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Utvärdering av Svenska Parkinsonakademien

I enlighet med överenskommelse översänder vi externa utvärderingar av Svenska Parkinsonakademien vid Skånes universitetssjukhus. Utvärderingarna är gjorda av prof Heinz Reichmann, Dresden, prof Angelo Antonini, Padua, samt prof Ray Chaudhury, London.

Utvärderingarna innehåller följande områden:

1. SPAs bakgrund och historia
2. Vetenskaplig kvalitet
3. Samarbeten
4. Extern kommunikation
5. Personal
6. Organisation och ledarskap
7. Tillfört värde

Om ni har några frågor kring utvärderingarna så hör gärna av er per mail eller telefon.

Med vänliga hälsningar

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Evaluation of the Swedish Parkinson Academy, SPA



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Background and History

Parkinson's disease (PD) is the second most common neurodegenerative disease. It is estimated that in Germany 400 000 and in Sweden 20 000 people suffering from PD. The prevalence is increasing and it has been calculated that there will be 20% more PD patients in 2025. The most common age to develop the motor symptoms defining PD is 55-70 years (about 75%), but we also see some patients who are younger than 40. PD is not only a major burden for the patients and caregivers but also for the economy. From literature I learnt that in Sweden the yearly (direct + indirect) costs for PD are around 2 billion SEK (about 200 million Euro).

For this reason it is extremely important to have a center of excellence for diagnosis and treatment of PD in Sweden. With this respect, Lund University has a national and international front-line position concerning PD-related research. It was the Nobel laureate, Professor Arvid Carlsson, who described dopamine as a neurotransmitter related to PD. Soon after these eminent insights into pathophysiology of PD the focus changed to fetal cell transplantation as a method for repair in the brain, led by professors Anders Björklund and Olle Lindvall. In a time when such treatment caused a lot of ethical concern, it was the integrity of these Swedish researchers and neurologists that resulted in substantial international attention. Presently, about 150 scientists work on PD-related projects at Lund University, most of these in experimental neuroscience.

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Many of the experimental research projects performed in Lund have a clear clinical relevance and the potentials for translational research projects is strong. This concerns: 1. Projects aiming for understanding the molecular background and pathobiochemistry and pathophysiology of the disease 2. Projects on wet (blood, CSF) and imaging biomarkers for PD. 3. Projects aiming for stem cell-based therapies for PD 4. Projects on gene therapy based interventions in PD. 5. Projects aiming for new symptomatic and disease-modifying pharmacological therapies for PD.

The Swedish Parkinson Academy, SPA

According to the internet and colleagues from Lund University, the formal decision to start the Swedish Parkinson Academy, SPA (<http://www.skane.se/default.aspx?id=201929>) was made by the Lund University Hospital Director Dr. Bent Christensen on December 13th, 2006. This was a joint initiative from the Medical Faculty at Lund University, the Lund University Hospital and the Swedish Parkinson Association (Svenska Parkinsonförbundet). The main aim with SPA is to develop and support a strong clinical PD research platform, making it possible to perform internationally leading translational and clinical PD research projects in Lund. This concerns projects aiming both for sophisticated methods for detection and diagnosis of PD, as well as, new symptomatic and disease-modifying therapies. A further aim with SPA is to support Lund in improving Parkinson care and research on a national level in Sweden; this includes education and information about the disease, as well as stimulating research collaboration between Swedish Universities and other institutions involved in PD related research.

The establishment and the continued activity of SPA has been made possible through a continuous and generous support from the Olle Engkvist foundation (Stiftelsen Olle Engkvist Byggnästartare, OEB), starting in March 2007. I learnt that OEB has supported SPA with 20 million SEK since 2007. SPA has also received economic support for its central activities from the Swedish Research Council (Vetenskapsrådet, VR), The Swedish Parkinson Foundation (Parkinsonfonden), AFA insurance, Prins Carl Gustafs Stiftelse and a number of pharmaceutical/pharmacotechnical industries, including Solvay, Abbott/AbbVie, Boehringer Ingelheim, Boston Scientific, Britannia, General Electric Health, Global Kinetics, GSK, Lundbeck, Medtronic, Nordic Infucare and UCB. Thus, it is obvious that it was an extremely good decision to create SPA as an incubator for top-notch PD research. It is also noteworthy, that individual scientific projects supported from SPA, have received substantial further support from a large number of sources, including the European Union, which further underlines the high quality of funded researches and their projects.

