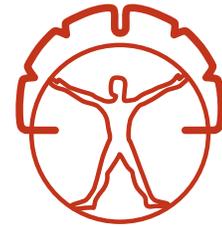


MOVING ALONG

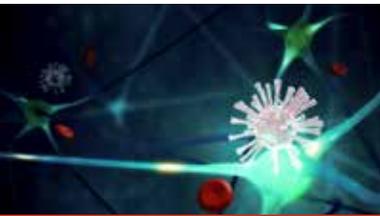
Editor, Antonio Strafella, MD, PhD, FRCPC



International Parkinson and
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MDS Hosts First Virtual Congress

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International Parkinson and
Movement Disorder Society

MDS *Virtual* Congress 2020

SEPTEMBER 12–SEPTEMBER 16





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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.

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Editorial

On behalf of the *Moving Along* Editorial Board, we hope that you and your family had a great summer and continue to be healthy and safe during the challenging time of the coronavirus (COVID-19) pandemic.

We would like to thank the entire MDS community for the enthusiasm demonstrated in contributing new, exciting content for this latest issue of *Moving Along*, during this struggling time. The Editorial Board deeply appreciates the contributions of the authors and worked tirelessly to pull together the articles presented in this issue.

The MDS International Congress recently went virtual for the first time, and was open free to healthcare professionals across the globe, with a robust program of research updates, teaching courses, video sessions, sponsored symposia, virtual exhibits, and more than 1,500 accepted abstracts on a broad range of topics related to Parkinson's disease and other Movement Disorders. More highlights and details from this historic meeting have been prepared by the MDS Virtual Congress Task Force and can be found on page 6. We also will continue to feature topics and speakers from the MDS Virtual Congress 2020 in the next issue of *Moving Along*.

The third issue of 2020 also looks at other recent global events, activities, and highlights from our Society, including updates from the MDS Non-Motor Parkinson's Disease Study Group, as well as the Scientific Issues Committee. Both of these articles were published as Early View on the MDS website and social media channels. This issue also features discoveries related to recent scientific articles in *Lancet* and *Brain*, as well as a review of a recent book on Gilles de la Tourette. Lastly, Prof. Claudia Trenkwalder discusses the newly revised MDS Diversity and Inclusion statement, while also contributing the "President's Corner," which continues to introduce young members to our MDS community.

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



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President's Corner

As we continue to maneuver this challenging year amidst the COVID-19 pandemic, the Society finds itself in a much different place now than we were when 2020 began. While the world has seen many things canceled this year, MDS worked to move forward and adapt Society activities to match the current climate, while continuing to provide top-notch educational opportunities and resources to our members and the global Movement Disorders community.

At the onset of the pandemic, the Society quickly launched a series of OnDemand webinars, podcasts and blogs, with topics relevant to COVID-19 and movement disorders. In addition, the MDS Past-Presidents were invited to speak via a webinar series, with lecture topics unique to their expertise. This MDS Presidential Perspective webinar series launched in August on the MDS website, and will continue into 2021. In addition, the MDS Regional Sections have all transitioned their educational programs into Online Regional Courses, featuring on demand lectures and live question and answer sessions. The first of these online courses was the popular "Aspen Course" (A Comprehensive Review of Movement Disorders for the Clinical Practitioner), which launched in a virtual format in July with over 1,700 participants, compared to the typical 200 registered each year. This was the 30th anniversary of the program, and it still provided participants with opportunities for career development and mentorship, as well as live interactive sessions with the faculty, including the well-attended Video Rounds Session. Thank you to the Virtual Aspen Course Directors, Michael Okun and Cindy Comella, as well as the entire faculty, who made this a very successful virtual event.



In February, the MDS-PAS held the 3rd Pan American Parkinson's Disease and Movement Disorders Congress in Miami, FL, USA, followed by the MDS-AOS Rare Movement Disorders Course in Bengaluru, India, in early March. These were the last in-person meetings hosted by the Society in 2020, before COVID-19 quickly took its toll on Asia and Europe, and ultimately the rest of the world. Knowing how important these meetings are to our members and the community, the Society established a special Task Force to make strategic decisions in establishing how to transform the International Congress into a virtual event.

