

THE MOVEMENT DISORDER SOCIETY 1999–2000



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Forthcoming Meetings in 1999

International Botulinum Toxin and Tetanus Toxin Symposium

**17–20 November 1999
Orlando, Florida, USA**

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Scientific Issues:	D.J. Brooks
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Movement Disorders journal

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Moving Along

December 1999

A Movement Disorder Society UPdate

Volume 2, Issue 2

Editors: Dr Bill Koller and Dr Eduardo Tolosa

President's letter

Meetings '99

So far this year we have completed three sponsored meetings: Muscle Stiffness held in Port Douglas, Australia; Gait Disorders held in Prague, Czech Republic; and Ataxias held in Seattle, USA. We have one more meeting this year on Botulinum Toxin; this will be held in Orlando, USA, on 17–20 November.

The main goal of these small focused meetings is to consolidate our knowledge in specific areas of movement disorders and to suggest directions for new research. These meetings have proved to be very successful, and we are already looking forward to the meetings planned for 2001, which will focus on Brainstem Function and Movement Disorders, and Wilson's disease.

6th International Congress of Parkinson's Disease and Movement Disorders, 2000

Our attention is now mainly focussed on our next International Congress, which will be held in Barcelona, Spain 11–16 June, 2000. Convenor Eduardo Tolosa is planning a terrific program for this meeting that includes some formal teaching courses. A novel addition to the programme in Barcelona will be the Tapas Seminar. Because of the laid-back Spanish life style, the typical early morning breakfast seminars that would normally be held at an international congress just don't fit in. Thus, the breakfast seminars have been moved

to the late afternoon, and while the special lecture topics are delivered, tapas will be served! Don't miss this exciting feature!

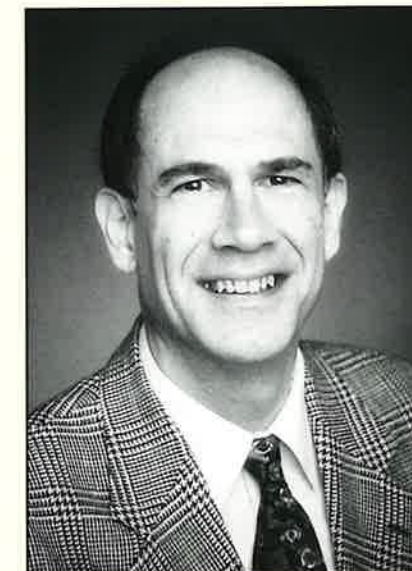
New MDS Secretariat

After a lengthy process, the Movement Disorder Society (MDS) International Executive Committee has selected Executive Director Incorporated (EDI) to be a permanent secretariat for our organization. The main office is in Milwaukee, Wisconsin, and there are branch offices in London and Paris. The secretariat's Executive Director is John Reichertz in Milwaukee; his Assistant Executive Director is Karen Hanley in London, while Rick Iber (also based in Milwaukee) is the Managing Partner of EDI.

We believe their international scope and board experience will be valuable for the MDS as we grow and evolve over the next few years. We are grateful to the Talley Management Group for having provided interim support over the last two years.

MDS–Roche Parkinson's Disease Award

I would like to offer my personal congratulations to Dr Susan H. Fox, MRCP, PhD, the winner of the MDS–Roche Parkinson's Disease Award, our first research grant. Dr Fox, of Mersey Region Walton Centre for Neurology and Neurosurgery, at the Liverpool and Manchester Movement Disorders



Dr Mark Hallett, President of the MDS

Laboratory, Division of Neuroscience, University of Manchester, was selected by Yves Agid, our Awards Committee Chair, and the International Executive Committee. Please read the article on page 4 for more details about the award and Dr Fox's research proposal.

Addressing issues of medical practice

Under the overall guidance of David Brooks, the Chair of our Scientific Affairs Committee, the MDS is preparing some documents concerning issues of medical practice that should be useful. Together with the American Academy of Neurology, we have organized a team of experts to review the literature that has been published on surgery for Parkinson's disease.



New sections of the MDS worldwide

MDS officers and the International Executive Committee (IEC) have endorsed a policy to enhance the regional activities of the MDS worldwide.