Scientific Quality

SPA gives a substantial support to PD-related translational and clinical research at the Lund University Hospital. This is done in mainly two ways: 1. Establishment of a clinical PD research platform, including Parkinson research nurses and project coordinator. This platform can be used by all participating investigators. 2. Support of individual projects, mainly through financing research positions and research time for clinical scientists.

PD research platform

The clinical research platform is optimized for translational PD studies, but also suitable for clinical research projects, both non-commercial and commercial. The platform is presently located at the outpatient and day-care unit at the Department of Neurology at Skåne University Hospital. The platform provides all investigators with 5 full-time Parkinson research nurses. The allocation of study nurses is done by the SPA steering group. In most instances the investigators have to co-finance the nurses with about 50%. It was reported that so far all applications for research time could be granted. The steering committee plans to add a research neurologist to the platform. In addition, professional support for statistical planning and evaluation of clinical studies is provided. With respect to this a close collaboration with the Department of Clinical Sciences at the University is implemented. The platform also provides all tools, such as validated scales, for objective and quantitative assessment of PD patients. This also included electronic diaries, systems for movement analysis (the PKG and PLM systems), as well as video documentation of patient investigations with possibility for blinded evaluation. Thus the Department of Neurology is in the best position to participate with all clinical and translational studies, both commercial and non-commercial.

Support of individual research projects

SPA supports individual translational and clinical research projects with a research nurse and also by paying partly for junior staff members, sometimes also for senior scientists. I had the chance to evaluate and learn about one of many research projects:

Biomarkers: Associate professor Oskar Hansson and his research group run projects aiming for improved possibilities for early and precise diagnosis of Parkinsonism, using both wet biomarkers (in CSF and blood) and imaging biomarkers. In the frame of the Swedish Bio-FINDER study they have included more than 300 Parkinson patients and 400 controls in these projects. The group is front-line also internationally in this area and have produced a large number of publications in the last years (see enclosed annual reports).

In addition there are many more excellent projects such as the one on neural cell transplantation by Prof. Håkan Widner and Associate professor Gesine Paul-Visse. Lund has a world-leading role in this research area, where proof of principle has been shown in single patients, where substantial long-term clinical improvement was documented

Gene therapy based treatments are coordinated by Dr. Carl Rosenblad and are closely related with previous work by Prof. Anders Björklund and his research groups. It is intended to perform the first clinical studies in 2016.

Continuous drug delivery (CDD) is one of the main domains for which Prof. Per Odin and his group are well-known. Presently their work concerns mapping of effects and improvement of methodology and is performed in international collaborations. Prof. Odin is a highly respected neurologist and has the talent to motivate national and international collaborations with an extremely impressive publication record. Another field of interest of Prof. Odin are non-motor symptoms. Again, he collaborates with many international colleagues and academic institutions.

As a side-note, I am fully aware that these examples are just the tip of the ice-berg, because there are so many more excellent and national and international well-known groups.

Collaborations

Within the Lund environment about 150 scientists are working with projects related to Parkinson's disease. Two important research networks in this environment are BAGADILICO (<http://www.med.lu.se/bagadilico>) and Multipark (<http://www.med.lu.se/multipark>). BAGADILICO supports and organizes research related to Parkinson's and Huntington's diseases and has a strong focus on experimental neuroscience. Multipark supports and organizes research related to Parkinson's disease and other neurodegenerative diseases. SPA has an excellent collaboration both with BAGADILICO and Multipark. All organisations are represented in each other's boards/steering groups and many research activities are co-sponsored. Parkinson's disease is regarded as a prime research area both from the University Hospital and Lund University.

