



International Parkinson and
Movement Disorder Society

2018 MDS Global and Regional Support Opportunities

July 2018

Industry partners enable the International Parkinson and Movement Disorder Society (MDS) to educate more than 11,000 physicians and other health care professionals each year. This prospectus shares the Society's upcoming educational and research activities, showing the range of MDS programming. We hope that you will identify those specific projects that will best forward your objectives.

Please contact Joel Rittle at +1 414-276-2145 or jrittle@movementdisorders.org with any questions or to receive additional information about courses in the development phase.

International Parkinson and Movement Disorder Society
555 East Wells Street, Suite 1100
Milwaukee, WI 53202 USA
Tel: +1 414-276-2145 Fax: +1 414-276-3349
E-mail: jrittle@movementdisorders.org

Opportunities at a Glance

Research Projects (Page 3):

- MDS Scale on Psychosis in Parkinson's disease
- Development of a Resource Utilization Questionnaire for Patients with Parkinson's Disease and Their Caregivers (MDS-RU-PD)
- Analysis of Non-English Translations of the MDS-Unified Parkinson's Disease Rating Scale (MDS-UPDRS)
- Development of the MDS-Non-Motor Symptoms Scale (MDS-NMSS)

Industry Resources on the MDS Website (Page 4)

MDS LEAP Program: International Leaders Program for Young Neurologists (Page 4)

Computer-based Education Programs (Page 4)

22nd International Congress of Parkinson's Disease and Movement Disorders (Page 4)

Regional Courses (Page 5):

Asian and Oceanian Section:

- Basic Science Summer School: Osaka, Japan, August 3-4, 2018
- MDS Neuroimaging Educational Course: Hong Kong, China, October 4, 2018
- School for Young Neurologists: Dubai, UAE, November 15-17, 2018

Africa:

- First MDS African School for Young Neurologists: Fundamentals of Movement Disorders

European Section:

- 2nd Summer School on Neuromodulation for Movement Disorders: Wurzburg, Germany, September 6-8, 2018
- Basic Neuroscience of Movement Disorders: Stockholm, Sweden, September 14-15, 2018
- Physiotherapy School: Torres Vedras, Portugal, September 14-16, 2018
- 2nd School for Nurses: Bridgend, Wales, November 2-4, 2018
- Movement Disorders in Children and Young Adults: Groningen, Netherlands, November 23-25, 2018
- Advanced Deep Brain Stimulation for Movement Disorders: London, United Kingdom, November 29-30, 2018

Pan-American Section:

- Allied Health Team Training for Parkinson's Disease and Other Movement Disorders: Puebla, Mexico, August 24-25, 2018
- MDS-PAS 1st Summer School on Neuromodulation for Movement Disorders: Ottawa, ON, Canada, September 7-8, 2018
- Neuroscience of Movement Disorders: San Diego, CA, USA, November 2, 2018
- Ataxias and Spastic Paraplegias: From Molecular Biology to Bedside and Treatment: Sao Paulo, Brazil, November 9-10, 2018
- MDS-PAS School for Young Neurologists: Lima, Peru, November 16-18, 2018

Research Projects

Society committees, task forces and special interest groups pursue projects to further the Movement Disorders field. Sponsors will be acknowledged on any articles published as a result of the project.

MDS Scale on Psychosis in Parkinson's disease

This study will develop a validated rating scale for Parkinson's disease Psychosis (PDP) employing best clinimetrics practices. Currently, we conceptualize this new scale as a severity measure; however, it may incorporate a diagnostic measure as well. Best clinimetrics practices include: using a modified Delphi approach and focus group methods for definition of the domains of importance and specific scale items to assess PDP; cognitive pretesting of potential items to identify problematic wording and logical structure at the item level; and assessment of reliability and validity of the assessment method at the scale level. To accomplish this goal, we propose the following study aims:

1. Identify the domains of interest and potential scale items that could be used to assess PDP.
2. Perform cognitive pretesting on the proposed scale items to determine clarity, comfort, and ease of use for raters and patients/caregivers in using the scale items.
3. Conduct clinimetrics investigations of the optimized rating scale and individual scale items for PDP in a cohort of patients demonstrating a range of psychotic symptoms.

Glenn Stebbins, Ph.D. of Rush University is the primary investigator of the two-year project. MDS is seeking \$500,000 for the initial steps of the project.

Development of a Resource Utilization Questionnaire for Patients with Parkinson's disease and Their Caregivers (MDS-RU-PD)

Currently no validated instrument/model exists to evaluate the resource use and costs associated with patients with Parkinson's disease. The data from different health economic evaluations and cost of illness studies vary considerably, limiting exact conclusions that can be drawn from such results. One reason for the considerable discrepancies in available cost data on Parkinson's disease, and in general, in the health economic literature stems from the methods for collecting data differ substantially within and between countries.

