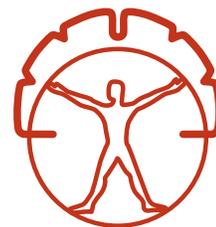


# MOVING ALONG

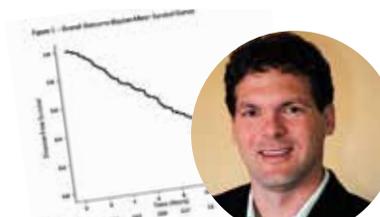
Editor, Antonio Strafella, MD, PhD, FRCPC



International Parkinson and  
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**6** Highlights from the 6th  
AOPMC in Hangzhou



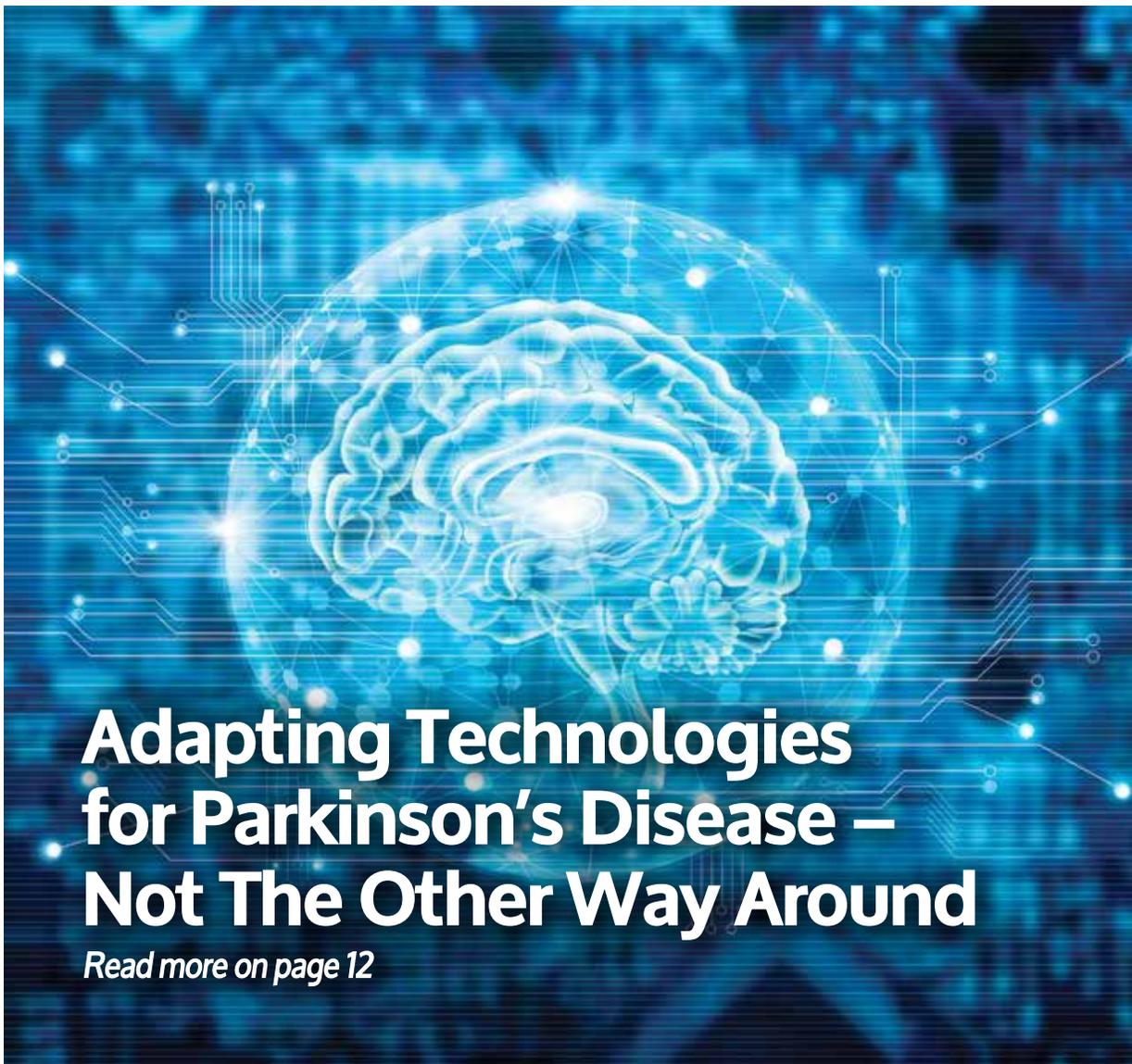
**10** Neurodegeneration in  
Idiopathic REM Sleep  
Behavior Disorder: Nailing  
Down the Numbers



**13** Health Professional (Non-  
Physician) Special Interest  
Group: A Conversation  
About Young Onset  
Parkinson's Disease



**14** Reflections on Revision  
vs. Reconstruction:  
Parkinson's Disease  
Research at a Crossroads

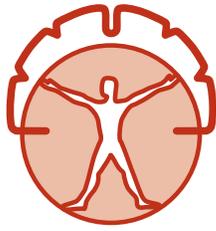


## Adapting Technologies for Parkinson's Disease – Not The Other Way Around

*Read more on page 12*

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## Table of Contents

- 4 Editorial: Antonio Strafella, MD
- 5 President's Letter: Christopher G. Goetz, MD, MDS President
- 6 6th Asian and Oceanian Parkinson and Movement Disorders Congress (AOPMC)
- 8 My Great Honor: Winning the 2019 Yoshikuni Mizuno Lectureship Award
- 10 Neurodegeneration in Idiopathic REM Sleep Behavior Disorder: Nailing Down the Numbers
- 12 Adapting Technologies for Parkinson's Disease – Not The Other Way Around
- 13 Health Professional (Non-Physician) Special Interest Group: A Conversation About Young Onset Parkinson's Disease
- 14 Reflections on Revision vs. Reconstruction: Parkinson's Disease Research at a Crossroads
- 16 Overview of Movement Disorders for Physicians, Nurses and Allied Health Professionals – Moshi, Tanzania
- 18 Atypical Parkinsonian Syndromes – Munich, Germany

## Letters to the Editor *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.

### Address your communications to:

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## Editorial

As the incoming Editor of *Moving Along*, I am particularly honored to take on this important duty. I would like to start on a more personal note to thank Drs. Mark Stacy and Carlo Colosimo, who served as Editors for the past ten years. They have done an outstanding job in implementing a number of structural changes, bringing the newsletter to the format and level that is today.

Everyone is well aware that in the last decade, there has been a significant growth of social media influence, which has made communication through these channels a critical component of our academic and professional lives. In this rapidly evolving landscape, we should be ready to adapt to these new standards and start a more dynamic format of *Moving Along*. We should be readily informing the international MDS community on new and exciting developments in the field of Movement Disorders in a more timely fashion. In particular, we want to highlight recent advances in basic and clinical research and provide a forum to discuss the many controversial issues raised by the scientific progress. We have a variety of research and clinical activities conducted by our MDS members, through several Study Groups, Task Forces, etc., that can be highlighted, making our MDS community an important component of the new format of *Moving Along*.