The aim is for the MDS to sponsor and encourage regional scientific and educational activities in the field of movement disorders, beyond the organization of biannual international congresses, MDS sponsored satellite meetings, and the distribution of the *Movement Disorders* journal.

A task force has been set up to develop concepts for MDS regional sections for Australasia, Latin America, and Europe. Members of the task force are:

W Poewe (chair) Austria
A Berardelli Italy
G Deuschl Germany
O Gershanik Argentina
J Moore Australia
W Oertel Germany
C Tanner USA
E Tolosa Spain
N Yanagisawa Japan

While there are no imminent plans for an MDS Australasia section, the Latin American Movement Disorder Group SOLAMA is in the process of becoming an affiliate member of the MDS.

Current European MDS officers and IEC members have formed a steering group for the creation of an MDS European section (ES). Members of the Steering Group are:

A Berardelli Italy
G Deuschl Germany
J Obeso Spain
W Oertel Germany
W Poewe Austria
N Quinn UK
O Rascol France
E Tolosa Spain

Having obtained the full endorsement of the MDS IEC, this group is now in the process of finalizing the constitution for this new MDS section by nominating a first slate of officers and executive committee members. The ES will formally be launched at the Movement Disorder Congress in Barcelona (11–16 June, 2000) and will organize its first

teaching course and European scientific movement disorder section jointly with the EFNS (European Federation of Neurological Societies) at their congress in Copenhagen (14–18 October, 2000).

The steering group is looking forward to active and lively participation from all European MDS members including all European neurologists with a special interest in movement disorders. In particular the MDS/ES is offering to co-sponsor Basal Ganglia Clubs in all regions of Europe, where the principal local organizers are MDS members.

Ideas and proposals for future activities for this new MDS/ES are welcome and will be reviewed by the steering group. Please send your suggestions to:

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Email: werner.poewe@uibk.ac.at

The IVth Pan-American Congress of Neurology

The IVth Pan-American Congress of Neurology was held in Cartagena de Indias, Colombia 8–14 October, 1999. Over 2000 delegates from around the world attended the congress in this beautiful historic seaside city.

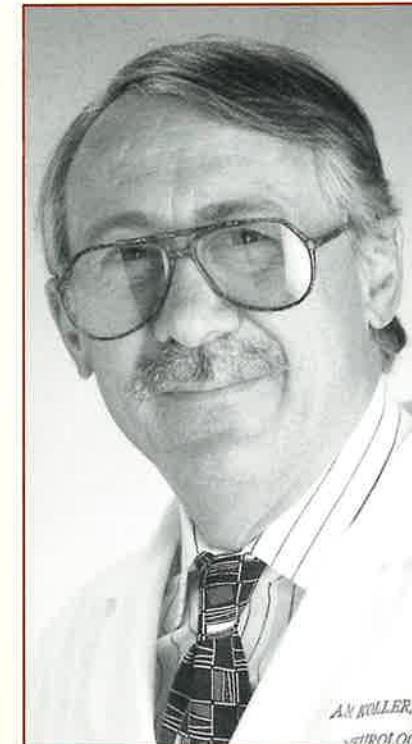
On behalf of the World Federation of Neurology Dr Kimura from Japan opened the congress, while Dr Padilla from Colombia presided over the meeting. The plenary session on the first day was a symposium on

movement disorders. Speakers for the session included: Dr Tolosa from Spain; Dr Lees from the United Kingdom; Professor Koller from the United States; Dr Cardoso from Brazil; and Dr Fernandez from Colombia.

Dr William C Koller, MD, PhD, Treasurer of the Movement Disorder Society

Dr William C Koller is currently Professor of Neurology for the Department of Neurology at the University of Miami Medical Center, as well as being Director of the University of Miami National Parkinson Foundation, at the Center for Parkinson's Disease and Related Movement Disorders. Dr Koller is also Director of Research at the National Parkinson Foundation at their World Headquarters in Miami, Florida.

