

## THE MOVEMENT DISORDER SOCIETY

1999



### Officers

President: M. Hallett  
President-Elect: W. Poewe  
Secretary: P.A. LeWitt  
Secretary-Elect: N. Quinn  
Treasurer: W.C. Koller  
Treasurer-Elect: R.E. Burke  
Past-President: E. Tolosa

### International Executive Committee

M. DeLong W. Oertel  
A. Lozano O. Rascol  
E. Melamed P. Thompson  
J. Nutt N. Yanagisawa  
J. Obeso A. Young

### MDS-sponsored meetings

#### International Movement Disorder Society Satellite Meeting on Muscle Stiffness

26-29 August, 1999

Sheraton Mirage Resort  
Port Douglas, Australia

Local Organizing Committee: Professor Philip D. Thompson  
Meeting Secretariat: Conference Action Pty Ltd., PO Box 1231,  
North Sydney NSW 2059, Australia.

Fax: +61 9956 5154

#### International Symposium on Gait Disorders

4-6 September, 1999

Prague, Czech Republic

Convenor: Associate Professor Evžen Růžicka, MD, PhD  
Symposium Secretariat: A. Kürfurstová, c/o Czech Medical  
Association J. E. Purkyne, PO Box 88, Sokolská 31, 120 26 Prague 2,  
Czech Republic.

Telephone: +420 2 29 72 71, 29 68 89

Fax: +420 2 29 46 10, 242 168 36

E-mail: KURSFURSTOVA@CLS.CZ

Website: <http://congress.cls.cz/gaitdisorders>

#### Inherited Ataxias

13-15 October, 1999

Seattle, Washington, USA

Contact: S. H. Subramony, M.D. Department of Neurology,  
University of Mississippi Medical Center, 2500 North State Street,  
Jackson, MS 3921-4505.

Telephone: +1 601 984 5500

Fax: +1 601 984 5503

E-mail: s-h@sehotmail.com

### The Movement Disorder Society Secretariat

#### New secretariat from July 1 1999

John J Reichertz, Executive Director  
611 East Wells Street  
Milwaukee, Wisconsin 53202  
USA

Telephone: +1 414 276 2145

Fax: +1 414 276 2146

E-mail: [jreichertz@movementdisorders.org](mailto:jreichertz@movementdisorders.org)



# Moving Along

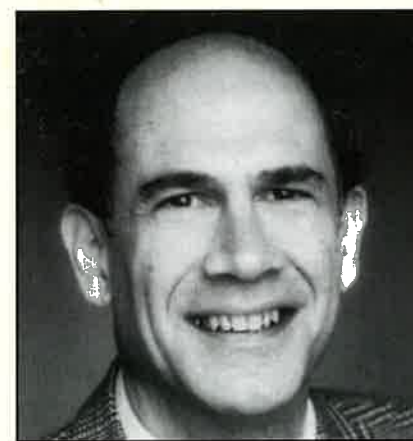
June 1999

## A Movement Disorder Society Update

Volume 2, Issue 1

Editors: Dr Bill Koller and Dr Eduardo Tolosa

## President's letter



Mark Hallett, President of the MDS

I am pleased to have this opportunity to communicate with members of the MDS. Thank you for your trust in electing me as President during these busy times. I am looking forward to the challenges of steering our organization towards more extensive activities, with greater involvement in international events relating to Parkinson's disease and other movement disorders.

### Thanks to Professor Eduardo Tolosa

Firstly, I would like to thank our newly retired President, Professor Eduardo Tolosa of Barcelona. Professor Tolosa worked tirelessly for our organization and has much to show for it. The organization of our central activities has been improved with one Administrative Secretariat, Talley Management Group, in charge. The Movement Disorders journal and the biannual Movement Disorder Congress also continue to thrive. We are

reaching out internationally and have begun to interact with local Movement Disorder Groups, where they exist, and are aiding their birth when requested. Professor Tolosa initiated an important liaison with the World Health Organization; he is a member of their Parkinson's disease task force, and also organized the second World Parkinson's Disease Day with them in Barcelona. Many thanks, Eduardo!