To facilitate the process of acquiring new, exciting content and material for future *Moving Along* issues, I am receiving help from a very active and dynamic Editorial Board, comprised of LEAP graduates from the various MDS Regional Sections (see below). We are meeting on a regular basis, brainstorming about new ideas on how to engage the MDS community at large. Given the explosion of the social media platforms, we have started working on improving the electronic format of *Moving Along* to

be closely linked to the MDS social media channels. The new format of *Moving Along* will feature the release of "Early View" articles on the MDS website and shared through the MDS social media channels on a rolling basis. The articles will then culminate quarterly into a full issue, which will also be promoted on the social media channels upon publication. The editorial board has been asked to share content with the MDS communications team, with the intent to provide more relevant scientific content to our members on a regular basis.

We are transitioning *Moving Along* to the next phase with the objective to create a highly dynamic newsletter which would highlight the most relevant scientific activities among the MDS community. For this, we would like to thank the MDS Officers, International Executive Committee, Regional Section leadership, and all of the MDS staff for their amazing support in making this possible.

We hope you enjoy this and the future issues of *Moving Along*.

Warm regards,



Antonio Strafella, MD, PhD, FRCPC  
*Moving Along* Editor, 2019-2021



## 2019-2021 Moving Along Editorial Board



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## President's Letter

The International Parkinson and Movement Disorder Society (MDS) is pleased to announce that Antonio Strafella, has accepted the position as sole Editor of *Moving Along* (2019-2021). Antonio and the new Editorial Board (Bettina Balint, Margherita Fabbri, Anhar Hassan, Carlos Juri, Prashanth L. Kukkle, Jee-Young Lee, Daniel Martinez-Ramirez) have put together a great first issue.

As part of the MDS Strategic Plan, this new and improved newsletter will bring more science to our members. Moreover, the collaboration and contribution over social media will broaden the impact of MDS publications. I look forward to the excitement and energy that Antonio and the new board will bring to the newsletter. On behalf of the MDS Officers, I wish them the best as they transition to a successful new phase of *Moving Along* in the years to come.

The Society also recently launched an all-new, redesigned website. The new layout will assist users for effortless website navigation, as well as better access the valuable tools and educational content that remain the foundation of MDS. We are excited to share this new online experience with you at [www.movementdisorders.org](http://www.movementdisorders.org).

There have been other key activities that have occurred over the last few months. The 6th Asian and Oceanian Parkinson's Disease and Movement Disorders Congress took place this past April. I want to thank all of our members who joined us in Hangzhou. In addition, Movement Disorder sessions at the 5th Congress of the European Academy of Neurology in Oslo, June 29- July 2, were done in collaboration between MDS-ES and the EAN. A special thanks to Evžen Růžička, MDS-ES Chair, who has continued to increase MDS-ES visibility at the EAN Congresses.

The next MDS International Congress will take place in Nice in September, during which the Society will hold its biennial election at the Annual Business Meeting. I encourage all MDS members to participate in voting for the upcoming leadership, either in person in Nice or via the mailed proxy ballot.

With the impending conclusion of the election process and end to my term as MDS President, it would be remiss of me not to express my gratitude to the 2017-2019 MDS Officers, Claudia Trenkwalder, Oscar Gershanik, Susan Fox, Bastiaan Bloem, Victor Fung, and Louis Tan. It has been a tremendous honor to serve alongside them for the past two years, and I greatly appreciate their unending dedication and guidance in leading the Society. I am pleased to be handing the gavel over in Nice to the next MDS President, Claudia Trenkwalder, who I know will continue to lead the Society to even more success during her tenure.

Sincerely,



Christopher G. Goetz, MD  
MDS President, 2017-2019



## 6th Asian and Oceanian Parkinson and Movement Disorders Congress (AOPMC) – Hangzhou, April 12-14, 2019

– Beomseok Jeon, MD, PhD, Professor, Seoul National University Hospital, Seoul, Korea; Chair, MDS-AOS; Chair, AOPMC Oversight Committee

Following the previous memorable AOPMCs in the Philippines, Singapore, India, Taiwan and Thailand, there is no doubt that the 6th AOPMC in Hangzhou, China has continued a legacy of providing quality movement disorder education to the Asian and Oceanian nations. Thus, with a total of 1,088 foreign and local attendees, representing 30 countries, the biennial activity broke registration records to become the largest AOPMC yet.

There were 62 faculty hailing from 17 countries in the Asian and Oceanian region and beyond. Together they presented at 16 sessions in addition to the corporate symposiums and the Video Tournament. The AOPMC and industry symposia began on April 12 and continued over the lunch hours on subsequent days, while the main scientific program had three parallel sessions each on April 13 and 14. The plenary sessions on specific movement disorders in the Asian and Oceanian region (Historical and Recent Developments and Genotype-Phenotype Correlation in Ataxia: An Asian Perspective) gathered a large audience resulting in standing room only. In addition to the lectures, the 6th AOPMC had a total of 216 accepted posters, many of which were recipients of the 21 awarded travel grants.



Left to right: Haibo Chen, Oscar Gershanik, Beomseok Jeon, Baorong Zhang

On April 14, at the same venue, 168 Parkinson's disease patients and caregivers came for the occasion of the 12th International Symposium of the Asian and Pacific Parkinsonism Association (APPA). Local and foreign

faculty speakers were invited to discuss PD expectations, care and treatment. The APPA representatives had the opportunity to meet a day prior, in order to discuss how to fortify the association and future meetings.



Participants and Panel of Experts from the AOPMC Video Tournament on April 13, 2019

6th Asian and Oceanian Parkinson and Movement Disorders Congress (AOPMC), continued on p.7

6th Asian and Oceanian Parkinson and Movement Disorders Congress (AOPMC), continued from p.6

## 6th AOPMC Highlights

The Welcome Ceremony on April 12 commenced with an elegant dance performance representing the changing of the seasons. The Chair of the Local Organizing Committee, Baorong Zhang, officially opened the 6th AOPMC with the keynote address. Oscar Gershanik, Haibo Chen, and Huawei Luo graced the occasion delivering their welcome remarks alongside the MDS-AOS Chair, Beomseok Jeon. Following the Opening Ceremony attendees were entertained with a local light and water show as they mingled at the Welcome Reception.

The Video Tournament was held on the evening of April 13, and was hosted by Anthony Lang and Victor Fung. The event involved many of the younger MDS members, residents and

fellows. There were four teams of three people with one group emerging as the winners.

This video tournament was made possible by the committee comprised of Yih-Ru Wu and Huifang Shang along with input from the Hosts.