Also on the national level, SPA is well known and well integrated. SPA has made it possible for Lund to host Sweden's Parkinson research network, SWEPAR-net (Chair: Prof. Per Odin, Lund). SWEPAR links all Swedish University departments for Neurology and Neurosurgery, as well as, a number of experimental research groups with activities related to PD. With the help of this consortium clinical and translational research (Duodopa vs. DBS; comparing different apomorphine preparations, PKG system to monitor motor fluctuations) SWEPAR is also scientifically responsible for setting up a Swedish Parkinson Patient registry, ParkReg. ParkReg, which is up and running since 2 years, presently have data on 1800 Swedish PD patients, who are followed up yearly. SPA has made it possible to have the network secretariat also for ParkReg in Lund (coordinator: Dr Sven Pålhagen, Lund). Furthermore, SPA has a close interactions with the Swedish patient organisations, especially The Swedish Parkinson Association (Parkinsonförbundet). SPA also has regular communication with the Swedish Health Authorities, especially the Board of Health and

Welfare (Socialstyrelsen). Several SPA board members are engaged in the development of National Guidelines for Parkinson's disease.

On an international level, Lund is well integrated in European and Global Neuroscience, not least concerning Parkinson's disease, with a large number of collaborations. SPA is instrumental in supporting international exchange and collaboration such as financing invitations of foreign scientists to Lund and supporting travels from Lund to other centres and international congresses.

External communication

SPA has contributed to extensive educational activities in Lund and over the rest of Sweden. This included conferences, symposia, lectures, courses and production of written and computer-based educational material. This included paramedicals, nurses, and physicians. Six to eight times per year SPA organizes "Forum Parkinson Lundense" where we invite leading international PD scientists for lectures and scientific discussions. Since 2009 SPA has organized seven 2-day courses for doctors, nurses and paramedics on different aspects of PD. A special highlight was the involvement of SPA in 2014 into the local organization of the International Congress on Parkinson's disease and Movement Disorders in Stockholm (4500 participants from 86 countries, 196 lectures and 1558 posters over 5 days). SPA has been hosting international educational meetings on pump treatments in advanced PD in collaboration with AbbVie over several years; from 2016 this type of pump education will take place in collaboration with the International Parkinson and Movement Disorder Society, MDS.

SPA also provides the network secretariat for the Swedish Movement Disorder society, SWEMODIS (www.swemodis.se; Chair: Prof. Håkan Widner, Lund; Coordinator: Ulrika Mundt-Petersen, Lund). SWEMODIS is responsible for the Swedish national guidelines for Parkinson's disease. SWEMODIS is also a central partner when the Swedish Board of Health and Welfare now develop evidence-based national guidelines for PD in Sweden and several persons from SPA are involved as experts in this process (Per Odin is chair of the scientific committee, Sven Pålhagen is chair of the priority committee).

SPA also provides the network secretariat for the Scandinavian Movement Disorder Society, ScandMODIS (www.scandmodis.org; Chair: Prof. Per Odin, Lund; Coordinator: Ulrika Mundt-Petersen, Lund). ScandMODIS is responsible for Scandinavian guidelines on advanced PD therapies.

Participating personnel

Ulrika Mundt-Petersen is coordinator for SPA. The principal investigators linked to SPA come from the Dept of Neurology, Lund (Sara Hall, Oskar Hansson, Olle Lindvall, Christer Nilsson, Per Odin, Gesine Paul-Visse, Sven Pålhagen, Andreas Puschmann, Carl Rosenblad, Ruben Smith, Yulia Surova, Håkan Widner, Klas Wictorin), Dept of Neurosurgery, Lund (Hjalmar Bjartmarz, Stig Rehncrona, Anna-Lena Törnqvist), the Memory Clinic, Malmö (Oskar Hansson, Elisabeth Londos) and Dept of Health Sciences, Lund (Susanne Iwarsson, Maria Nilsson). Additionally, a large number of doctoral students are connected.

Organisation and Leadership

SPA is formally organized under the Director of Research within the Division for Research and Development at Skåne University Hospital. SPA has recently got the status of a permanent activity within the hospital. The activities within SPA are regulated by

its statutes. Decisions on activities within SPA are made in the steering group, which consists of the following members: Per Odin (Chair of SPA; Neurology, Skåne University hospital), Ingemar Petersson (Director of Research, Skåne University Hospital), Hjálmar Bjartmarz (Neurosurgery, Skåne University hospital), Angela Cenci Nilsson (Lund University), Peter Hagell (Kristianstad University), Susanna Lindvall (Parkinson foundation), Maria H Nilsson (Lund University), Gensine Paul--Visse (Neurology, Skåne University hospital), Andreas Puschmann (Neurology, Skåne University hospital), Klas Victorin (Neurology, Skåne University hospital), Håkan Widner (Neurology, Skåne University hospital). The steering group meets 4 times per year and at demand. The steering group makes decision on SPAs strategy, its economy and shall also be involved in recruiting qualified personnel to SPA's activities.