A team consisting of health economists, Movement Disorders specialists, psychologists, and statisticians with significant experience in their respective area will develop a new scale including medical, nonmedical, indirect and intangible costs. The scale will initially be developed and validated in German and English. The resulting scale will then be validated by trial in ten countries. Translation into additional languages is possible upon completion. The effort will be led by Prof. Richard Dodel of University Marburg and Dr. Anette Schrag of University College London. We are seeking a multiple funders for the project's total budget of \$820,000 USD.

Analysis of Non-English Translations of the MDS-Unified Parkinson's disease Rating Scale

The MDS-UPDRS was developed by the Society to be a comprehensive clinical rating scale covering motor and non-motor elements of Parkinson's disease (PD) and has been designated by the NIH Common Data Elements as the recommended scale for the overall assessment of PD. In the development of new treatments for PD, large-scale clinical trials are required by regulatory agencies. Most trials involve multiple countries and languages, and although originally written and tested in English, the clinimetric program for MDS-UPDRS includes a process to provide validated non-English translations for cross-cultural and cross-language clinical trials. To date, sixteen non-English versions are officially validated and nine other programs are in the testing stage.

By analyzing the official non-English translations of the MDS-UPDRS, this project will identify different translation "packages" which provide the best combination of languages and subject demographics to

decrease measurement error and increase sensitivity to change. It will also provide a data-driven set of specific guidelines for researchers using the MDS-UPDRS on how to resolve inadvertent missing values without loss of useful total scores of each part of the MDS-UPDRS. This project is led by Sheng Lou, PhD (University of Texas); Nancy LaPelle (University of Massachusetts); Pablo Martinez-Martin (Carlos III Institute of Health); and Christopher Goetz, MD and Glenn Stebbins, PhD (Rush University). We are seeking a single funder for the project's total budget of \$100,000 USD.

Development of the MDS–Non-Motor Symptoms Scale (MDS-NMSS)

MDS is seeking to revise the NMSS Scale developed in 2006. Taking into account:

1. The use of NMSS in clinical trials and clinical practice.
2. The experience of clinical raters who have used the NMSS in relation to the use of individual questions contained within the NMSS.
3. Feedback from patient groups in relation to the use of NMSS in “real life.”
4. Experience of correlation of NMSS items flagged in NMS questionnaire (NMSQ).

Based on this review, a revised scale will be written in English and translated to Italian, German and Spanish. The scale will be tested on a total of 735 participants at 9 sites in 7 countries.

This project is led by K. Ray Chaudhuri (King's College Hospital), Pablo Martinez-Martin (Carlos III Institute of Health), Anette Schrag (Royal Free and University College), and Dan Weintraub (University of Pennsylvania). We are seeking multiple funders towards the project's total budget of \$425,000 USD.

Industry Resources on the MDS Website

Reach physicians, researchers or patients by placing an educational resource on the Industry Resources page of the MDS website. Examples include referral criteria and tools or clinical trial results. We are seeking multiple sponsors at \$50,000 USD each to include their resource for one year.

MDS LEAP Program: International Leaders Program for Young Neurologists

The LEAP Program supports the growth, development and success of young movement disorder specialists while preparing them to contribute to the goals and objectives of MDS. We will accomplish this by teaching the principles of leadership to twelve young movement disorder specialists across the globe and pairing them with a mentor. We are seeking multiple funders at \$10,000-\$20,000 USD each.

Web-Based Education

Web-based education programs enable participants to receive Continuing Medical Education (CME) credit while learning from leading clinicians without leaving their home or office. MDS members may take modules without cost as a member benefit and non-members may purchase individual sessions. We are seeking multiple funders at \$10,000 or more. Sponsors will be acknowledged on marketing materials and the web-based education program homepage.

22nd International Congress on Parkinson's Disease and Movement Disorders

The 22nd International Congress on Parkinson's Disease and Movement Disorders will occur October 5-9, 2018 in Hong Kong. Sponsorship, advertising and exhibiting information is available on the Congress website (www.mdscongress.org).

Regional Courses (sorted by date)

Basic Science School:

Osaka, Japan, August 3-4, 2018

Stockholm, Sweden, September 13-15, 2018

These courses will confront the next generation of Basic Scientists and Young Clinicians with the latest advances of preclinical disciplines in Movement Disorders. The goal of these courses is to create a common language to generate ideas that will allow the development of new translational projects developed by the next generation of researchers in movement disorders during morning lectures and afternoon group discussion sections.