The 3rd Philip Thompson and Yoshikuni Mizuno Lectureship awards were bestowed accordingly to Shengdi Chen (Topic: Diagnostic Biomarkers of Early Parkinson's Disease: Current and Future) and Ruey-Meei Wu (Topic: Application of Precision Medicine and Pharmacogenomics for Parkinson's Disease).

All said, the 6th AOPMC was made possible through the hard work and leadership of the AOPMC chair, Beomseok Jeon, and Baorong Zhang and his Local Organizing Committee and volunteers, including the APPA team, headed by Jiali Pu.



AOPMC Opening Ceremony dance performance on April 12, 2019



Ruey-Meei Wu accepting the Yoshikuni Mizuno Lectureship Award



Shengdi Chen accepting the Philip Thompson Lectureship Award

## My Great Honor: Winning the 2019 Yoshikuni Mizuno Lectureship Award

– Ruey-Meei “Robin” Wu, Professor, National Taiwan University, Taipei, Taiwan

Prof. Yoshikuni Mizuno is the mentor of my spirit in my academic career of research in Parkinson’s disease. It was indeed an emotional and honorable moment for me when I learned that I was the winner of the 2019 Yoshikuni Mizuno Award Lectureship Award at the 6th AOPMC in Hangzhou. I am sincerely grateful for Prof. Mizuno’s cultivation to my research career. It should be noted that my first clinical research paper on the risk factors of motor variance and dyskinesia in Parkinson’s disease was published in the *Journal of Neural Transmission* in 1992, when Prof. Mizuno was the Chief Editor. Another genetic paper on the CYP2E1 study was published in the same journal in 2002. He was the organizer of the 2nd Asian and Pacific Parkinsonism Association (APPA) held in Tokyo in 1999, when he invited me to give the first speech at the international conference on the “Care of advanced parkinsonian patients and their carers in Taiwan”. In early 2000, Prof. Mizuno had organized several years of Asian Scientific Symposiums on Parkinson’s Disease and Restless Legs Syndrome in Tokyo with rich educational contents and many participants, including more than 30 faculties and 400 delegates from across the Asian region to promote the regional research and communication among Parkinson’s disease specialists. These grand events not only provide a great opportunity for young researchers to present updated findings, but also strengthen the bond of friendship among the Asian delegates.

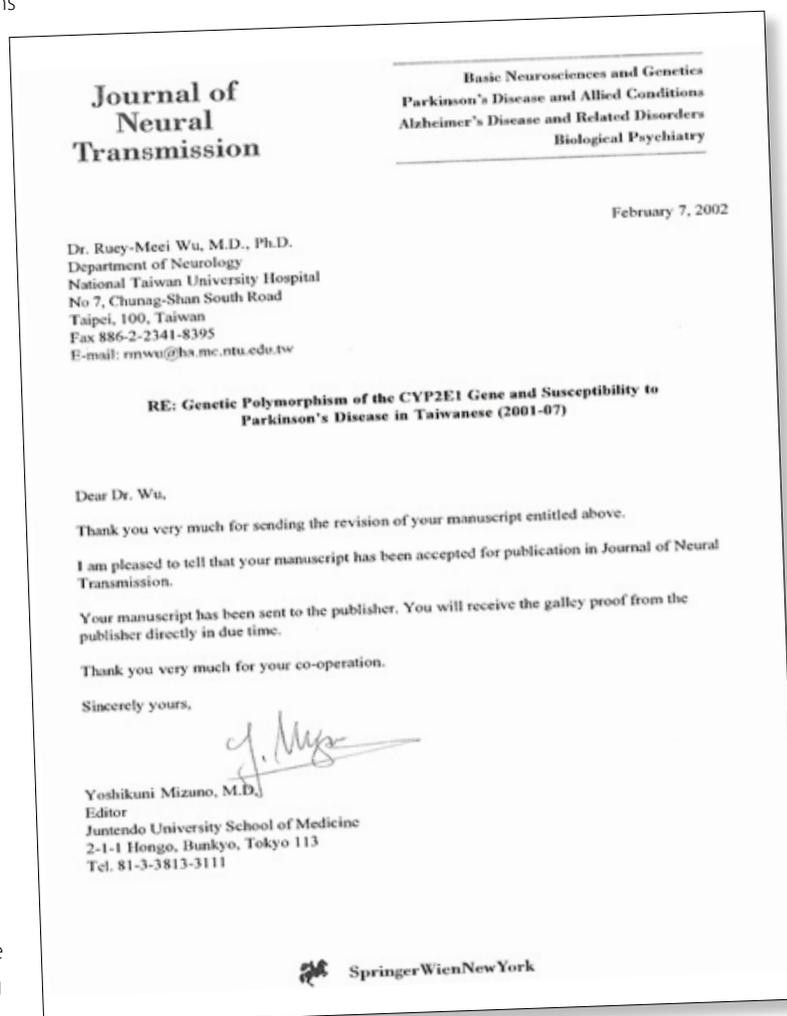
Regarding my research achievement in past decades, my research focuses on the etiology, clinical genetics and pathophysiology of Parkinson’s disease. Our group identified G2385R and R1628P of LRRK2 as the unique genetic risk factors in Asian population of PD. Using the integrated approach of combining gene dosage analysis and next generation sequencing, we specified the clinical phenotypes and genetic causes in early-onset and familial PD in Taiwanese Han Chinese and identified a novel UQCRC1 mutation affecting the mitochondria complex III activity in families with multiplex Parkinsonism syndrome and autosomal-dominant inheritance pattern. Based on the nationwide population cohort study, we reported anxiety, constipation, depression and antihypertensive agents as risk factors in PD. Our group first found hyperphosphorylation of HTRA2 protein in mitochondria contributing the neuronal death with HTRA2 gene mutation. Furthermore, our team discovered lovastatin protected neurite degeneration in LRRK2-G2019S parkinsonism through the activation of Akt/Nrf pathway and inhibition of GSK3 $\beta$  activity. Clinically, we led the work of Traditional Chinese translation of the MDS-UPDRS and the Unified Dyskinesia Rating Scale. Using the new versions of MDS rating scales, we verified the cross-cultural differences of the non-motor

symptoms between Taiwanese and western populations in PD. We also established the “Center of Excellence for Parkinson’s Disease and Movement Disorders” at National Taiwan University Hospital, qualified by International Parkinson Foundation to provide multidisciplinary care to patients to improve their quality of life.

Finally, I would like to thank my patients and my colleagues on the Parkinson team for their consistent support and hard work. This honor goes for their great contribution in the research of Parkinson’s disease in past decades.



