



## Motor Symptoms are the Major Determinants of Quality of Life in Parkinson's Disease

—Rajesh Pahwa, MD, Laverne and Joyce Rider Professor of Neurology, University of Kansas Medical Center, Kansas City, KS, USA

Quality of life (QoL) refers to a person's or a group's overall sense of well-being and usually encompasses physical, social and emotional aspects that are important to the individual. Quality of life will vary from person to person even when the same set of symptoms are present since perceptions of individuals differ. Therefore, in most reports of QoL, outcomes are based on the average perceptions of the entire group and there are often wide ranges of responses.

The cardinal symptoms of Parkinson's disease (PD) namely tremor, bradykinesia, rigidity and postural instability are motor symptoms and have been the focus of clinical care with little attention having been paid to the non-motor symptoms of PD. However, in recent years non-motor symptoms have received a lot of attention and this has led a number of investigators to suggest that the non-motor symptoms may be stronger determinants of QoL than the motor symptoms of PD.

A recent review by Soh, et al. (2011) identified 29 reports that satisfied the criteria for review of health related QoL determinants in PD. Three non-motor symptoms namely depression, anxiety and fatigue and five motor symptoms namely gait impairment, complications of therapy, disease severity, duration of disease and motor scores were identified as major determinants of QoL in a number of studies. The authors suggested that the depressed individuals with more advanced disease and higher levels of disability are most likely to report a poorer QoL in PD.

PD patients are typically taking anti-parkinsonian medications but they may not be consistently taking anti-depressants, anti-anxiety medications or treatments for other non-motor symptoms of PD. Hence one of the major weaknesses of studies that identify non-motor symptoms especially depression as the major determi-

## Non-Motor Symptoms are the Major Determinant of Quality of Life in Parkinson's Disease

—K. Ray Chaudhuri, MD, Dsc, FRCP, National Parkinson Foundation International Centre of Excellence, Kings College Hospital and Kings College (Denmark Hill Campus), London, United Kingdom

The first issue to contemplate in this debate is what do we mean by the term "quality of life" or more accurately, health related quality of life (HrQoL). The World Health Organization's definition of HrQoL

is the definition of global QoL, which is "the individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns".<sup>1</sup> In Parkinson's disease (PD), HrQoL can also be regarded as the perception of impact of PD and its effects on life as judged by patients, and the latter depends on communication and a "holistic" approach to treatment.<sup>2</sup>

The "traditional" concept is that the visible symptoms of PD such as the motor deficits (the visible part of the iceberg of PD symptomatology) are the key determinants of HrQoL in Parkinson's. But this is a somewhat "tunnel vision" approach to a condition that has considerable phenotypic and patho-physiological heterogeneity and evidence is gathering that it is the "burden" of non-motor symptoms (NMS) and not just single NMS such as depression, that is the major determinant of HrQoL. This can

be evidenced from three points: (a) the clinical perspective, (b) the patients' perspective and (c) a data-driven approach.

The clinical perspective is based on the fact that a range of NMS occurs in early and untreated PD (contrary to commonly held views and as translated from the Braak hypothesis)<sup>3</sup> and indeed two major multicentre "holistic" prevalence studies of NMS in PD, the NMS-Quest study and PRIAMO as well as a post-mortem study suggest a high load of NMS in "early" including drug naïve PD cases<sup>4,6</sup> while it is well established that in advanced disease NMS predominates and poses the greatest challenge to treatment.<sup>7</sup> The Hoehn and Yahr (HY) staging, a cornerstone of clinical assessment, as well as the Unified Parkinson's Disease Rating Scale (UPDRS) are based almost



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We hope you will enjoy this latest edition of *Moving Along*. We are grateful that Drs. Raj Pawha and Ray Chaudhuri submitted articles for the Controversies Section. Together, they review the importance of the non-motor and motor symptoms as a function of quality of life in Parkinson's disease (PD). This multi-faceted topic is becoming increasingly important to our society, especially given the favor quality of life measures receive from the European and American regulatory agencies. Please know that we believe an invitation to contribute to the *Moving Along* Controversies section is the highest honor an MDS member can receive – and hope you will say “yes” when we come begging! We would also invite any reader to suggest topics for future issues.

This issue also features the many highlights of the 15th International Congress in Toronto. Congratulations and thanks to the organizing committee for a tremendously successful meeting. We also extend congratulations to the award winners and to the Society Secretariat for the continued growth in our educational activities. We also provide messages from MDS President, Günther Deuschl; and from the Regional Section Chairs.

The MDS Website Medical Editors, Hubert Fernandez and Marcelo Merello, update us on the continuing growth of the Society electronic communications, now expanded to include social media outlets and mobile phone applications that link to our print publications via QR codes. While at first glance, the QR symbol may stand for a “Quasi-Rorschach,” please know that these “Quick Response” symbols will connect you with Society information by mobile phone. Take advantage of this new technology to gather information on



Carlo Colosimo, MD; Elizabeth Laur, MDS Secretariat; Mark Stacy, MD

Rating Scales, the MDS Oral Histories project and MDS Health Professionals group.

Several education initiatives are also featured, including the successful Basic Movement Disorders course held in conjunction with the Congress. Other featured educational activities include “Movement Disorders for non-Neurologists,” held in El Salvador, and the International Symposium to be held in La Paz, Bolivia in March, 2012. The AOS has named Thailand as the next host for the 4th AOPMC in 2014. In addition, the 2011 MDS-ES Summer School was held in Naples last July, while the Winter School is scheduled for Innsbruck in February. There is also a summary from MDS Dopamine Transporter Imaging course in Greece in July.

We are grateful for the support of the staff members of MDS, particularly Elizabeth Laur, pictured above, trying to focus her *Moving Along* Newsletter editors at the Congress in Toronto.

## They are finally here—QR codes! But what are they?

—Hubert Fernandez, MD and Marcelo Merello, MD, PhD, MDS Co-Website Medical Editors

While browsing through this issue of *Moving Along*, you may notice a strange looking symbol next to a few of the articles. No, it's not a typographical error – it's a QR code, short for Quick Response code.

This symbol is placed next to new and relevant articles that link to the MDS website. In order to use it, you first need to download a **QR Reader app** onto your mobile phone. To download a free QR code reader app, search “QR” in the App feature on your mobile phone. Then, simply snap a picture of the code with your camera phone and the related webpage will download directly on your phone for instant viewing.

One of our goals is to utilize new technology to connect you, **faster, anytime, anywhere**, to valuable information, updates and tools on the MDS website. Soon, with QR codes you will be able to view videos, podcasts, editorials, and articles from your own phone... at lightning speed!

Check out the QR code on this page and see for yourself!





The *Movement* Disorder Society



It is a great honor for me to assume the position of President of The *Movement* Disorder Society. I would like to express my gratitude to our Past-President, Philip Thompson, for his outstanding leadership over the past two years,

and I look forward to working with the Officers and International Executive Committee (IEC) to ensure the continued success of our Society.

I would also like to thank Oscar Gershanik, Tony Lang and Dan Tarsy, our outgoing Officers, who worked tirelessly for our Society as well as the outgoing members of the IEC (Giovanni Abbruzzese, Alim Benabid, Irene Litvan, Demetrius Maraganore and Cristina Sampaio). Their leadership also has helped ensure the continued success of our Society.

### 15<sup>th</sup> Congress in Toronto, Canada

The 15<sup>th</sup> International Congress of Parkinson's Disease and Movement Disorders in Toronto, Canada, June 5-9, 2011, was a tremendous success attended by over 3,700 enthusiastic delegates. I would like to thank and congratulate the Congress Scientific Program Committee, Local Organizing Committee and International Congress Oversight Committee. A full report on Congress activities is available on page 4 of this newsletter.

Through attendee surveys, the Society is continually monitoring feedback to ensure the Congress continues to provide members with high quality education. After each Congress, the MDS Continuing Medical Education (CME) Committee meets to assess evaluation data to ascertain that the Society has continued to meet its educational goals. This year, the CME Committee Chair reported that 85% of the 213 learning objectives in 71 sessions of the 15th International Congress in Toronto met the established threshold of effective learning. The Committee measures the participants understanding of session topics before and after the educational activity and the percent change in understanding. Additionally, all faculty members are evaluated. Nearly 100% of the 15th International Congress of Parkinson's Disease and Movement Disorders speakers received excellent evaluations from participants regarding expertise, clarity and effectiveness of presentations, and lack of commercial bias.

With feedback from this year's Congress participants, the Society has started planning for the 16<sup>th</sup> Congress in Dublin, Ireland. Thank you to all the members and attendees who submitted session ideas and filled out evaluation forms. David Burn and his Congress Scientific Program Committee are hard at work on the scientific program for the next Congress!

### Society to Undergo Strategic Planning

Every three years, the Society embarks on a strategic planning process to identify priorities for the Society in the coming years. The next such planning process will begin in September 2012, and will confirm the 2013-2016 iteration of the MDS Strategic Plan. Representatives from the IEC, Past-Presidents, the journal and the website will convene to discuss the future goals and objectives of MDS. New challenges are ahead to foster the creation of scientific and clinical collaborations within the Society which will be followed in the next year. Should members have feedback or suggestions about future activities, please email Pam Fierst at [pfierst@movementdisorders.org](mailto:pfierst@movementdisorders.org).

### Society to Establish Special Interest Groups (SIGs)

At the Toronto Congress, the Officers and IEC members agreed to establish Special Interest Groups (SIGs) for neurosurgeons and health professionals (non-physician). These groups will be open to MDS members with who share these interests. The SIGs will meet during future MDS Congresses and be responsible for proposing educational topics in their area of interest, for maintaining a presence on the MDS website and for generating proposals for activities for their interest group. Information on how to join SIGs will be available on the MDS website shortly. I welcome you to participate in the SIGs.

Through our International Congresses, journal, committees, sections and task forces we are pursuing our mandates of educating physicians throughout the world, encouraging scientific developments and improving the care of patients suffering from the many neurological diseases that result in Movement Disorders. As you know, the success of our Society depends heavily on the dedication and diligence of its members. I look forward to serving as your President and welcome your insights to ensure the continued growth of our Society.

Günther Deuschl, MD  
MDS President 2011-2013

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## 15<sup>th</sup> International Congress Highlights

The 15<sup>th</sup> International Congress of Parkinson's Disease and Movement Disorders was held in Toronto, ON, Canada on June 5-9, 2011. Returning back to North America since the Chicago Congress in 2008, the ethnically diverse city of Toronto provided a perfect setting for The *Movement Disorder Society's* international attendees. With the eclectic culture that Toronto has to offer, MDS delegates always had something to experience when they weren't taking part in the exciting Scientific Program and social events during the Congress.

