MINUTES

Present: Victor McConvey, Elaine Book, Gila Bronner, Siok Bee Tan, Mariella Graziano, Vicki Segro, Ruth Hagestuen, Maria Elisa Pimentel Piemonte, and John Dean

Staff Liaison: Samantha Surillo

Background & Agenda

• Twenty individuals, from across the globe, holding Health Professional roles in the Movement Disorders and/or Parkinson’s disease (PD) community were invited to participate in the MDS HP SIG Leadership Basecamp Meeting (online).

• Participants were given 72 hours to submit feedback and suggestions to agenda items put forth by the Chair.

• The Chair requested Individuals provide feedback, from their unique perspectives / roles in the community, by addressing the following topics for Multi-disciplinary care in Parkinson’s:

  I. What Models of Multi or interdisciplinary care are there?
  II. How do people access specialist teams?
     - Social models of care (Free service E.g. via a National Health Service) or privately funded?
  III. Do all people have access to a specialist Movement Disorder Team (MDT)?
  IV. Are there regional differences as to who is in the MDT? What disciplines are in the teams?
  V. How do people find a skilled team and how could we increase the ability of people to access skilled health care professionals? Would tools like https://www.partnersinparkinsons.org/find-movement-disorder-specialist be useful if extended to HP’s?
  VI. What are some ideas or themes you would like the group to consider exploring regarding Young onset PD? Ideas and themes put forth may be used as framework for a base camp meeting later in the year.

• The intent of the Meeting was to provide a focused discussion surrounding Multi-disciplinary care in Parkinson’s disease.
Letter from the Chair & Meeting Summary

Dear Colleagues,

I would like to thank everyone whom participated in this meeting for your time and insightful input provided via Basecamp. The rich conversation that took place over the 72-hours dedicated to this meeting has identified an increasing importance for Health professional roles in supporting people living with movement disorders.

The global conversation in the following pages identifies some important and common points:

- The practice environment influences the services that are available, with variance related to geographic location, insurance and socio economic variables.

- The environment shapes the model of care and who is in the multi-disciplinary team.

- There are some capacity issues affecting access to Health Professionals and a need to increase knowledge of movement disorders amongst more Health care Professionals (considering the increase in incidence of Parkinson’s disease globally).

- There are multiple models of Multi-Disciplinary Team (MDT) care available, globally, which is very encouraging; however, less encouraging is that there is often limitation in the ability to access health professionals.

- An increasing need for individuals to navigate health care systems themselves and advocate for their own care- identifying a need to be health literate, confident, and resilient enough to do this.

- An increasing need for consumers to be provided with the tools to find appropriate professionals.

From this meeting, the Health Professional Special Interest Group (HP SIG) of the International Parkinson and Movement Disorder Society (MDS) was able to identify the true value and roles Health Professionals play in providing multi-disciplinary care for people with Parkinson’s disease.

With the aim of supporting growth and increased services for people living with Movement Disorders, the MDS HP SIG also identified a need to gather further evidence to support the growing importance for HPs to be included in the Multi-disciplinary approach (both in regards to patient care and economical terms).

The information collected within the 72-hour basecamp meeting also has some potential to form the basis of a white paper calling for more investigation and investment into the health professionals and team approaches.

Lastly, some of the true value of the following conversations is the insight it has provided into different models of delivery of Multi-disciplinary care, and provides a starting point for more conversation, sharing and collaboration.

With best regards, Victor

Victor M McConvey, RN, MACN
Chair, Health Professional Special Interest Group (HP SIG)
International Parkinson and Movement Disorder Society (MDS)

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Welcome & Introduction

The Meeting started with the International Secretariat welcoming group members to the discussion board and notifying all the discussion was now open on Basecamp to submit feedback.

Health professionals whom participated in the online Basecamp meeting practice in locations such as Vancouver, BC, Canada; Ramat-Gan, Israel; Singapore; Sao Paulo, Brazil; Esch-Sur-Alzette, Luxembourg; and various locations across the United States, such as Englewood, CO; Minnetonka, MN; and Boulder, CO.

