Tracking Parkinson’s  
The PRoBaND study  

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December 2016
Study Progress up to Now

- February 2012 (study start)
- Original study (0-36 months)
- Interim extension (42-54 months)

- 2011 recent onset participants recruited
- 256 young onset participants recruited
- Total 2270
Progress: Patients for Visit 8

- Consistent recruitment to the extension this year
- Average of 41 per month in 2016
Progress: Patients for Visit 9

- First V9s recruited in Glasgow in summer
- Should average double figures per month in 2017
Most relatives have been involved already: total 339 (target 860)

Recruitment open until at least November 2017

Relative follow-up visits to start in mid-to-late 2017
Extension: Common Queries (1)

IQ-CODE

- Please remind patients to bring a relative or friend with them if possible
- The test can be given to the patient to take away with them, to be completed at home, if this isn’t an option
- Alternatively, it can be completed over the phone

New Assessments Reminder

- Likelihood of Diagnosis and Dyskinesia Rating Scale
Funding

• Claims for V8/9 funding made via Tracking Parkinson’s website

• Frequency of payment varies by site, mainly according to patient volume

Reminder:

• £73.55 for a V8

• £169.30 for a V9
• Ethics submitted; approval likely to be early next year

• Visits move to 18-month intervals: Visit 10 at 72 months (6 years) and Visit 11 at 90 months (7 and a half years).

• Content will follow the established format; we will send out new consent and information sheets once approval is granted.
New Journal Articles

• Malek et al., 2015. “Tracking Parkinson’s: Study Design and Baseline Data.”

• Swallow et al., 2016. “Statins are underused in recent-onset Parkinson’s disease with increased vascular risk: findings from the UK Tracking Parkinson’s and Oxford Parkinson’s Disease Centre (OPDC) discovery cohorts.”

• Malek et al., 2016. “Variation in recent onset Parkinson’s disease: implications for prodromal detection.”

• Malek et al., 2016. “Olfaction is Parkin single and compound heterozygotes in a cohort of young onset Parkinson’s disease patients.”

All can be found on PubMed and Google Scholar.
New Website

www.trackingparkinsons.org.uk

All old ClinBase functions are under the “Clinicians” tab.

These are mostly in the same format.

Participants will have the option to enter their own data for future visits.
Staff Changes

- I’m just beginning a PhD with Dr. Grosset
- Alison retiring March 2017
- Replacement staff to join us early 2017
Any questions, please ask