The Metro Toronto Convention Centre was the venue where delegates learned about the latest research and perspectives in the field of Movement Disorders and where they networked and collaborated with colleagues. Everyone's participation made for several highlights during the week:

- 74 countries represented
- 142 Travel Grants awarded
- 213 faculty members participated in the Scientific Sessions
- 1,155 posters and 28 late-breaking posters accepted
- 4 Therapeutic Plenary Sessions
- 9 Plenary Sessions
- 24 Parallel Sessions
- 8 Teaching Courses
- 10 Video Sessions
- 11 Skills Workshops
- 3 Scientific Discussions
- 16 Guided Poster Tours
- 33 companies exhibited
- 25 representatives from the press attended



*A group of delegates listen to a presentation during one of the Guided Poster Tours in the new E-Poster format.*

Under the direction of Christopher Goetz, the Congress Scientific Program Committee (CSPC) made every effort to ensure that the science for the 15<sup>th</sup> International Congress was diverse and educational. The 2011 Scientific Program incorporated Therapeutic Plenary Sessions, Corporate Therapeutic Symposia, Plenary and Parallel Sessions, Teaching Courses, Video Sessions, Skills Work-

shops, Scientific Discussions, Controversies, Blue Ribbon Highlights, Poster Sessions and Guided Poster Tours. There were 12 sessions that were related to this year's theme of "Behavioral and motor interfaces of movement disorders: From laboratory to patient care" which allowed participants to have an educational and comprehensive overview on this subject.

E-Posters debuted for the first time at an MDS International Congress. Of the 16 Guided Poster Tours that were available for people to sign up for, eight of them were electronic. These posters were displayed on a screen while people sat and listened to the authors present an overview of their findings. As the E-Posters were well received, MDS will continue to do this style for all of the posters featured in the Guided Poster Tours next year in Dublin.

All eight Teaching Courses from the 15<sup>th</sup> International Congress are available on DVD-ROM for purchase which includes slides, audio, video and the accompanying syllabi. New this year! All 12 Themed Courses are also available on DVD-ROM for purchase which includes slides, audio and video. To order these DVDs, please visit <http://www.movementdisorders.org/congress/congress11/>.



*Prof. Philip Thompson presents Dr. Oscar Gershanik with the President's Distinguished Service Award during the Opening Ceremony.*

For the last time during his MDS presidency, President Philip Thompson distributed the following awards during the Opening Ceremony:

### Honorary Member Awards:

John GL Morris, *Sydney, Australia*  
Masaya Segawa, *Tokyo, Japan*

### President's Distinguished Service Award:

Oscar Gershanik, *Buenos Aires, Argentina*

### Stanley Fahn Lecturer:

Anthony E. Lang, *Toronto, ON, Canada*

### C. David Marsden Lecturer:

Serge Przedborski, *New York, NY, USA*

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15<sup>th</sup> International Congress Highlights CONTINUED FROM PAGE 4**Junior Award – Clinical Research:**

Alexander Schmidt, *Lübeck, Germany*

**Junior Award – Basic Science:**

George K. Tofaris, *Oxford, United Kingdom*

**Public Service Award:**

Michael J. Fox

Additionally, 142 Travel Grants were distributed. Please see page 8 for more information on these awards.

The first official evening of the 15<sup>th</sup> International Congress commenced with the Welcome Reception which followed the Opening Ceremony. This particular social event was a great way for attendees to network and have fun with their colleagues. Local flavor was evident during this evening with everything from the Nathaniel Dett Chorale who performed during the Opening Ceremony, to the Fort York Guards who stood at command at the doors of the Welcome Reception, the maple syrup taffy lollies that were made on demand, Les 7 Doigts de la Main dance and circus troupe who performed and even the local ice wine which was served at the ice bar. Different parts of Toronto were brought together in one room during the Welcome Reception for the delegates to experience.

About 1,500 delegates gathered to watch unique Movement Disorder cases on the evening of Wednesday, June 8 during the 4<sup>th</sup> Annual VO Games. The cases presented were selected from a large number of submissions by an international panel of reviewers. Led by the Masters of Ceremony Anthony Lang and Kapil Sethi, the world-renowned Panel of Experts engaged the audience by guiding them through the thought process of diagnosing challenging cases. The two teams of Experts who competed for the highest number of correct diagnoses that they made were as follows:



*Participants of the Fourth Annual VO Games: Presenters, Panel of Experts and the Masters of the Ceremony.*

**Team 1:**

Carlo Colosimo, *Rome, Italy*

Steven Frucht, *New York, NY, USA*

Jose Obeso, *Pamplona, Spain*

Marie Vidailhet, *Paris, France*

**Team 2:**

Roongroj Bhidayasiri, *Bangkok, Thailand*

Stewart Factor, *Atlanta, GA, USA*

Timothy Lynch, *Dublin, Ireland*

Kathleen Shannon, *Chicago, IL, USA*

The 11 cases that were presented to the Panel of Experts and the five cases that were shown as part of an Audience Challenge came from Movement Disorder Centers around the world which offered an enjoyable spirit of competition to this event. The Gold medal was awarded to the University of California, San Diego in the United States (presented by Jennifer Friedman; Dopamine Responsive Dystonia), the Silver medal was awarded to the Academic Medical Centre, Amsterdam in The Netherlands (presented by Evelien Zoons; Alpha-mannosidosis) and the Bronze medal was awarded to The Royal Melbourne Hospital of Australia (presented by Tom Wellings; Kuf's Disease).

Other institutions represented in the presentations and the Audience Challenges were: University of Calgary (Canada), Toronto Western Hospital (Canada), Pitia Salpatriere Movement Disorders Unit (France), Dublin Neurological Institute (Ireland), Movement Disorder Society Japan (Japan), Seoul National University Hospital (Korea), Auckland City Hospital (New Zealand), Chulalongkorn Memorial Hospital (Thailand), The National Hospital for Neurology and Neurosurgery (United Kingdom), King's College Hospital (United Kingdom), Thomas Jefferson University (United States) and the University of Florida Center for Movement Disorders and Neurorestoration (United States).

The *Movement Disorder Society* would like to thank all of the institutions and national Movement Disorder groups who submitted a Letter of Intent at the start of this process and would especially like to thank those who were selected to present their case during the VO Games. Many thanks to David John Burn, Francisco Cardoso, Victor Fung, Beom Jeon, Wolfgang Oertel, Stephen Reich, Anthony Lang and Kapil Sethi for reviewing the Letters of Intent and submitted cases and for choosing the final cases for presentation. A DVD-ROM of the VO Games is available for purchase by ordering from the MDS website at [www.movementdisorders/congress/congress11/](http://www.movementdisorders/congress/congress11/). Please watch the website for more information about upcoming deadlines if you are interested in participating in the 5<sup>th</sup> Annual MDS Video Games to be held in Dublin on June 20, 2012.

For the first time ever, MDS hosted a Fun Run on Tuesday, June 7. Despite a stormy early morning, over 70 participants braved the weather to participate in the scenic 5k run. The race began at the Westin Park Square and followed the lakefront west on an out-and-

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## 15<sup>th</sup> International Congress Highlights CONTINUED FROM PAGE 5

back course to the Toronto Music Garden turnaround. Many participants commented that it was a fast course with the majority of runners finishing under 24 minutes. Prizes were awarded to the top three male and female finishers with other fun prizes for first time participants and individuals who came from the furthest away.



*Robert Leiry Photography*

*Runners competing in the first-ever MDS Fun Run.*

MDS would like to thank GAITRite and Sensonics for supporting the Fun Run.

The *Movement* Disorder Society would also like to extend their gratitude to faculty, supporters, exhibitors and delegates for coming to Toronto and for helping make the 15<sup>th</sup> International Congress of Parkinson's Disease and Movement Disorders another successful meeting.

To claim CME credit for your participation in the MDS 15<sup>th</sup> International Congress, please visit [www.movementdisorders.org/congress/congress11/cme/](http://www.movementdisorders.org/congress/congress11/cme/) and complete the on-screen instructions using your registration file number.

Mark your calendars! MDS is already planning for the 16<sup>th</sup> International Congress in Dublin, Ireland on June 17-21, 2012. Please visit our website for current details regarding this Congress at [www.mdscongress2012.org/](http://www.mdscongress2012.org/) or contact the International Secretariat at [congress@movementdisorders.org](mailto:congress@movementdisorders.org) with any questions.

## 2012 MDS International Congress Travel Grant Program

The *Movement* Disorder Society (MDS) is offering up to 100 travel grants of a maximum amount of \$1,000 USD each in partial support of International Congress delegates in financial need to facilitate their travel to and participation in the 16<sup>th</sup> International Congress of Parkinson's Disease and Movement Disorders in Dublin, Ireland, June 17-21, 2012.

International Congress registration fees will be waived for all travel grant recipients, and the amount of each travel grant given will be determined by the Awards Committee based on criteria including the applicant's location in relation to the 2012 International Congress. Candidates must complete and return the official Travel Grant Application as well as send a copy of the abstract they have submitted to the 16<sup>th</sup> International Congress. The 2012 Travel Grant Application can be found on the MDS website.

**The deadline for the receipt of completed travel grant applications is January 9, 2012.** Successful awardees will be notified at the end of February, 2012.

Please address correspondence to:  
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16<sup>th</sup> International Congress of Parkinson's Disease and Movement Disorders

**DUBLIN, IRELAND** JUNE 17-21, 2012

## 2011 MDS Awards Announced

During the 15<sup>th</sup> International Congress of Parkinson's Disease and Movement Disorders, June 5-9, 2011 in Toronto, the Society was proud to honor the following MDS award recipients:

### President's Distinguished Service Award

*The President's Distinguished Service Award is given in recognition of long and distinguished service to The Movement Disorder Society (MDS).*

#### 2011 Recipient

Oscar Gershanik  
Buenos Aires, Argentina

Previous recipients of the President's Distinguished Service Award include Anthony Lang (2010), Serge Przedborski (2009), Cynthia Comella (2008), C. Warren Olanow (2007), Eduardo Tolosa (2006), Stanley Fahn (2005), and Mark Hallett (2004).