### Meetings '99

For 1999, there are many important events for you to know about. The MDS have contributed financially to some terrific meetings, which we hope you will enjoy attending. Muscle Stiffness will be the subject of a meeting in Port Douglas, Australia, 26-29 August; while Gait Disorders will be discussed in Prague, Czech Republic, 4-6 September, and a meeting on the Ataxias is scheduled in Seattle, USA, for 14-15 October. In addition we are sponsoring The Therapeutic Use of Botulinum Toxin, Orlando, USA, 17-20 November, at which we also encourage your attendance. The MDS also provided sponsorship for the third World Parkinson's Disease Day in New York on 10 April; please read the report on page 4 to hear about the activities that went on there.

### Meetings for 2000 and beyond

Looking ahead, in 2000 we will have our next International Congress in Barcelona and in 2001 we have planned sponsored meetings on Wilson's Disease and Brainstem Function and Movement Disorders. In 2002, our

International Congress will be in Cartagena de Indias. This year we will be seeking advice for both the 2004 and 2006 Congresses. We are moving the decision time for the International Congresses from 4 years in advance to 6 years in advance, in order to be able to reserve hotel space. Let us know if you have any suggestions.

### MDS/Roche Parkinson's Disease Award

The MDS is enthusiastic about supporting research and awarding its most deserving members. We are therefore pleased to announce our first research grant, the MDS-Roche Parkinson's Disease Award, which is supported by an educational grant from F. Hoffmann-La Roche Ltd. The award of SFr 30,000 is intended to encourage young investigators in clinical research into Parkinson's disease. The MDS Award Committee will be judging the applications submitted, and are particularly interested in how the proposed research will impact on the quality of life of patients with Parkinson's disease. The recipient of the award will be notified in July 1999. The name of the winner will also be announced on our website, [www.movementdisorders.org](http://www.movementdisorders.org).

### MDS committees

A number of the MDS committees have been revitalized. I will highlight one of these now, and devote space to others in subsequent issues of this newsletter. Dr. Chris Goetz is Chair of the Liaison Committee, which seeks to arrange official liaisons between the MDS and





## 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 2002

Cartagenas de Indias

Principal organiser: Miguel Rueda

## 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

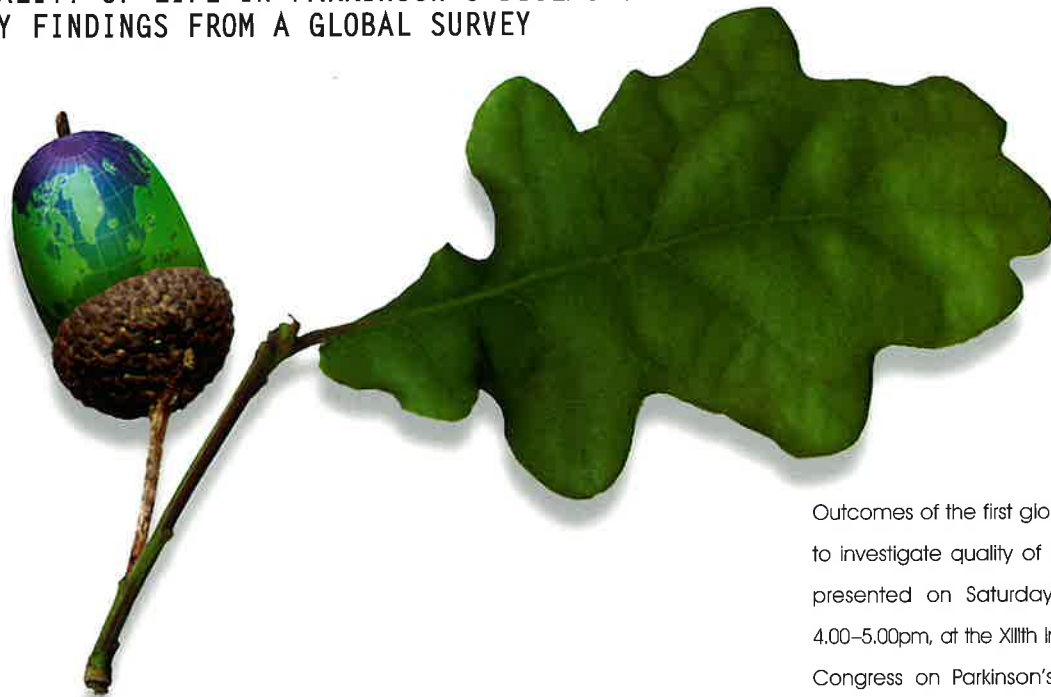
#### Neurological Aspects of Wilson's Disease

