

Neurology Research Unit Coordinator

[Per Odin]

1. Short description of the infrastructure.

The neurology research unit is located on the ground level of the Wigert building (Remisgatan 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 research related to Parkinson's disease and other Movement Disorders.

The research unit has one research coordinator financed by Multipark (80%). This coordinator works 50% for stem therapy and that part of her work is covered by the infrastructure report from there. Here we cover the other 30% of her position. She mainly works with legal aspects of clinical studies. This includes ethical applications, patient information, KVB applications, contracts with sponsors and partners etc.

The research unit also has a second research coordinator, fully financed over the Swedish Parkinson Academy. Her focus is administration of the unit and its research.

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 miljon SEK/year.

3. Number and names of MultiPark senior researchers using the infrastructure in the period 2018-2020¹.

Professor Angela Cenci Nilsson, Basal Ganglia Pathophysiology
Docent Maria Nilsson, Active and Healthy Ageing Research Group
Professor Per Odin, Restorative Parkinson Unit, Neurology
Professor Gesine Paul Visse, Translational Neurology Group
Docent Maria Swanberg, Translational Neurogenetics

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

-

¹ If the infrastructure was first established in 2020, please include this information.

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

The units have all relevant documents for the ongoing clinical studies on an intranet platform. This is continuously updated. The coordinator leads this work.

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.

There are no fees for the coordinators.

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)³.

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.

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.

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

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

Multipark infrastructure report form 2021

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.

Klingelhoef L, Jost W, Odin P, Storch A, Ray Chaudhuri K, Reichmann H. (2019) [Dystonia Non-Motor Symptoms Questionnaire (DNMSQuest) for assessment of non-motor symptoms in dystonia : Intercultural adaptation in the German language]. *Nervenarzt.* 91(4):337-342.

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, Volkman 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.

Ehlers C, Timpka J, Odin P, Honig H (2020) Levodopa Infusion in Parkinson's Disease: Individual Quality of Life. *Acta Neurol Scand.* 142(3):248-54.

Multipark infrastructure report form 2021

Hommel ALAI, Meinders MJ, Lorenzl S, Dodel R, Coelho M, Ferreira JJ, Laurens B, Spampinato U, Meissner WG, Rosqvist K, Timpka J, Odin P, Wittenberg M, Bloem BR, Koopmans RT, Schrag A and the CLaSP consortium (2020) The prevalence and determinants of neuropsychiatric symptoms in late stage parkinsonism. *Mov Disord Clin Pract.* 7(5):531-542.

Schrag A, Hommel ALAI, Lorenzl S, Meissner W, Odin P, Coelho M, Bloem BR, Dodel R and the CLaSP consortium (2020). The late stage of Parkinson's – Results of a large multinational study on motor and non-motor complications. *Parkinsonism Relat Disord.* 75:91-96.

Hommel ALAJ, Meinders MJ, Weerkamp NJ, Richinger C, Schmotz C, Lorenzl S, Dodel R, Coelho M, Ferreira JJ, Tison F, Boraud T, Meissner WG, Rosqvist K, Timpka J, Odin P, Wittenberg M, Bloem BR, Koopmans RT, Schrag A, and the CLaSP consortium (2020) Optimizing treatment in undertreated late-stage parkinsonism: a pragmatic randomized trial. *J Parkinsons Dis.* 10(3):1171-84.

Kalampokini S, Hommel ALAJ, Lorenzl S, Ferreira J, Meissner W, Odin P, Bloem B, Dodel R, Schrag A (2020) Caregiver burden in late stage Parkinsonism and Its Associations. *J Geriatr Psychiatry Neurol.* Oct 23:891988720968233. Doi: 10.1177/0891988720968263.

Hosking A, Hommel ALAJ, Lorenzl S, Coelho M, Ferreira JJ, Meissner WG, Odin P, Bloem BR, Dodel R, Schrag A; Care of Late Stage Parkinsonism (CLaSP) Consortium (2021) Characteristics of Patients with Late-Stage Parkinsonism who are Nursing Home Residents Compared with those Living at Home. *J Am Med Dir Assoc* 22(2):440-5.

van Wamelen DJ, Martinez-Martin P, Weintraub D, Schrag A, Antonini A, Falup-Pecurariu C, Odin P, Ray Chaudhuri K; International Parkinson, Movement Disorder Society Parkinson Disease Non Motor Study Group. (2021) The Non-Motor Symptoms Scale in Parkinson's disease: validation and use. *Acta Neurol Scand.* Aug 19. doi: 10.1111/ane.13336. *Acta Neurol Scand* 143:3-12.

Lindholm B, Brogårdh C, Odin P, Hagell P (2021) Longitudinal prediction of falls and near falls frequencies in Parkinson's disease: a prospective cohort study. *J Neurol.* 268(3):997-1005.