Beginning in April, the MDS Virtual Congress 2020 Task Force worked hard to provide the best possible Virtual Congress for the global community. The Society is pleased to report that the Virtual Congress 2020, held September 12-16, was our largest attended event to date with over 20,000 participants registered from over 145 countries. The Virtual Congress also included over 1,500 accepted abstracts and 61 scientific sessions, with 190 Faculty from 37 countries. You can read more about the MDS Virtual Congress 2020 from one of the Task Force members and CSPC Chair, Vincenzo Bonifati, on page 6. I personally would like to thank all of the members of the Task Force, the MDS International Secretariat staff, and our industry sponsors for making this historic event possible and successful. I hope that we all are able to meet again in person, but until that day comes, I am very proud to see the MDS community come together virtually to continue achieving our mission.

Lastly, a critical aspect of in-person MDS events is the ability to network with peers and collaborate with thought leaders in the field, share knowledge, successes, and challenges. As a result, MDS has realized the immediate need to develop networking opportunities through the creation of the MDS Networking Engagement Series, which will provide virtual opportunities for members to connect with their peers, experts and thought leaders. The MDS Young Members group, with oversight from MDS Secretary, Bas Bloem, will oversee this engagement series. It is with this initiative in mind that I would like to introduce two more members of the Young Members Steering Committee (see page 5).

Sincerely,

A handwritten signature in black ink, appearing to read "Claudia Trenkwalder". The signature is fluid and cursive, with a large, sweeping flourish at the end.

Claudia Trenkwalder, MD
MDS President, 2019-2021

President's Corner, continued from p. 4



Thiago Cardoso Vale, PhD
Juiz de Fora (Minas Gerais), Brazil

I am currently working as a Professor of Neurology at the Federal University of Juiz de Fora, where I supervise the neurology residents and coordinate the Movement Disorders Outpatient Clinic of the University Hospital. Most of my current activities are devoted to seeing movement disorders

patients at the hospital, as well as at my private clinic. In addition, there are many academic lessons and supervision of residents and students interested in research. My PhD study, supervised by Prof. Francisco Cardoso, involved a parkinsonian sample of an elderly cohort of individuals from the community (Pietà study). I am particularly interested in studying how ageing and vascular changes may affect motor and cognitive aspects of Parkinson's disease and other parkinsonian disorders.

I have been a member of MDS since 2010, when I was doing my residency. I became actively involved with MDS back in 2014 when I was invited to create the Young Members Group, which had its first meeting in Stockholm. We were only eight members at that time, but thanks to the commitment and enthusiasm of the team, we were able to organize many activities devoted to young members. Now, I am proud to say that the group had substantially increased and gained credibility. I was also invited to participate in other Committees, such as the MDS Education Committee, the MDS-PAS Education Committee (which I Co-Chair) and the Web-Based Learning Subcommittee (which I Chair). I had also a great opportunity to participate in the LEAP 2017 Program in Vancouver.

I have plans to increase my research activities and do a Post-Doctoral research fellowship abroad when my kids grow a bit older. In the meantime, I plan to carry on helping with the neurology education of students and residents. I also plan to continue my volunteer work within MDS, helping the Society to achieve its main goal of education in Movement Disorders. For hobbies, I do like travelling a lot, going to nice restaurants, visiting museums or just wandering around the cities. At home, I spent most of my spare time enjoying family, playing and listening to music or, more specifically, to the Irish rock band U2!