Dr Koller received his undergraduate training at Marquette University, Milwaukee in Wisconsin, and gained an MS, a PhD in Pharmacology, and an MD degree in 1976, at the Northwestern Medical School in Chicago. He conducted his internship and residency in neurology at Rush Presbyterian Medical Center in Chicago, where he worked with the late Harold Klawans. Having been a member of staff at the University of Illinois and Loyola Medical Center, he became Professor and Chairman of the Department of Neurology in 1987, as well as being a Professor of Pharmacology at the University of Kansas Medical Center, where he remained until 1 July, 1999.



Dr William C Koller,
Treasurer of the MDS

Dr Koller is a Fellow of the American Academy of Neurology and a member of the American Neurological Association. He was on the Executive Board of the Parkinson Study Group, and is a member of many advisory boards.

Having published over 200 peer reviewed articles, Dr Koller has also edited many books on Parkinson's disease, including: 'The Handbook of Parkinson's Disease'; 'Therapy of Parkinson's Disease' (with Dr George Poulson); and more recently 'Movement Disorders Neurological Principles and Practices' (McGraw Hill), which he co-edited with Dr Ray Watts. Dr Koller has also written 'A Monograph on Tremor' with Dr Rodger Elble, which was published by Johns Hopkins Press in 1990. Dr Koller is a series editor for 'Neurological Disease and Therapy', which is published by Marcel Dekker in New York; this series has published 50 books on various topics in neurology.

Dr Koller's main interest is the treatment of Parkinson's disease, and in particular, surgical treatment with deep brain stimulation. In addition, he also has a long-standing interest in the pathogenesis and treatment of essential tremor. The International Tremor Society, the only society dedicated to patients with essential tremor, was founded by Dr Koller in 1990.

Videotapes available

1. Toronto-Western Spasmodic Torticollis Rating Scale (TWSTRS) Training Videotape
2. Instructional Videotape for Motor Fluctuation Diaries in Parkinson's Disease
3. Unified Parkinson's Disease Rating Scale Training Videotape

For more information or to order videos,
please contact the MDS Administrative Secretariat



MDS dyskinesia clinical rating scale

The MDS has recognized that a universally applicable scale for levodopa-induced dyskinesias should be developed as one of the society's important activities.

Therefore, the MDS has pledged to support and help finance the development of a clinical rating scale for levodopa-induced dyskinesias. Professor John Nutt, Professor of Neurology at the Oregon Health Center in Portland, Oregon, will head this project.

MDS portrait of David Marsden

The MDS has commissioned a portrait of the late Professor C. David Marsden, to be painted from existing photos. This memorial portrait will be unveiled at the upcoming congress of the MDS in June 2000, in Barcelona, Spain. It will have its home at the National Hospital in Queen's Square, London, where Professor Marsden was former Chair of the Neurology Department and Dean of the Medical School. The Executive Committee of the MDS commissioned the portrait as a tangible memorial to Professor Marsden, from the Society that he helped to co-found.

MDS-Roche Parkinson's Disease Award

The MDS-Roche Parkinson's Disease Award of \$20,000 (SFr 30,000) has been granted to Dr Susan H. Fox, MRCP, PhD. The award, which has been supported by an educational grant from F. Hoffmann-La Roche Ltd., is for clinical research in Parkinson's disease. It is particularly aimed to encourage young researchers who have novel and innovative approaches to offer.

The MDS Awards Committee judged the proposals based on their potential for improving quality of life for people with PD.

The grant will support Dr Fox's proposed research project, which is entitled 'Assessment of the Potential

of Opioid Receptor Antagonism as an Approach to L-dopa Treatment-related Dyskinesias in Parkinson's Disease'. The aim of her research is to test the hypothesis that opioid peptide stimulation underlies the generation of L-dopa-induced dyskinesias, and to investigate the value of developing opioid receptor antagonists to treat this condition.

Since February 1999, Dr Fox has held the post of Specialist Registrar Neurologist, at the Mersey Region Walton Centre for Neurology and Neurosurgery, in the Liverpool and Manchester Movement Disorders Laboratory, Division of Neuroscience, at the University of Manchester.

Forthcoming Congresses

6th International Congress of Parkinson's Disease and Movement Disorders

11-16 June, 2000

Barcelona, Spain

Congress organizer: Eduardo Tolosa

Congress Secretariat: AKM Congress Service, PO Box CH-4005 Basel, Switzerland.