Summer 2001

Dearborn, Michigan, USA

Organized by: Peter LeWitt

## QUALITY OF LIFE IN PARKINSON'S DISEASE: KEY FINDINGS FROM A GLOBAL SURVEY



Outcomes of the first global survey to investigate quality of life will be presented on Saturday 24 July, 4.00-5.00pm, at the XIIIth International Congress on Parkinson's Disease, Vancouver, Canada.

BE THERE AT THE START OF SOMETHING BIG...



# Remembering David Marsden

With the passing of David Marsden, the world of neurology and neurosciences lost one of its most gifted leaders and prolific writers. More importantly, his children lost a loving father and his friends lost a companion with an extraordinarily intelligent and engaging personality.

David's zest for life was legendary. I remember the excitement in his eyes as he danced to country and western music (one of his many passions), during one of his visits to Houston. Our friendship began during the formative years of the MDS and was later enriched during our annual movement disorder courses in Aspen. I will always cherish the lunches and dinners during which time Stanley Fahn, David, and I shared stories about our recent experiences and our families, and reflected on our personal goals and aspirations. Although characteristically British, his humor and wit transcended comfortably all cultures and ethnic backgrounds. He earned the respect and admiration of his colleagues not only for his numerous scientific contributions, but also because of his impeccable professional integrity. I will always miss David's smile, charm, eloquence, and wise counsel. My memory of this unique individual, scholar, teacher, and close friend will never fade.

*By Joseph Jankovic, M.D., Professor of Neurology, Director, Parkinson's Disease Center and Movement Disorders Clinic, Baylor College of Medicine, Houston, Texas, USA.*

### Memories of David

I arrived in David Marsden's department at the Institute of Psychiatry in July 1975 on a Moseley travelling fellowship from Harvard Medical School. David was then 37 years old and 3 years into his Professorship. Already there was an active research laboratory, both in physiology and pharmacology; Peter Jenner was leading the pharmacology operation. David himself ran the physiology laboratory and showed me

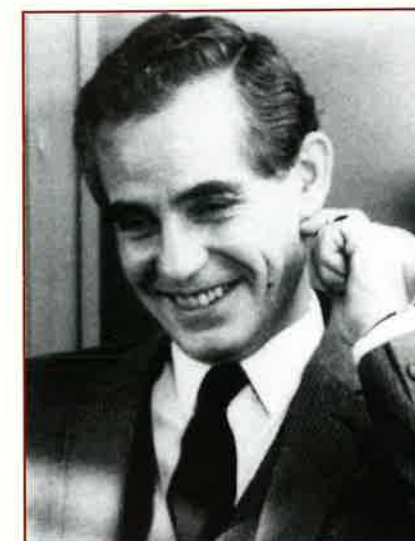
how to use the equipment when I first arrived. The laboratory was a duplicate of one that Bert Morton had set up at Queen Square, where David, Bert and Pat Merton did experiments at weekends. I was let into the inner circle on few occasions and observed the marvelous synergy between neurology, physiology, and engineering that produced pioneering research in motor control. The other physiologist in the laboratory was Jane Adam, a PhD student from Cambridge, who was John Rothwell's predecessor.

Meetings with David were invariably in the late afternoon over a glass of sherry. There were two glasses, one large and one small – David always had the large one. We discussed scientific projects, data analysis, and manuscripts. David was already a master at producing papers at a rapid rate and, on one occasion, he showed me how to do it. As we finished analyzing the data on a project, David said, "Let's write the paper". He took out a dictaphone, and began to dictate the paper onto a cassette. When we came to figures, he changed cassettes and dictated the figure legends. We were done in less than an hour! Most people think in sentences, and we admire people who think in paragraphs. David could think in manuscript-sized chunks.