Professional roles of Participants consisted of: Clinical Social worker; Sex therapist/specialist; Deputy Director of Nursing in Advanced Parkinson’s Disease; Professor of Physiotherapy; Nurse Practitioners (NP); Directors of Foundations such as the Davis Finney and National Parkinson’s; as well as practitioners in Physiotherapy (PT) and Speech Language Pathology (SLP).

The following is a synopsis of discussions, cumulatively, across the 72-hour meeting period.

Comments and Feedback

I. Models of Multi or Interdisciplinary Care

Elaine Book initiated discussions, noting there are many models of multi and interdisciplinary care in Parkinson’s disease (PD) just in British Columbia, as well as most of Canada at large.

Siok-Bee Tan noted, in Singapore, their clinics currently only offer People with Parkinson’s (PwPs) care from Movement Disorder neurologists, Nurse Specialists, and other allied Health Care Professionals (HCPs), such as Physiotherapists. When needs for other HCPs or social workers arise, referrals are typically made outside the clinic. In the future, they are planning to start a one-stop service centre, however.

Vicki Segro, working in a private practice in Englewood, CO, USA, noted while they have “advanced-” or “palliative care” clinics available for advanced disease patients whom may require interdisciplinary care, they more often refer PwPs to specialists individually based upon their needs, and have a good group of professionals across disciplines whom take most insurances.

John Dean, shared his experience from Boulder, CO, USA noting while he does not currently work in an interdisciplinary environment, he has developed a number of networks of interdisciplinary rehab teams for Life Care Centers of America using a model gleaned largely from the Dutch ParkinsonNet program and relying heavily on training from the Allied Team Training Programs (ATTP).

John suggested there may be a bit of a “final mile” issue with sustaining interdisciplinary teams in the United States; highlighting Vicki Segro’s program as only one of just two interdisciplinary Parkinson’s programs in Colorado that has a truly full contingency of an interdisciplinary team. Furthermore, both programs are just 10 miles of the other in the greater downtown Denver Metropolitan area. John identified how Vicki’s team includes a movement disorders specialist, among services from rehabilitation, psychology/neuropsychology, social work, and other specialists.

John emphasized, while there are other movement disorder specialists in Colorado, most typically work as solo practices or within a larger neurology practice, tending to refer services out to other HCPs that specialize in rehab or therapy services.

Maria Elisa Pimentel Piemonte mentioned the Brazil Parkinson Association, which is the largest patient association in the country, has an inter professional team of its own which is composed of a Physiotherapist (PT), Speech Therapist (ST), psychologist, nutritionist, physical trainer, dentist, music therapist, and art therapist. The team interacts well and even offers some transdisciplinary interventions, such as “senior dance,” which is an activity planned and guided by a PT and Psychologist. Similarly, at the University of Sao Paulo-Brazil, Dr. Piemonte works on an inter professional team with a PT, ST, and an Occupational Therapist (OT). Often times, some therapies are pursued via a transdisciplinary model following an evaluation utilizing the International Classification of Functioning, Disability and Health (ICF) framework. The majority of people with PD in both public services are typically in the intermediate stage of the disease, while in most private practices throughout Brazil, the uni-disciplinary approach is predominant.
Individuals of the HP SIG agreed that team models or approaches could highly depend on any of the following:

- Need (for) or availability (of) allied health / specialist care / expertise / resources;
- Differing ways in which team members may work together (varying from consultative to team-care planning with goal setting and follow-up);
- Region of the world (and even country);
- Varying Health Care Systems; among other challenges.

Ruth Hagestuen reiterated that models of care can vary greatly from one location to another – both regionally and internationally, adding that variabilities in uniqueness of each location can even have an impact on how care strategies may be organized.