Telephone: +41 61 686 77 11

Fax: +41 61 686 77 11

E mail: info@akm.ch

7th International Congress of Parkinson's Disease and Movement Disorders

10-14 November, 2002

Miami, Florida, USA

Depression is a significant factor in quality of life Report from the XIIIth International Congress on Parkinson's Disease

Depression is one of the most important factors to influence the quality of life of patients with Parkinson's disease (PD). Results from what has been the largest international quality of life survey to be undertaken in PD – the Global Parkinson's Disease Survey (GPDS) – were presented for the first time at the XIIIth International Congress on Parkinson's Disease in Vancouver on the 24 July, 1999. The results of this survey clearly indicate that depression, as assessed by the Beck's Depression Inventory (BDI), in addition to disease stage and medication, explain almost 60% of the variation in quality of life, compared with only 17% without BDI.

The findings of the GPDS, presented by Professor Leslie Findley from the Essex Neurosciences Unit and South Bank University, UK, were highly significant ($P < 0.001$). Although it has previously been speculated that depression plays a role in quality of life, this is the first comprehensive data that support this hypothesis. Of more surprise to the investigators was the finding that 'patient's satisfaction with the explanation given at diagnosis' and 'current levels of optimism' had small,

but significant effects on quality of life (both $p < 0.05$).

Professor Findley was joined by Professor Ali Rajput (Canada), Professor William Koller (USA), and Dr Tobias Eichhorn (Germany) at the Roche-sponsored symposium, entitled 'Quality of life in Parkinson's disease: key findings from a global survey'. The presenters focussed on the rationale for an international quality of life survey, how the methodology for such a large international survey was developed, and on the clinical implications of the findings. The meeting, chaired by Professors William Koller and Yoshikuni Mizuno (Japan), was well received by over 350 delegates from around the world.

In the final presentation Dr Eichhorn explored more deeply how depression, the initial diagnosis, and patient's level of optimism may be included in management guidelines. The GPDS has confirmed the high prevalence rates of depression associated with PD; 50% of patients assessed in the GPDS were actually found to be depressed. However, despite this high figure only 1% of patients and 2% of caregivers reported depression (in relation to the

patient). This discrepancy highlights that depression is not easily recognised in PD, even by the patient's caregiver. Dr Eichhorn therefore stressed that there is a real need to address this aspect of the condition.

The conclusion of the symposium was that more attention should be paid to quality of life as a whole, and the results obtained from the GPDS should help to develop holistic guidelines that will reflect this. One patient who attended the meeting was quick to point out how the findings of the GPDS reflect his own circumstances, and emphasized the relevance these have for the future management of patients.

Once analyzed, the information collected in the GPDS will enable us to answer a multitude of questions in PD. For example: Are the factors influencing quality of life different across the six countries? How do the clinicians, patients, and caregivers beliefs about quality of life differ? Do these beliefs correlate with quality of life measures such as the PDQ-39? Do the three factors identified in the GPDS also influence those patients with PD who suffer dementia? And the list goes on.



The GPDS faculty along with representatives from the GPDS Steering Committee and F. Hoffmann-La Roche Ltd.

The GPDS Steering Committee is currently looking for sponsorship to continue the analysis of the wealth of data provided by the survey. If you would like further information about the GPDS, please contact the GPDS Secretariat at FSP International:

Telephone: +44 (0)20 7501 4026

Fax: +44 (0)20 7720 3525

E mail: abrown@medicusgroup.co.uk



A paper describing the results of our review should be published soon in *Neurology*, and a summary will appear in *Movement Disorders*. In addition, Werner Poewe is directing a group effort to summarize the world's literature on medical therapy for Parkinson's disease, while Jay Nutt is organizing

the development of a clinical rating scale for the objective measurement of levodopa-induced dyskinesias.

Your views

We are always seeking the views of our members about your needs and wishes, both about the society and our newsletter, *Moving Along*. Look out

for a survey appearing shortly, and please let us know your comments and feedback, so that the society and the journal can meet your expectations. I look forward to hearing from you!