*By Mark Hallett, M.D., Clinical Director, NINDS, Bethesda, USA.*

### David Marsden – a personal recollection

It was on the cusp of spring in 1983, when David and I were both attending the WFN Huntington's Disease meeting in Chicago, organized by Harold Klawans, a contemporary of David's who also died last year. Unusually, we shared a room, and when I arrived at the hotel there was, needless to say, an excellent Californian Chardonnay in the ice bucket already. Chicago was cold, but from there we independently flew to sunny,



*Professor C. David Marsden*

warm San Diego for my first experience of both California and the AAN. It was only last year that I learned that David had met Claudia Kawas for the first time when he sat next to her on that flight.

My first wife, whom I had also met on an airplane, had set up trade as a typesetter, and kindly agreed to set my lecture slides, since in those days the only alternative was letaset. David always rehearsed junior members of the department like myself through their talks. The day before my presentation we went to a Tex/Mex restaurant for lunch. Over a few beers, David watched and listened politely whilst I went through my routine, and at the end raised one of his formidable eyebrows, and with a barely suppressed grin said: "Excellent, but what is this drug levopoda (sic) that features on every slide?" Too late to correct them, we agreed I had to brazen it out with a joke about not letting one's wife make one's slides, which was a source of some amusement in the lecture hall the next day.

*By Andrew Lees, MD, Professor of Neurology, The National Hospital for Neurology and Neurosurgery, Queen Square, London, UK.*





National Neurology Societies, and with other societies interested in movement disorders. These associations should help the MDS to maintain contact with concerns all around the world, and will improve our ability to spread educational information internationally.

We are always looking for volunteers to help on our committees and other projects. If you would like to volunteer or have any suggestions, please let me know either directly, or via our Executive Secretary, Susan Whitehouse, at the Administrative Secretariat.

*Dr Mark Hallett*

Dr Mark Hallett,  
President of the MDS

# Meet the officers: MDS Secretary Peter A. LeWitt, M.D.



Peter LeWitt, MDS Secretary

On 1 January 1999, Dr Peter LeWitt took up office as Secretary of the MDS. Dr LeWitt was appointed Professor of Neurology, Psychiatry and Behavioral Neurosciences in 1989, at Wayne State University School of Medicine. His undergraduate studies, MD, and Master's Degree in Medical Science (Biochemical Pharmacology) were all conducted at Brown University. He gained his post-graduate training in medicine from Philadelphia General Hospital (University of Pennsylvania Division), and in neurology from Stanford University Medical Center. Dr LeWitt next served as a Clinical Fellow at the National Institute of Health (NIH) in the National Institute of Neurological and Communicative Disorders and Stroke. At the NIH he worked with Dr Donald Calne and Dr Thomas Chase in experimental

therapeutics of Parkinson's disease, dystonia, Huntington's disease, and tremor.

Dr LeWitt's clinical practice in movement disorders is now located in Southfield, Michigan, USA. He has served on the editorial boards of *Movement Disorders*, *Clinical Neuropharmacology*, and *Acta Neurologica Scandinavica*. Advisory positions have included the International Tremor Foundation, the United Parkinson Foundation, and the National Spasmodic Torticollis Association. Dr LeWitt co-directs a National Parkinson Foundation Center of Excellence.

The clinical aspects and therapeutic trials of movement disorders, including the etiology of Parkinson's disease and biomarkers for neurodegenerative disorders, are Dr LeWitt's main focus. As one of the founding members of the Parkinson Study Group, he served on the Steering Committee of the DATATOP study, as well as other clinical trials. He has participated in the development of several Alzheimer's and Parkinson's disease therapies, and botulinum toxin.

In 1986, Dr LeWitt demonstrated that tetrahydrobiopterin administration reversed the symptomatology of diurnally fluctuating dystonia, Segawa's disorder. This finding contributed to the understanding of

the tetrahydrobiopterin synthetic defect of this disorder, which has now been genetically linked to GTP cyclohydrolase deficiency.

Currently, Dr LeWitt's group investigates interactions between striatal dopamine and purine metabolism, oxidative stress markers *in vivo*, and inflammatory mechanisms in neurodegenerative disease. Another area of research has been an animal model of Parkinsonism, induced by sub-lethal injections of a micro-organism, *Nocardia asteroides*. Dr LeWitt is the author of more than 250 clinical and basic neuroscientific publications, and has recently edited, with Professor Wolfgang Oertel, *Parkinson's Disease: The Treatment Options* (Martin Dunitz Publishers).