### Honorary Member Award

*The Honorary Member Award recognizes individuals who have made extraordinary contributions to the field of Movement Disorders or otherwise to The Movement Disorder Society.*

#### 2011 Recipients

John GL Morris  
Sydney, Australia

Masaya Segawa  
Tokyo, Japan

Previous recipients of the Honorary Member Award (formerly the Career Award) include Ann Graybiel (2010), Andrew Lees (2010), Yoshikuni Mizuno (2009), Ira Shoulson (2009), Alim Benabid (2008), Mahlon DeLong (2008), Eldad Melamed (2007), Ali H. Rajput (2007), Niall Quinn (2006), Patrick McGeer (2006), Peter Jenner (2005), Thomas Chase (2005), Roger C. Duvoisin (2004), Hiroshi Shibasaki (2004), Yves Agid (2004), Stanley Fahn (2002), Oleh Hornykiewicz (2002) and Gerald Stern (2002).

### Public Service Award

*MDS established the Public Service Award in 2010 to honor individuals who have made outstanding contributions to the field of Movement Disorders through distinguished service. The Public Service Award recognizes individuals who exhibit the highest standard of excellence, dedication, and accomplishment over a sustained period of time. These contributions may be in a wide variety of areas, including but not limited to increasing public awareness of the mission of the Society and the promotion of research, education and training in Movement Disorders and related neurological sciences.*

#### 2011 Recipient

Michael J. Fox

### Junior Award

Two Junior Award recipients were selected based on their significant contribution to clinical and basic science research in the field of Movement Disorders. One award was presented for excellence in clinical research, and another for excellence in basic science research.

#### 2011 Recipients

Alexander Schmidt, Clinical Research  
Lübeck, Germany

George K. Tofaris, Basic Science Research  
Oxford, United Kingdom

Previous recipients of the Junior Award include Roberto Cilia (Clinical 2010), Raphael Hourez (Basic Science 2010), Helen Ling (Clinical 2009), Carlos Juri (Basic Science 2009), Luke Massey (Clinical 2008), Binith Cheeran (Basic Science 2008), Christine Daniels (Clinical 2007), Myriam Khondiker (Basic Science 2007), Andre Troiano (Clinical 2006), Akiko Imamura (Basic Science 2006), Peter Novak (Clinical 2005), Nutan Sharma (Basic Science 2005), David Williams (Clinical 2004), Pedro Gonzalez-Alegre (Basic Science 2004), Sylvie Raoul (Clinical 2002) and Jan Raethjen (Basic Science 2002).


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**Travel Grants**

MDS Travel Grants are offered annually in partial support of International Congress delegates in financial need to facilitate their travel to and participation in the International Congress of Parkinson's Disease and Movement Disorders.

**2011 Recipients**

Marjolein Aerts <i>Nijmegen, Netherlands</i>	Kathrin Czarnecki <i>Boston, MA, USA</i>	Chris Hess <i>Teaneck, NJ, USA</i>	Brianada Koentjoro <i>Sydney, Australia</i>
Melissa Armstrong <i>Toronto, ON, Canada</i>	Patricia Araujo Dare <i>Curitiba, Brazil</i>	Julius Huebl <i>Berlin, Germany</i>	Maja Kojovic <i>London, United Kingdom</i>
Iciar Aviles-Olmos <i>London, United Kingdom</i>	Aloysius Domingo <i>Manila, Philippines</i>	Philippe Huot <i>Toronto, ON, Canada</i>	Naomi Kouri <i>Jacksonville, FL, USA</i>
Krzysztof Banaszkiwicz <i>Krakow, Poland</i>	Darius Ebrahimi Fakhari <i>Geissen, Germany</i>	Catherine Hurt <i>London, United Kingdom</i>	Nikola Kresojevic <i>Belgrade, Serbia</i>
Amit Batla <i>Ghaziabad, India</i>	Robert Fekete <i>Houston, TX, USA</i>	Sameea Husain <i>Scottsdale, AZ, USA</i>	Puneet Kumar Bansal <i>Barnala, India</i>
Kelly Bertram <i>Melbourne, Australia</i>	Soumya Ghosh <i>Toronto, ON, Canada</i>	Anna Hussl <i>Innsbruck, Austria</i>	Do Young Kwon <i>Ansan-city, Korea</i>
Pedro Braga-Neto <i>Sao Paulo, Brazil</i>	Kathryn Gaines <i>Charleston, SC, USA</i>	Alicia Jensen <i>Minneapolis, MN, USA</i>	Travis Larsh <i>Cincinnati, OH, USA</i>
Lissa Brod <i>Portland, OR, USA</i>	Anna Gamaleya <i>Moscow, Russia</i>	Ketaki Jhavar <i>Bangalore, India</i>	Johannes Levin <i>Munich, Germany</i>
Norbert Brüggemann <i>Luebeck, Germany</i>	Ziv Gan-Or <i>Tel Aviv, Israel</i>	Harikesh Kalonia <i>Chandigarh, India</i>	Natlada Limotai <i>Nonthaburi, Thailand</i>
Lena Burbulla <i>Tuebingen, Germany</i>	Gaia Giannicola <i>Milan, Italy</i>	Rukmini Kandadai <i>Hyderabad, India</i>	Ellen Lirani-Silva <i>Sao Paulo, Brazil</i>
Miryam Carecchio <i>Santhia, Italy</i>	Sergiu Groppa <i>Kiel, Germany</i>	Sachin Kapur <i>Chicago, IL, USA</i>	Arpan Maiti <i>Kalyani, India</i>
Anna Castriotto <i>Perugia, Italy</i>	Jifeng Guo <i>Changsha, China</i>	Panagiotis Kassavetis <i>London, United Kingdom</i>	Vladana Markovic <i>Belgrade, Serbia</i>
Ozlem Celebi <i>Ankara, Turkey</i>	Abdallah Hadj Tahar <i>Quebec, QC, Canada</i>	Surasa Khongprasert <i>Patumwan, Thailand</i>	Ignacio Mata <i>Seattle, WA, USA</i>
Lama Chahine <i>Philadelphia, PA, USA</i>	Era Hanspal <i>New York, NY, USA</i>	Annie Killoran <i>Rochester, NY, USA</i>	Tiago Mestre <i>Toronto, ON, Canada</i>
Nora Chan <i>Los Angeles, CA, USA</i>	Angela Hardwick <i>Gainesville, FL, USA</i>	Young Eun Kim <i>Seoul, Korea</i>	Patricio Millar-Verneti <i>Buenos Aires, Argentina</i>
Tyler Cheung <i>New York, NY, USA</i>	Anhar Hassan <i>Rochester, MN, USA</i>	Hee Jin Kim <i>Seoul, Korea</i>	Nathaniel Miller <i>Ann Arbor, MI, USA</i>
Tania Cruz Mariño <i>Holguin, Cuba</i>	Muralidhar Hegde <i>Galveston, TX, USA</i>	Katsuo Kimura <i>Yokohama, Japan</i>	James Morely <i>Philadelphia, PA, USA</i>
Huashun Cui <i>Boston, MA, USA</i>	Helke Heskamp <i>Paris, France</i>	Ji Hyun Ko <i>Toronto, ON, Canada</i>	Inder Singh Mudila <i>New Delhi, India</i>

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Somnath Mukherjee <i>New Delhi, India</i>	Gesine Respondek <i>Marburg, Germany</i>	Arun Singh <i>Munich, Germany</i>	Diana van Rooijen <i>Leiden, Netherlands</i>
Julie Nantel <i>Stanford, CA, USA</i>	Luigi Romito <i>Milan, Italy</i>	Paolo Solla <i>Cagliari, Italy</i>	Okeanis Vaou <i>Dedham, MA, USA</i>
Ivana Novakovic <i>Belgrade, Serbia</i>	Manuela Rosa <i>Milan, Italy</i>	Wei Song <i>Chengdu, China</i>	Christina Vaughan <i>Chicago, IL, USA</i>
Oluwadamilola Ojo <i>Lagos, Nigeria</i>	Diane Ruge <i>London, United Kingdom</i>	Carolina Souza <i>Sao Paulo, Brazil</i>	Frances Velez-Lago <i>Guaynabo, Puerto Rico</i>
David Okai <i>London, United Kingdom</i>	Jost-Julian Rumpf <i>Leipzig, Germany</i>	Meredith Spindler <i>Philadelphia, PA, USA</i>	Rodrigo Vitorio <i>Sao Paulo, Brazil</i>
Sandipan Pati <i>Phoenix, AZ, USA</i>	Tabish Saiffee <i>Chiswick, United Kingdom</i>	Rebecca St. George <i>Beaverton, OR, USA</i>	Richard Walsh <i>Toronto, ON, Canada</i>
Kathryn Peall <i>South Wales, United Kingdom</i>	David Salat Foix <i>Calgary, AB, Canada</i>	Maria Stamelou <i>London, United Kingdom</i>	Xiao-Ping Wang <i>Shanghai, China</i>
José Luiz Pedroso <i>Sao Paulo, Brazil</i>	Paulo Sales <i>Fortaleza, Brazil</i>	James Stevenson <i>Vancouver, BC, Canada</i>	David Weise <i>Leipzig, Germany</i>
Zhongxing Peng Chen <i>Gainesville, FL, USA</i>	Naomi Salins <i>Phoenix, AZ, USA</i>	Tanja Stojkovic <i>Belgrade, Serbia</i>	Daniel Weiss <i>Tuebingen, Germany</i>
Mariya Petrova <i>Sofia, Bulgaria</i>	Cristina Sanchez-Castaneda <i>Rome, Italy</i>	Matthis Synofzik <i>Tuebingen, Germany</i>	Diane Whitmer <i>Stanford, CA, USA</i>
Nicolas Phielipp <i>Toronto, ON, Canada</i>	Jasper Santos <i>Sao Paulo, Brazil</i>	Zi-Kheng Tan <i>Johor, Malaysia</i>	Ari Wilkenfeld <i>Somerville, MA, USA</i>
Ilse Pienaar <i>Oxford, United Kingdom</i>	Kaveh Saremi <i>Torrance, CA, USA</i>	Arben Taravari <i>Skopje, Macedonia</i>	Marc Wolf <i>Mannheim, Germany</i>
Margarita Pondal <i>Toronto, ON, Canada</i>	Justyna Sarna <i>Calgary, AB, Canada</i>	Mary Ann Thenganatt <i>New York, NY, USA</i>	Olga Yacuts <i>Minsk, Belarus</i>
Cynthia Poon <i>Chicago, IL, USA</i>	Rodolfo Savica <i>Rochester, MN, USA</i>	Amanda Thompson <i>Gainesville, FL, USA</i>	Lihua Yu <i>Chengdu, China</i>
Markos Pouloupoulos <i>New York, NY, USA</i>	Mohit Saxena <i>New Delhi, India</i>	George Tofaris <i>Oxford, United Kingdom</i>	Ji Y Yun <i>Seongnam, Korea</i>
Nirendra Rai <i>New Delhi, India</i>	Julia Schicks <i>Tuebingen, Germany</i>	Juan Toledo <i>Philadelphia, PA, USA</i>	Alessandra Zanon <i>Bolzano, Italy</i>
Laila Raissouni <i>Rabat, Morocco</i>	Alexander Schmidt <i>Luebeck, Germany</i>	Christopher Tolleson <i>Nashville, TN, USA</i>	Jinxia Zhou <i>Sydney, Australia</i>
Prashanth Reddy <i>London, United Kingdom</i>	Daniel Schneider <i>New York, NY, USA</i>	Aleksandra Tomić <i>Belgrade, Serbia</i>	Evelien Zoons <i>Amsterdam, Netherlands</i>
Martin Reich <i>Kiel, Germany</i>	Binit B. Shah <i>Toronto, ON, Canada</i>	Yevgen Trufanov <i>Lugansk, Ukraine</i>	<i>The 2011 Travel Grant Program was partially supported by an unrestricted educational grant from Merz Pharmaceuticals, LLC.</i>
Andrew Resnick <i>Tampa, FL, USA</i>	Alexander Shtilbans <i>New York, NY, USA</i>	Ryosuke Tsutsumi <i>Tokyo, Japan</i>	

