parkinson's UK website: <http://www.parkinsons.org.uk/professionals>. Any PwP or health care professional can sign up to this network and join an online community for help and advice. The UK is divided into several regions, with the TVEN led by Dr Michele Hu, Consultant Neurologist/Associate Professor and cohort lead of the Oxford Parkinson's Disease Centre (OPDC) at Oxford University.

**Meeting Summary:** As in 2015, the meeting was held in the Holiday Inn Oxford on 10.06.16, with 51 attendees.

Two PwP represented each of the local Parkinson's UK support groups (Oxford, Banbury, Henley-on-Thames, Milton Keynes, Aylesbury, Amersham and High Wycombe, Reading, Newbury, Bracknell and District, Slough and District and Swindon and District Branches- see page 6 for contact details). We also had a variety of health professionals from across the region including PD Nurse specialists (PDNS), physiotherapists, clinical psychologists, GP's, Consultants in Elderly Care, Psychiatry and Neurology, and Pharmacists. The patient contribution for this first time this year was particularly valued, and led to some highly interactive and pertinent discussions.



**Dr Michele Hu**  
TVEN Lead



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#### Next steps:

- Working groups
- Future meetings
- TVEN Website



## The Swindon Experience

Rachel Gardner (PDNS) and Dave Logan (Chair, Swindon and District Branch) gave a thought-provoking presentation showing how the local branch (valiantly led by Dave) have worked with SEQOL (an independent social enterprise business), the local PDNS/clinical team, Clinical Commissioning Group, Hospital Trust and PWP to support everyone affected with Parkinson's in the Swindon area to make the most of their lives. SEQOL provide a range of community health and adult social care services, which are owned by their employees and some GPs, with any profit made further invested into developing services (<https://www.seqol.org/about-us>).

Innovative local PD initiatives include joint neurology/elderly care/ PDNS clinics, newly diagnosed clinics, joint PDNS/Physiotherapy clinics, hospital based educational sessions on self-management, non-motor symptoms, branch-funded Balance and Exercise, a free 4 week LIFT course to consider the impact of Parkinson's on emotional well-being and introduce Cognitive Behavioural Therapy (CBT)-based skills and techniques. The group also have an active website, have donated pill timers to hospital wards, and have shown through careful audit of locally defined outcomes working with the CCG that they have: 1) improved accessibility and quality of care for PWP and their families 2) reduced emergency admissions and length of stay in acute care related to PD complications. The key encouragement of this group is how local clinicians have worked effectively with charities and PwP to deliver excellent services.



Dave Logan Swindon Branch Chair and Rachel Gardner, PDNS

## Mental Health issues in Parkinson's

Issues such as anxiety, depression, hallucinations, confusion and memory loss can be common problems as Parkinson's progresses. These mental health issues have major effects on the health and well being of PwP, but due to the social stigma attached are often unrecognised, rarely spoken about, and untreated. Clinical neuropsychologist Dr Niels Deter, based at Oxford University Hospitals NHS Foundation Trust (OUH) gave a thoughtful and compassionate overview of anxiety and depression, and discussed self-help techniques such as cognitive behavioural therapy (CBT) and Mindfulness. Niels has led Mindfulness courses at Oxford for PwP and other neurological disorders, and presented results showing this can be as effective as medication in treating anxiety and depression. Improving access to these new therapies will be key to improving quality of life for PwP in the future. Dr David Okai, newly appointed Consultant Psychiatrist at OUH also talked about medical treatments of mental health issues for PwP and is working with the OUH PD team in a new clinic where PwP can get help quickly.



Dr Niels Deter



Dr David Okai



## Sally Bromley: The First Steps Programme

Sally Bromley is Chair of the Oxford Parkinson's UK support group, and kindly gave an overview of this course for newly diagnosed PwP. The course was inspired and set up by local group members from Oxford (Sally Bromley, Peter Harling and others) who had visited the European Parkinson Therapy Centre in Brescia, Italy set up by Alex Reed, an English businessman following his own PD diagnosis (<http://www.terapiaparkinson.it/en>). The Centre provides several weeks of intensive inpatient rehabilitation for PwP. The unique strength of First Steps is that it is designed and delivered by local PwP volunteers, supported by Parkinson's UK to help PwP take back their lives. While the NHS can't manage several weeks of therapy, this course takes place over 1-2 days in the lovely surroundings of Witney Lakes Golf club, and has had excellent feedback from participants. PwP from across the TV can self-refer to this course directly by **contacting Kathryn McLoughlin on 020 7963 9381 or email [kmcloughlin@parkinsons.org.uk](mailto:kmcloughlin@parkinsons.org.uk)**