The MDS sponsored meeting on neurological aspects of Wilson's Disease, to be held in 2001, is being arranged under the aegis of Dr LeWitt. Over the past year, he has worked with other MDS officers on plans for the continued international growth of this organization. He is particularly interested in new MDS initiatives that will enhance the identity of movement disorder specialists and foster regional meetings of clinicians and researchers.

# European Parkinson's Disease Association

The European Parkinson's Disease Association (EPDA) was formed in Munich in June 1992, with an initial membership of nine European Parkinson's organizations; the association has now grown to a membership of 30 European organizations. Through collaboration, partnership, and commitment, the EPDA has developed many initiatives that have helped to achieve its aim of promoting international understanding of Parkinson's disease. By enabling people living with this chronic neurological illness and their families to draw on best caring practice worldwide, the EPDA facilitates access to the latest medical and surgical advice, so that patients may make informed choices in order to achieve the best quality of life possible.

The last 18 months have seen an increase in the acknowledgement and respect for the work of the EPDA. Our partnerships with the World Health Organization, international Parkinson's disease associations, healthcare professionals, and the pharmaceutical industry have strengthened, forming a strong alliance to achieve improved quality of life for people with Parkinson's disease and their families.

The table below outlines some of the initiatives the EPDA is currently involved with.

The EPDA looks forward to maintaining a close working relationship with other organizations throughout the global community. There is a great need to share information, expertise, and knowledge. It is only by working

together in harmony, whilst respecting the needs of individuals and listening to what people with Parkinson's disease and their families have to say, that the quality of life of these people can be improved.

For further information please contact: Lizzie Graham, EPDA Liaison, c/o Parkinson's Disease Society of the United Kingdom, 215 Vauxhall Bridge Road, London SW1V 1EJ, UK.

Telephone: +44 (0)171 932 1304.  
Fax: +44 (0)171 233 9226.  
Email: Lizzie@epda.demon.co.uk



Initiative or study	Sponsorship and collaborative societies	Aims and objectives	Participating countries
Evaluation of physical therapies	Phase I: Glaxo Wellcome Phases II and III: European funding is currently being sought	<ul style="list-style-type: none"><li>To identify and define best practice, and to describe the treatment modalities used by physiotherapists</li><li>To validate a model of data collection so that research processes across Europe can be standardized</li></ul>	
Economic and emotional cost of care	Phase I: Du Pont Pharmaceuticals Phase II: European funding is currently being sought	<ul style="list-style-type: none"><li>To generate robust data on the socio-economic burden of Parkinson's disease</li></ul>	France, Germany, Italy, Spain, UK
Global Parkinson's Disease Survey	Total sponsorship provided by: F. Hoffmann-La Roche Ltd, in collaboration with the NPF and World Health Organization	<ul style="list-style-type: none"><li>To identify and assess factors, other than disease severity and anti-Parkinson's disease medication, which impact on the quality of life of people living with Parkinson's disease</li><li>Presentation of results at the XIII International Congress on Parkinson's Disease, Vancouver, Canada 24th July, 1999</li></ul>	USA, UK, Italy, Spain, Japan, Canada
Participation in Life Survey	Total sponsorship provided by: Pharmacia & Upjohn	<ul style="list-style-type: none"><li>The results from this survey of 5232 people with Parkinson's disease identified those areas affecting participation in life including symptoms of the disease, medication, and emotional and psychological problems</li><li>The results will be presented at the Participation in Life Conference in Krakow, Poland, 2-4 July, 1999</li></ul>	Belgium, Czech Republic, Denmark, Finland, France, Netherlands, Poland, Republic of Ireland, Spain, Sweden, UK

## Movement Disorders journal

If you are receiving your subscription to Movement Disorders as a benefit of your membership, please contact the MDS Administrative Secretariat (not the publisher) if you are having problems with the delivery of your journal or if you wish to make any changes to your address.  
MDS Administrative Secretariat  
Telephone: +1 414 276 2145  
Fax: +1 414 276 2146  
E-mail: jreichertz@movementdisorders.org

## 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, contact the MDS Administrative Secretariat.





# Parkinson's disease specialists and organizations address world wide challenges and opportunities

The Movement Disorder Society hosted the Third Annual World Parkinson's Disease Day on 10 April at the UN Regal Plaza Hotel in New York. Representatives from international health and neurological organizations, international patient advocacy groups, national patient advocacy groups, pharmaceutical companies, and distinguished scientific research and treatment specialists presented the latest information on world wide efforts to treat Parkinson's disease. The event carried on the tradition started by Mary Baker MBE, the President of the European Parkinson's Disease Association, who initiated the first major international event, held in the United Kingdom in 1997. This was followed by an event hosted by the Movement Disorder Society in Barcelona in 1998.