Prof. Yoshikuni Mizuno

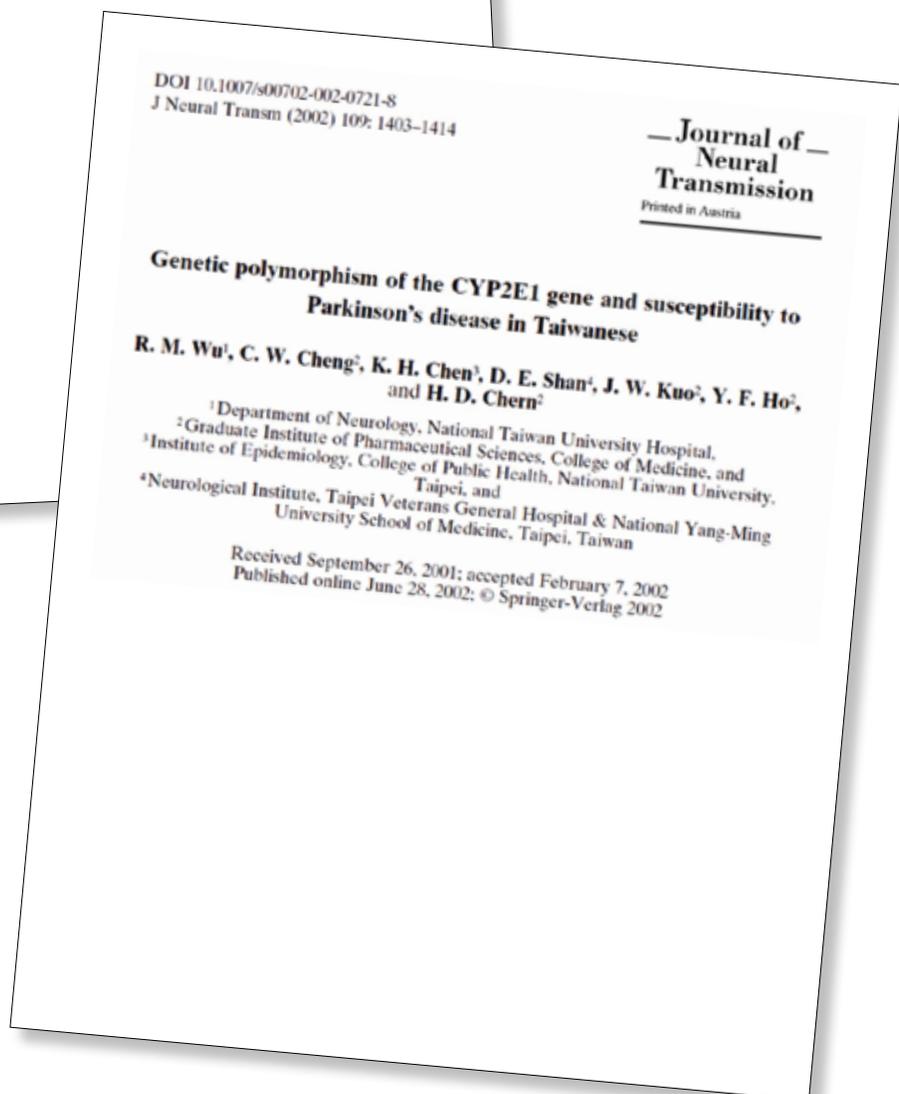
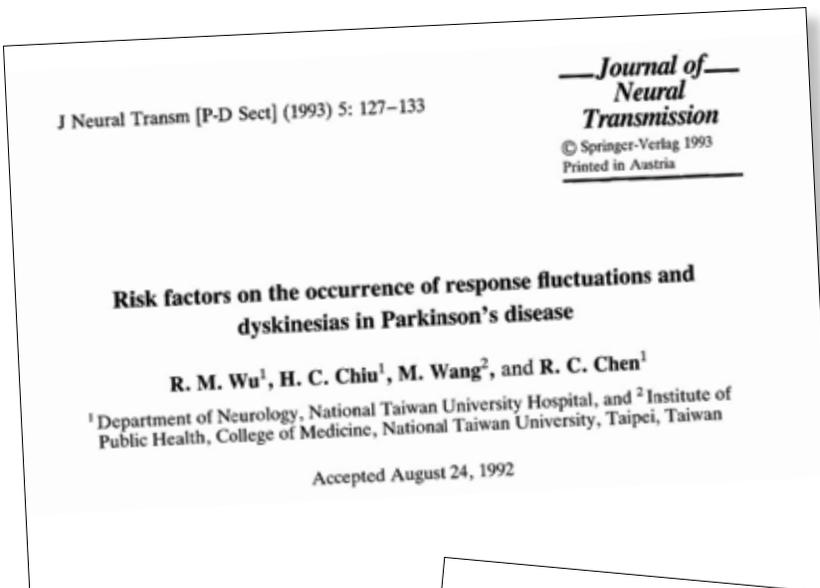


Acceptance Letter signed by Prof. Yoshikuni Mizuno

My Great Honor: Winning the 2019 Yoshikuni Mizuno Lectureship Award, continued on p.9

My Great Honor: Winning the 2019 Yoshikuni Mizuno Lectureship Award, *continued from p.8*

## Early Papers Accepted by Prof. Yoshikuni Mizuno



## Neurodegeneration in Idiopathic REM Sleep Behavior Disorder: Nailing Down the Numbers

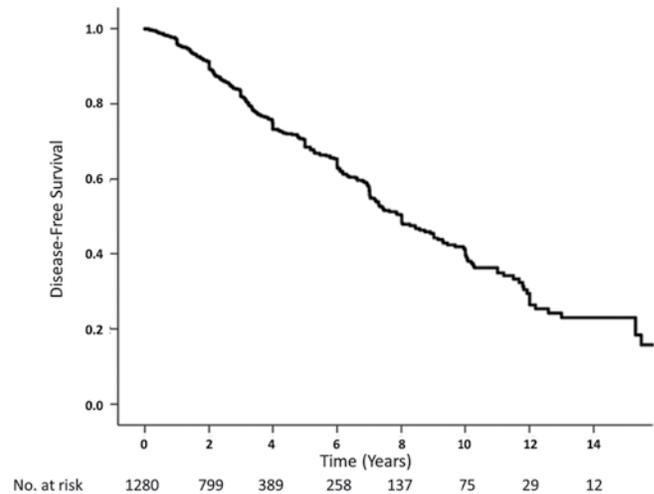
– Ron Postuma, MD, MSc, McGill University Health Centre, Montreal General Hospital, Montreal, QC, Canada

For over twenty years we have known that patients with idiopathic REM sleep behavior disorder (RBD) are at high risk of developing neurodegenerative synucleinopathies (PD, DLB, and MSA). Those single centers with the longest follow-up have found that over 80% of their cohort eventually phenoconverts to fully defined neurodegenerative disease. This has huge implications for the field, especially for the possibility that neuroprotective therapies could be applied at these beginning stages, early enough to have lasting impacts. There remain some important residual questions, especially: 1) is this a universal phenomenon in all sleep centers? 2) what is exactly the risk of phenoconversion? (we need precise numbers to plan interventions accurately), 3) are there simple and reliable ways to identify those who will convert sooner? and 4) what sample sizes are needed for definitive neuroprotective trials?