Mark Hallett

Dr Mark Hallett,
President of the MDS

Meet our colleagues

The MDS is a truly international organization. As of 15 June, 1999, we have 1420 members who come from over 60 different countries world-wide (see Table 1). The MDS is proud of its global appeal, and we hope and believe that the number of members (as well as the number of countries) will continue to grow in the future.

'Meet our colleagues' is a new column that we are introducing in this issue. This section will highlight different members of the MDS from various corners of the world, describing both their education and their work. Although obviously it may take a long time to publicize the total membership, we believe this is a step towards getting to know some of our colleagues a little better.

If any of our members would like to propose themselves or others to be introduced in our 'Meet Our Colleagues' section, please contact John Reichertz at the MDS Administrative Secretariat.

In this first 'Meet our colleagues' we feature our very own Treasurer of the MDS and Newsletter Editor, Dr William C. Koller, MD, PhD.

Afghanistan.....1	Greece.....8	Poland.....7
Argentina.....20	Honduras.....1	Portugal.....14
Australia.....41	Hong Kong.....5	Russia.....1
Austria.....24	Hungary.....1	Saudi Arabia.....2
Belgium.....53	India.....9	Singapore.....1
Brazil.....30	Ireland.....4	Slovak Republic.....1
Canada.....52	Israel.....8	Slovenia.....4
Chile.....7	Italy.....69	South Korea.....1
China.....3	Jamaica.....1	Spain.....41
CIS.....1	Japan.....79	Sweden.....17
Colombia.....5	Korea.....16	Switzerland.....17
Costa Rica.....1	Luxembourg.....3	Taiwan.....14
Croatia.....1	Malaysia.....1	Thailand.....5
Czech Republic.....7	Mexico.....2	Trinidad.....1
Denmark.....12	Netherlands.....29	Turkey.....9
Ecuador.....2	New Zealand.....2	United Kingdom.....71
Egypt.....3	Nicaragua.....1	United States.....539
El Salvador.....1	North Ireland.....1	Uruguay.....2
England.....1	Norway.....6	Venezuela.....5
Estonia.....2	Panama.....1	Yugoslavia.....1
Finland.....6	Peoples Republic of China.....1	
France.....36	Peru.....2	
Germany.....106	Philippines.....2	
		Total:1420

Table 1: A summary table to show the number of members of the MDS in each country of the world.

Announcement of the new MDS Secretariat

The MDS is pleased to announce that Executive Director Incorporated (EDI) has been chosen to be our new Administrative Secretariat, and that John Reichertz has been selected to be the Executive Director.

John Reichertz graduated from the University of Wisconsin-Milwaukee in 1978, having gained a bachelor's degree in educational studies with an emphasis on the cultural foundations of education. In addition to his responsibilities with the MDS, he is also the Director of Continuing Medical Education for the American Academy of Allergy, Asthma, and Immunology. This is the largest professional medical specialty organization in the United States, representing allergists and clinical immunologists from all over the world. John Reichertz is also past Executive Director of the Clinical Immunology Society.

EDI is a full service management association that has been in business since 1962. It provides a high quality, cost-effective service to clients, and functions at community, state, national, and international levels.

EDI makes the following commitments to its clients:

- To help clients realize their vision
- To provide a personalized, cost-effective service
- To create an active partnership to ensure client success
- To deliver innovative service solutions

EDI has offices in Milwaukee, Wisconsin, USA; Illinois, USA; London, United Kingdom; and Paris, France, providing a service to both trade and professional associations, as well as other related organizations.



John Reichertz, Executive Director
of the MDS

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MDS 2001 Sponsored Satellite Meetings

International Movement
Disorder Society

Brainstem Function and Movement Disorders
2nd European Meeting on Brainstem Function
and Pathophysiology

May 2001

Amsterdam, The Netherlands

Organized by: B. W. Ongerboer de Visser

Neurological Aspects of Wilson's Disease

Summer 2001

Dearborn, Michigan, USA

Organized by: Peter LeWitt

MDS membership directory

The 1999 membership directory was produced and distributed to all MDS members who were active in either 1998 or 1999. Additional copies of the membership directory are available from the MDS Administrative Secretariat.