Dr. Mark Hallett, the President of the Movement Disorder Society, introduced the event and welcomed all participants. He highlighted that the mission of the Society is to bring together the world's clinicians, other health professionals, researchers and policy makers in movement disorders (including Parkinson's disease) to share the latest information on research and treatment.

Several organizations were represented at the event including the National Parkinson's Foundation, the European Parkinson's Disease Association, the American Parkinson's Disease Association, the Parkinson's Disease Foundation and WeMove. Dr. Melvin Yahr, represented the Extraparallel Research Group of the World Federation of Neurology which has for 30 years focused on stimulating research in Parkinson's Disease.

## Scientific advancements

Recognized movement disorder and Parkinson's disease specialists commented on the latest scientific advancements:

- Dr. Warren Olanow, Professor and Chairman, Department of Neurology at Mt. Sinai Hospital, presented the latest information on the etiology, pathogenesis and mechanisms of cell death
- Dr. Werner Poewe, Professor & Chairman, Director of the Department of Neurology at the University of Innsbruck, Austria, addressed the history and current trends in drug treatments for Parkinson's disease, describing how we have moved from purely treating symptoms to potentially modifying the underlying progression of the disease
- Dr. Matthew Stern, the Director of the Parkinson's Disease and Movement Disorders Center and Professor of Neurology at the University of Pennsylvania Health System at Pennsylvania Hospital, provided information on the latest genetic therapies which improve dopamine delivery to the brain
- Dr. Mahon DeLong, the William Timmie Professor and Chairman of the Department of Neurology at the Emory University School of Medicine, spoke on the reintroduction of pallidotomy in the 1990's which involves the surgical inactivation of portions of the internal pallidum by radio frequency lesioning
- Dr. William Koller, Professor and Chairman of the Department of Neurology at the University of Kansas, discussed the improvement

in quality of life that can be provided with deep brain stimulation

- Finally, Dr. Peter LeWitt, Professor of Neurology, Psychiatry and Behavioral Neuroscience Center at Wayne State University, discussed the latest animal research and aborted human fetal tissue transplantation studies. There are indications that there may be benefits to patients from this procedure beyond that currently offered by medications.

## Support

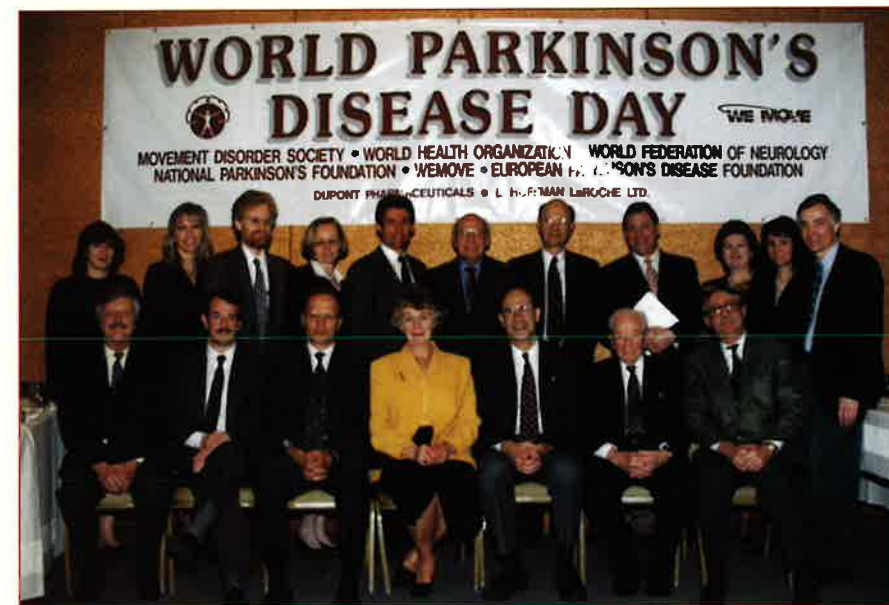
The World Health Organization, a co-sponsor of the event from its inception, has included Parkinson's disease in the WHO Global Initiative on Neurology and Public Health which aims to raise awareness of this condition. In addition, WHO has established a Working Group on Parkinson's disease. This multi-disciplinary group brings together leading experts in the field as well as representatives from key international patient groups. The Working group aims to identify key issues and develop high profile initiatives which will have a positive impact on the treatment and care of people with this chronic and debilitating condition.

