

Moving Along

A Movement Disorder Society UPdate



Dr. Bill Koller, co-editor of Moving Along

A word from the editors

any organizations and societies have a newsletter. The usual purpose of this form of communication is to keep society members up-to-date on the activities of the organization.

This includes activities and issues that are relevant to the membership. Dr. Tolosa has asked me to co-edit *Moving Along* with him. I accepted as I think this is a very important activity that the MDS should do. F. Hoffmann-La Roche has agreed to underwrite the cost of the newsletter but will have no say in it's management or contents. We thank them for their generosity.

I am sure that we will, with time, learn more how to create the best newsletter, particularly as we get feedback from the membership. However, with this first issue we have made a start, and Dr. Tolosa and the members of the executive committee look forward to further communication with our friends and colleagues by means of our newsletter.

Bill Koller Co-editor, *Moving* Along

President's Report

President of the Movement Disorder Society gets under way, I would like to share with you some of the progress that the Society has experienced over the past few months. This message opens Moving Along, the Society's newsletter which will be published three times a year. Its aim is to inform you of all relevant issues about the Society, and news that we believe will be of interest to the membership.

I wish to thank Bill Koller for having accepted the task of editing it with me. I would also like to thank F. Hoffmann-La Roche who have initiated this project through an educational grant.

New Administrative Secretariat

Although most of you are probably aware, it is my obligation to inform you that the Officers of the Society, with approval of the IEC, decided to change the Administrative Secretariats. Therefore, since



Dr. Eduardo Tolosa, President, Movement Disorder Society

July 1997 the Administrative Secretariat of MDS has been run by Talley Management Group, based in New Jersey (see address on page 6). Susan Whitehouse is the current Executive Secretary. I wish to thank AKM for having run the Secretariat through the difficult first years of the Society which led to its consolidation and present healthy state. In particular, I wish to thank Beat and Brigitte Dettwiler for their important and successful efforts in running the Secretariat and several of the biannual congresses and sponsored meetings of MDS.

Membership

The membership is growing and the Society is managing to carry

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President's Report cont'd

on its activities on a sound financial base in the able hands of our Treasurer, Ira Shoulson. This is a major responsibility and, if our finances are to remain in good order, it may be necessary in the very near future to raise the membership dues.

Thanks to the excellent science submitted by the membership and the work of the current editors, Andrew Lees and Tony Lang, our journal is now firmly established as the leading journal in the field of movement disorders. Movement Disorders now has an impact factor of approximately 2. It incorporates new sections such as the Historical Section, Editorial and Controversies. and an Expedited Publication section. The Table of Contents can be reviewed by visiting the journal website (www.movementdisorders.org). Plans are also under way to send the Table of Contents by e-mail to all members two months before the issue is distributed.

A number of MDS activities have been possible thanks to the assistance and support of WE MOVE. Such activities include others MDS and among Movement Disorders journal maintenance and website support, promotion of MDS and its activities, and shared booth expenses and staffing at selected events. I wish to acknowledge and thank Mitch Brin and Judith Blazer for their contribution to our Society. MDS intends to formalize the existing relationship with WE MOVE, as well as considering further joint opportunities.

Meetings '97

Last year two MDS grantsponsored meetings took place: one, on Multiple System Atrophy, was organized by Niall Quinn and a second on Tremor Disorders by Gunter Deuschl. We thank and congratulate both of them for having organized two outstanding meetings. They both set a standard level for MDS sponsored meetings that will be difficult to surpass. As an aftermath of the Kiel meeting, Deuschl et al have elaborated a Consensus Report on Tremor, which, once approved by the Scientific Issues Committee of the Society, will be published in Movement Disorders.

Events for '98 and beyond

Efforts to provide education to our members through 1998 are numerous. Among the various activities, the International Congress on Parkinson's Disease and Movement Disorders stands out as one of most important. It will take place in New York in October. Stanley Fahn, with the help of the Local Organizing Committee and the International Organizing Committee, has obviously prepared an event of the highest educational and scientific value.