- The intended audience is Young General Neurologists, Young Movement Disorder Specialists, Graduate Students, Post-doctoral Students and Junior Scientists all younger than 40 years old.
- We anticipate 60 participants.
- Support is sought from multiple sponsors in the amount of \$5,000 or more each.

Allied Health Team Training for Parkinson's Disease and Other Movement Disorders, Puebla, Mexico, August 24-25, 2018

The Allied Health Team Training for Parkinson's disease is a three-day course designed by the International Parkinson and Movement Disorder Society Pan American Section (MDS-PAS) to increase knowledge about Parkinson's disease, to build capacity for comprehensive inter-professional care in the treatment of PD. An interdisciplinary faculty of senior movement disorder specialists will teach this program. Over the three day course, many topics such as an introduction to the disability of Parkinson's disease from medical to social approaches related to the Latin American perspective, advocacy of patients living with PD, the different aspects that limit self-determination as in, eating, communication, sleep, cognitive issues, and how different technologies used to improve a better way of living can actually limit daily functions will be covered.

- The intended audience is nurses, physical therapists, occupational therapists, speech language pathologists, social workers, psychologists, neurologists and general physician's assistants, the majority of whom already have some experience with the management of Parkinson's disease and are interested in further education and collaboration.
- We anticipate 100 participants.
- Support is sought from multiple sponsors in the amount of \$5,000 or more each.

2nd Summer School on Neuromodulation for Movement Disorders, Wurzburg, Germany, September 6-8, 2018

This course provides an overview on neuromodulation techniques with hands-on sessions, in particular concerning deep brain stimulation (DBS). Students will attend lectures and panel discussions with question and answer sessions in the morning. They will also see an online DBS surgery. In the afternoon, attendees will have the opportunity to see how the surgical trajectories and neurophysiology recordings are made, how to select surgical candidates, and how to examine them. Students will also see how to program and follow real patients with DBS, and engage in a constructive discussion with the international experts.

- The intended audience is: Neurologists, Neurosurgeons, Nurses and other Health Professionals.
- We anticipate 40 participants.
- Support is sought from multiple sponsors in the amount of \$5,000 or more each.

MDS-PAS 1st Summer School on Neuromodulation for Movement Disorders, Ottawa, ON, Canada, September 7-8, 2018

The 1st MDS-PAS School on Neuromodulation for Movement Disorders will provide a unique opportunity for neurologists, neurosurgeons, nurses, psychiatrists, neuropsychologists, and other health allied personnel to receive an overview on current neuromodulation techniques with a particular emphasis on hands-on teaching with live patients and real time programming sessions. Topics will focus on all aspects of this surgical modality for Parkinson's disease, dystonia, and tremor.

- The intended audience is: Neurologists, Neurosurgeons, Nurses and other Health Professionals.
- We anticipate 40 participants.
- Support is sought from multiple sponsors in the amount of \$20,000 or more each.

Physiotherapy School: Torres Vedras, Portugal, September 14-16, 2018

The Physiotherapy Summer School is a two and a half day course and the educational objectives are intended to improve the evaluation, clinical reasoning and treatment skills of graduated physiotherapists in order to optimize the delivery of exercise programs for patients with Parkinson's disease and related disorders.

- The intended audience is aimed at qualified Physiotherapists who want to specialize in treating patients with Parkinson's disease or atypical Parkinsonism.
- We anticipate 40 participants.
- Support is sought from multiple sponsors in the amount of \$1,500 or more each.

MDS Neuroimaging Educational Course, Hong Kong, October 4, 2018

This course has been conceived in light of the work being conducted by the MDS Neuroimaging Study Group. The course will give an opportunity for scientists and clinicians to be upskilled on the latest advances in the field of Neuroimaging across multi-modal techniques. The meeting will be conducted as a series of lectures but there is good opportunity both during the meeting but also at the subsequent MDS congress for cross-fertilization and collaboration.

- The intended audience is Neurologists and other physicians managing Parkinson's and related conditions as well as Basic Scientists across neurodegeneration, imaging, physics, engineering, and radiochemistry.
- We anticipate 200 participants.
- Support is sought from multiple sponsors in the amount of \$5,000 or more each.

Neuroscience of Movement Disorders 2018 – San Diego, CA, USA, November 2, 2018

This course plans to translate the research of Parkinson's disease to blend with clinical aspects to create a common language between researchers and clinicians. This will occur by bringing experts to speak on the pathology, etiology, neurodegenerative and neuroprotective mechanisms of Parkinson's disease and other Movement Disorders along with new translational approaches to understanding and treating PD and other Movement Disorders.

- The target audience for this course is Basic and Translational Scientists, including Graduate Students, Postdocs and Faculty.
- We anticipate 50 participants.
- Support is sought from multiple sponsors in the amount of \$5,000 or more each.