Now a 24-center, 1280 patient study from the International REM Sleep Behavior Disorder Study Group has helped answer these questions<sup>1</sup>. Its main findings:

- 1) The spectacularly high neurodegenerative risk is not a local phenomenon – these rates are seen across the world, with all centers documenting substantial phenoconversion risks
- 2) Conversion rates averaged 6-7% per patient per year, so 50% will develop dementia or parkinsonism by 8 years of follow-up.
- 3) Many markers predicted faster phenoconversion. Unsurprisingly, motor variables were among the strongest predictors; abnormal motor tests were associated with 3-fold increased phenoconversion rates. What was surprising was that simple quantitative motor tests were as predictive in this population as were more sophisticated neuroimaging procedures such as DAT scan. Also notable, motor variables predicted 'dementia-first conversion' and 'parkinsonism-first' conversions equally (in fact, subtle motor findings are seen even longer before diagnosis of DLB than in PD without dementia). The similarity of the pre-dementia/parkinsonism states was not just a motor phenomenon; except for cognitive variables, all measures predicted dementia and parkinsonism equally. Olfactory tests were the next strongest predictors, with hazard ratios of just under 3 (higher if you exclude MSA). Color vision (generally a test of visuospatial cortical function) specifically predicted dementia. Constipation and erectile dysfunction marked a 1.7-fold increased

Figure 1 - Overall Outcome (Kaplan-Meier Survival Curve)



- risk. Variables that did not predict phenoconversion included sex, mood disorders, other sleep conditions, and substantia nigra ultrasound (although negative findings need to be interpreted cautiously given possible floor effects in very long-duration markers, confounding by antidepressant-triggered RBD, etc.).
- 4) Sample size calculations are encouraging. For an unselected RBD population in a 2-year trial, using an agent that reduces rate of phenoconversion by 50%, it would require 366 patients per arm to demonstrate prevention of parkinsonism/dementia. Selecting patients on factors such as motor testing or olfactory loss could reduce sample sizes to as low as 150 patients per arm. Given that the study included 1280 patients, it seems that a trial-ready population for neuroprotection already exists in the centers of the RBD study group.

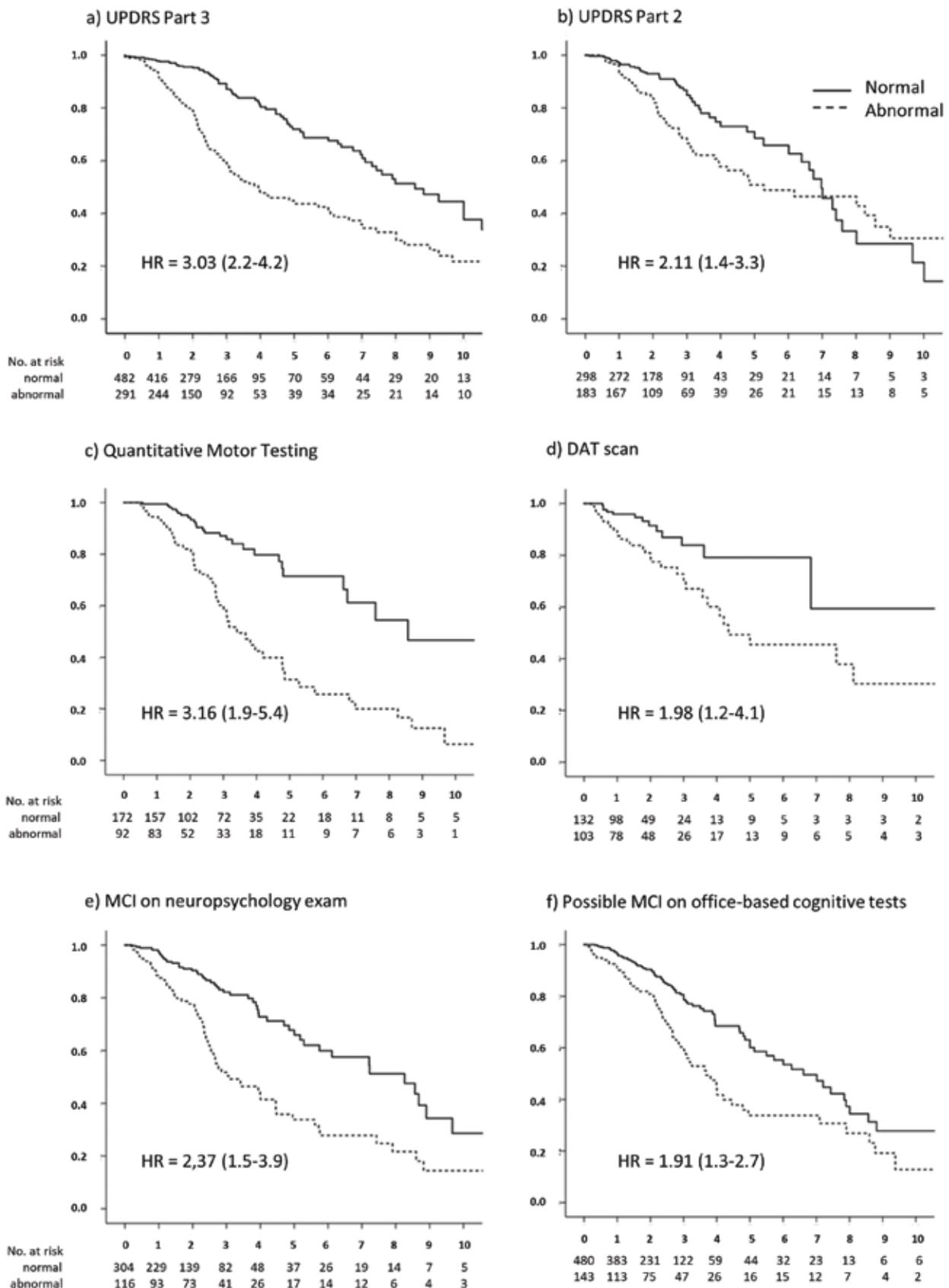
So, the ground work has been prepared. With numerous exciting potential neuroprotective agents in preclinical or early clinical testing, we now eagerly await the first neuroprotective trial in prodromal PD.

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Neurodegeneration in Idiopathic REM Sleep Behavior Disorder: Nailing Down the Numbers, *continued from p.10*

Figure 2 – Motor and Cognitive Predictors of Outcome



## Adapting Technologies for Parkinson's Disease – Not The Other Way Around

– Alberto J. Espay, MD, MSc, James J. and Joan A. Gardner Family Center for Parkinson's Disease and Movement Disorders, University of Cincinnati, Cincinnati, OH, USA; Chair, MDS Task Force on Technology

– Walter Maetzler, MD, Department of Neurology, Christian-Albrechts University, Kiel, Germany; Co-Chair, MDS Task Force on Technology

With the miniaturization of technology, the last couple of decades have brought an increasing panoply of devices that capture a range of behaviors of interest, many of interest in the field of Movement Disorders. The developmental sequence, however, has been as follows: Company A develops Product X and offers it as a means to “learn” more about [tremor, bradykinesia, mobility, dyskinesia, etc.] in patients with Parkinson's disease. Meanwhile, Companies B through F develop Products Q through U, ostensibly also focused on quantifying the granularity of the same behaviors, and ask that we help with validating each of these products to find a way into our patients.