This coming April, MDS has also organized a symposium, co-

sponsored by the World Health Organization, to mark World Parkinson's Disease Day. Under the title 'Uniting for tomorrow', the symposium will take place in Barcelona on 2 April. It intends to foster the idea that an alliance needs to take place between patients and their associations, physicians, and the pharmaceutical industry to try to solve the numerous problems Parkinson's disease patients and their families suffer. (See also page 5.)



The WHO is most interested in promoting quality care for Parkinson's disease and has created a WHO Working Group on Parkinson's disease. This group will meet for the second time on 3 April and will try to design a global strategy to fight the consequences of Parkinson's disease. Several members of MDS, including myself, are part of this WHO group.

MDS has also sponsored two other events in 1998: the IX annual edition of the Reunion Latinoamericana de Movimientos Anormales (RELAMA) which will take place this March in La Habana and the 3rd European Parkinson's disease Association Multidisciplinary Conference organized by the European Parkinson's Disease Association, under the leadership of Mary Baker, and cosponsored by the World Health Organization.

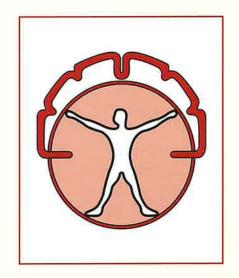
We must prepare the educational activities for the forthcoming years and it is now time to request bids for the organization of the International Congress on Parkinson's Disease and Movement Disorders of the year 2002. Similarly, those wishing to organize MDS grant supported symposia in the year 2001 should send their applications promptly to meet deadlines and requirements (outlined on page 7). The site of the International Congress and the selection of the symposia will be decided next October by the International Executive Committee during the New York Congress.

Election

This year is election time for MDS. As dictated by the Bylaws, elections will take place this year (an even numbered year) for officers and IEC members whose terms will begin in January 1999. This year we will be electing a President-Elect, Secretary-Elect, Treasurer-Elect, and 5 members of the IEC. Last year I appointed

Stan Fahn as chairman of the Nominations Committee. His committee has been hard at work to select a slate of nominees that can be voted upon by the membership.

I encourage all of you to vote and to propose or select those members that you think are best prepared to take over the new posts in our Society. I am sure the Nominations Committee will do an excellent task in searching for candidates and, when doing so, will take into consideration the geographic distribution as well as other possible obligations these candidates might have which could interfere with their tasks for the MDS if elected.



Committee meetings

Starting last year, the Financial Affairs Committee and the Officers of the Society began meeting regularly three times a year. These meetings have been of great help in the adequate running of the Society's activities. Still, it is my feeling as

President's Report cont'd

well as those of my fellow Officers that important changes need to be implemented in the Society in order to maintain a strong and competitive stance. We have organized a three day Strategic Planning meeting of the Officers and IEC members next July to develop a strategy to efficiently plan our needs for the next few years in the areas of education, research, and other goals of the Society. We shall obviously keep you all

informed of the results of this meeting.

The officers and the IEC are eager to continue the good works of our predecessors and to devise new and better ways to serve our members. Please let us know how you think we might improve our performance.

I look forward to seeing all the members at our International Congress in New York this autumn. Hasta pronto, amigos, Sincerely,

Melve

Eduardo Tolosa President



The Udall Bill

The passage of the Morris K. Udall Parkinson's Research Act of 1997 was achieved by the Congress of the United States.

The act provides that the NIH shall establish a program for Parkinson's research and training, including co-ordination of research among the several institutes, and a research planning conference every two years. The Act's implementation is not limited to any particular NIH institute. The Act 'authorizes' up to \$100 million in 'Parkinson's-focused' research in FY98, and 'such sums as may be necessary' thereafter. This means the NIH may spend

up to \$100 million in 1998 for Parkinson's research and funding may exceed \$100 million in FY99 and thereafter. Because Congress 'authorizes' but has not specifically earmarked the money, the NIH must find the necessary funding within that provided.

The Act also authorizes certain new programs, which supplement existing options, such as RO1's. For example, the Act provides for up to 10 Udall Center Grants, as well as Udall Awards Grants for research excellence to individual investigators. Udall Center Grants may be awarded to a single qualifying institution or a con-

sortium of co-operating institutions, which are required to conduct both basic and clinical research. Beyond the criteria specified, the NIH's standard peer-reviewed system and other procedures would determine how the grants are awarded.