Participants agreed and identified the following disciplines as common to an interdisciplinary team, regardless of location:

- Movement Disorder Specialists;
- Neurologists;
- Nurses (Varying from: Specialist; Clinical; Practitioner; Registered; to Advanced Practice);
- Physical/ Physio Therapists;
- Occupational Therapists;
- Speech / Language Pathologists;
- Social Workers (occasionally); and even
- Psychologists / Neuropsychologists

Other disciplines participants identified, which may occasionally be seen on the team (but not widely so), include:

- Neurosurgeons;
- Sex Therapists;
- Music Therapists;
- Dieticians;
- Pharmacists;
- Psychiatrists;
- Chaplains; among
- Others

Group members agreed on the importance for rehabilitation professionals to be included within the interdisciplinary team and identified the following evolving trends for interdisciplinary care of PD and other Movement Disorders:

- Telemedicine
- Teams developing specialized interdisciplinary or inter professional clinics (for different stages or age groups)
- Establishing Advanced Care clinics
- Creating Palliative Care Teams
- Creation of specialized programs and strategies for newly diagnosed and early onset PD
- Involving wellness initiatives
- Including well-organized educational programs as part of integrative approach to comprehensive care
- Formation of Competitive landscapes (i.e. once one clinic is established, others tend to pop up near the area to compete)
- Including components that incorporate local subacute and skilled nursing facilities; and
- Providing internal training for Parkinson’s and interdisciplinary care
Group members identified the following difficulties or challenges faced when establishing a successful interdisciplinary team:

- Establishing a balanced level of collaboration within the team
- Replicating the level of collaboration that occurs within successful interdisciplinary teams
- Getting the right leadership, advocacy, and a large enough network to move things forward
- Identifying Leadership that will champion and manage the team and ultimately push things forward
- Keeping programs or momentum of interdisciplinary teams once leadership changes or moves on
- Working in an Open-system, where quality of training, and clinicians providing the services is not fully controlled (unlike Kaiser Permanente, which is a closed-system and well-controlled)
- Replicating Kaiser Permanente’s (in Netherlands) program within an uncontrolled system in the USA

John shared some goals the group may consider when developing networks of Interdisciplinary teams:

- Have patients continue to see their movement disorders specialists; while also
- Seeing other clinicians at outpatient clinics based within skilled nursing facilities (which can also serve as subacute rehabilitation)
- Keeping or establishing ongoing therapy / care near to the patient

Group members identified the awareness of the following interdisciplinary models, among other international models not mentioned:

- NPF Centres of Excellence (CoE) - as a Gold Standard;
- Dutch ParkinsonNet;
- Kaiser Permanente in the USA (replicated Dutch-model, with assistance from Dutch professionals);
- Park Nicollet Struthers Parkinson’s Center;
- TEAM PD Network, Oregon Health and Science University (OHSU);
- Allied Team Training Program (ATTP);
- Networks of interdisciplinary rehab teams, Life Care Centers of America;
- AMPARO;
- Brazil Parkinson Association; and
- various University-based movement disorders clinics throughout the USA

John highlighted Kaiser Permanente in particular, from both Southern California and the Netherlands, where membership in Parkinson as a clinician is well controlled (intentionally) in order to provide and maintain a balanced level of appropriate-client load and clinician availability for patients.

John identified other programs underway or explored in the past that have merit:

- Expanding success of Kaiser Permanente (Southern California) to Northern California, led by Suketu Khandhar;
- (Informal) Ad hoc network for clinicians to refer throughout North Carolina, led by Dr. Nina Browner of the University of North Carolina

John took a moment to explain that although he believes the NPF CoEs and many other university-based movement disorders clinics around the country are top level programs, providing excellent care, he feels that doesn’t always trickle down to many of the regions of the country where people with Parkinson’s are living. John addressed this concern by suggesting tele-practice may help alleviate that issue in the future, but for the near future, it may be a good approach perhaps to find a way to direct referrals to clinicians outside of these facilities, whom also provide excellent care (and are geographically convenient for the care recipient).
II. How People Access Specialist Teams: free social models, private funding, and other access approaches

Elaine, mentioned throughout British Columbia (BC), as well as most of Canada, it is typical for teams or interdisciplinary care models to be publicly funded.