—Hubert Fernandez, MD, Cleveland, Ohio and Marcelo Merello, MD, PhD, Buenos Aires, Argentina, MDS Co-Website Medical Editors

## Welcome to MDS Mobile!

We are happy to be able to offer our members quick, easy access to the many tools and features available on the MDS website now on your web-enabled phone. Take us with you wherever you go!



The **MDS Mobile** for your smart phone includes direct access to the following features:

- Member login
- *Movement Disorders Journal* access
- Announcements of workshops, conferences, seminars
- International Congress information
- Membership Directory and Membership account management
- Rating Scales Reviews and Papers
- Links to all of the Society's social media networks
- MDS Contact Information

## 15<sup>th</sup> International Congress goes social

For the first time, the Society introduced Twitter to Congress delegates, tweeting daily updates about the sessions, speakers and social activities surrounding our biggest meeting of the year. To date, more than 400 people are following MDS on Twitter. Be sure you're following us @movedisorder. Go to [www.twitter.com](http://www.twitter.com) for information on getting started!

Also during the Congress, we once again held a website survey contest, which drew 260 entries for a chance to win one of three Apple iPads. The winners were: Ronald Barber (UK), Clecio Godeiro (Brazil) and Ramon Kruschewsky (Brazil).



Ronald Barber (UK)



Clecio Godeiro (Brazil)



Ramon Kruschewsky (Brazil)

## Rating Scales

New! One of our goals is to make clinical tools available to our members for their daily practice. As part of the **MDS Mobile** project, we now have available in downloadable PDF format, 13 MDS-owned rating scales:



- Brief Ataxia Rating Scale (BARS)
- Jankovic Rating Scale-Blepharospasm Disability Index (JRS-BSDI)
- Non-Motor Symptoms Scale (NMSS) (Includes NMSQ)
- Parkinson's disease - Cognitive Rating Scale (PD-CRS)
- Rating Scale for Psychogenic Movement Disorders
- Rush Dyskinesia Rating Scale
- Rush Videobased Tic Rating Scale
- Toronto Western Spasmodic Torticollis Rating Scale (TWSTRS) (Video only)
- UFMG Sydenham's Chorea Rating Scale (USCRS)
- Unified Dyskinesia Rating Scale (UDysRS)
- Unified Dystonia Rating Scale (UDRS)
- Unified Multiple System Atrophy Rating Scale (UMSARS)
- Unified Parkinson's Disease Rating Scale (MDS-UPDRS)

## A 'Thank You' to nine who served

The Co-Medical Editors would like to extend their sincere thanks and appreciation to nine MDS members who served on the Web Editorial Board through the 2011 International Congress. They are:

- Tim Anderson, BSc, MBChB, FRACP, MD, *New Zealand*
- Kailash Bhatia, MD, DM, FRCP, *United Kingdom*
- Francisco Cardoso, MD, PhD, *Brazil*
- Joaquim Ferreira, MD, PhD, *Portugal*
- Nir Giladi, MD, *Israel*
- She-Leong Ho, MD, FRCP, *Hong Kong*
- Joachim Krauss, MD, *Germany*
- Peter LeWitt, MD, *USA*
- Janis Miyasaki, MD, MEd, FRCPC, *Canada*



## Let's Face(book) it: Social Networks Are Here to Stay

—Laura Silveira-Moriyama, MD, PhD, UCL Institute of Neurology,  
London, MDS Web Editorial Board Member

If you are new to Facebook, or are thinking about joining MDS' group page, here are some basic facts you might want to know.

### 1. What are "social network" services?

Social network services such as Facebook are online programs which allow people to interact with each other. Each person creates his/her own profile, and can look at other people's profiles and invite them to be "friends." Friends can send messages to each other, share interesting things (messages, photos, links) and also promote events and activities.

### 2. What is Facebook?

Facebook is the most popular social network service in the world, and The *Movement* Disorder Society has a group page on it. You can access it from a link on the home page at [www.movementdisorders.org](http://www.movementdisorders.org).

### 3. What is "the wall" in Facebook?

The wall is a part of your Facebook contents. It is similar to a noticeboard, where you and your friends and acquaintances can put little notes ("posts"), links to interesting things, photos or videos.

### 4. What are "posts" in Facebook?

Posts are messages that people publicly send to other people, or to a community. They are little notes, which you can add to someone's wall. You can also respond to posts from other people. This sometimes generates a short conversation between your friends.

### 5. What are "messages" in Facebook?

A "message" usually means a private message, which you send to a person directly. It is not meant to be seen by others.

### 6. Will people from MDS who are not my friends be able to see my profile?

Everyone who joins the MDS Facebook group will be able to see your name and your profile picture. How much more of your profile they see will depend on your privacy settings. In your privacy settings you can ask that only your friends see events, photos, posts and so on. The others in the group who are not your friends would only see your profile picture and the basic information you allow non-friends to see. You can also "customize" your privacy settings so only a few select people can see the contents (like photos and videos of you, for example).

### 7. How can I customize my privacy settings?

You can do this using "Privacy Settings" on the "account" tab on your Facebook page. For a guide on how to use it, visit [www.facebook.com/privacy/explanation.php](http://www.facebook.com/privacy/explanation.php).

## MDS Health Professionals (Non-Physician) Special Interest Group

The MDS Health Professionals (Non-Physician) group is a virtual international, interdisciplinary group of nurses, rehabilitation specialists and counselors, and genetic specialists recently designated by MDS President, Günther Deuschl, and the IEC as a Special Interest Group.

Our goal is to further establish MDS as a premier organization. In doing so, we intend to enrich and broaden the scope of care through education, advocate for interdisciplinary management through collaboration and stimulate further research in movement disorders. Find us on the web at: [www.movementdisorders.org/healthprofessionals](http://www.movementdisorders.org/healthprofessionals)

The Society has always welcomed membership and encouraged participation by non-physician health professionals (Bylaws, 1985; MDS Strategic Plans, 2006 and 2010). Congress sessions and posters by health professionals have increased in recent years, yet our membership numbers are less than 150.

### We need your help to increase the number of Health Professional Members in the Society. Here is what you can do:

- 1) **Encourage** your colleagues who are advance practice nurses, physical, occupational or speech therapists, nutritionists, neuro- and clinical psychologists, genetic counselors, and social workers to submit abstracts for the 2012 Dublin Congress and the 2013 Congress in Sydney, Australia.
- 2) **Invite** them to visit our webpage and introduce themselves by completing our survey;
- 3) **Fund** their first year of MDS membership at the reduced fee of \$100 USD so they can experience the wealth of resources directly.

MDS membership gives your colleagues access to the Society's online project management tool (Basecamp) where our Special Interest Group works collaboratively on outreach, education, and other projects. When clinical practice improves by cross-training (one discipline learning from another), our patients and families benefit.



## MDS Task Force on Rating Scales in Parkinson's Disease – 10 Year Anniversary

—Werner Poewe, MD, University Hospital Innsbruck, Austria

—Christopher Goetz, MD, Rush University Medical Center, Chicago, IL, USA

—Anette Schrag, FRCP, PhD, Royal Free and University College, London, United Kingdom

The number of different scales used to evaluate the motor and non-motor aspects of Parkinson's disease has expanded very considerably over the years. By 2001, the bewildering range of available scales and relative lack of knowledge concerning their relative strengths and weaknesses prompted the then MDS President Werner Poewe to suggest a comprehensive review to guide researchers in this area and highlight areas of need for further research.

“At the time, MDS, as an organization had not yet been very much involved in sponsoring scientific review, let alone the development of rating scales in the field of PD and related movement disorders. It seemed appropriate that MDS as the premier scientific organization in the field should take a leading role in this important arena of clinical movement disorder research.”

This led to an initiative by The *Movement Disorder Society*, chaired by Christopher Goetz, to fully review and assess the evidence in this area. A team of members enthusiastic about establishing an evidenced-base for patient-based outcomes was formed. In addition to Christopher Goetz and Werner Poewe, the original team also included Olivier Rascol, Cristina Sampaio and Glenn Stebbins, later to be joined by Anette Schrag, the subsequent chair. Christopher Goetz says, “I accepted this post without a clear knowledge of the full work-scope and long-standing commitment, but it has been a very satisfying and educational effort, thanks to the excellent colleagues who have become personal friends.”

From the beginning, the mission of this Task Force was three-fold: to critique existing scales in a uniform manner; to identify clinical areas not adequately covered by current rating instruments; and to make recommendations on maintaining, modifying and developing new scales to keep paces with evolving scientific advances.