Smilowska K, van Wamelen DJ, Pietrzykowski T, Calvano A, Rodriguez-Blazquez C, Martinez-Martin P, Odin P, Chaudhuri KR (2021) Cost-effectiveness of Device-Aided Therapies in Parkinson's Disease: A structured Review. *J Parkinson's Dis* 11(2):475-89.

Leta V, Rodriguez-Violante M, Abundes A, Rukavina K, Teo JT, Rota S, Falup-Pecurariu C, Bhidayasiri R, Storch A, Odin P, Antonini A, Chaudhuri KR. (2021) Parkinson's disease and Post-COVID-19 syndrome: Argument for a Long-COVID spectrum. *Mov Disord* 36(6):1287-9.

Norlin JM, Willis M, Persson U, Andersson E, Pålhagen S, Odin P (2021) Swedish Guidelines for Device-aided Therapies in Parkinson's Disease – Economic Evaluation and Implementation. *Acta Neurol Scand* 144(2):170-8.

Rosqvist K, Kylberg M, Löfqvist C, Schrag A, Odin P, Iwarsson S (2021) Perspectives on care of late stage Parkinson's disease. *Parkinsons Dis.* 2021 Mar 15;2021:9475026. doi: 10.1155/2021/9475026.

Scharfenort M, Timpka J, Sahlström T, Henriksen T, Nyholm D, Odin P. (2021) Close relationships in Parkinson's disease patients with device-aided therapies. *Brain Behav.* 5:e02102. doi: 10.1002/brb3.2102.

Rosqvist K, Odin P, Lorenzl S, Meissner W, Bloem B, Ferreira J, Dodel R, Schrag A and the CLaSP consortium. (2021) Factors associated with Health-Related Quality of Life in Late-Stage Parkinson's Disease. *Mov Disord Clin Pract* 8(4):563-70.

Grigoriou S, Martinez-Martin P, Chaudhuri KR, Rukavina K, Leta V, Hausbrand D, Falkenburger B, Odin P, Reichmann H (2021) Effects of safinamide on non-motor symptoms in patients with fluctuating Parkinson's disease. *Brain Behav* 3:e2336. Doi: 10.1002/brb3.2336.

Leta V, Dafsari HS, Sauerbier A, Metta V, Titova N, Timmermann L, Ashkan K, Samuel M, Pekkonen E, Odin P, Antonini A, Martinez-Martin P, Parry M, van Wamelen DJ, Ray Chaudhuri K (2021) *J Pers Med* 11(8):773.

Meinders MJ, Gentile G, Schrag AE, Konitsiotis S, Eggers C, Taba P, Lorenzl S, Odin P, Rosqvist K, Chaudhuri KR, Antonini A, Bloem BR, Groot MM. (2021) Advance Care Planning and Care Coordination for

Multipark infrastructure report form 2021

People with Parkinson's Disease and Their Family Caregivers – Study Protocol for a Multicentre, Randomized Controlled Trial. *Front Neurol* 5;12:673893.

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.

Hjalte F, Norlin JM, Kellerborg K, Odin P. (2021) A register-based study of resource use and costs in Parkinson's disease. *Acta Neurol Scand* doi: 10.1111/ane.13502.

Norlin JM, Kellerborg K, Odin P (2021) Patient utilities in health states based on Hoehn and Yahr and off-time in Parkinson's disease – A register-based study in 1823 observations in Sweden. *Pharmacoeconomics* doi: 10.1007/s40273-021-01056-z.

Antonini A, Odin P, Pahwa R, Aldred J, Alobaidi A, Jalundhwala YJ, Kukreja P, Bergmann L, Inguva S, Bao Y, Chaudhuri KR (2021) The Long-term Impact of Levodopa-Carbidopa Intestinal Gel on „Off“-time in Patients with Advanced Parkinson's Disease: A Systematic Review. *Adv Ther* 38(6):2854-90.

Mulroy E, Ilinca A, Gonzalez-Robles C, Magrinelli F, Puschmann A, Bhatia KP. Throat-clearing vocalisations in primary brain calcification syndromes. *Mov Disord Clin Pract*, accepted.

Prudencio M, Garcia-Moreno H, Jansen-West KR, Al-Shaikh H, Gendron TF, Heckman MG, Spiegel MR, Carlomagno Y, Daugherty LM, Song Y, Dunmore JA, Byron N, Oskarsson B, Nicholson KA, Staff NP, Gorcenco S, Puschmann A, Lemos J, Januário C, LeDoux MS, Friedman JS, Polke J, Labrum R, Shakkottai V, McLoughlin HS, Paulson HL, Konno T, Onodera O, Ikeuchi T, Tada M, Kakit A, John FD, Ataxia Study Group, Wszolek ZK, Giunti P, Petrucelli L. Towards allele-specific targeting therapy and pharmacodynamic biomarker for spinocerebellar ataxia 3. *Sci Transl Med*. 2020 Oct 21;12(566):eabb7086.