Siok-Bee informed the group, in Singapore, individuals are able to access specialist teams through private funding or free social models of care, such as the National Health Service; noting there are also private and restructured government centres, and even government subsidies for individuals unable to afford health care.

Mariella Graziano chimed in, stating in Luxembourg, they also have social models of care or private funding similar to what Siok-Bee identified. Mariella went on further to state that more and more people access specialist teams via the internet, which raises an issue whether people are consulting a reliable source or not; noting if the patient is guided by the National Health or Private Insurances, they’re more likely to be pointed to a good source.

Vicki identified that access to specialists in Colorado, USA is based upon availability of the specialist (often requiring advanced booking for new patient evaluations) as well as the type of insurance accepted. Vicki also mentioned that Colorado has a privately funded non-profit with a list of movement disorder specialists available for people to locate specialists.

Dr. Piemonte noted that non-profit associations in Brazil typically offer lists with names and addresses of Neurologists, PTs, OTs and other specialists in PD. However, most of these professionals work in private practices solely, where multi or trans-disciplinary approaches are relied on less.

III. Do all people have access to Movement Disorder Specialist teams?

As Elaine previously mentioned, in BC, Canada, care is typically publicly funded, which makes it available to all people; however, access for some can be challenging or prohibitive as it often depends on their location within each province. Another challenge for individuals accessing these teams in BC can be long waitlists and generally only annual appointments with Neurologists while being able to see Allied Health Professionals throughout the year.

Siok-Bee mentioned, considering the Social models of care available in Singapore, most people with Parkinson’s have access to a Movement Disorder team, with a small population following up with Geriatricians or other Specialists.

While Mariella previously identified similarities with Singapore’s social models of care, she noted in Luxembourg, not all people have access to a specialist MDT, unlike Singapore. Mariella illustrated, however, there may be considerations that telemedicine might solve difference in the near future.

Vicki identified that similar to Luxembourg, not all individuals in CO, USA have access to MDTs, and typically, the Parkinson’s Association of the Rockies only encourages people to see PD specialists if they are already connected to the non-profit organization. Vicki went on further, stating there seems to be a reluctance for general neurologists to refer patients out to PD specialists, raising the idea that perhaps it is more likely due to financial implications than any other reason.

Ruth chimed in that although not universally true, rural areas in particular tend to lack access to movement disorder specialists and MDTs. Ruth went on to note that interestingly, there are a number of interprofessional MDTs developing, even in the aforementioned rural areas. However, reiterating John’s earlier points - this is often only as a result of motivated leadership, professional and community partnerships, or university systems working within a community to progressively build such capacity.

Dr. Piemonte identified that even in the most developed (and wealthiest) cities of Brazil, few people have access to a specialist team, noting that some rehabilitation centres and universities have specialist MDTs, though the waiting time to
start treatment can be very long, similar to the scenario Vicki described where access is limited due to requirements of advanced appointments.

### IV. Regional Differences and Similarities: Disciplines within the Movement Disorders Teams (MDT)

Group members proceeded to identify differences and similarities within the Movement Disorders team, by Discipline, across different areas of the world; comments have been organized by MDS regional section.

#### Pan American Section

**Sao Paulo, Brazil**

Dr. Piemonte informed the group that Brazil is divided into five regions, which has important differences in terms of social-economic development. Dr. Piemonte works in Sao Paulo city, which is in the Southeast-most developed region of Brazil, where opportunities are better in comparison with the 4-lesser developed regions of the country. As can be seen in other countries, it was reiterated that significant differences occur within the country of Brazil, where region to region MDTs can vary drastically. Even more so, in Brazil, there is a larger network called AMPARO (https://amparo.numec.prp.usp.br/) which takes the MDT a step further by bringing together PwPs, families and caregivers of PwPs, as well as professionals interested in PD in order to improve the interprofessional care across all of Brazil, regardless of region.

