

## Neurology Research Unit Nurses

[Per Odin]

### 1. Short description of the infrastructure.

The neurology research unit is located on the ground level of the Wigert building (Remissgatan 4, Skane university hospital, Lund). It consists of 9 office rooms and 4 rooms for clinical examinations. The research unit is well equipped concerning know-how and equipment for clinical and translational research related to Parkinson's disease and other Movement Disorders. They continuously update their knowledge and skills in the Parkinson area, i.e. by conducting part time doctoral studies and master studies respectively.

The research unit presently has 6 Parkinson research nurses (RN) (Working hours as RN: 50%, 75%, 87,5%, 100%, 100% and 100% respectively). This will be expanded with two further full-time RN during fall 2021/spring 2022. The nurses have a very high level of expertise concerning clinical research in the diseases in question and perform both commercial and non-commercial clinical studies. Duties:

#### **Providing nursing care to research study patients:**

- Ensures compliance with each study's protocol by providing thorough review and documentation at each subject study visit.
- Participates in recruitment and selection of study participants by interviewing and documenting medical history to determine compliance with eligibility requirements.
- Performs medical tests, including, but not limited to, vital signs, validated clinical rating scales, imaging studies, and electrocardiograms.
- Administers investigational medications and performs patient assessments during clinic visits to determine presence of side effects; notifies Principle Investigator of findings/issues.
- Provides patient education and medical information to study patients to ensure understanding of proper medication dosage, administration, and disease treatment (compliance).
- Documents medical data in patient chart to capture protocol requirements.
- Managing Parkinson patient registries.

This infrastructure is a prerequisite for all clinical and translational Parkinson-related research at Lund University and thereby helps Multipark to fulfill its strategic plan. There are no alternative infrastructures at LU offering the same service.

### 2. Is this infrastructure receiving support also from other Strategic Research Areas (SRAs) or organizations at Lund University (e.g. Medical faculty, LBIC). If yes, please specify the type of support and its amount.

The research unit is co-financed with The Swedish Parkinson Academy (SPA, which mainly is supported by the Olle Engkvist Stiftelse (Olle Engkvist Foundation). SPA contributes with 1.3 million SEK/year.

**3. Number and names of MultiPark senior researchers using the infrastructure in the period 2018-2020<sup>1</sup>.**

Professor Angela Cenci Nilsson, Basal Ganglia Pathophysiology  
Professor Oskar Hansson, Clinical Memory Research Unit  
Professor Susanne Iwarsson, Active and Healthy Ageing Research Group  
Associate Professor Maria Nilsson, Active and Healthy Ageing Research Group  
Professor Per Odin, Restorative Parkinson Unit, Neurology  
Professor Malin Parmar, Developmental Neurobiology Lab  
Professor Gesine Paul Visse, Translational Neurology Group  
Associate Professor Andreas Puschmann, Clinical Neurogenetics, Neurology  
Associate professor Maria Swanberg Translational Neurogenetics  
Professor Håkan Widner, Regeneration in Movement Disorders, Neurology

**4. Number and names of senior researchers outside of Multipark and/or non-academic partners using the infrastructure 2018-2020.**

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**5. Does the infrastructure have a steering document accessible to the users? If yes, when was it last updated?<sup>2</sup>**

The unit has all relevant documents for the ongoing clinical studies on an intranet platform. This is continuously updated.

A steering group oversees the work at the infrastructure. The work is coordinated by Prof. Per Odin and Research coordinator Ulrika Mundt-Petersen.

**6. Is the infrastructure charging user fees? If yes, state the amount and what is covered by the user fees.**

The PIs for the clinical studies pay 50% of the salary of the RN when using the study nurses. In case the study is commercial or EU-financed the user pays 100% of the salary.

**7. List publications generated with the help of this infrastructure during the past 3 years (2018-2020). Do not include manuscripts in preparation and please give the full reference (i.e., complete author list, complete title, journal name with year, volume, pages)<sup>3</sup>.**

Standaert DG, Boyd JT, Odin P, Robieson WZ, Zamudio J, Chatamra K. (2018) Systematic evaluation of levodopa-carbidopa intestinal gel patient-responder characteristics. *NPJ Parkinsons Dis.* 24;4:4.