Houyam Tibar, MD, PhD Candidate
Guelmim, Morocco

I am a consultant neurologist at The Regional Hospital of Guelmim, and I did my neurology training as a resident at the University Hospital Ibn Sina in the capital of Morocco "Rabat". In my first years of practice, I worked closely with Professor Wafa Regragui, a specialist in Parkinson's

disease and movement disorders. I was fascinated by the richness of this field, which started my passion for Parkinson's disease and Movement Disorders. In my third year of residency, I began a PhD thesis under the co-supervision of Professor Regragui and a pioneer in the deep brain stimulation area, Professor Abdelhamid Benazzouz. I had the chance to work on his research team for one year at the University of Bordeaux, where I made a dream come true, as I worked on rat models of Parkinson's disease. My area of research is non-motor symptoms of Parkinson's disease, which is a very rich subject and still not well known.

After I became a neurologist, I moved to a public hospital in the south of Morocco in a beautiful small city called Guelmim. This was a chance for me to continue my work in the same field but in a slightly different population. I am happy to bring the knowledge I gained during my training and make this population benefit from it as well.

My involvement with MDS dates back to 2013, during my first year of residency. Our National Society of Movement Disorders was organizing activities in collaboration with MDS. I was curious to know more about the Society, so I immediately joined and have been a member ever since. In 2015, I was selected to participate in an MDS summer school in Prague. I was the first Moroccan neurology resident participating in such school, so I encouraged many of my colleagues to do the same. This participation was very special, and it allowed me to learn more about MDS and its activities. I also was introduced to many MDS professors, including Professors Joaquim Ferreira and Evžen Růžička, who both encouraged me to get more involved in the MDS community.

Currently, I am a member of the MDS African Section and serve on the Steering Committee of the MDS Young Members group. I am proud to be an MDS member, because this community is so active and tries its best to make knowledge about movement disorders accessible to all physicians around the globe. So In addition, it provides opportunities of mentorship and leadership to a global audience. I also am grateful that the MDS chose to provide free membership for developing countries with low outcome. This is a very generous action, which makes knowledge accessible for all equally.

Outside the professional sphere, occasionally when I get the chance to grab a time out for myself, I like horse riding and swimming. I am also a mother of a seven-year-old daughter, and it is my wish that she will be proud of her mom one day.

MDS Hosts First Virtual Congress – September 12-16, 2020

— Vincenzo Bonifati, MD, PhD; Chair, MDS Congress Scientific Program Committee

— Oscar Gershanik, MD; Chair, MDS International Congress Oversight Committee

— Claudia Trenkwalder, MD, FEAN; MDS President, 2019-2021

on behalf of the MDS Virtual Congress 2020 Task Force

This year, for the first time ever, the MDS International Congress took place in a virtual format, September 12-16, 2020. The MDS Virtual Congress 2020 joined more than 20,000 healthcare professionals from 145 countries, with an exciting program with more than a hundred hours of research updates, teaching courses, video sessions, sponsored symposia, virtual exhibits, and more than 1,500 accepted abstracts on a broad range of topics related to Parkinson's disease and the other Movement Disorders. The meeting theme this year was *"The Combined Multidisciplinary Approach to Movement Disorders"*.

As a response to the COVID-19 crisis, the Society made the strategic decision to go virtual with the full program, in order to continue to fulfill its mandates to disseminate knowledge, promote research and ultimately improve the management of patients with movement disorders worldwide. The entire program was available on demand free through October 1, 2020, for those who had registered by September 16, 2020. The program is now available on demand for all MDS members, including those who had not previously registered, through the end of 2020.

Transforming a large and complex event, such as the International Congress, into a virtual event was a big challenge; therefore, a special task force - the MDS Virtual Congress 2020 Task Force – was created, co-chaired by MDS President, Claudia Trenkwalder, together with the Chair of the International Congress Oversight Committee, Oscar Gershanik, and the Chair of the Congress Scientific Program Committee (CSPC), Vincenzo Bonifati. Other members include MDS President-Elect, Francisco Cardoso, MDS Past-President, Christopher Goetz, the CSPC Co-Chair, Andrew Siderowf, the CSPC Past-Chair, Buz Jinnah, the Chair of the 2020 Congress Local Organizing Committee, Matthew Stern, the MDS Treasurer, Louis Tan, and the Chair of the MDS Young Members Group, Margherita Fabbri. Together with the MDS International Secretariat, we worked very hard over the past few months, in order to provide our community with the best possible Congress, despite these difficult times.