**British Colombia, Canada**

Disciplines within teams of this location were described as tending not to be determined by region so much as funding sources, noting Registered Nurses (RNs) and Physical Therapists (PTs) are often funded first, followed by SWs; where outsourcing to community resources such as SLPs and OTs are performed on an as needed basis.

**United States (USA) as a ‘Whole’**

It was highlighted how in some rural areas, Movement Disorders specialists are quite limited and the ratio of specialists to those in need can be quite drastic or even non-existent; where underserved areas such as Wyoming or Utah are lacking access to specialists due to their geographic location and limited to no specialists even residing in those states. It was noted that although Kansas, Nebraska, and Colorado all have excellent programs, they are often limited to the metropolitan statistical areas, which highlights a significant disparity in quality of care that is largely engendered by the distance necessary to travel for expertise within States across the USA.

**Colorado, USA**

It was described that, even within the state of Colorado, regional differences exist based on specialists’ level of experience and bank of knowledge; where some neurosurgeons perform DBS implants regardless of pursuing a comprehensive evaluation with a Neuropsychology specialist while other centres provide excellent care undergoing aforementioned consultation. Others in the group agreed that level of experience/knowledge, in itself, is a good description of regional challenges regarding access to care and differences from regional to even region within the US (or other countries).

**Minnesota, USA**

Movement Disorders core teams were identified as ideally consisting of a Neurologist (often including a NP), Nurse, PT, OT, SLP, SW, and Psychologists. The most common staffing problem identified, regarding this core group (on an outpatient basis) is having available funding for nurses and SWs. Despite the common rationale and wide-recognition that both these disciplines play an important and essential role within the interdisciplinary team, it was suggested that more work needs to be done to document the value of each discipline as part of the Parkinson’s disease and MDTs. Other disciplines some MDTs have been able to include are music therapists, dietitians, pharmacists, chaplains, among others.

#### Asian & Oceanian Section

**Singapore**

It was described, while private hospitals may not have MDTs, most restructured government hospitals do have individuals across most disciplines, such as: Neurologists, Nurses (Advanced Practice and Specialist), Therapists (Physio-, Speech, and Occupational), Psychologists, Social Workers, as well as Pharmacists to serve the PD community.
Israel
The group was informed about the format of two multidisciplinary centres Gila Bronner works at as a Sex Therapist in Israel: the Tel-Aviv and Sheba Medical Center(s). Gila informed the group, at both centres, she works with other Health Professionals and Physician staff in two capacities: phone counselling or personal-professional intervention directly with the person seeking treatment. Similarly, cases that are more complicated are discussed at staff meetings for either centre, where most specialists from all disciplines treating PD are a part of the team meeting.

Luxembourg
It was identified that a standard MDT in this location would mostly contain disciplines such as neurologists, nurses, neurosurgeons, physio- and speech therapists, and may sometimes have OTs join the team as well; with presence from specialties outside the aforementioned depending on funding as well as availability of specialized professionals.

Mariella pointed out how some entities or centres may even consider themselves MDTs, having specific knowledge in PD, but perhaps the full expertise is not yet developed or up-to-date based on the current standards elsewhere. Mariella highlighted how this identifies the need to raise awareness and encourage continuous training, while establishing a base guideline of requirements in order for an entity to self-identify as a MDT. Mariella went on to suggest that MDS would be a good platform to develop this guideline and address the issue mentioned.

V. Locating and Increasing visibility of skilled PD care across Disciplines of Health Care Professionals (HCPs)

Elaine suggested starting with increasing Value awareness of having HCPs on the patient’s team; noting that perhaps tools such as the Movement Disorder Specialist / Physician Finder with ‘Partners in Parkinson’s’ may be great to expand to including HCPs. Siok-Bee seconded Elaine’s thoughts, asking the group if they also believed tools such the Finder may be useful if extended to HCPs across disciplines (https://www.partnersinparkinsons.org/find-movement-disorder-specialist#).