**Stop Press: This pioneering course can only be guaranteed for funding till December 2016.**

At the meeting, all present members of the TVEN were surveyed on their thoughts on future continuation of the programme in writing. Here are their responses:

### First Steps – Next Steps?

**Would you like to see First Steps Programme continue into 2017?**

**If so, explain how please...**

Everyone diagnosed with PD should have the opportunity to do 'First Steps'. "Knowledge" is "power" and the more knowledge PwPs gain the more they can take control of their lives. It should be rolled out to the whole of the UK. PUK should be promoting this in all their publications etc. (*local group committee member*)

Yes – it has helped so many of my patients with Parkinson's manage their illness proactively, come to terms with their illness and have a better outcome! (*Consultant*)

Expand the programme – provide activities such as dance/ singing/ walking groups/ tai chi which would be available to a greater number of PwPs. These activities are positive and help with the quality of life of PwP. PwPs can help each other/ support each other (*person with Parkinson's*)

***Given the highly positive response all round, will Parkinson's UK now commit to funding this crucial programme in 2017, and rolling it out beyond the TV to the wider UK? Current research funding applications, to properly assess outcomes and delivery led by Professor Helen Dawes, Physiotherapist at Brookes University, and supported by the group are in progress...Watch this space!***

## Ewan Stutt: The Younger Onset PD group (YOPD)

Ewan was diagnosed with Parkinson's three years ago in his early forties. After a difficult first few years coming to terms with his diagnosis and its implications, Ewan has now emerged to champion the cause of PwP. He has done this by launching a new charity for PwP: website <http://parkinsons.me>.

Since its launch, the website has had in excess of 55,000 hits, with virtually 100% engagement of its users.

Michele Hu gave an overview to the group of YOPD which in its strictest definition refers to those diagnosed under the age of 40 years (some studies accept 50 years (!)), and affects less than 5% of all PwP. Specific issues relating to this group include issues of pregnancy, contraception and the menstrual cycle for women, as well as more general issues of employment, caring for children, and sexuality. Medication can be a complex choice for the patient and clinician, but there is growing evidence that levodopa rather than dopamine agonists are better tolerated in this group, as in most PwP, with no added advantage of dopamine agonists over levodopa in terms of the future development of treatment complications eg dyskinesias.

Ewan spoke openly and movingly about his personal experience of being diagnosed and living with Parkinson's. For him, exercise, regular physiotherapy and the right medications have made such a tremendous difference that following a talk he gave recently in Swindon, someone came up to him and asked if he really did have Parkinson's as he looked so well with excellent movement!

Supported by Rachel Honey who also has YOPD, and Parkinson's UK, Ewan is now setting up a YOPD TV support group. **For further details, email him at: [ewan@parkinsons.me](mailto:ewan@parkinsons.me)**

### Research opportunities for Parkinson's in the Thames Valley: Michele Hu

Part of the remit of the TV and national Excellence Network is to improve life for PwP through research, not only into the causes of Parkinson's, but to develop better treatments and ultimately a cure. Through her role as co-principal investigator of the Oxford Parkinson's Disease Centre (OPDC: [www.opdc.ox.ac.uk](http://www.opdc.ox.ac.uk)) and chair of the excellence network research engagement committee, Michele Hu is passionately committed to research as the only way that future meaningful change for the best can occur for PwP. Find out more about research going on at Oxford via the OPDC website above, which also includes recent podcasts of talks given about our work at one of our annual cohort days. Details include our stem cell work from a simple skin biopsy, where we are developing new treatments by using these cells from patients to 'model Parkinson's in a dish'. You can also get involved in research by downloading a patient expression of interest to participate form from the website. By completing this, and sending it to us, you allow us to store your details on our research database, so we can alert you about future studies in Parkinson's. The OPDC cohort is currently recruiting up to 300 male volunteers without Parkinson's or a family history of this condition, and people with rapid eye movement sleep behaviour disorder (RBD) till 2020, so we can compare results to those from PwP. We are no longer recruiting PwP, as we have reached our target of >1000 PwP in 2015- thanks to your support! Further details can also be found on the biannual OPDC newsletter which you can also download from this site.