The first and most obvious scale to review was the Unified Parkinson's Disease Rating



Olivier Rascol, Cristina Sampaio, Werner Poewe, Christopher Goetz, Anette Schrag, Glenn Stebbins

Scale (UPDRS), the main outcome measure for virtually all clinical studies in PD. A thorough review of the available evidence led to the conclusion that the scale had multiple strengths, including its universal use, acceptable clinimetric properties and good coverage of motor problems; but also several shortcomings, including its relative lack of coverage of some non-motor features of PD, and weakness in some metric properties. Recommendations were made to improve this scale whilst retaining its core features and strengths. As a result, following an enormous international effort involving both researchers in the development team and a large number of volunteering co-investigators who helped validate the scale in their patients, The *Movement Disorder Society*—sponsored revision of the UPDRS (MDS-UPDRS) was developed, tested, and finally introduced in 2008. A full web-based training program is now launched at the MDS website, and a large translation program has been initiated to develop official non-English versions. French, German, Chinese, Japanese, Korean, Hebrew, Russian, Dutch, and Slovakian programs are currently active; the Italian and

Estonian versions are approved; and the Spanish version is currently being analyzed.

The next scale to be reviewed was the relatively old, but still widely used Hoehn and Yahr, which despite never having been intended as an outcome measure, has been used widely as such and as a convenient means of assessing the stage of PD.

Further individual Task Forces were formed, and chairs asked to lead reviews on the scales pertaining to most aspects of PD. As a result evidence-based review on scales of dyskinesia, wearing-off fluctuations, psychosis, depression, anxiety, apathy, anhedonia, fatigue, sleep, dysautonomia in PD have been completed, with yet more ongoing or planned.

These reviews are intended to help inform researchers and clinicians about which instrument to use and how to interpret their findings by establishing the strengths, weaknesses and level of evidence available for each. They are conducted and written by researchers in the areas that are reviewed and represent expertise of researchers in neurology, scales development, statistics and areas

## MDS Oral Histories Project

—William Weiner, MD, University of Maryland School of Medicine, Baltimore, MD, USA, Chair of MDS Archives Committee

The Archives Committee began recording interviews of prominent leaders in the Society in 2009 in order to preserve the personal accounts of how the Society was formed and has grown through the years. Since the Movement Disorder discipline is relatively young, we have the unique ability to archive personal narratives regarding the development in our understanding and treatment of the disorders. The Archives Committee plans to interview all past presidents, all honorary members and those who have made important contributions to Movement Disorders.



By watching, listening or reading the personal accounts of those the Archives Committee has interviewed, we learn what drives these influential leaders and how they have contributed to our Society. The interviews focus on the education and training of the interviewed individuals and try to explore the early success and failures that each endured. The discussion of problems they may have overcome is often interesting and more importantly may give some insight to younger members encountering similar problems. It is valuable to hear from early participants in our field what their perspective was on developments at the time important discoveries were being made.

The interviews also explore personal and family pressures that were encountered and how each tried to overcome them. Special emphasis on how to incorporate professional activities and family life is discussed.

Through these interviews we learn personal accounts of careers, mentors, advice for young neurologists who are interested in Movement Disorders, reflections on their biggest challenges in their careers and speculations on where the study of Movement Disorders is headed. The insight and history of the development of the Society and movement disorders in general is unparalleled in any other area of our society. We hope you enjoy and take advantage of the wealth of knowledge that we have the unique ability to access.

At this point, we have the following interviews on the MDS website on the Archives Committee homepage:

Ali Rajput interviewed by Alexander Rajput  
 Andres Lees interviewed by David John Burn  
 Anthony Lang interviewed by William Weiner  
 Roger Duvoisin interviewed by Mark Stacy  
 Stanley Fahn interviewed by Joseph Jankovic  
 Yves Agid interviewed by Etienne Hirsch  
 Alfredo Berardelli interviewed by Mark Hallett  
 Gerald Stern interviewed by Niall Quinn  
 Richard Morimoto interviewed by Serge Przedborski  
 Yoshikuni Mizuno interviewed by Werner Poewe  
 Reiner Benecke interviewed by Mark Hallett  
 Christopher Goetz interviewed by Stanley Fahn  
 Mark Hallett interviewed by Christopher Goetz  
 Oleh Hornykiewicz interviewed by Barbara Sommer

### MDS Task Force on Rating Scales in Parkinson's Disease – 10 Year Anniversary CONTINUED FROM PAGE 12

relevant to the topic, from around the world. Whilst they do not provide new evidence in themselves, they highlight deficiencies and need for better scales and more evidence. These reviews have also informed the NINDS Common Data element exercise.

This tremendous output would not have been possible without the engagement of a large group of eminent experts among the MDS members who served as project leaders and lead authors on the majority of these publications.

Where next? The Task Force has now almost finished its initial grand aim of providing a comprehensive evidence base for scales of PD. This, however, will inevitably remain a work in progress, and will require updating as new evidence becomes available and more sophisticated scale development and assessments emerge. However, this enormous body

of work has provided a firm baseline with numerous subsequent studies both using the recommendations and starting to fill the gaps that have been identified. However, scales for other areas such as dystonia, tremor or restless legs syndrome clearly also need assessment and review. The new MDS President, Günther Deuschl, in recognizing the importance of the MDS in taking the lead in rating scale development, has now decided to replace the MDS Task Force with a Standing Committee on Rating Scales. Anette Schrag, who has led the Task Force since taking over from Christopher Goetz in 2009, has been appointed to lead this new MDS Committee which will comprise both new and established Task Force members on a rotating basis. She says "I am honoured to take over this important task, and to work with this distinguished team. This enormous body of work, started by Werner Poewe and

Chris Goetz, and made possible through the efforts of numerous experts over many years, has demonstrated the strength of information we can gain from available scales and highlighted deficits and weaknesses which are now being addressed. This effort has helped standardize and improve assessment of patients with Parkinson's disease, and has stimulated further research. I look forward to carrying forward this work to help inform research in other movement disorders." All of us involved in the original Task Force over the past 10 years will continue to support the new Committee and are grateful for MDS for having given us not only the opportunity to work on such an important topic but also to enjoy the many pleasures of collegiality and friendship.

We invite those interested in contributing to the effort of reviewing scales in other movement disorders to contact us for suggestions.

## Pilot Basic Movement Disorders Course Hailed as Success

Over 220 attendees from 33 countries around the world attended the pilot course on basic movement disorders in Toronto, ON, Canada held on June 4, 2011 – the day before the 15<sup>th</sup> International Congress began. The Basic Movement Disorders Course provided an overview of Movement Disorders and a clinical approach for the evaluation and management of common Movement Disorders.

For participants like this individual, who also attended the 15<sup>th</sup> International Congress, this course provided a foundation for the International Congress. “This was a fantastic educational experience! It was a nice introduction before starting the MDS Congress.”

This curriculum was specially developed for trainees, internists, general neurologists and other clinicians interested in acquiring a basic understanding of movement disorders. Twelve movement disorder topics were covered during the day including two special discussions on early and advanced Parkinson’s disease. The course also featured an Audience Response System (ARS) to gauge audience learning. The ARS was used in each topic as well as a pre- and post-test. Results indicated positive learning.

Evaluations praised the course as “a very impressive day session - one of the very best sessions in medicine I have ever attended in my career.” It was a “privilege to be in the audience of such esteemed presenters - all were very informative and understandable.”



*Basic Movement Disorders Course faculty members from left to right: Raymond Rosales, Carlo Colosimo, Robert Iansek, Louis Tan, Claudia Trenkwalder, Susan Fox, Joaquim Ferreira, Roongroj Bhidayasiri, and Victor Fung celebrate a course well done.*

The Basic Movement Disorders Course Director Dr. Susan Fox, and Task Force Chairs, Dr. Louis Tan and Prof. Claudia Trenkwalder would like to thank the MDS Education Committee for their support and the Task Force members who volunteered their efforts to create the curriculum.

## MDS Visiting Professor and Ambassador Programs

The *Movement Disorder Society’s* Visiting Professor Program (VPP) and Ambassador Program have both had a significant impact in countries that are historically underrepresented within the Society and have played an important role in establishing a bridge between physicians in these areas and the international Movement Disorders community.

The ultimate goal of the VPP, which was established in 2003, is to increase the quality of care to those who are living with a movement disorder. The VPP increases physician awareness and knowledge of movement disorders through lectures and workshops that are presented by an expert in the field. Since its inception, MDS has hosted visiting professors in over 9 countries; allowing MDS to have contact with over 1,200 individual physicians in China, Thailand, Armenia, India, Tunisia, Chile, Romania, South Africa and more. One of the most notable programs was held in Beijing, China in 2009, where the organizers set up a live video link to 8 other cities within the country; this program had participants from 104 hospitals and attendance of 563 physicians. MDS is pleased that this program continues to be well received, and is happy to be hosting a VPP in Georgia this October.

The Ambassador Program, which was established more recently in 2008, has had similar success. The overarching goal of the Ambassador Program, like the VPP, is to improve care and diagnosis for patients living with movement disorders; however, the Ambassador Program also promotes lasting professional relationships between physicians. In addition, this program helps MDS to network with other societies and to take part in their major meetings. In order to

reach these goals, this program provides funding for an acknowledged movement disorder specialist to travel to, and speak at, recognized neurological meetings that do not have sufficient funding to bring in visiting speakers. The Ambassador program has helped speakers attend meetings in over 6 countries, which has allowed MDS to have contact with over 1,000 physicians. A recent event that was sponsored by the Ambassador Program took place in Dhaka, Bangladesh in December 2010. Two international experts spoke at a bi-annual seminar hosted by The Society of Neurologists of Bangladesh, and highlighted diagnosis and management of Dystonia, as well as phenomenology and secondary dystonias. Through the Ambassador Program the Society was able to devote the first day of their two-day seminar to movement disorders. Another recent event took place in El Salvador in March of 2011 with help from the Ambassador Program. The program in El Salvador is particularly exciting because it is the first Ambassador Program that was hosted in South America.

Applications for both of these programs are always accepted. These programs are specifically meant for underrepresented areas that lack opportunities for Movement Disorder education. In order to apply, a potential host should submit an application with a statement regarding the economic and educational needs of the area and how the program will meet those needs. MDS will support the costs of airfare and honoraria for MDS faculty. For additional eligibility requirements and support details, visit [www.movementdisorders.org/education](http://www.movementdisorders.org/education), or email the MDS International Secretariat at [education@movementdisorders.org](mailto:education@movementdisorders.org).