The program featured most of the classic and popular sessions from the International Congress, including the Presidential Lectures Session with the Marsden and Fahn Awards lectures and the Junior Awards, the MDS Video Challenge, Controversies, and the Highlights Sessions, as well as the Therapeutic Plenary Sessions, several Scientific Plenary and Parallel Sessions, Special Topics, Teaching Courses, Video Sessions, and Skills Workshops. Two non-CME 'Science of Industry' Sessions took place again this year, after the success of the 2019 edition. Each session consisted of pre-recorded lectures along with a chat feature for the attendees to ask questions related to the lectures. The Chairs then collected these questions and selected the most relevant which the faculty answered during a question and answer "live" segment at the end of each session.

Each year, the CSPC strives to put together the best program possible,

including the hottest topics and the best faculty, while at the same time promoting the young members, and respecting the gender balance and the representativeness of the geographical diversity of MDS.

This year, the Virtual Congress included 61 scientific sessions, with 190 Faculty from 37 countries, and a high number of young Faculty who had not spoken before at this Congress, as well as women, and colleagues from Asia, Oceania, South America, and Africa.

In addition, we were proud to include new features, specially intended to further enhance the scientific excellence of the congress, and inspire the current and the next generation of movement disorders professionals. In a new Plenary Session, called "Neuroscience Bridges", two world-renowned neuroscientists, Beth Stevens and Karl Diesseroth, provided overviews of their cutting-edge research. With this keynote lecture, the Society provided special recognition to pioneering researchers, while offering our community the opportunity to meet prominent scientists, who would not usually attend the International Congress.

We also intended to give more emphasis to excellence in the original research data presented by our own community. All accepted abstracts were available in a Virtual Poster Hall for the entire duration of the Virtual Congress, and a selection of the highly-scored abstracts were illustrated during 16 virtual Guided Poster Tours. Furthermore, 18 Top Abstracts, chosen among those that received the highest scores from the CSPC, were presented during some of the Parallel Sessions, after the invited lectures. The work of 18 young colleagues were therefore honored with very large visibility, and those fellows have now gained an opportunity and experience of joining more established Faculty in a large session.

The impact of the COVID-19 on our patients with Parkinson's disease and other movement disorders, as well as on the way we manage our patients in these challenging times, were the subject of a dedicated Parallel Session, as well as a new category of posters, "COVID-19 and Movement Disorders."

Some structural changes were also necessary to profile the virtual format of the Congress for a global attendance. The duration of the whole event took place within five days, from Saturday, September 12, to Wednesday, September 16, plus the Welcome Ceremony on Friday, September 11. However, compared to the traditional in-person editions of the International Congress, the duration of each day's program was much shorter, and more sessions were presented concurrently, including some



MDS Hosts First Virtual Congress, continued on p. 7

MDS Hosts First Virtual Congress, *continued from p. 6*

of the scientific Plenary Sessions. However, the virtual format allowed each of us to benefit from more content compared to the in-person experience, with the additional advantage that we were able to enjoy our preferred sessions while sitting at home on the couch, and perhaps with a good drink and a snack!

A virtual congress with a global attendance also has the challenge of the different time zones over the world. Some sessions, namely the Therapeutic Plenary and the Video Challenge, were launched a second time (encore sessions), with different Chairs, to be viewed by our colleagues in the Eastern hemisphere at times that were most convenient for them.

Perhaps the most important aspect is that the virtual format, open for free, represents an unprecedented educational opportunity for the thousands of colleagues, practising clinicians, allied health professionals, researchers, residents, and undergraduate students, who are living in underdeveloped and underserved areas of the world, and who could not afford the costs of traveling to attend an in-person International Congress. This is a consequence of the COVID-19 pandemic, which might have profound, paradoxically beneficial implications for the dissemination of knowledge and the growth of the Movement Disorders community across the globe, and these implications might go beyond the 2020 edition of the Congress. For a long time, the Society has been intent in providing free access to membership and educational content and activities to as many colleagues as possible. Free access to the MDS

Virtual Congress 2020 is another example of the path we have chosen and showcases the Society's mission and goals.

