



**International Parkinson and Movement Disorder Society (MDS)
MDS Neurosurgery Special Interest Group (SIG)**

MDS Neurosurgery SIG Meeting

20th International Congress of Parkinson's disease and Movement Disorders

Monday, June 20, 2016

From 14:00 – 15:00 (Local Berlin Time)

Berlin CityCube, Room M3

Berlin, Germany

PRESENT: Michael Okun; Ankur Butala; Kelly Mills; Zoltan Mari; Gabriel Arango;
Maria Fiorella Contarino; Gertrud Tamas; Francesca Morgante; Leo Verhagen;
Michel Panisset; Kelly Foote; Justin Hilliard; Karl Sillay; and Keyoumars Ashkan.

STAFF: Samantha Surillo

MEETING MINUTES

Call to Order and Introductory Remarks

The meeting came to order at 14:01. Karl Sillay initiated the meeting by dialing in remotely and welcoming those participating in Berlin, Germany.

I. Preliminary Results: DBS Survey

K. Sillay invited Ankur Butala and colleagues to lead the discussion on the DBS Survey they conducted, who in turn provided a brief synopsis of the following survey (See Attachment I), along with a PowerPoint outlining important findings (See Attachment II):

A Multi-Site Survey of Parkinson Disease Deep Brain Stimulation Center Best Practice: Moving Towards a Standard of Care for DBS (Ankur A. Butala, Kelly A. Mills, Peter Schmidt, Michael S. Okun, and Zoltan Mari) Attachment I.

A. Butala and colleagues identified this Survey's development as:

- Prompted due to a lack of data consensus availability regarding DBS Patients (in both referral as well as pre- and post-operative evaluation and management);
- A first step in clarifying real world best practices towards forming a standard of care for persons with Parkinson's disease (PD);
- A multi-disciplinary team approach, with the intent of trying to identify where to focus efforts to improve upon DBS;
- Trying to identify which practices are associated with improved outcomes (noting some tools in online trials could assist); and
- Evidence that performing a survey on a large scale can be possible.

Members of the SIG congratulated A. Butala (and colleagues) on the study's success, suggesting they consider relying on the Society's resources and support during continuation and expansion of the survey.

K. Ashkan offered for A. Butala and colleagues to connect with him regarding further development, as centres in the United Kingdom have already started collecting similar data through a National DBS Registry.

Challenges of the multicenter international DBS Survey identified by the SIG included:

- Obtaining and analyzing qualitative data;
- Keeping outcomes objective;
- Identifying and utilizing multiple like-minded centers to participate;
- Syncing processes across Centers;
- Finding hard outcomes to demonstrate potential value;
- Combining data across centers to show differences;
- Finding characteristics that can drive incentive to participate and apply to all.

SIG Members provided suggestions for A. Butala (and colleagues) to consider, which included:

- Requesting funding from MDS to collect data;
- Looking for projects focused on outcomes across the world (which would align with the public health system's practices);
- Focusing on also capturing patients' social integration and re-integrating into the Society (as current scales that capture that are not very good);
- Commissioning as an incentive driver (as it works well in the UK, with data requirements of centers).

The SIG discussed whether the process in the UK, now linking data collection, including outcome data, to funding may in some way inform the process here.

K. Mills acknowledged the differences in funding schemes worldwide and highlighted patient reported outcomes as being very important. He shared that in the United States, a DBS center with good outcome data and participating in such a project may have more opportunities for funding by the insurers.

How and what outcome measures to collect was considered as another challenge. Members of the SIG referenced similar studies performed that have come close to determining a standard, but have not been completely successful:

- Bas Bloem's efforts in collecting multidisciplinary data and ensuring reliability; and
- Lars Timmerman's study, highlighting self-report by centers – showing that subjective measures could be useful.

Leo Verhagen stated the group would need to validate Patient Satisfaction scales. Others noted that Quality of Life (QoL) is something you do not typically see in a standard scale and something the patient values highly and would be able to inform-on. SIG Members agreed that adverse effects play a large part in determining patient satisfaction.

Other concerns regarding selection of participants mentioned by the group included:

- Flexibility in Selection;
 - Large vs. Small Hospitals;
 - Clinics specializing in DBS vs. Clinics offering a multitude of services

- Differences in Base Criterion (or lack thereof) from country to country; and
- Selections driven by individual economics.

K. Ashkan highlighted factors related to patient satisfaction derived from his experience working in a large DBS centre (King's College Hospital) in the UK:

- Patient satisfaction should be a key driver for the service;
- Satisfaction is actually more related to expectation than the outcomes;
- It is therefore important to manage patient expectation pre-operatively;
- Having a DBS team which provide uniform information at multiple time points is key to improve patients' understanding of the procedure and rationalization of their expectation;
- At King's, patients have often met with five other staff members prior to seeing him as a surgeon and so are already well informed about the procedure, excited and ready to go;
- Things go smoother and surgery is easier to perform when all team members have communicated the same information.