**Werner Poewe, MD**  
*Chair, MDS-ES*

Having had the honor to serve as President of MDS International from 2001-2002 I feel grateful and honored to have again received the trust of the membership and to assume the Chair of the European Section. Having a group of dedicated and outstanding Movement Disorder colleagues from Europe to support me in the roles of Officers and European Section Executive Committee members, as well as the expertise of the new European Education Committee members, will be crucial as I follow the successful Chairmanship of my predecessor, Alfredo Berardelli. Alfredo has been an outstanding Chair of the Section. He has encouraged Movement Disorders groups within Europe to affiliate to MDS, and has furthered the relationship with the European Federation of Neurological Societies (EFNS) through his Chairmanship of the joint EFNS/MDS-ES Scientist Panel on Parkinson's disease and other movement disorders, overseeing the development of several European clinical recommendations. I would like to also acknowledge the contribution of the Officers and ESEC members who left the Section leadership in Toronto; Wolfgang Oertel, Gregor Wenning, Anette Schrag, David Burn, Regina Katzenschlager, Joaquim Ferreira, and Jaime Kulisevsky – we owe them all a debt of gratitude for their service. I welcome Olivier Rascol as Chair-Elect, Claudia Trenkwalder as Secretary-Elect, Murat Emre as Treasurer-Elect, and Christine Klein, Per Odin, Paolo Barone and Pierre Pollak to the ESEC.

Education will continue to be a central plank in the activities of the Section, and I am particularly grateful that Joaquim Ferreira has agreed to Chair the European Education Committee for a second term. Serving with him on the Committee will be Pille Taba, Klaus Seppi, Mario Miguel Rosa, Angelo Antonini, Evzen Ruzicka, Cristian Falup and Claudia Trenkwalder. The MDS-ES Summer Schools have been one of our most appreciated educational activities, enjoyed by faculty and students alike, and in a separate article in this newsletter Paolo Barone and Alfredo Berardelli tell us about the Summer School that has just taken place in Naples. The Summer Schools have all been oversubscribed with twice the number of applicants for the number of places available, and to meet this demand we are for the first

time offering a Winter School, to take place in Innsbruck 24-26 February, 2012.

Our collaborative agreement with the EFNS is very important to the Section, particularly for the opportunity that the EFNS Congress provides for us to offer Movement Disorders education for general neurologists in Europe. The agreement currently runs until 2012 but is due for renewal in 2011. The Section Officers will meet the leadership of EFNS in Budapest to determine what will happen in 2013, when there is no EFNS Congress because of the World Federation of Neurology Congress taking place in Vienna, and look to the future as the EFNS and the ENS hold their first joint Congress in 2015 and consider a possible merger.

You have elected your Section leadership to move the field of Movement Disorders in Europe further forward, and to do this our aims will be to:

- Expand further the MDS-ES outreach to underserved areas of Europe, the Middle East, and North Africa
- Promote the field of Movement Disorders more widely amongst young neurologists
- Continue to develop interactions with national movement disorders groups, and other general neurology organizations, and to strengthen links within the MDS Regional Sections
- Further develop and diversify MDS-ES educational programs
- Promote communication and collaboration with allied health professional groups in Europe

I look forward to working for you and with you to achieve these objectives over the next two years.

With best regards,

Werner Poewe, MD  
Chair, MDS-ES

## MDS-ES Summer School – Naples, Italy, July 1-3, 2011

—Paolo Barone, MD, PhD and Alfredo Berardelli, MD, 2011 MDS-ES Summer School Course Directors

The 2011 MDS-ES Summer School was held in Naples from 1-3 July. The principal location for the scientific program was the Hermitage Clinic in Via Cupa delle Tozzole, Capodimonte while two hotel locations were chosen to accommodate the participants; Hotel San Francesco, Corso Vittorio Emanuele, for the participant delegates and Hotel Parker's, Corso Vittorio Emanuele for the accommodation of the faculty. The latter hotel was also the venue for the video dinner of the evening of Saturday 2 July.

Forty-three student delegates from European and non-European countries attended the Summer school; the program was directed by Paolo Barone (Naples, Italy), Alfredo Berardelli (Rome, Italy) and Werner Poewe (Innsbruck, Austria). A further 12 faculty Professors agreed to

participate: Angelo Antonini (Milan, Italy), Kailash Bhatia (London, UK), Bastiaan Bloem (Nijmegen, Netherlands), David Brooks (London, UK), Giuseppe De Michele (Naples Italy), Joaquim Ferreira (Lisbon, Portugal), Alessandro Filla (Naples, Italy), Wolfgang Oertel (Marburg, Germany), Niall Quinn (London, UK), Evžen Ružicka (Prague Czech Republic), Jens Volkmann (Würzburg, Germany), Gregor Wenning (Innsbruck, Austria). Prof. Wolfgang Oertel was unable to attend for personal reasons.

Onsite assistance, patient clinical case-study information, translation and interpreting was provided by the fellows of the Department of Neurology, Università degli Studi di Napoli Federico II.

The patients for the case studies were selected from the clinics of Prof. Paolo Barone in collaboration with Prof. Alessandro Filla and Prof. Giuseppe De Michele. The above-mentioned fellows contributed with the preparation of clinical records and the preparation of the examination sessions with slide presentations. On day 1, thirteen patients were presented, two during the plenary lecture session in the morning and 11 in the afternoon "break out" session. On day 2, the delegates and faculty had access to nine different patients.

The three-day program ran according to previous summer schools. Two novelties were introduced with respect to previous years:

1. During the "break out" patient examination sessions, in order to allow the delegates to benefit from

the medical expertise of as many faculty as possible while also allowing the faculty to see various cases, a system of rotation from one patient to another was organized, both of the faculty and likewise of the delegates.

2. The work program was divided over days 1 and 2. The first day focused on hypo-kinetic disturbances and the second day, on hyperkinetic disturbances, both in the morning plenary lecture sessions and in the afternoon patient examination sessions.

The Summer School was concluded with a video dinner on the evening of 2 July at Hotel Parker's, where nine faculty members presented their cases with a selection of videos, during dinner with the delegates; the session lasting from 8:30pm to 11:15pm. On the last day, the three best video cases presented by the students were awarded to Joana Marques (Portugal), David Breen (United Kingdom), and Vaya Zatzirua (Namibia).

In conjunction with the MDS-ES Summer School, an additional grant was provided to support the participation of three young neurologists from Sub-Saharan Africa, resulting in the first Afro-Neapolitan School of Movement Disorders meeting. The doctors, from Namibia, Tanzania, and Mali, were able to participate in the MDS-ES Summer School, as well as study at the clinic prior to the beginning of the Summer School.

The Summer School was another great success for MDS-ES, enjoyed by students and faculty alike.



WINTER SCHOOL for Young Neurologists

*Innsbruck ~ AUSTRIA*

FEBRUARY 24-26, 2012

APPLICATION DEADLINE: **NOVEMBER 7, 2011**

## Dopamine Transporter Imaging in Neurological Practice – Athens, Greece, July 17, 2011

—Georgios A. Tagaris, MD, Senior Consultant of Neurology and Movement Disorders Specialist at the G. Gennimatas General Hospital, Athens, Greece

On June 17, the first ever MDS-sponsored course in Greece took place at the Georgios Gennimatas General Hospital. The course was attended by 45 neurologists and nuclear medicine specialists from Greece and several other countries of Europe and the Middle East. The workshop focused on the proper use of dopamine transporter imaging and its potential usefulness in neurological practice.

The first part of the course was an overview of the various clinical aspects of Parkinson's disease. Prof. Kostić, Dr. Konitsiotis and Dr. Stathis described motor and non-motor symptoms, apathy and impulse control disorders, as well as, dementia in Parkinsonism patients.

In the second part, Prof. Brooks, Dr. Scherfler and Dr. Tagaris focused on the principles of DTI, the proper interpretation of the images, potential pitfalls, the potential over- or under-use, and situations where the diagnostic value is maximized.

Finally, the course concluded with three small group workshops where the participants had the opportunity to participate in interactive detailed presentations of several patient cases and correlate clinical data with imaging findings.

MDS would like to thank GE for their support through an unrestricted educational grant for this course.



*DTI Athens Faculty from left to right: Dr. Pantelis Stathis, Dr. Spyridon Konitsiotis, Dr. Georgios Tagaris, Prof. David Brooks, Dr. Vladimir Kostić. Not pictured: Dr. Christoph Scherfler*

## 2<sup>nd</sup> Neuroscience Congress – Bamako, Mali, September 25-28, 2011

Two Past-Presidents of MDS, Eduardo Tolosa (Barcelona) and Andrew Lees (London), and the Chair of the MDS Sub-Saharan Africa Special Interest Group, Richard Walker (Newcastle upon Tyne, UK), represented the Society at the 2<sup>nd</sup> Neuroscience Congress held at the International Conference Centre in Bamako, Mali. The four day meeting (September 25-28, 2011) organized by Professor Moussa Traoré was attended by 355 physicians and basic scientists from Benin, Burkina Faso, Djibouti, Ivory Coast, Senegal, Togo, Ghana, Guinea and Mauretania as well as Mali. Invited faculty included neuroscientists from France, Germany, USA, Canada, Belgium, Tunisia, and Ghana and covered cutting edge research in neurology and psychiatry. The audience at the opening ceremony was treated to the haunting music of the Ensemble Instrumental National an impromptu interruption by a griot and moving speeches by Professor Traoré, Professor Guy Rouleau from Montreal and the Minister of Women, Family and Children, Dr. Konare Mariam Kalapo. The Minister then confirmed that the Mali government had agreed to reimburse l-dopa for all Parkinson's disease patients in the country for the first time. After three days of high quality presentations and lively discussion, Dr. Ousmane Touré, a Ministry of Health spokesman, closed the meeting to warm applause. Neurological diseases of the elderly are now starting to

receive increasing attention in West Africa, and MDS has pledged its educational support to assist future initiatives in the region.



*Andrew Lees and Eduardo Tolosa with Moussa Traoré at the Opening Ceremony of the Neuroscience Congress in Bamako, Mali.*



**Bhim Singhal, MD, FRCP**  
*Past-Chair, MDS-AOS*

It has been a great pleasure for me to have served as the Chairman of the MDS-AOS section. I would like to thank MDS for having given me this opportunity. It has been very satisfying to witness the considerable progress in our region and to be able to build on the strong foundation laid by my predecessors. I sincerely thank all my officers and committee members for their unstinted support.