## Future Directions of the TVEN

As a result of our analysis of the 2016 Parkinson's UK national audit for Parkinson's and discussions at the June 16 meeting, the TVEN have decided to focus on the following areas/projects:

Project Title	Project lead	Planned Outcome	Action	Responsible for action
Mental Health in Parkinson's	David Okai, Consultant Psychiatrist RBH Niels Detert, Clinical Psychologist RBH Jo Bromley, PDNS John Radcliffe Hospital	Promotion of consistent good practice in response to mental health issues in Parkinson's	Development of Special Interest Group/Network.	David Okai
Complex Therapies	Michele Hu & Bin Cheeran, Consultant Neurologists John Radcliffe Hospital.	All stakeholders aware of benefits/criteria/contraindicators for advanced therapies.	Develop integrated pathway for DBS, Duodopa and Apomorphine across TV PEN.	Michele Hu
Website Development	Michele Hu White ADM Parkinson's UK Bromley PDNS	Improved communication on TV PEN developments across all stakeholders	Development of TV PEN website to be accessed by both clinicians and PWP	Michele Hu Abi White Jo Bromley Mike Searle & John Inglis - Volunteers
Exercise Interventions		Promotion of consistent good practice in relation to exercise	Development of professional network of neuro physios interested in exercise in TV PEN area.	Michele Hu
Younger people with PD	Ewan Stutt PWP Rachel Honey PWP	Improved peer support for people with young onset Parkinson's	Establishment of Young People's network for TV PEN area.	Ewan Stutt
First Steps Pilot	Michele Hu	Better support for all newly diagnosed PWP from the point of diagnosis	Development of a support package for newly diagnosed PWP that also establishes a relationship for all with Parkinson's UK	Val Buxton, Director of External Relations, Parkinson's UK
Guidelines and Pathways for GPs	Olivia Moswela UCB	Improved practice within primary care in Oxford.	Development of GP centred pathway "tool" for Parkinson's in Oxford.	Michele Hu
Annual Event	Michele Hu	Opportunity for sharing of activity and identifying needs and new workstreams.	Annual event held June 2016, supported by Risha Goswamy at Parkinson's UK.	Michele Hu

### Key planned developments in the next 12 months are:

- Development of the above focus groups and future strategy
- Additionally, focus on improving hospital care for PwP in Oxfordshire
- Development of a TVEN website for care, research and communication
- Apply for long term funding for First Steps Programme
- A further 1 day meeting focusing on complex therapies (apomorphine, surgery and duodopa) and mental health issues in Parkinson's is planned around December 2016 for health professionals
- The third annual TVEN meeting in June 2017



## Contact details of Parkinson's UK local support groups:

Ps there is no group in Faringdon (Swindon and Oxford Branches serve this area)

Oxfordshire	Oxford Branch	Sally Bromley	Chair	<a href="mailto:oxford.sally@gmail.com">oxford.sally@gmail.com</a>
	Banbury Branch	Tony Klepping	Secretary	<a href="mailto:anthony.klepping@btinternet.com">anthony.klepping@btinternet.com</a>
	Henley on Thames Branch	Terry Dudeney	Chair	<a href="mailto:tpd44@sky.com">tpd44@sky.com</a>
Buckinghamshire	Milton Keynes Support Group	Doug Eaglesfield	Lead contact	<a href="mailto:deaglesf@sky.com">deaglesf@sky.com</a>
	Aylesbury Branch	Lorraine Tierney	Chair	<a href="mailto:lorrynetierney429@gmail.com">lorrynetierney429@gmail.com</a>
	Amersham and High Wycombe Branch	Trevor Owen	Chair	<a href="mailto:trevor.owen@parkinsonsAHW.org.uk">trevor.owen@parkinsonsAHW.org.uk</a>
Berkshire	Reading Branch			
	Newbury Branch			
	Bracknell and District Branch			
	Slough and District Branch			
Swindon UA, Wiltshire	Swindon and District Branch	Dave Logan	Chair	<a href="mailto:davelogan_parkinsons.swindon@outlook.com">davelogan_parkinsons.swindon@outlook.com</a>

Reading: David Adbby - Chair - [david.adby@tesco.net](mailto:david.adby@tesco.net)

Newbury: David Russell Cmmte member - [russell834@btinternet.com](mailto:russell834@btinternet.com)

Newbury Sparkies - John Inglis - [johnpinglis@ymail.com](mailto:johnpinglis@ymail.com)

Bracknell: Will Hague - sec -

[secretary@bracknell.parkinsons.org](mailto:secretary@bracknell.parkinsons.org)

Slough: Gillian Wilson - Chair - [xjg544@gmail.com](mailto:xjg544@gmail.com)

Henley: Terry Dudeney - Chair - [tpd44@sky.com](mailto:tpd44@sky.com)