Final Evaluation

As outlined above SPA has had a strong and important impact Lund University and especially on Neuroscience and patient care at the Department of Neurology. With the existence of SPA international exchange programs could be established and excellent collaborations could be built up. This and the outstanding clinical research and patient care makes Lund a special place for PD and neuroscience as a whole. Remarkable contributions in the field of transplantation, stem cell research and therapy, pre-motor and non-motor symptoms and especially treatment in the advanced stage of PD were fostered by the establishment of SPA. The steering committee has succeeded in supporting the best and by that enlarged the number of scientists and clinicians which finally allows top-notch quality. Based on the infrastructure of SPA also the support and partially establishment of SWEMODIS, ScandMODIS, SWEPAR and the Swedish Parkinson patient registry. This has put Lund University in the centre of clinical and scientific Parkinson-activities in Sweden and Scandinavia. As a reviewer from abroad I can only congratulate SPA of all achievements which started by giving the leadership into good hands and having a committee with foresight and visions. Thus, SPA has become a leading catalyst for excellency in Movement Disorders.



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Venice, January 18th, 2016

Evaluation of the Swedish Parkinson Academy and it's activities

1. Background and History

The Swedish Parkinson Academy (SPA) was started in 2006 with the objective to develop a clinical platform enabling the University of Lund to lead and perform international research projects with clinical and translational relevance in Parkinson disease. The focus of the research was improvement of methods to detect Parkinson disease and develop new disease modifying and symptomatic therapies.

Moreover, an important aim was to improve patient care, develop information material for patients and stimulate research collaborations between Swedish universities. So far a number of pharmaceutical companies and industries have contributed to the Swedish Parkinson Academy and additional funding has been provided through research projects funded by The European Union.

SPA objectives are fully in line with the historical research focus of the University of Lund and further expanded the project spectrum by directly involving the patient association in the decision algorithm and therefore facilitating its translation into clinical practice.

2. Scientific quality

SPA supports Parkinson research at the University of Lund by the establishment of a clinical research platform with five full-time PD research nurses and a project coordinator available for investigators based on their projects and the amount of financial support. In addition financial support is provided to specific projects.

The ongoing projects are of high scientific content and have already produced a large number of publications in high quality journals.

One of the projects is on biomarkers and focuses on CSF, blood and imaging for the detection of Parkinson. This has so far more than 300 patients and controls included.

The Neural Cell Transplantation consists of a number of individual subprojects aiming at establishing methodology for brain repair through transplantation of embryonic dopaminergic neurons. Other projects concern the development of new medications as well as improving the methods of deep brain stimulation and particularly developing new electrodes which should ameliorate the efficacy of this treatment strategy. Finally additional projects are



on the genetic causes Parkinson, on rehabilitation, non-motor symptoms, pharmacoeconomic evaluations and continuous drug delivery including pump therapies.

The scientific content of these activities is excellent as well as the number of publications. Given the fact that several key projects have entered into their operational phase it is critical that adequate support is provided.

3. Collaboration

SPA has collaborations with a number of scientific research institutions and networks, many international. The network called "Bagladilico" supports and organizes research in the Parkinson and Huntington disease with focus on neuroscience. The network "Multipark" supports research related to Parkinson and other neurodegenerative diseases.

Both these networks are very important and can provide excellent research. Their activities should be further strengthened.

4. External Communication

The Swedish Parkinson Academy has organized a number of conferences, symposia lectures, courses and produced educational material. The Swedish Parkinson Academy provides support for both the Swedish movement disorder society as well as the Scandinavian movement disorder society.

5. Participating personnel

The personnel is adequate considering the large number of activities.

6. Organisation and leadership

SPA has an efficient organization and recently received a permanent status within the University of Lund. Its leadership is evident from the numerous research and educational projects and represents an added value in the field of neuroscience.

Global evaluation

SPA has made an important contribution to the academic and research activities at the University of Lund and increased its international visibility and leadership. The university is now host of a number of networks and coordinates several research projects which





are not only on basic science but contain very important translational aspects. Further support is therefore highly recommended in the interest also of the many patients with Parkinson disease that look at SPA and at the University of Lund with great hope.

