

International Parkinson and Movement Disorder Society (MDS) Endorsed Parkinson's Disease Non-Motor Study Group

— K. Ray Chaudhuri, MD, FRCP, DSc, Chair, MDS Parkinson's Disease Non-Motor Study Group

Non-motor symptoms (NMS) of Parkinson's disease (PD) affect virtually every patient, and are the major cause for poor quality of life for both people with Parkinson's (PwP) and their caregivers. In spite, NMS are under-reported as often healthcare workers nor patients recognize them as symptoms of PD and treatment remains poor and quality of life progressively deteriorates. As a consequence, the burden of NMS represents one of the biggest challenges faced by health care professionals working with the PD community. This is also partly because focused research to understand the cause and progression of common NMS is scarce. Funding for non-motor issues as a whole in PD seldom receive priority compared to for instance, investigations of genetic causes of PD and the search for a cure.

While several strands of research has focused on individual NMS, such as cognition and depression and others on pre-motor aspects of PD, there is little research that has made the issue of NMS burden as a priority although this is what is reflected in what patients tell us and is the key issue in "real life". The MDS endorsed Parkinson's Disease Non-Motor Study Group (PD-NMSG) was formed in 2013 and aims to focus its research on NMS as a whole rather than a "piecemeal" approach and address some key unmet needs. The group, led by K. Ray Chaudhuri, has a significant track record in the field having developed MDS adopted tools such as the NMS Questionnaire, the Parkinson's Disease Sleep Scale, the NMS Scale, and key publications related to the impact of NMS burden on quality of life in PD as well as pathophysiology of poorly understood NMS such as fatigue, sleepiness and pain.

The group has now met twice: in Stockholm and at the recent San Diego MDS International Congress. Several teleconferences have taken place between the steering group members Anette Schrag, Dan Weintraub, Pablo Martinez-Martin, Angelo Antonini and Per Odin. The group has an overall membership of 20 members with a global representation and also representation from nursing/ allied health specialists and junior trainees in Movement Disorders (Anna Sauerbier, Milica Krannenberg, Haider Salimi Dafsari and Lisa Kllinghoefer, Roberto Erro). A membership form is used to elect interested members from MDS; however, at present membership of the group is full.

A web page for the group can be found on the MDS website, and in future the group would like to work to develop a full website linked from the PD-NMSG web page. A regular report of the group's activity is currently submitted for the review by the MDS officers and the International Executive Committee.

The key objectives and outputs of the group are underpinned by several work packages and the most significant is a six stage development of global validation of a new MDS-NMS scale based on the original NMSS, which was validated in 2007 and as such needed updating and signifi-



Members of the MDS PD-NMSG at the 19th International Congress in San Diego in June, 2015

cant revision. The pilot stages (1+2) of the MDS-NMSS has already been completed and having been funded by a grant from MDS after external peer review. Further funding for the stages 3-6 are being sought through MDS, as well as independent application to charitable funders and the industry. We hope members of MDS will assist in the global validation of the MDS-NMSS in the near future.

Another key work package is one related to pain in PD with Santiago Perez-Lloret, Michele Tinazzi, Alexandra Rizos and Pablo Martinez-Martin. Initial work has led to the publication of a novel pain scale (The Kings PD pain scale), the pilot study being funded by Parkinson's UK and pilot validation and field testing completed and published in *Movement Disorders* in 2015. A global study of use of KPP is planned, as is linguistic validation. A key trial addressing the first ever randomised placebo controlled trial in PD associated severe pain using oxycodone prolonged release with naloxone versus placebo has been completed and utilised the KPP as an outcome measure.

Other key work packages include deep brain stimulation in PD and NMS led by Lars Timmerman, and results of an open label European multicenter study has been reported and due to be published in *Brain Stimulation*. A related work package addressing infusional therapies and NMS led by Per Odin and Pablo Martinez-Martin has published the first ever comparative NMS data between apomorphine and levodopa infusion therapy (the Euroinf Study) in *Movement Disorders* in 2015 using the PD-NMSG network. Additionally, special research packages of the group is focusing on refining the concept of non-motor subtyping in PD and discovery of relevant markers and biomarkers and apply these to enriching populations selected for clinical trials for instance.



The PD-NMSG is also keen to ensure that there is true translational work to link advances in basic sciences to a tangible clinical benefit. As such work packages are also, where possible linked to animal model based studies, another key unmet need in the scientific unravelling of the mysteries of PD.

The MDS PD-NMSG would of course like to specially thank the support of Past-Presidents, Günther Deuschl and Matt Stern, current President, Oscar Gershanik, as well as valuable support from Liz Clausen at the MDS International Secretariat.

To spread the message of the importance of various aspects of NMS in PD the PD-NMSG has also organised international NMS based meetings mostly in Europe, the most recent being held in London in January 2015. This MDS supported meeting took place at the historic Great Hall and the Safra lecture theatre of King's College London UK, on the 23rd and 24th of January 2015.

The aim of the meeting was to focus on various aspects of non-motor Parkinson's, which remains a key unmet need in relation to diagnosis, recognition as well as treatment. This meeting, led by K. Ray Chaudhuri, King's College London, and supported by MDS and the MDS European Section (Olivier Rascol, France, and Angelo Antonini, Italy), hosted some of the leading opinion leaders in the field of non-motor research in Parkinson's disease from Europe with 21 lectures spread over a course of two days.

Steve Ford, Chief Executive of the foremost Parkinson's patient organization in the UK, opened the meeting along with Mark Richardson, the Vice Dean of Neuroscience, Kings College. The closing comments were provided by K. Ray Chaudhuri who also thanked all pharmaceutical support towards this meeting. The program consisted of a two-day event including 6 different sessions covering: (1) "Pre-motor Non-motor symptoms" chaired by Niall Quinn, UK; (2) "Non-motor subtyping" chaired by Davide Martino, UK; (3) "Biomarkers" chaired by K. Ray Chaudhuri (4) "Drug or Parkinson related non-motor symptoms" chaired by Michael Samuel, UK, and Niall Quinn. (5) "System based non-motor symptoms" chaired by Per Odin, Sweden and Fabrizio Stocchi, Italy (6) "Treatment" chaired by Angelo Antonini. Speakers included all of the above as well as Peter Jenner, UK; Alexander Storch, Germany; Claudia Trenkwalder, Germany; Anette Schrag, UK; Olivier Rascol, France; Fabrizio

Stocchi, Italy; David Brooks, UK; Antony Schapira, UK; and Paolo Barone, Italy. Over 250 participants, mostly from Europe but also from Asia attended the mini-congress. A similar meeting addressing tools for assessing non-motor symptoms of Parkinson's disease will be held in Madrid in March 2016.

MDS Endorsed PD-NMSG

Chair: K. Ray Chaudhuri

Steering Group: Daniel Weintraub, Anette Schrag, Pablo Martinez-Martin, Per Odin, Angelo Antonini

Co-coordinators: Alexandra Rizos, Anna Sauerbier

Members: Paolo Barone, David Brooks, Richard Brown, Peter Jenner, Beom Jeon, Kelly Lyons, Nicola Pavese, Anthony Schapira, Fabrizio Stocchi, Lars Timmermann, Yashio Tsuboi, Michele Tinazzi, Michele T.M. Hu, Davide Martino, Cristian Falup-Pecurariu, Alexander Storch, Marios Politis

Trainee/ Junior representation: Anna Sauerbier, Milica Krannenberg, Haider Salimi Dafsari, Roberto Erro, Lisa Killingelhofer

Nursing Representation/Advisors: Anne Martin, Miriam Parry