Siok-Bee noted the advantage it would present for all entities involved to have a common platform to access Parkinson’s information across disciplines, including for Private specialists whom may not have MDT to support their patients or be aware of individuals to refer patients to for further care outside their own specialty.

John agreed with both Elaine and Siok-Bee, noting the advantage he sees in expanding the Finder to HCPs, but can see why not all may agree. John elaborated further on the counter argument, highlighting how if you are a movement disorder physician, you are likely vetted by a third-party and almost guaranteed to have expertise. This does not mean, however, that HCP practitioners don’t receive proper training, as ATTP LSVT, PWR!, among other programs may perhaps serve as, at bare minimum – a secondary resource to individuals experiencing care-accessibility issues.

The idea was raised that if practitioners of these programs like ATTP and LSVT were included, it may allow people in outlying regions to have access to rehab and other services without having to travel all the way down to a university program or CoE. It was highlighted that these types of considerations may be less burdensome on the person seeking 6-10 sessions of therapy over the course of a month, versus someone whom may only be traveling an hour to see a specialist every once in a while. It was added that many therapists also end up developing exercise programs and other classes in the region that can provide ongoing service at a much lower cost.

John suggested that the HP SIG consider if there may be a way to figure out how to accredit HCPs, and perhaps the HP SIG may be able to supplement it with discipline specific training (which may be a revenue source for MDS if produced as continuing education).

Vicki noted that surprisingly, some people look to social media – such as Facebook for information about skilled professionals, therefore it might be good for more local non-profits and national organizations to list these types of teams and become more tech savvy in order to do so.
VI. Ideas or Themes to Explore regarding Young Onset Parkinson’s Disease

Elaine offered the idea for special needs to be considered for partners of people with Young Onset Parkinson’s Disease (YOPD), as well as, the needs of the children, teens, and young adults within these families.

Siok-Bee noted how Parkinson’s is a long journey; thus, creating a friendly atmosphere with mutual trust among providers and receivers can lead to optimal care, therefore, it might be good for the group to consider exploring the psychosocial needs, and how to strengthen individuals’ coping abilities whom may be affected by YOPD.

Mariella noted her interest in YOPD and would encourage the HP SIG to explore the concept of self-management in YOPD as well as individualized strategies to cope in daily life and society.

Vicki stated her interest in the YOPD topic as well, noting that in Colorado, they have a group of actual YOPD patients whom act as an organized peer support network for newly diagnosed YOPD individuals, wherein many of her own patients will look to the internet for support as well. Vicki went on to note that a lot of support groups tend to not always be as helpful for YOPD people, as PD support groups can more commonly have many elders or elders leading the groups.

Dr. Piemonte added the topic idea of impact of PD on the participation domain, according to the ICF model; considering that young persons are in re-productive age, many times having children and a lot of responsibilities, the challenges imposed by PD under social aspects are very important for PwPs and their families. Another important topic Dr. Piemonte raised is strategies to improve the level of physical activity considering possible long-term neuroprotective effects.

Lastly, John raised the idea how the YOPD community may be more comfortable with technological solutions, which has potential opportunity for leveraging relatively inexpensive tech that could also reach the larger community. John went on to state as older generations with PD become more familiar and comfortable with tech, it presents a possible new vector to reach out to PD communities that are underserved (due to geographic limitations). John went on to suggest the group consider exploring tech as it relates to the YOPD community.

The Secretariat ended the meeting and thanked all for their thoughts and participation.

Meeting Adjourned.

Respectfully submitted,

Samantha Surillo
International Secretariat
MDS Health Professional Special Interest Group
International Parkinson and Movement Disorder Society (MDS)