Yours sincerely,



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12.02.2016

Re: external evaluation of the Swedish Parkinson Academy, SPA

Dear Per,

Thank you for asking me to provide an external assessment report on the activities (clinical and research) of the Swedish Parkinson Academy, SPA.

My feedback and report is as follows and takes into account the various research activities that have been undertaken under its premise.

1. Background and history:

The programme of the Swedish Parkinson Academy, SPA (<http://www.skane.se/default.aspx?id=201929>) was started by the Lund University Hospital director Dr. Bent Christensen on 13. December 2006, this being a joint initiative of the Medical Faculty at Lund University, the Lund University Hospital and the Swedish Parkinson Association (Svenska Parkinsonförbundet). The main aim of the SPA is to develop and support aspects of credible, strong and noteworthy clinical PD research and development in Lund which can translate to a major research force nationally as well as internationally. Translational and clinical PD research projects addressing improved methods for detection and diagnosis of the Parkinson's syndrome as well as developments in new symptomatic aspects of disease-modifying therapies, a key unmet need, were developed and continue to flourish. In addition, the SPA is also focussed on improving Parkinson care at a national level in Sweden via education and information about Parkinson's disease (PD) and fostering increasing research collaboration between Swedish Universities as well other institutions and universities involved in PD related research. This important programme has been made possible through a continuing and generous support from the Olle Engkvist foundation (Stiftelsen Olle Engkvist

Byggmästare, OEB), which started in March 2007. Such a generous donation to such a worthy cause should act as a pathfinder for other relevant foundations.

The importance of the support of the Olle Engkvist foundation:

The support from the Olle Engkvist foundation allows the SPA to support a range of PD-related translational projects which have made significant advances to the field of PD. In addition there is also a strong focus on clinical research at the Lund University Hospital which has also gained international acclaim. The latter research focus addresses:

1. Establishment of a clinical PD research platform, with a multi-disciplinary setup including leading the way in Sweden for development of and maintaining pivotal roles of Parkinson research nurses and also supporting the key role of a project coordinator, which is central to seamless working and research applications initiated by all investigators within the remit of SPA.
2. The SPA has also continued to support high quality peer reviewed individual projects, by financing research costs of salaries, consumables, travel as well as other directly and indirectly incurred costs.

2. Activity Base and resources:

The current clinical research platform is mainly aimed towards translational PD studies, while also encompassing high quality clinical research projects, non-commercial as well as pivotal commercial trials. The research is based mainly in an outpatient based resource as well as day-care units located at the Skåne university hospital department of Neurology. The resource base currently is supporting 5 full-time Parkinson's research nurses who share workload of the funded studies. The individual scientists and principle investigators (PI) are made to apply for research nurse time for their projects to a steering group of SPA which makes a decision re funding based on the merit of the projects.

The PI's would co-finance the nurse time that is unfunded thereafter from their own sources. This mechanism thus ensures that all good and relevant projects receive funding, at least in part. Additionally, a research neurologist is planned to be added to the central group so as to enhance clinical and commercial research delivery. The research setup would also allow support for statistical planning and evaluation of clinical studies. This venture is made possible by an active collaboration with the Department of clinical sciences at the University. This doubles up in a role of a CRO, which could help the establishment of study protocols, development of case report forms (CRF's) as well as to allow monitoring of studies.

Additional resources available include a repository of objective and quantitative assessment of PD patients, including validated scales (in English and Swedish), electronic diaries, systems for movement analysis (the Parkinson's KinetoGraph (PKG) and periodic leg movement (PLM) systems), as well as video documentation of investigational processes.

Currently, the SPA Lund research platform is supporting 6 non-commercial studies.

3. Scientific quality of the applications:

The scientific quality of the application continues to be outstanding, internationally known as well as translational in benefit. Work has focussed on biomarkers for PD, and associate professor Oskar Hansson's group are addressing the ways for precise

accurate and early diagnostic markers of Parkinsonism, using both wet tissue based biomarkers (in CSF and blood) as well as imaging techniques in the Swedish BioFINDER study. This ongoing important study has now included over 300 Parkinson patients and 400 controls and several high quality publications have resulted. In practice the group has now performed approximately 300 magnetic resonance (MR) brain scans, with dual MRI scans in 80 patients. The analysis has focussed on specific pathways in the brain using an advanced MRI technique known as spherical deconvolution, which has shown relevant pathway's atrophy in atypical variants of Parkinson's disease. Resting state functional MRI (fMRI), which is another advanced MR technique, has shown an under-stimulation of the thalamus. The data have been reported in Plos One as well as at the AD/PD conference in Nice in March 2015.