While the Udall Act's passage explicitly expands the federal Parkinson's research program, how the expansion takes place is not specified. The NIH Director remains responsible for deciding when, how and to what extent these options are used for research into Parkinson's disease.



World Parkinson's Disease Day, April 2, 1998

'Uniting for tomorrow' is the focus of this year's World PD Day. The Movement Disorder Society has developed an extensive program which highlights the strength of forming partnerships between industry, physicians, and patients. The program will consist of a session for a general audience called 'Joining together to fight PD', and a scientific session which examines the progress and future management of this disease.

According to Professor Tolosa, 'Developing strong alliances between key organizations such as the International Movement Disorder Society, the PD organizations, the World Health Organization, and pharmaceutical companies, such as F. Hoffmann-La Roche, is vital if PD management is going to progress any further.'

Specialists, researchers, and representatives from patient

associations will meet with representatives from the pharmaceutical industry to discuss a variety of topics including the impact of scientific developments in PD, patient perspectives and new treatment approaches.



PD committee formed

Dr. Tolosa and the executive committee of the MDS have decided that it is important that the Society has an active role in the decisions of treatment strategies for the management of movement disorders.

As a means to this end, a committee has been formed, chaired by Dr. Werner Poewe from Innsbruck, Austria to formulate treatment algorithms for Parkinson's disease. Dr Koller has been asked to co-chair this committee, which will consist of 10 society members from around the world. The purpose of this

group is to produce an unbiased treatment scheme for Parkinson's disease that will be reviewed by the Scientific Issues Committee of the MDS. This will eventually be published in the *Movement Disorders* Journal.

While pharmaceutical company finances will be sought for the educational activities of the Society, they will not be involved in any other manner in the generation of this work. It is hoped that treatment schemes for other movement disorders will also be developed in the future.

MDSsponsored

meetings, 1999

STIFFNESS

August 26-29 Cairns, Australia

Contact: Phillip D. Thompson

INTERNATIONAL SYMPOSIUM ON GAIT DISORDERS

September 4-6 Prague, Czech Republic

Contact: Evžen Růžička

ATAXIAS

October 13-15
Location to be confirmed

Contact: S. H. Subramony

RELAMA meets in La Habana

The IX Anual Reunión Europeo-Latino Americana de Movimientos Anormales (RELAMA) took place this year in La Habana on March 18-19. It was held at the Centro Internacional de Restauración Neurológica (CIREN) and organized by Drs Macias and Tolosa.

The meeting consisted of an update on Movement Disorders and incorporated a Video Clinic for the presentation and discussion of unusual cases. The

meeting also featured a lecture on the Spanish influence (both good and bad) on the city of La Habana, given by the historian Nicanor Leon. **Participants** included speakers from Europe (Lees from London, Tolosa from Barcelona), South (Alarcon from Quito, Alvarez and Macias from Habana, Chouza from Montevideo, Merello from **Buenos Aires) and North America** (Kaufman from New York, Juncos from Atlanta, Koller from Kansas City). The symposium was given in Spanish.

RELAMA objectives are educational and designed for physicians in training and practice who care for patients with movement disorders. Previous meetings have taken place in Quito, Santafe de Bogotá, Caracas, Fortaleza, Aracaju, Panamá City, Valparaiso and Buenos Aires. These have been well attended.

New MDS Administrative Secretariat

Talley Management Group, Inc (TMG) of Mt. Royal, NJ was selected as MDS's new Administrative Secretariat last summer. TMG, which has extensive experience with scientific and medical professional societies, is an association management firm that provides complete headquarter management services, convention and exhibit management, and corporate symposia management to the nonprofit and corporate communities.

TMG's headquarters division will support MDS with administrative and membership services, strategic planning, journal administration, website support, and the continuing development of corporate relations.