Enter the MDS Task Force on Technology. On its second incarnation, the group has been mandated by our President, Dr. Christopher Goetz, to enact the vision of maximizing the diagnostic and therapeutic potential of mobile health technologies. The driving force has been to move our role from passive recipients of technology, guiding clinicians and patients to make decisions on available technologies, to active stakeholders, informing how technology should be adapted to meet the clinical and research needs to enhance the monitoring and care of patients. Indeed, the Task Force was born with the mission “to facilitate the rational development and integration of technologies in order to enhance relevant behavioral measurements and delivery of treatments to patients with movement disorders.”

The MDS Task Force on Technology recently suggested a roadmap for reorganizing the developmental flow of mobile health technologies into patient-centered digital outcome measures.<sup>1</sup> Key components includes the creation of an open-source platform to integrate mobile health technology output and standard operating procedures in the assessment of clinical suitability of the data



Members of the MDS Task Force on Technology, meeting in Hong Kong. Left to right, front row: Jeff Hausdorff, Alice Nieuwboer, Serene Paul, Lynn Rochester, Fay Horak, Alberto Espay, Paolo Bonato; back row: Tiago Mestre, Álvaro Sanchez Ferro, Walter Maetzler, Ralf Reilmann, Bas Bloem, Björn Eskofier (guest), and Jochen Klucken. Absent: Ray Dorsey and Aristide Merola.

yielded by these technologies to assist with the regulatory approval of devices and algorithms.

The low-hanging fruit to aim for in the near future, and an early proof of concept of the proposed framework, is the reconfiguration of a Parkinson's diary for the digital age. While the available diaries, mostly paper-based, have been helpful in providing hard endpoints for clinical trials, forcing patients into their “off” and “on” dualism is not adequate for clinical care or to measure the nuanced behaviors associated with fluctuations in motor and non-motor symptoms. The Task Force has issued a proposal for an e-Diary/Tracker that would harness the complementary information provided by diaries and wearable sensors.<sup>2</sup> The latter stands to provide continuous, objective measures, independent from patient feedback; the former, digested through machine learning algorithms, relevant context. Combined, such e-Diary/Tracker would individualize the range and severity of patients' fluctuations, anticipate the likelihood of “good” and “bad” times, and empower patients themselves with actionable information, which could accomplish what no other mobile

health technology has: long-term adherence.

Pending further deliberations with Dr. Goetz and the MDS Officers, the MDS Task Force on Technology will plan to enact the work proposed through collaborations with method experts on the generation of a central, ideally MDS-sanctioned technology-integrating platform. Such common-language portal will read and integrate data from diverse proprietary technologies, allowing users to select the most suitable “channels” of information. The synchronized and integrated data could be accessed from familiar interfaces such as, smartphones, tablets, computers, and electronic health records, yielding potential benefits to all stakeholders.

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## Health Professional (Non-Physician) Special Interest Group: A Conversation About Young Onset Parkinson's Disease

– Victor McConvey, RN, MACN, Nurse Consultant, Parkinson's Victoria, Australia; Chair, MDS Health Professional (Non-Physician) Special Interest Group

It is estimated that 10 to 20 percent of people diagnosed with Parkinson's disease are under the age of 50<sup>1</sup>. While this figure may need some further validation, it is a reality that people who are of working age are a feature in all of our clinics and clinical practices. This group of patients can be complex and can experience symptoms differently and it is likely their duration of illness will be much longer than our most commonly encountered clients.

The focus of this article will share the results of a global conversation amongst members of the MDS Health Professional (Non-Physician) Special Interest Group from Australia, Singapore, Portugal, Luxemburg, Israel, Brazil, United States and Canada, which focused on young onset Parkinson's disease (YOPD) and will highlight some of the challenges and considerations in planning care.

### Access to Services Sensitive to the Needs of People Living with Young Onset Parkinson's Disease

The conversation identified that people with YOPD were able to be seen with in the normal neurology clinics and access multidisciplinary teams, where available, as any person with Parkinson's is able to do. There were no healthcare services which specifically had programs or streams designed with the needs of someone who was of working age (e.g. clinics did not operate outside of business hours making access easier). A willingness of both healthcare professionals and physicians is needed in order to attempt to accommodate the specific needs of this group as they were identified during the consultation (e.g. occupational therapists supporting someone to remain within the work place or social work supporting the children with a parent who is living with YOPD). The conversation identified the role tele-health and online health coaching could potentially play in supporting access, however these were in their infancy and challenges surrounding reimbursement, particularly in the United States, were identified as being inhibitory.

There were some specific peer support opportunities available for people living with YOPD, which were often supported by the local Parkinson's associations. Parkinson's peak bodies or associations, in collaboration with health care providers, also developed specific education opportunities, seminars and conferences dedicated to people with YOPD. There were also a number of online supports, such as Facebook pages dedicated to YOPD, which are largely generated by young people with Parkinson's and were frequently unmoderated spaces.

### Challenges and Services

The participating healthcare professionals were able to identify a number of gaps or unmet needs experienced by this group. These particular needs were often related to specific psychological supports, discussing and educating children about the diagnoses a parent may be living with, managing work and discrimination, and conceiving and having children when you are living with Parkinson's disease. Conversely, when a child is diagnosed with YOPD, access to counselling and the sense of guilt experienced by the parent is difficult and unacknowledged.

In regard to pregnancy, there is little published research or case reports on how to manage pregnancy or breast feeding while taking medication for Parkinson's disease. What is identified is that it is possible to conceive and deliver a healthy baby on medication including intra jejunal levodopa infusions<sup>2</sup>. The conversation was able to identify that prenatal and postnatal care involved a high degree of collaboration between neurologists and obstetrics.

A key challenge identified in the discussion were concerns people living with young onset Parkinson's experienced related to financial insecurity, maintaining work and discrimination. These concerns were often supported by interventions from healthcare professionals, such as physiotherapy, occupational therapy and social work, in addition to referral to appropriate legal and financial counselling where available. In developing regions, the absence of welfare or appropriate supports often resulted in increased reliance on extended family becoming impoverished with related poor outcomes.

The participating healthcare professionals also identified that the young cohort of patients were more likely to over use medication particularly to manage work and periods of heightened stress, and were at greater risk of developing Dopamine dysregulation syndrome<sup>3</sup>.