Dr. Louis Tan and Prof. Ryosuke Takahashi (Co-Chairs of the AOS Education Committee) and their committee members should take the credit for the extremely well organized educational activities in our region. Since 2009, 15 education courses were organized in 7 countries including Bangladesh, Indonesia, Malaysia, Philippines, Vietnam, and several different regions of China and India. Collectively these programs were attended by over 2200 participants and all enjoyed a very positive response. Through these programs, in addition to movement disorder specialists, we were able to reach out to many non-movement disorder neurologists and trainees, and other Health Professionals that manage the care of patients with movement disorders.

The 3<sup>rd</sup> AOPMC and 8<sup>th</sup> APPA at Taipei in 2011, organized by Prof. Robin Wu and her colleagues, were both a great success. Besides the highly appreciated scientific program, Prof. Philip Thompson, MDS President, was struck by the camaraderie among the Asian delegates. Truly, the AOS continues to develop as a community. I am pleased to inform you that the Taiwan Movement Disorder Society (TMDS) will soon be the sixth MDS Affiliate Member Society based in the AOS. The TMDS will join the Movement Disorder Society of Australia, the Hong Kong Movement Disorder Society, the Movement Disorder Society of Japan, the Korean Movement Disorder Society, and the Movement Disorder Society of the Philippines.

My sincere thanks go to Prof. Tim Anderson and Dr. Wing Lok Au for making the AOS webpage user friendly and a better resource for our members. You will also be pleased to learn that useful and important pages have now been translated into the Chinese language, including the MDS Membership webpage. The new AOS e-newsletter, launched in October 2010, is also furthering communication between the Section and its members. The e-newsletter provides updates on upcoming AOS activities, as well as reports from other movement disorder groups in the region, and reaches 1500 contacts quarterly.

I am also happy to inform you that MDS Congress registration fees for Waived Dues Members are now totally waived by MDS. This took effect at the recent meeting in Toronto. I look forward to seeing many more neurologists from our AOS region join MDS. For a listing of who is eligible for Waived Dues Membership, please visit the MDS Membership webpage.

I must emphasize that all this would not have been possible without the support of the administrative staff, in particular Anne McGhie, Pam Fierst, Kate Breckenridge and Danielle McLean. They would often have to be up at odd hours in order to organize the teleconferences from Milwaukee to the AOS region.

I am confident that under the able leadership of Prof. Robin Wu and her team, the AOS will continue to make rapid strides in the field of movement disorders to fulfill the objectives of the MDS.

With regards and best wishes,

**Bhim Singhal, MD, FRCP**  
 Past-Chair, MDS-AOS



**Ruey-Meei (Robin) Wu, MD, PhD**  
*Chair, MDS-AOS*

It is my great honor to introduce myself as Chair of the MDS Asian and Oceanian Section (AOS) for the 2011-2013 term. Within a relatively short period of time, the MDS-AOS has successfully grown and established itself as the main representative of the Movement Disorders community in this region. I am fortunate to have such a strong foundation from which to lead the continued development of AOS. An excellent team has recently been formed; the officers: Victor Fung, Eng-King Tan who are now, respectively, our Secretary and Treasurer; Bhim Singhal, our esteemed Past-Chair; Louis CS Tan, Chair-elect who has contributed towards the advancement of MDS-AOS and its educational programming since its inception; Roongroj Bhidayasiri as Secretary-Elect, and Yoshikazu Ugawa as Treasurer-Elect. We anticipate the active contribution of our Executive Committee members: Beom S. Jeon, Asha Kishore, Minh Le, Shen-Yang Lim, Apichart Pisarnpong, Raymond L. Rosales, Barry J. Snow, Ryosuke Takahashi, Jonas Hon Ming Yeung and Zhen Xin Zhang. Education is one of the main priorities for this Section. We find it particularly important to facilitate movement disorder programming in the regions of AOS where the service of patients with movement disorders is largely provided by general neurologists or in part by internists. Our new AOS Education Committee is chaired by both Ryosuke Takahashi and Madhuri Behari. Working with them on this committee are Roongroj Bhidayasiri, Saeed Bohlega, Shu-Leong Ho, Roland Dominic G. Jamora, Kwang-Soo Lee, John Daniel O'Sullivan, HuiFang Shang and Yih-Ru Wu. Danielle McLean, MDS

Program Manager, will continue to provide robust administrative support to both of these committees and the AOS as a whole.

The congress of AOS in Parkinson's disease and Movement Disorders is the largest educational activity and assembly in this region. The 3<sup>rd</sup> AOPMC/8<sup>th</sup> APPA at Taipei in 2011 attracted 1082 delegates from 30 countries throughout Asia/Oceania and the world. Thailand has been chosen as the next host for the 4<sup>th</sup> AOPMC in 2014. In order to provide better support to the AOPMC host, an AOS Congress Oversight Committee has recently been formed to develop Congress programs and teaching courses in advance to meet regional needs.

The team members of the MDS-AOS look forward to promoting the benefits of membership and recruiting new MDS members in the region. We will continue to lead this section under the MDS mission by disseminating updated knowledge, promoting research and providing advocacy for patients with movement disorders across the Asian and Oceanian regions.

Best regards,

Ruey-Meei (Robin) Wu, MD, PhD  
 Chair, MDS-AOS



**Jorge L. Juncos, MD**  
*Chair, MDS-PAS Organizing Committee*

The mission of the Pan American Section (PAS) of MDS continues to be promoting movement disorders education throughout the region which encompasses Northern Canada to Tierra del Fuego. This seemingly daunting task is being tackled with grace by the Organizing and Education Committees. Since our meeting in Toronto the PAS Education Committee has expanded its membership to absorb additional work stemming from new initiatives planned in the Americas. At the beginning, PAS concentrated on the development of education programs in Central America and South America as mandated by the Organizing Committee. The goal was to better these regions with the MDS educational opportunities and to better coordinate the excellent working relationship that already existed among members of these regions. Our goal is to build stronger bridges between activities in the Americas and the Caribbean and in the process enhance the learning experience for all.

The role of the MDS-PAS Organizing Committee has been to identify and prioritize initiatives to help the educational mission of the PAS and to organize the section's first elections in 2013. Priorities have been organized based on input received by the PAS Organizing Committee Members using a survey and analysis of strengths and weaknesses. These questionnaires have helped to identify local resources, regional interests, potential sources of funding and members that are willing to take a leading role in the organization of educational courses and regional symposia. Committee members are encouraged to work with local and international organizations in order to provide traction and synergy for educational activities and to avoid redundancy. One example is the International Symposium being planned in La Paz, Bolivia in March of 2012. Under the leadership of Dr. Janeth Laguna, MDS is in the process of organizing a satellite Movement Disorders Symposium to the WFN Pan American Congress. It is our hope that these types of courses help to build links between MDS and the general neurology community and expand the reach of our educational opportunities.

With the development of the first "Pan American School for Young Neurologists", course directors Francisco Cardoso and Carlos Rieder hope to do just that. This unique learning oppor-

tunity was developed by MDS members in the European Section and has seen much success over the last four years. We hope to generate as much enthusiasm from participants and faculty alike when debuted in the PAS October 28-30 in São Paulo, Brazil. This three-day course will combine didactics, video presentations and the examination of local patients that display a broad spectrum of movement disorders. This course will provide students with one-on-one collegiality with national and international experts in the field and information to students seeking training opportunities.

In addition to these courses, the PAS continues to utilize the MDS Ambassador Program throughout the region. Past activities have been characterized by the broad participation of general physicians as well as specialty neurologists. In fact, movement disorders specialists have been in the minority. In many cases, particularly during the most recent activity held in El Salvador, organizers were able to reach general internal medicine practitioners and other non-neurology groups that were particularly interested in hearing about the more common movement disorders. The presentations were extended to include participation by patients and their families through a symposium for patients with Parkinson's disease. With my shameless use of Spanish, I joined local experts to bring the audience an update on this condition.

The PAS Organizing Committee continues to lay the groundwork for the first electoral process to take place in 2013. We will soon select a nominating committee and create a timeline for these elections. Proposed bylaws will be translated into various constituent languages and distributed to the membership for comment. Voting on these bylaws will be a first order of business for the newly elected PAS Executive Committee.

Look forward to reading about our ongoing activities in future issues of *Moving Along*.

Atentamente,

Jorge L. Juncos, MD  
 Chair, PAS Organizing Committee



**Surgical Management of Movement Disorders: DBS and Beyond**  
**BUENOS AIRES, ARGENTINA • NOVEMBER 4-5, 2011**

Raul Carrea Institute for Neurological Research (FLENI)



The Movement Disorder Society  
 Pan American Section

## PAS Ambassador Program – El Salvador, May 19-21, 2011

From 2009-2011 the Medical Board of “Asociación de Ciencias Neurológicas de El Salvador” (ACNES) aimed to develop an educational program for “non-neurologist” health practitioners (family medicine, specialists, paramedics, students, nurses and other health care personnel). Through these courses they provide participants with updates on diagnostic and therapeutic advances of the most common neurological diseases in daily practice to promote early diagnosis, prevention and proper treatment to such diseases.

This year San Salvador, El Salvador was host to the First Course on Movement Disorders for Non-neurologists, the Second National Course on Practical Neurology for Non-neurologists and the Symposium for Caregivers, Family and Persons with Parkinson’s Disease. 381 neurologists, neurosurgeons, health care personnel and Parkinson’s disease patients attended El Salvador’s first Ambassador Program of The *Movement Disorder Society - Pan American Section* on May 19-21, 2011. Dr. Jorge Luis Juncos, MD

(MDS Ambassador) discussed important topics in Parkinson’s disease, movement disorders and other neurological diseases common in daily practice.

The symposium began with a lecture on the “Role of Neurosurgery and DBS in the Management of Parkinson’s Disease” (Mechanism, patient selection and results) by Dr. Jorge Juncos (MDS Ambassador), followed by “Clinical Cases of DBS on the First 3 Patients in El Salvador” by Dr. Luis Ernesto González Sánchez (El Salvador), “Dystonias: Diagnosis, Treatment and Therapeutic Botulinum Toxin Uses in Neurology” by Dr. Ricardo López-Contreras (El Salvador), and “Tremors: Differential Diagnosis and Treatment” by Dr. Ernesto Cornejo Valse (El Salvador). Other neurological diseases were discussed by local Salvadorian doctors and the engineer Antonio Contreras Hernandez, president of the “Asociación Parkinson de El Salvador”, spoke about his personal experience in “Learning to Live with Parkinson’s Disease”. Later, Dr. Jorge Luis Juncos (MDS Ambassador) discussed “Par-



Dr. Ernesto Cornejo, Dr. Jorge Luis Juncos (MDS Ambassador), Dr. Ricardo López-Contreras

kinson’s Disease: Evolution and Treatment. Patient-centered Perspective” and ended the conference with a panel discussion for all participants and faculty.