Iron metabolism has also been investigated using two new methods, diffusion kurtosis imaging and susceptibility weighted imaging, and early results indicate high iron deposition in PD in the substantia nigra and the rubral nucleus compared with healthy individuals, and furthermore, iron deposits correlate with the duration of disease. The findings may have major potential therapeutic potential in relation to response variation to treatment in PD.

The group has also collaborated with Professor Omar El-Agnaf and studies the toxic oligomeric form of the clumped/aggregated alpha-synuclein in the cerebrospinal fluid showing increased levels in PD with dementia compared with healthy people as well as patients with Alzheimer's. This finding could therefore pave the way for early diagnosis in PD dementia.

Daniel Lindqvist, a specialty registrar, post-doctoral researcher has continued to work with Oskar Hansson and others exploring biomarkers and aspects of non motor symptoms in PD. A specific focus has been on substances that stimulate new blood vessel growth (angiogenes) and cognitive, as well as motor symptoms of PD. His findings suggest that angiogene markers are higher in PD and PD with dementia, and that higher levels of this marker could correlate with gait difficulties, postural intolerance as well as a damage to the blood brain barrier.

Other key areas of major research enterprise have included:

Work of the group of Gesine Paul-Visse, which has focussed on the regenerative properties of adult stem cells, in various neurological diseases including strokes as well as inflammation. The findings have been published and additionally the group has characterised a new mouse model that may mimic early PD, a key unmet need.

The work has been translated to a clinical study investigating a novel growth factor as a potential treatment for PD. An international multi-centre study will start in 2015-2016, the study being co-financed by the EU, and Lund is the principal and coordinating centre. In addition there is already an ongoing transplantation study in which the clinical group is addressing the safety and the effect of transplantation of fetal dopaminergic cells in patients who are in the early phase of Parkinson's disease (Transeuro, www.transeuro.org.uk).

The project "Home and Health in People Ageing with Parkinson's Disease: a Prospective Longitudinal Cohort Survey Study" is novel and initiated by Maria Nilsson who is the Principal Investigator (PI). The programme combines merged different research methodology (neurology, health and care sciences, rehabilitation and gerontology) and addresses complex interaction between health aspects in PD, home

stay and environmental factors with a focus on Parkinson's-specific gait and balance issues (falls and fear of falling).

Professor Peter Hagell addresses patient related outcomes, novel developments of health related quality of life tools as well as comparative work on methods for measuring key NMS such as fatigue.

Professor Per Odin has led a number of highly relevant and internationally recognised studies addressing development of delivery systems for advanced therapies in PD as well as NMS of PD. His group's work has continued work related to on characterising advanced therapies for Parkinson's disease, focussing on infusion of L-dopa/carbidopa gel intraduodenally (Duodopa) as well as subcutaneous apomorphine. He was part of the first randomised, controlled study (data published in Lancet Neurology) confirming the efficacy of continuous dopaminergic therapy in (1) management of hyperactivity (dyskinesia), (2) the health economics aspects of pump therapy (Walter and Odin, 2014) and (3) the first ever comparative analysis of the motor and non motor effects of Apomorphine and Duodopa (Euroinf study). He is also actively participated in various task forces who have produced a (1) systematic survey article on advanced therapies (Volkman et al., 2013), (2) completed a renewal of the third edition of a textbook on apomorphine therapy (Hagell and Odin, 2014) as well as (3) led an international consortium, the NAVIGATE PD, the recommendations of which have just been published.

Research from the group of Per Odin has also focussed in non-motor aspects of PD and he has played a key part in a published major European multicentre study which addressed the problems and rates of PD patients waking with an "off" period when they are often unable to move, have pain, are depressed and have little motivation for the day (Rizos et al., 2014). He has also taken part in another European study addressing withdrawal effects of dopaminergic drugs in PD while another study focuses on the global quality of life for Parkinson's patients – with an aim to optimise the care and treatment of patients to ensure quality of life is as good as possible.