Another co-sponsor was The National Institute on Neurological Disorders and Stroke (NINDS), represented by Dr. Hallett in the absence of Dr. Fischbach, the Institute's Director. Parkinson's disease is a primary interest of the Institute, and through the Morris K. Udall Parkinson's Disease Research Act, NINDS currently funds three research centers. The Institute also provides a free phone (800) number Parkinson's information service through

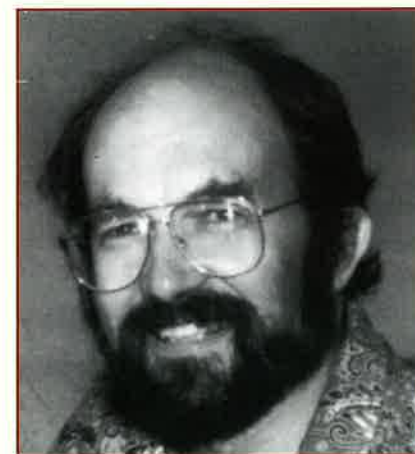
the Office of Communications and Public Liaison.

The event was made possible by generous educational grants from DuPont Pharmaceuticals and F.Hoffmann-La Roche. Both pharmaceutical companies are leaders in developing treatments for patients with Parkinson's disease and representatives of these companies were there to point out the important role industry plays in the search for a cure for this disease.

*Representatives from around the world meet in New York to mark the Third Annual World Parkinson's Disease Day*



## In memoriam for Jack Penney



*Dr. Jack Penney*

John B. Penney, Jr., MD was born on 10 December 1947 in Winthrop, Massachusetts. He died from an acute myocardial infarction on 31 January 1999 at his home in Boston, Massachusetts.

After receiving his undergraduate degree at Dartmouth College, Jack entered John Hopkins University Medical School where he met and married Anne B. Young. Together, Jack and Anne forged a remarkable duo in nurturing their family of professional colleagues and trainees

as well as creating their own wonderful family. Jack was an unabashed family man as a dedicated husband and father, as well as being able to reach out to support his patients and their relatives.

As Professor of Neurology at the Harvard Medical School and Massachusetts General Hospital, Jack was engaged in unraveling neurodegenerative disorders and developing more effective therapies for Huntington's, Parkinson's, and Alzheimer's disease. He possessed a rare blend of analytical scientific skills and compassionate human concerns, working with one foot in the laboratory and the other planted firmly in the clinic. Few investigators have the wherewithal to succeed in both basic and clinical research. Jack Penney attained this rare combination, and was admired by basic scientists and clinical investigators alike.

When Jack's life was tragically cut short in the prime of his personal and professional achievements, his organs and tissues were donated so that

those living might enjoy enduring benefits. This final act of humanity came as no surprise to those of us who were fortunate to know Jack and work with him. He found hypocrisy disdainful, and in his actions he did not shrink from his beliefs. Jack believed that therapeutic gains would come eventually from a steady commitment to research, both fundamental and applied. He left an enduring legacy to his family of patients, so that they might continue to benefit from his passion to care for and treat persons affected by neurodegenerative disorders.

Dr Penney's family has established the John B. Penney, Jr., MD Memorial Fund for Parkinson's Disease and Huntington's Disease Research. For those who would like to contribute, please contact: c/o VBK 915, Neurology Department, Massachusetts General Hospital, 32 Fruit Street, Boston, Massachusetts 02114, USA.

By Ira Shoulson, MD. Professor of Neurology, Pharmacology, and Medicine, University of Rochester, New York, USA.