In addition to the symposium, a press conference was held to publicize the importance of health education in Parkinson’s disease and other movement disorders for health care practitioners and the general population. ACNES hoped to promote early diagnosis and better care of these patients through their message to major print, television and radio media in the area.



**La Paz**  
**BOLIVIA**  
MARCH 4, 2012

**Update on the Pathogenesis and Treatment of Parkinson’s Disease and Related Disorders**

The Movement Disorder Society – Pan American Section

**Course Location and Date**  
La Paz, Bolivia  
March 4, 2012

**Course Description**  
Latin America has very few neurologists training in movement disorders and a limited number of centers currently providing surgical treatments. Those that do offer surgical treatments lack a clear candidate identification process. As a consequence, the majority of the patients have little control over their symptoms and very few have the opportunity for surgical treatment. It is for this reason that this particular region is in critical need of instruction on Parkinson’s disease and other movement disorders.

The purpose of this satellite symposium of the Pan American Congress of Neurology is to offer a forum for clinical and surgical discussion on Parkinson’s disease and on a variety of movement disorder topics, including the presentation of current research and available treatments.

We have selected a group of sessions with specific themes allowing participants to have an educational and comprehensive overview on subjects of broad interest to our community which will allow us to improve the quality of life of our patients.

**Learning Objectives**  
At the conclusion of this activity, you should be able to accomplish the following:

- Document the evolution of view of basal ganglia function
- Discuss recent advances in the genetics of movement disorders including new research perspectives with a specific focus on dominant parkinsonism
- Discuss new concepts of neurodegeneration
- Develop a strategy to implement a range of treatments available for the management of motor symptoms in the early and advanced Parkinson’s disease
- Understand the frequency and relevance of non-motor symptoms in Parkinson’s disease and their impact on quality of life
- Distinguish the major atypical parkinsonian disorders
- Identify the underpinnings and potential of using these disorders to understand and treat specific proteinopathies (i.e. alpha synucleinopathies and tauopathies)
- Define the clinical spectrum of cognitive and neuropsychiatric problems occurring in Parkinson’s disease, Huntington’s disease, and Tourette
- Recognize new developments in ablative lesions and DBS surgery for movement disorders
- Discuss indications and techniques to approach multiple targets
- Assess the relative advantages and disadvantages of ablative lesions versus DBS in Parkinson’s disease
- Explain how basic science has helped to understand clinical manifestation, current management and future therapies of each disease

**Audience**  
This course is recommended for Movement Disorder specialists, general neurologists, general physicians, physicians in training, and students.

**Registration/Fees**  
Non-Member \$50.00 USD; MDS Member \$40.00 USD; Residents/Fellows/Waived Dues\* \$20.00 USD  
\* Applies to MDS Junior and Waived Dues Members, Residents, Fellows, and those training in healthcare or scientific research.

This workshop is subject to cancellation if enrollment is insufficient. In the event of cancellation, registration fees will be fully refunded. MDS is not responsible for airfare, hotel, or other costs incurred by participants.

Visit [www.movementdisorders.org/education](http://www.movementdisorders.org/education) or contact the MDS International Secretariat for more information. MDS International Secretariat [education@movementdisorders.org](mailto:education@movementdisorders.org) +1 (414) 276-2145

## Motor Symptoms are the major determinants for Quality of Life in Parkinson's disease CONTINUED FROM COVER

nant of QoL in PD patients is that those patients are treated with anti-parkinsonian medications to control the motor symptoms of the disease but are often not treated for non-motor symptoms related to PD such as depression. For example, Van der Hoek and colleagues reported that 36% of the patients studied had minor depression and only 9% of these patients were being treated and 13% had major depression and only 30% of the patients were taking anti-depressants. Similarly, Gallagher et al [2010] found that patients reported an average of 11 non-motor symptoms yet an average of only five non-motor symptoms were reported in their medical records. Depression and other non-motor symptoms of PD are generally easily identified and can be treated; however, if these patients are only treated for the motor symptoms of PD with non-motor symptoms going untreated then in these patients the non-motor symptoms would be the predominant symptoms affecting QoL. This would not mean that motor symptoms would not be the major determinant of QoL if they were to also go untreated. Therefore, in order to adequately compare the impact of motor and non-motor symptoms of PD, it would be necessary to control for not only if the symptoms were being treated but also if the treatment was adequate.

Although most non-motor symptoms of PD can generally be treated and relatively well-controlled if recognized, motor symptoms such as gait difficulty and motor complications often cannot be adequately controlled as the disease progresses. These motor symptoms often lead to falling and associated injuries that are a primary reason for hospitalization and even death in PD patients. Hence, if we adequately treat our PD patients for non-motor symptoms, motor disability would be the primary determinant of QoL in the majority of PD patients. Of course, this does not mean that in some patients, non-motor symptoms such as dementia are not a significant determinant of QoL, but this would be in the minority of patients and would not negate the impact of the motor symptoms. In the majority of patients who are adequately treated for both motor and non-motor symptoms the motor symptoms, are still the major determinant of QoL.

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## Non Motor Symptoms are the major determinants for Quality of Life in Parkinson's disease CONTINUED FROM COVER

entirely on motor assessment (apart from the revised version of UPDRS) and can easily project a wrong assumption of a patient's HrQoL. For instance, a patient judged to have early/mild disease based on HY or UPDRS may have a very poor HrQoL because of a range of NMS such as low mood, pain, apathy, fatigue and sleep problems. These symptoms (the submerged aspects of the iceberg) are often "undeclared" to the neurologists partly because they are focussed on addressing motor symptoms. A recent European study of 242 patients which showed that up-to 60% of some NMS are not declared to the doctors leading to sub-optimal management and analysis shows that these patients, with "good motor state" but advanced NMS burden have poor HrQoL.<sup>8</sup>

The patient's perspective highlights issues regarding lack of communication in this respect. I quote Tom Isaacs, a sufferer and president of the Cure Parkinson's Trust, "the only person that can fully assess the QoL of an individual patient is the patient himself or herself" – "unless there is adequate communication there is little chance of tailoring treatment to suit that person's lifestyle".<sup>9</sup> Quoting a personal patient caregiver, "please do something about his mood and sleepiness, I can put up with the shakes but not him dozing off to sleep while we are talking!" also underpins the role of NMS in HrQoL not just of the patient but also the caregiver.

The final point is the data-driven approach. Among many others, Schrag et al. have suggested depression was the key determinant of HrQoL while evidence that the overall burden of NMS is the major driver for predicting HrQoL is gathering now that comprehensive tools that addresses a range of dominant NMS in one or related

scales such as the NMSS and SCOPA are validated and available.<sup>10-14</sup> A recent multicentre international study of 411 patients, addressed comprehensive assessment of the burden of NMS along with validated motor measures and HrQoL tools.<sup>15</sup> This first holistic study, showed a strong correlation ( $r_s=0.70$ ) of NMS with PDQ-39, widely accepted to be a validated measure of HrQoL while correlations with motor state were moderate. The standardised beta for the NMSS total score was 0.52 compared to 0.20 for SCOPA motor complications and 0.17 for SCOPA motor examination. The study included patients from all motor stages of PD.

The evidence of the whole NMS being the key determinant of HrQoL in PD is therefore, compelling. It is time to recognise therefore, that without a comprehensive approach to management of PD, which encompasses motor and a "holistic rather than piecemeal" non motor assessment, treatment may be sub-optimal with resultant poor "quality of life" of patient and carer.

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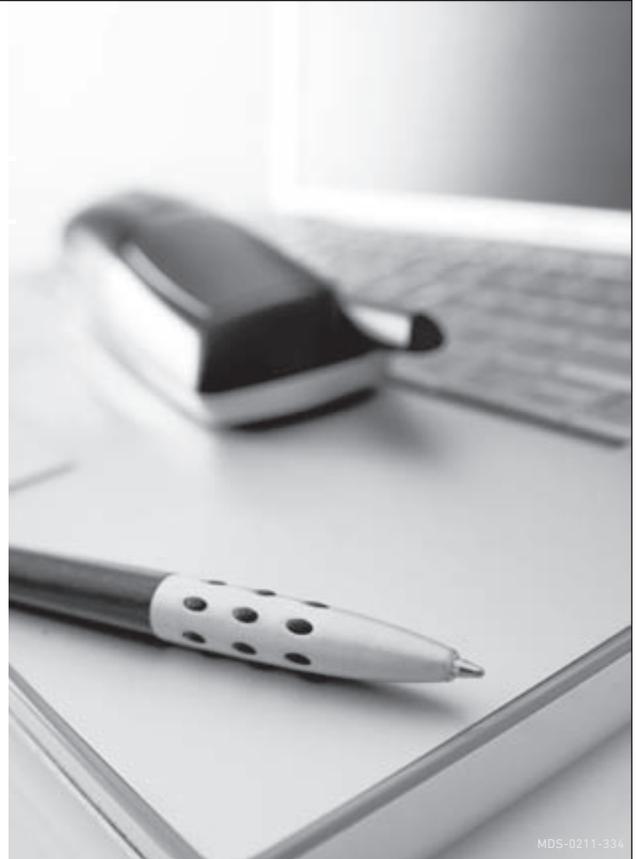
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- Fellowship or career opportunities?
- Information on available grants?
- Professional notices?

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The *Movement* Disorder Society



MDS-0211-334

## LETTERS TO THE EDITORS *Your Comments and Questions Are Always Welcome*

### Editorial Policy

As part of its democratic commitment, MDS welcomes the input of all its members about the features and articles that appear in this newsletter. Have a comment or question? Each issue will include responses in the "Letters to the Editor" section. All materials submitted become the property of MDS.

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## Non Motor Symptoms are the major determinants for Quality of Life in Parkinson's disease CONTINUED FROM COVER

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# SAVE THE DATE

Registration opens:	December 1, 2011
Preliminary Program available:	January 2012
Abstract Submission deadline:	January 6, 2012
Early registration deadline:	April 20, 2012
Final registration deadline:	May 30, 2012
16th International Congress of Parkinson's Disease and Movement Disorders:	June 17 – 21, 2012



The *Movement* Disorder Society

16<sup>th</sup> International Congress of Parkinson's Disease and Movement Disorders

# DUBLIN, IRELAND

# JUNE 17–21, 2012