The TMG meetings division, which has extensive experience in planning and carrying out international events for both nonprofit associations and industry, has already been working with MDS on the 5th International Congress on Parkinson's Disease and Movement Disorders to be held October 10-14, 1998 in New York City. The TMG Exhibits Division, which is well known for producing

successful trade shows in the medical field, will work closely with the Meetings Division of the MDS on the congress exhibits. If you need assistance in determining which division at TMG can help you, contact Executive Secretary Susan Whitehouse in the Executive Office.

(Cont'd on page 7)

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5th International Congress on Parkinson's Disease and Movement Disorders

October 10-14, New York

By now you should have received your brochure for the 5th International Congress on Parkinson's Disease and Movement Disorders. This was mailed out to all MDS members in mid March, along with 2 copies of the Call for Abstracts. If you have not received your brochure, please contact the MDS Administrative Secretariat Meetings Department: Tel: 609-423-7222, ext. 350, or e-mail at mdsmtg@mds.smarthub.com. Fax: 609-423-3420.

New MDS Administrative Secretariat (cont'd)

The Movement Disorder Society holds a business meeting of the general membership at least once every two years. The next meeting of the Society will be in New York, USA during the 5th International Congress of Parkinson's Disease and Movement Disorders, October 10-14, 1998.

For more information on MDS, visit our website at: www.movementdisorders.org

MDS satellite meetings for 2001

The MDS Administrative Secretariat is now accepting applications from meeting organizers who wish to receive MDS sponsorship for scientific meetings in the year 2001. Applications are available upon request from the Administrative Secretariat by mail, fax or e-mail. Completed applications must be submitted to the Administrative Secretariat by August 1. All completed applications will be

referred to the Education Committee which will recommendations to the International Executive Committee. The IEC will announce those meetings selected as MDSsponsored meetings for the year 2001 during the 5th International Congress on Parkinson's Disease and Movement Disorders to be held 10-14 October, 1998 in New York City.

1998 MDS Officers/ IEC/ Committee Meetings

<u>April</u>

Movement Disorders EditorialBoard Meeting

April 29, American Academy of Neurology, Minneapolis, MN, USA

MDS Officers Meeting

April 30, American Academy of Neurology, Minneapolis, MN, USA

June

MDS IEC/Officers Strategic Planning Meeting

June 30-July 3, Aigua Blava, Spain

October

MDS 5th International Congress on Parkinson's Disease and Movement Disorders

October 11-14, New York, NY, USA

MDS Officers/IEC meeting

October 9

MDS Business Meeting

October 13

Bids accepted for 7th congress in 2002

The MDS Administrative Secretariat is accepting applications for host cities for the 7th International Congress on Parkinson's Disease and Movement Disorders for the year 2002. Specifications can be requested from the Administrative Secretariat by mail, fax or e-mail. Letters of intent must be submitted to the Administrative Secretariat by June 1 and

completed bids must be submitted to the Administrative Secretariat by September 1. All completed bids will be referred to the International Executive Committee which will announce the site of the 7th Congress during the 5th International Congress on Parkinson's Disease and Movement Disorders being held October 10-14, 1998 in New York.

MDS membership, 1998

Dues bills for 1998 membership in MDS have recently been sent out. To prevent any interruption of membership benefits including receipt of *Movement Disorders* journal, please pay your dues as soon as you receive the invoice. Non-USA members are encouraged to pay by credit card in order to receive the best exchange rate.

The new Administrative Secretariat is building and revising the MDS database to ensure that the upcoming 1998 MDS Membership Directory will be accurate. Please be sure to fill out and return the Data Profile Update form that accompanies your bill.

Videotapes available

- Toronto-Western
 Spasmodic Torticollis Rating
 Scale (TWSTRS) Training
 Videotape
- Instructional Videotape for Motor Fluctuation Diaries in Parkinson's disease

For more information or to order videos, contact Michele Puliti, MDS Administrative Assistant, at the Administrative Secretariat.

THE MOVEMENT DISORDER SOCIETY



Officers

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President-Elect: M. Hallett
Secretary: A.E. Lang
Secretary-Elect: P.A. LeWitt
Treasurer: I. Shoulson

Treasurer-Elect: W.C. Koller
Past-President: J. Jankovic

International Executive Committee

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W.H. Oertel A.B. Young

Past Presidents

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