Victorin K, Puschmann A. Myoclonus-dystonia (DYT11, DYT-SGCE) - a channelopathy? *Neurol Neurochir Pol*. 2020;54:3-5.

Ilinca A, Martinez-Majander N, Samuelsson S, Piccinelli P, Truve K, Cole J, Kittner S, Soller M, Kristoffersson U, Tatlisumak T, Puschmann A, Putaala J, Lindgren A. Whole-Exome Sequencing in 22 Young Ischemic Stroke Patients With Familial Clustering of Stroke. *Stroke*. 2020;51:1056-63.

Gorcenco S, Vaz FM, Tracewska-Siemiatkowska 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.

Ygland E, van Westen D, Englund E, Rademakers R, Wszolek ZK, Nilsson K, Nilsson C, Landqvist Waldo M, Alafuzoff I, Hansson O, Gustafson L, Puschmann A. Slowly progressive dementia caused by MAPT R406W mutations: longitudinal report on a new kindred and systematic review. *Alzheimers Res Ther*. 2018;10:2.

Quadri M, Mandemakers W, Grochowska MM, Masius R, Geut H, Fabrizio E, Breedveld GJ, Kuipers D, Minneboo M, Vergouw LJM, Carreras Mascaró A, Yonova-Doing E, Simons E, Zhao T, Di Fonzo AB, Chang HC, Parchi P, Melis M, Correia Guedes L, Crisculo C, Thomas A, Brouwer RWW, Heijtsman D, Ingrassia AMT, Calandra Buonauro G, Rood JP, Capellari S, Rozemuller AJ, Sarchioto M, Fen Chien H, Vanacore N, Olgiaiti S, Wu-Chou YH, Yeh TH, Boon AJW, Hoogers SE, Ghazvini M, AS IJ, van IWFJ, Onofri M, Barone P, Nicholl DJ, Puschmann A, De Mari M, Kievit AJ, Barbosa E, De Michele G, Majoor-Krakauer D, van Swieten JC, de Jong FJ, Ferreira JJ, Cossu G, Lu CS, Meco G, Cortelli P, van de Berg WDJ, Bonifati V, International Parkinsonism Genetics N. LRP10 genetic variants in familial Parkinson's disease and dementia with Lewy bodies: a genome-wide linkage and sequencing study. *Lancet Neurol*. 2018;17:597-608.

Davidsson J, Puschmann A, Tedgard U, Bryder D, Nilsson L, Cammenga J. SAMD9 and SAMD9L in inherited predisposition to ataxia, pancytopenia, and myeloid malignancies. *Leukemia*. 2018;32:1106-15.

Eggertsen G, Puschmann A, Hall S, Warne AK, Kvorning O, Olin M, Eriksson M, Bjorkhem I. Tidig diagnos och behandling med gallsyra avgörande vid cerebrotendinös xantomatos. *Lakartidningen*. 2018;115.

Published Meeting Abstracts:

Multipark infrastructure report form 2021

Nilsson K, Puschmann A. Disappearance of familiarly aggregated paralysis agitans in subsequent generations: a 135-year follow up study. *Parkinsonism Relat Disord.* 2020;79:e27.

Ygland Rödström E, Puschmann A. Long term outcome of Parkinson's disease and validation of a new clinical classification system. *Parkinsonism Relat Disord.* 2020;79:e35-e36.

Gorcenco S, Karremo C, Kafantari E, Puschmann A. Ataxia project in Scania, Sweden: Study outline and current status. *Parkinsonism Relat Disord.* 2020;79:e112.

Almasoudi W, Nilsson C, Puschmann A. Co-occurrence of leukoencephalopathy with ataxia and SPG56 in one family. *Parkinsonism Relat Disord.* 2020;79:e112-e113.

Tesi B, Davidsson J, Voss M, Rahikkala E, Holmes T, Chiang S, Komulainen-Ebrahim J, Gorcenco S, Nilsson AR, Ripperger T, Kokkonen H, Bryder D, Fioretos T, Henter J, Mottonen M, Niinimäki R, Nilsson L, Pronk CJ, Puschmann A, Qian H, Uusimaa J, Moilanen J, Tedgård U, Cammenga J, Bryceson YT. Gain-of-function SAMD9L mutations cause a syndrome with cytopenia, myelodysplastic syndrome, immunodeficiency and neurological disease. *Eur J Hum Genet.* 2018;26:315-6.

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