K. Ashkan identified that having a coherent and effective team is perhaps more important than having a high volume practice to achieve good patient outcomes although a minimum number of cases per centre was probably appropriate. He added, sharing data with patient groups and having their involvement was invaluable in obtaining the patient's perspective.

K. Mills highlighted another limitation of the study in that the study did not address the surgical aspects. K. Ashkan stressed that it would be essential to have the involvement of the neurosurgeons in such studies/ surveys moving forward. M. Okun agreed that this would be essential in ensuring the success of such projects.

SIG Members encouraged A. Butala and colleagues to publish their findings, acknowledging the limitations of the study and perhaps combining it with a review of the literature.

II. DBS complications scale

M. Okun stated the SIG will need to work on something concrete in the near future, or the MDS International Executive Committee (IEC) will disband it.

Leo Verhagen, being an original member of the SIG, added that the Neurosurgery group started as a Task Force years back; and he would also like to see something concrete the group can work on that is do-able. K. Ashkan noted that he has a draft plan from 5 years ago of a project to develop "a DBS complication scale" the group focused on when initially formed, but it was never finalized.

K. Ashkan stated he would try to resurrect the complications scale as a lot went into the project but the project was never completed and this may have been a key reason for disheartening those members that left the group. K. Foote agreed and identified that surgically oriented projects such as reporting of complications scales are significant and would think it is important to have more neurosurgeons directly involved.

ACTION: *K. Ashkan will connect with the past chair of the Neurosurgery SIG (Joachim Krauss, 2009-2011), to obtain the previous documents on the complication scale and distribute to the current members of the group in order to move forward with projects. K. Ashkan will then connect with Marcello Merello for feedback.*

III. Coordination between ASSFN for future activities

M. Okun noted the International Parkinson and Movement Disorder Society (MDS) annual International Congress will be moved to the Fall Season starting September of 2018. Therefore, it will no longer conflict with the American Society of Stereotactic and Functional Neurosurgery's (ASSFN) Annual meeting which also typically occurs in June each year (similar to MDS).

SIG Members stated that, overall, the surgical community has not been greatly engaged with the MDS, so it would be good to promote such engagement once the ASSFN and MDS activities no longer overlap, starting 2018.

IV. New Leadership Appointment and Transition

K. Sillay then informed the group he will be transitioning out of leadership and remaining a member, with requests for nominations of the SIG Leader for 2016 onward.

- *K. Foote moves to nominate K. Ashkan in replacement of K. Sillay.*
- *M. Okun second's the nomination of K. Ashkan*
- *Motion: **Approved***

K. Ashkan thanks the group for the nomination and verbally accepts to serve as Chair.

ACTION: *The International Secretariat will request MDS leadership consider the Nomination of Keyoumars Ashkan to serve as Neurosurgery Chair going forward.*

V. New Business/Other Key Issues

SIG Members agreed that one of the groups' main action items should be to involve more neurosurgeons, neurosurgery issues, and more neurosurgery talks at the Congress. Members also agreed a strong effort should be placed on getting Neurosurgery professionals involved, chairing sessions and meetings and to become a part of MDS.

SIG members agreed the group should also be identifying those neurosurgeons attending future MDS meeting to ask them to attend/ join the SIG. As the Congress is very international, this is a great way to break down barriers. Getting a group of people from different countries in the SIG really helps to get the discussion going on every aspect of the practice; ideal for mutual learning.

Similarly, SIG Members agreed that individuals from other specialties outside neurosurgery who have an interest in surgical management of movement disorders should be encouraged to join the SIG. Currently, the consensus within the SIG is that the group lacks in diversity; therefore, all members agreed to push the diversity the membership to include neuropsychologists and Allied Health Professionals.

The question of having a "Terms of Reference" for the group was raised. K. Ashkan identified that the group does indeed already have a Terms of Reference, which he will forward to the International Secretariat to share with the group after Congress.

ACTION: *The group will discuss key ways to further engage Neurosurgeons and other professionals to integrate them into the Society. The International Secretariat will assist in coordinating this through the new SIG Leadership.*

VI. Adjourn

The Meeting adjourned at 14:59.

ATTACHMENTS: _____ (2)

- DBS Poster Attachment I
- PowerPoint Attachment II

Respectfully submitted by,

Samantha Surillo
MDS International Secretariat
Staff Liaison, MDS Neurosurgery SIG