Kader M, Jonasson SB, Iwarsson S, Odin P, Nilsson MH. (2018) Mobility device use in people with Parkinson's disease: A 3-year follow-up study. *Acta Neurol Scand.* 2018 Apr 16. doi: 10.1111/ane.12942. [Epub ahead of print]

Sahlström T, Eklund M, Timpka J, Henriksen T, Nyholm D, Odin P. (2018) Workforce participation and activities in Parkinson's disease patients receiving device-aided therapy. *Acta Neurol Scand.* 138(1):78-84.

Rosqvist K, Horne M, Hagell P, Iwarsson S, Nilsson MH, Odin P. (2018) Levodopa Effect and Motor Function in Late Stage Parkinson's Disease. *J Parkinsons Dis.* 8(1):59-70.

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<sup>1</sup> If the infrastructure was first established in 2020, please include this information.

<sup>2</sup> Note that the Multipark leadership may ask to see this document with a very short notice.

<sup>3</sup> If the infrastructure was first established in 2020, please include this information here too.

Rosqvist K, Odin P, Hagell P, Iwarsson S, Nilsson MH, Storch A. (2018) Dopaminergic effect on non-motor symptoms in late stage Parkinson's disease. *J Parkinsons Dis.* 8(3): 409-20.

Kader M, Jonasson SB, Iwarsson S, Odin P, Nilsson MH (2018) Mobility device use in people with Parkinson's disease: A 3-year follow-up study. *Acta Neurol Scand.* 138(1):70-77.

Odin P, Chaudhuri KR, Volkman J, Antonini A, Storch A, Dietrichs E, Pirtošek Z, Henriksen T, Horne M, Devos D, Bergquist F (2018) Viewpoint and practical recommendations from a movement disorder specialist panel on objective measurement in the clinical management of Parkinson's disease. *NPJ Parkinsons Dis.* 10;4:14.

Martinez-Martin P, Rizos AM, Wetmore J, Antonini A, Odin P, Pal S, Sophia R, Carroll C, Martino D, Falup-Pecurariu C, Kessel B, Andrews T, Paviour D, Trenkwalder C, Chaudhuri KR; EUROPAR and MDS Non-motor PD Study Group (2018) First comprehensive tool for screening pain in Parkinson's disease: the King's Parkinson's Disease Pain Questionnaire. *Eur J Neurol.* 25(10):1255-61.

Antonini A, Stoessl AJ, Kleinman LS, Skalicky AM, Marshall TS, Sail KR, Onuk K, Odin P (2018) Developing consensus among movement disorder specialists on clinical indicators for identification and management of advanced Parkinson's disease: a multi-country Delphi-panel approach. *Curr Med Res Opin.* 24(12): 2063-73.

Balzer-Geldsetzer M, Ferreira J, Odin P, Bloem BR, Meissner WG, Lorenzl S, Wittenberg M, Dodel R, Schrag A. (2018) Study protocol: Care of Late-Stage Parkinsonism (CLaSP): a longitudinal cohort study. *BMC Neurol.* 18(1):185.

Kader M, Hagell P, Iwarsson S, Odin P, Nilsson MH. (2018) Assessing perceived walking difficulties in Parkinson's disease: Psychometric properties of the Walk.12G. Submitted.

Timpka J, Dahlström Ö, Spreco A, Nilsson MH, Iwarsson S, Timpka T, Odin P. (2018) Reduced workforce participation 5 years prior to first Parkinson's disease sick-leave. *NPJ Parkinsons Dis.* 4:36.

Dafsari HS, Martinez-Martin P, Rizos A, Trost M, Dos Santos Ghilardi MG, Reddy P, Sauerbier A, Petry-Schmelzer JN, Kramberger M, Borgemeester RWK, Barbe MT, Ashkan K, Silverdale M, Evans J, Odin P, Fonoff ET, Fink GR, Henriksen T, Ebersbach G, Pirtošek Z, Visser-Vandewalle V, Antonini A, Timmermann L, Ray Chaudhuri K; EUROPAR and the International Parkinson and Movement Disorders Society Non-Motor Parkinson's Disease Study Group. (2019) EuroInf 2: Subthalamic stimulation, apomorphine, and levodopa infusion in Parkinson's disease. *Mov Disord.* 34:353-365.

Martinez-Martin P, Rizos AM, Wetmore JB, Antonini A, Odin P, Pal S, Sophia R, Carroll C, Martino D, Falup-Pecurariu C, Kessel B, Andrews T, Paviour D, Trenkwalder C, Chaudhuri KR; EUROPAR & MDS Non-Motor PD Study Group. (2018) Relationship of Nocturnal Sleep Dysfunction and Pain Subtypes in Parkinson's Disease. *Mov Disord Clin Pract.* 6(1):57-64.