The CLASP (Care of Late Stage Parkinsonism) project. A doctoral student, physiotherapist Kristina Rosqvist, is working on the CLASP project for her thesis

Prof Per Odin and group also started the Swedish Parkinson Research Network, SWEPAR in 2010 with Ulrika Mundt-Petersen heading up the network's secretariat. The SWEPAR is instrumental in devising and developing a novel randomised multi-centre trial comparing Duodopa treatment and deep brain stimulation in advanced Parkinson's disease.

Other activities include setting up and continuation of the National Parkinson's Patient Registry since 2009, (first in world) supported by Sweden's municipalities and county councils (SKL), NeuralCell Transplantation techniques (Prof Widner), Gene therapy based treatments (Dr. Carl Rosenblad), new techniques of deep brain stimulation in PD (Dr. Hjalmar Bjartmarz, Anna-Lena Törnqvist and Prof. Jens Schouenborg), Neuronano Research Center in Lund, and evidence-based rehabilitation for PD.

The above reflects the powerful diversity of research projects, as well as a strong translational element.

4. Collaboration

The key to the success of the research collaborations have been a flourishing success of collaborations at a local, national and international level. At a local level for instance Dr. Sven Pålhagen has been engaged at the Swedish Parkinson Academy in a collaboration with MultiPark at Lund University (www.med.lu.se/multipark) since September 2011. Collaborations included the European Parkinson's Disease Association (EPDA), study groups of the Movement Disorder Society (MDS) (Prof Odin is a steering committee member of the Non-Motor PD Study Group), the European Union, as well as a flourishing contact with the Industry which has underpinned ventures such as the Navigate PD project.

Collaborations also included the BAGADILICO (<http://www.med.lu.se/bagadilico>) which supports and organizes research related to Parkinson's and Huntington's disease particularly experimental neuroscience and Multipark (<http://www.med.lu.se/multipark>). The SWEPAR-net is chaired by Prof. Per Odin, and links all Swedish University Departments for Neurology and Neurosurgery. The Swedish Parkinson Patient registry, ParkReg, is also a collaborative venture and currently includes data on 1800 Swedish PD patients with longitudinal follow up coordinated by Dr Sven Pålhagen, Lund.

5. External Communication

The external recognition of the research programme is evidenced by the extensive basic sciences, clinical and multidisciplinary contacts of the research staff, the range of peer reviewed international publication and roles in educational and research advisory committee of the personnel.

Educational courses and seminars are regularly held inviting key opinion leaders from across the world. A key forum is the "Forum Parkinson Lundense". Since 2009 SPA has organized seven 2-day courses for health care professionals and specifically in 2014 the SPA was involved in the local organisation of the successful annual meeting of the International Congress on Parkinson's disease and Movement Disorders in Stockholm (4500 participants from 86 countries attended).

6. Participating personnel

This is a well set unit and research platform coordinated by Ulrika Mundt-Petersen and hosting 5 PD nurses, a number of high calibre PI's from an multi-speciality background (neuroscience, neurosurgery, health sciences, psychiatry). There is clear evidence for excellent team work, data sharing as well as clinical translation.

6. Organisation and leadership

The setup of the organisation is transparent and well governed. The SPA is formally organized under the Directorate of Research within the Division for Research and Development at Skåne University Hospital as well as being recently awarded the status of a permanent activity within the hospital. There are clear terms of references.

7. Added value

The projects funded through this initiative have led to development, initiation, completion of several cutting edge and leading research projects which have continued to champion the pioneering and leading role of Lund University in the field of basic and clinical Parkinson's research. The evidence rests in developments of animal models, biomarker strategies, translational and genetic therapies, key advances in the field of non-motor research in PD, a major unmet need in addition to restorative, homecare therapies, rehabilitation and a development of multi disciplinary and quality of life focused research strategies.

The collaborative and research links along with clinical input has enabled Lund University to also be involved in the widely recommended development of new evidence-based national guidelines for PD in Sweden.

An international educational programme as well as involvement of key stakeholders from across Europe and USA as well as Asian programmes (via the MDS non-motor PD study group) further underpins the strategic and key importance of this research platform and in my view should be supported in all forms.

Yours sincerely



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