Another phenomena identified by several contributors was the impact on menstruation on Parkinson's symptoms, with the observation made that both motor and non-motor symptoms worsened at this time<sup>4</sup>.

The longer duration of illness was identified by the participants as creating some unique challenges in managing symptoms. It was this group of patients who had the greater uptake of advanced infusion therapies and also were more likely to receive DBS in the areas where it is available.

### Conclusion

This was an important conversation to have and has highlighted the complexity and needs of people living with YOPD. The impact of the condition on family, work and lifestyle and the duration of the illness amplify the symptoms and challenge us as healthcare professionals to be creative and sensitive in the ways we care for people living with YOPD. There are also opportunities to carry out more research and critically look at our service structures to identify the healthcare needs of people with YOPD and find better ways of supporting symptom management, duration and impact of illness.

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## Reflections on Revision vs. Reconstruction: Parkinson's Disease Research at a Crossroads

– Alfonso Fasano, MD, PhD, Movement Disorder Unit, Toronto Western Hospital, Toronto, ON, Canada

The 'Gap Philosophy' in Movement Disorders started when Francesca Morgante (London, United Kingdom), Alberto Espay (Cincinnati, OH, USA) and I inaugurated a new format for conferences in 2010, focusing on less popular topics and also giving voice to outside-the-box thinkers. Ten years and three editions later, we joined our visions and efforts with the Krembil Foundation in Toronto, ON, Canada, and several outstanding researchers led by Anthony Lang (other committee members included Andres M. Lozano, Lorraine Kalia, and Antonio Strafella). The Krembil Knowledge Gaps in Parkinson's Disease Symposium, held in Toronto, ON, Canada on April 24-26, 2019, gathered 35 internationally renowned speakers, assigned to seven thematic areas: 1) The Conceptual Challenges; 2) Big Data, Machine Learning, New Techniques, & Virtual Cohorts; 3) Disease Mechanisms; 4) Experiences in Other Diseases in Neurology and Medicine; 5) Transplantation & Other Strategies; 6) Trials - Biomarkers, Trial Designs, Consortia; and 7) Trials - Designs and Lessons Learned. The conference was endorsed by the American Parkinson Disease Association, Edmond J. Safra Philanthropic Foundation, the International Parkinson and Movement Disorder Society, the Michael J. Fox Foundation, and the Parkinson's Foundation.

This time we focused all of our energies on Parkinson's disease, as the goal was an ambitious one: rewriting what we have known about this disease thus far. How can disease modification in Parkinson's disease become a reality in the near future? If Parkinson's disease is not a single, homogeneous disorder, can advances in biomarkers and disease modification be revised to concentrate on commonalities of pathogenic mechanisms in large populations OR do they need to be reconstructed for application to smaller subgroups of patients, distinguished by well-



Faculty with members of The Krembil Foundation



Alfonso Fasano

Reflections on Revision vs. Reconstruction: Parkinson's Disease Research at a Crossroads, continued on p.15

## Reflections on Revision vs. Reconstruction: Parkinson's Disease Research at a Crossroads, *continued from p.14*

defined molecular characteristics? Rethinking Parkinson's disease starting from the many unsuccessful attempts to modify the natural course of the disease was very much needed at this point of our scientific journey, and certainly the very preliminary action towards more radical and impactful steps forward.

Did we succeed? I guess it is too early to say but the impressions and feelings of an important attendee are undoubtedly the most unbiased and accurate (see right).

*"What we observe is not nature itself, but nature exposed to our method of questioning."*

- Werner Heisenberg



*Benjamin Stecher speaks with Alberto Espay*

*- Benjamin Stecher, Patient Advisory Board, Movement Disorder Unit, Toronto Western Hospital, Toronto, ON, Canada*

I must admit, in the weeks leading up to this conference I was brimming with anticipation. I saw it as a chance to witness what I thought would be a historic event in the annals of our attempts to combat Parkinson's disease. Dozens of the world's greatest minds in the field were coming to Toronto, my hometown, to question the path we were on and discuss where we should go from here. Some wanted to strike out in a new direction, others believed in plodding forward on the path we have already chosen. I was reminded of Robert Frost: "Two roads diverged in a yellow wood." It felt like we were at that crossroad and about to choose - Do we continue on our current path, or do we take another less travelled by?

Now that a few months have passed, I must say that I think a more appropriate title for the conference may have been Revision vs. Reconstruction vs. Reluctance. Don't get me wrong, there were some brilliant

talks and some very lively debates, but the stated purpose of the conference was to try and approach some semblance of consensus as to whether we need to make minor alterations to the path we are on, or do we need to overhaul the entire approach and seriously rethink what we are doing. However, it seems that many of the key opinion leaders had made up their minds about the topics in question long before they even agreed to participate in the conference, and no amount of debate was going to sway them.

That said, I believe this conference was a necessary step. Some did take advantage of the opportunity to air grievances and voice dissenting opinions. There were also plenty of interesting and spirited discussions that made the symposium very enlightening. While it may not have lived up to my lofty expectations, I left slightly more optimistic about the future of this field because even though it seems we have reached an impasse in any attempt to form consensus, we are, I think, at least finally asking the right questions.

## Overview of Movement Disorders for Physicians, Nurses and Allied Health Professionals – Moshi, Tanzania , April 29 - May 3, 2019

– Roberto Cilia, MD, Parkinson Institute, ASST Gaetano Pini-CTO, Milan, Italy; Course Faculty

The Overview of Movement Disorders for Physicians, Nurses and Allied Health Professionals (AHP) course held in Moshi, Tanzania, from April 29-May 3, 2019, represented the quintessence of the education course by the International Parkinson and Movement Disorder Society (MDS). The course directors, Prof. Richard Walker (Past-Chair of the MDS Task Force on Africa) and PD Nurse Specialist Louise Ebenezer, proposed a program aiming to emphasize the need of a multidisciplinary approach to patients with movement disorders by creating a synergy among physicians, nurses and allied health professionals of several Eastern African countries, including coming from Egypt, Tunisia, Tanzania, Kenya, Uganda, Ethiopia, and Madagascar.

Surrounded by the beautiful landscape of the Kilimanjaro Christian Medical Center (KCMC) in Moshi, 45 participants, including physicians, nurses, and physiotherapists, had the opportunity to interact and share experiences about caring for patients. Indeed, besides attending frontal lectures in the morning which provided the basis of education on movement disorders (including basic science, genetics, neuroimaging, differential diagnosis and



*A joint session of physicians, nurses and allied health professionals*

pharmacological treatment -always considering what is locally available- as well as non-pharmacological management of symptoms and local health beliefs), several sessions actively involved participants in the discussion on the diagnosis and treatment of Parkinson's disease and other movement disorders. Among these latter sessions, it is worth mentioning a 'bring-your-own-patient' session, where participants were invited to present a patient from their own clinic and discuss with the faculty the most relevant diagnostic and management challenges. A similar program for a MDS course joining physicians and nurses was held in Accra, Ghana in September 2013, gathering participants from West Africa. Due to the positive feedback, it was therefore purposed again in Moshi, Tanzania.