2nd Summer School for Nurses: Bridgend, Wales, November 2-4, 2018

The MDS-European Section Summer School for Nurses is a hands-on educational opportunity for nurses in Europe who work within a neurology setting and are interested in specializing in Parkinson's disease. Participants will receive in-depth instruction from UK Parkinson's Disease Nurse Specialists, and other expert professionals in Movement Disorders. Students will attend lectures and panel discussions with question and answer sessions, and will have the opportunity to examine patients with Parkinson's disease. They will learn how to manage motor and non-motor symptoms of Parkinson's disease through the four stages of the disease trajectory. Students will present their own case-studies to small groups for discussion and critique, and will be involved in group presentations and case discussions.

- The intended audience are Nurses who work in a neurology setting and are interested in specializing in Parkinson's disease.
- We anticipate 48 participants.
- Support is sought from multiple sponsors in the amount of \$2,500 or more each.

Ataxias and Spastic Paraplegias: From Molecular Biology to Bed Side and Treatment: Sao Paulo, Brazil, November 9-10, 2018

Hereditary ataxias and spastic paraplegias are complex genetic disorders. The knowledge, information and concepts have expanded and evolved substantially during the past few years. The advances have established a solid base to potential therapeutic approaches.

This course will discuss clinical manifestations, physiopathology, rehabilitation, genetic aspects, management, as well as future directions in the field of ataxias and spastic paraplegias. This will be an interactive course with audience participation and patient videos on clinical cases.

- The intended audience are Medical Doctors, physiotherapists, speech therapists, physiatrists, medical students, allied health professionals
- We anticipate 100 participants.
- Support is sought from multiple sponsors in the amount of \$2,500 or more each.

School for Young Neurologists:

Dubai, United Arab Emirates, November 15-17, 2018

Lima, Peru, November 16-18, 2018

Cairo, Egypt, January 17-19, 2019

The course is an opportunity for Young Neurologists to receive in-depth instruction from internationally-recognized Movement Disorders experts and increase general enthusiasm for Movement Disorders as an exciting discipline in the field of neurology. Students will present their own case-study videos to small groups for discussion and critique, and will be involved in group presentations and case discussions.

Topics will focus on Parkinsonism, Hyperkinetic disorders and complex issues in Movement Disorders.

- The intended audience is Young Neurologists within five years of completion of general neurological training who are interested in specializing in Movement Disorders and Young Neurologists who are already enrolled in Movement Disorders training.
- We anticipate 30-58 participants per session.
- Support is sought from multiple sponsors in the amount of \$5,000 or more each.

Movement Disorders in Children and Young Adults, Groningen, Netherlands, November 23-25, 2018

“Movement Disorders in Children and Adolescents” features an internationally renowned faculty of clinicians who will present on the challenged of young-onset movement disorders in clinical practice. For clinicians the three main practical questions are: what do we see (phenotyping), what is the cause (etiology) and subsequently, what is the optimal treatment? Phenotyping comprises classification of the movement disorder type, but also the evaluation of other neurological and systemic features. The first day’s sessions will highlight the clinical spectrum of involuntary movements ranging from physiological movements to movement disorders. The second day focusses on etiology including genetic and acquired causes. At the end of the day different treatment options are discussed including DBS. During the two days course several patients will be presented ‘live’ in a ‘grand round’ format.

- We anticipate 75 participants who are movement disorder specialists, functional neurosurgeons, nurse practitioners, and trainees who are already involved in management of movement disorders in pediatric and adolescents.
- Support is sought from multiple sponsors in the amount of \$5,000 or more each.

Advanced Deep Brain Stimulation for Movement Disorders: London, United Kingdom, November 29-30 2018

Deep Brain Stimulation (DBS) has been proven an effective treatment for Parkinson’s disease and dystonia in over 150,000 patients worldwide. As such, general neurologists will be increasingly confronted with the management of these surgical patients, who suffer from chronic neurological conditions, thus requiring lifelong care. The course will focus on standards of care in the preoperative, intraoperative and post-operative patient management, a comparison of programming options in different DBS devices, advanced

programming options including visualized programming tools, and troubleshooting for failed DBS surgery and various therapy related adverse effects.

- The intended audience is Movement Disorder specialists, functional neurosurgeons, nurse practitioners, and trainees who are already involved in the selection, intra- or postoperative management of patients with movement disorders (tremor, dystonia, Parkinson's disease, etc.) treated by deep brain stimulation surgery and want to strengthen their knowledge in this field.
- We anticipate 50 participants.
- Support is sought from multiple sponsors in the amount of \$10,000 or more each.