Storch A, Rosqvist K, Ebersbach G, Odin P. (2019) Disease stage-dependency of motor and non-motor fluctuations in Parkinson's disease. *J Neural Transm.* 126:841-51.

Rosqvist K, Hagell P, Iwarsson S, Nilsson MH, Odin P. (2019) Satisfaction with care in late stage Parkinson's disease in Sweden. *Parkinsons Dis.* 2019:2593547.

Puschmann A, Jiménez-Ferrer I, Lundblad-Andersson E, Mårtensson E, Hansson O, Odin P, Widner H, Brolin K, Mzezewa R, Kristensen J, Soller M, Rödström EY, Ross OA, Toft M, Breedveld GJ, Bonifati V, Brodin L, Zettergren A, Sydow O, Linder J, Wirdefeldt K, Svenningsson P, Nissbrandt H, Belin AC, Forsgren L, Swanberg M. (2019) Low prevalence of known pathogenic mutations in dominant PD genes: A Swedish multicenter study. *Parkinsonism Relat Disord.* 66:158-65.

Hultqvist J, Sahlström T, Timpka J, Henriksen T, Nyholm D, Odin P, Eklund M. (2019) Everyday Occupations and Other Factors in Relation to Mental Well-Being among Persons with Advanced Parkinson's Disease. *Occup Ther Health Care.* 26:1-18.

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Svenningsson P, Odin P, Dizdar N, Johansson A, Grigoriou S, Tsitsi P, Wictorin K, Bergquist F, Nyholm D, Rinne J, Hansson F, Sonesson C, Tedroff J; IRL752 Collaborators. (2019) A Phase 2a Trial Investigating the Safety and Tolerability of the Novel Cortical Enhancer IRL752 in Parkinson's Disease Dementia. *Mov Disord*. 35(6):1046-1054.

Petry-Schmelzer JN, Krause M, Dembek TA, Horn A, Evans J, Ashkan K, Rizos A, Silverdale M, Schumacher W, Sack C, Loehrer PA, Fink GR, Fonoff ET, Martinez-Martin P, Antonini A, Barbe MT, Visser-Vandewalle V, Ray-Chaudhuri K, Timmermann L, Dafsari HS; EUROPAR and the IPMDS Non-Motor PD Study Group. (2020) Non-motor outcomes depend on location of neurostimulation in Parkinson's disease. *Brain*. 142(11):3592-3604.

Fasano A, Antonini A, Katzenschlager R, Krack P, Odin P, Evans AH, Foltynie T, Volkmann J, Merello M (2020) Management of Advanced Therapies in Parkinson's Disease Patients in Times of Humanitarian Crisis: The COVID-19 Experience. *Mov Disord Clin Pract*. 7(4):361-372.

Rizos A, Sauerbier A, Falup-Pecurariu C, Odin P, Antonini A, Martinez-Martin P, Kessel B, Henriksen T, Silverdale M, Durner G, Ray Chaudhuri K; EUROPAR and the IPMDS Non-Motor PD Study Group. (2020) Tolerability of non-ergot oral and transdermal dopamine agonists in younger and older Parkinson's disease patients: an European multicentre survey. *J Neural Transm (Vienna)*. 127(6):875-879.

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van Wamelen DJ, Sringean J, Trivedi D, Carroll CB, Schrag AE, Odin P, Antonini A, Bloem BR, Bhidayasiri R, Chaudhuri KR on behalf of the International Parkinson and Movement Disorder Society Non-Motor Study group (2021) Digital health technology for non-motor symptoms in people with Parkinson's disease: futile or future? *Parkinsonism Relat Disord* 89:186-94.

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Gorcenco S, Vaz FM, Tracewska-Siemiakowska A, Tranebjaerg L, Cremers FPM, Ygland E, Kicsi J, Rendtorff ND, Moller C, Kjellstrom U, Andreasson S, Puschmann A. Oral therapy for riboflavin transporter deficiency - What is the regimen of choice? *Parkinsonism Relat Disord.* 2019;61:245-7.

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I confirm that the infrastructure's steering group has been contacted and has agreed with the proposal.

Lund 13 Okt 2021

A handwritten signature in blue ink, consisting of several overlapping loops and a long horizontal stroke at the top.

Prof. Per Odin