The faculty consisted of 14 international and African members of MDS, including geriatricians (Richard Walker), neurologists (Jonathan Carr, Roberto Cilia, Juzar Hooker, Kigocha Okeng'o, Ali Shalash), nurse specialists (Louise Ebenezer, Jane Price, Olivia Msuya),

as well as a local physiotherapist (Victor Minde) and an occupational therapist (Sarah Mkenda), local neurologists from the KCMC (William Howlett, Marieke Dekker) and also Natasha Fothergill-Misbah, who is carrying out a PhD investigating attitudes to PD in Kenya. Surprisingly, a special guest of this MDS course was Dr. Anna Marsden, biochemist and daughter of MDS founder David Marsden. She is actively working close by at the KCMC in Moshi and held a very inspiring and motivating speech.

Dr. Anna Marsden was also interested to help out on the *Mucuna pruriens* project as an advisory addition to the KCMC team. In a session entitled "The Challenge of Providing Sustainable Drug Treatment," I described the evidence available so far on the safety and efficacy of the use of the powder obtained by roasting and grinding the seeds of a leguminous plant named *Mucuna pruriens*, which contains high concentration of levodopa (5-6%) and grows spontaneously in all tropical areas of the world. If proven safe in the long-



*Left to right: Dr. Marieke Dekker, Dr. Roberto Cilia, Dr. Anna Marsden*

**Overview of Movement Disorders for Physicians, Nurses and Allied Health Professionals, continued on p.17**

Overview of Movement Disorders for Physicians, Nurses and Allied Health Professionals, *continued from p.16*



Course participants and faculty

term (a multicenter study is ongoing in Ghana and will hopefully start soon in Tanzania and Kenya), it might be considered as a potential alternative to levodopa-containing medications for those patients with PD who cannot afford buying such drugs out of their pockets.

The course was a great success, also due to the interactive sessions and participants' feedback was very positive, including some stimulation suggestions for the future events. I strongly

believe that this kind of education program joining physicians and nurses is the most effective, as it emphasizes the importance of a multidisciplinary approach to patients, especially in middle-to-low income countries where health professionals face several limitation in the management of patients. For more than ten years, I have been collaborating with neurologists, general practitioners, nurses and AHP in Ghana and Zambia, where education on the diagnosis and treatment

of non-communicable diseases such as movement disorders is very limited, as well the access to diagnostic tools (e.g., neuroimaging) and medications (e.g., levodopa for PD). Considering that similar challenges are present also in several Asia-Pacific regions and Latin America, where life expectancy is increasing along with neurodegenerative diseases such as PD, it is mandatory to implement these kind of activities in the next few years.



## MDS Education ROADMAP



[www.movementdisorders.org/roadmap](http://www.movementdisorders.org/roadmap)

Navigate educational content according to three levels of Movement Disorders experience:



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**Intermediate**



**Advanced**

## Atypical Parkinsonian Syndromes – Munich, Germany, May 17-18, 2019

– Gesine Respondek, MD, Technical University Munich, Munich, Germany

– Günter Höglinger, MD, Technical University Munich, Munich, Germany; Course Director

– Gregor Wenning, MD, PhD, Medical University of Innsbruck, Innsbruck, Austria; Course Director

On May 17-18, 2019, the MDS-ES hosted the first summer school on Atypical Parkinsonian Syndromes in Munich, Germany, directed by Günter Höglinger and Gregor Wenning.

The summer school was dedicated to young neurologists wishing to obtain competence in 1) the identification of clinical signs and symptoms alerting for atypical parkinsonism, 2) the clinical differential diagnosis of atypical parkinsonism, 3) the understanding of the scientific concept and clinical application of diagnostic criteria, and 4) the selection of adequate treatment strategies for atypical parkinsonism.

The course was quickly at capacity, with a total of 52 participants from 19 countries. Together with an experienced, multinational faculty, these ambitious young neurologists created an inspiring atmosphere on the campus of the German Center of Neurodegenerative Diseases in Munich, at the same place where in 2017 the international consensus meeting for the MDS diagnostic criteria for progressive supranuclear palsy had taken place.

The course kicked off with lectures on pathology, etiology, clinical syndromes and treatment of atypical parkinsonian syndromes. Helen Ling (London, United Kingdom) introduced the first session with the neuropathological definitions of tauopathies and synucleinopathies, followed by presentations on the disease entities dementia with Lewy bodies (Günter Deuschl, Kiel, Germany), multiple system atrophy (Gregor Wenning, Innsbruck, Austria), progressive supranuclear palsy (Günter Höglinger, Munich, Germany) and corticobasal degeneration (Huw Morris, London, United Kingdom). Wolfgang Oertel (Marburg, Germany) demonstrated pitfalls in differentiating between Parkinson's disease and atypical parkinsonian syndromes



Left to right: Wolfgang Oertel, Günter Höglinger, Claudia Trenkwalder, Günther Deuschl



Course participant dinner at Erdinger Weißbräu

Atypical Parkinsonian Syndromes, continued on p.19

## Atypical Parkinsonian Syndromes, *continued from p.18*



*Atypical Parkinsonian Syndromes – Munich, Germany, May 17-18, 2019*

and Milica Jecmenica-Lukic (Belgrade, Serbia) concluded the session with examples of “atypical atypical parkinsonism”. Each lecture was accompanied by up-to-date scientific evidence with many video examples and future outlooks.

Next, the students were trained in clinical skills needed to identify specific signs and symptoms associated with atypical parkinsonian syndromes, including hypokinesia, bradykinesia and rigidity, tremor and myoclonus, dystonia and chorea, apraxia, ataxia, gait and posture, oculomotor abnormalities, autonomic dysfunction, sleep, behavioral and cognitive symptoms, speech and language symptoms as well as imaging parameters. This session was particularly animated by many videos and controversial discussions on advantages

and disadvantages of certain examination techniques. Lectures of this session were held by above mentioned experts as well as by Claudia Trenkwalder (Kassel, Germany), Gesine Respondek (Munich, Germany), Janine Diehl-Schmid (Munich, Germany), Johannes Levin (Munich, Germany), Matthias Höllerhage (Munich, Germany) and Thilo van Eimeren (Cologne, Germany).

Last but not least, participants could practice their skills in examination rounds, in which patients with atypical parkinsonian syndromes were demonstrated. While taking a focused history of the patients and applying the examination techniques learned, all students showed a strong performance and good team work skills.

Next to improving their professional competence, the participants had many opportunities for socializing. In particular, as the first day was rounded off with “Schnitzel” and beer at the Erdinger Weißbräu, a typical Bavarian brewery.

Students and faculty parted with fresh motivation and many new contacts. The extremely high level of interest on part of the many participants on atypical parkinsonian syndromes calls for a near-term repetition of this course.

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