With the 2020 Congress now behind us, the preparations for the 2021 Congress in Copenhagen, Denmark are already ongoing. Which format the 2021 Congress will have remains largely unpredictable at this junction. The good thing is that we learned a lot and gained experience in the preparations for the 2020 meeting. We are still considering all options, and are prepared for all of these, ranging from the traditional in-person format (which appears unlikely, given the current status of the COVID-19 pandemic), to once again a fully virtual 2021 Congress, or perhaps an hybrid format with a limited in-person local gathering, combined with a global Virtual Congress.

Last, let us express our deepest gratitude to the members of the CSPC, who developed the 2020 scientific sessions, and served as liaisons with the faculty to ensure each session was best harmonised and met its learning objectives; the Speakers and Chairs, who accepted the additional, time-consuming task to pre-record their lectures and contributions; the entire MDS International Secretariat, and particularly, Kate Hausner, Congress Program Manager, Jenny Quebbeman, Director of Meetings, and Jennie Socha, Executive Director, for a truly amazing amount of highly professional work and dedication.

We hope that you found our first Virtual Congress enjoyable, useful and inspiring!



Prof. Claudia Trenkwalder and other MDS leaders during the Virtual Congress Welcome Ceremony on September 11, 2020.

New International Parkinson and Movement Disorder Society (MDS) Statement on Diversity and Inclusion

— Claudia Trenkwalder, MD, MDS President, 2019-2021

The MDS Leadership recently announced a new [Statement on Diversity and Inclusion](#) for MDS. We are proud to share this with you now, and intend for all of our members to act according to these principles. As an International Society, our strength comes from the varied perspectives that our members possess. It is important that we recognize and use these perspectives in our work, and it is why we have focused on building broad international memberships for the Society's groups, including Committees and Task Forces. These groups do important work on behalf of MDS, and the volunteers that serve on these groups should match the diversity of our membership.

We must always look beyond our personal circles to celebrate the diversity within MDS. As you may know, MDS recently introduced an interest form process when introducing new groups. These interest forms collect basic information on a members' interest in participating in a group. This process can be seen during our committee appointments, which takes place every two years. The next committee term will begin at the Congress in 2021. Committees do the foundational work of MDS, including everything from overseeing MDS's education to selecting the award winners at the Congress. At the start of a new term, the incoming Committee Chairs, determined by the new President, will work with the new President to select candidates that can work well together and bring unique perspectives to serve our members.

The Society has also introduced interest forms for the creation of new Task Forces. Task Forces are appointed by the President to achieve a specific, time limited task and remain in place until the completion of the task. When the MDS Leadership approve a new Task Force, an interest form is distributed to the membership through the website, and the Task Force Chair and President build the roster from those interested members.

The interest forms for Committee, Task Force and other groups are hosted on the [Get Involved Webpage](#). If you are interested in stepping into a larger role with MDS, we encourage you to visit this page for opportunities and look for further announcements in the monthly e-newsletter.

As we reflect on the new Statement on Diversity and Inclusion, we are undergoing the important process of identifying the next leaders in MDS. Every two years, the Central and Regional Section Nominating Committees prepare slates of candidates to become the next MDS Leadership. The Nominating Committees strive to create a diverse slate that celebrates the expertise that exists within MDS across the world. To do this, the committees rely on members to submit candidate profiles for the leadership positions. These profiles let the committee know more about your background and what your vision is for the future of MDS. Each member is entitled to recommend a candidate for a leadership position to the nominating committee.

The candidate profile submissions process is now underway for the Regional Section leadership positions, and we encourage you to submit a profile to serve as a Regional Section Officer or Executive Committee member. To learn more, submit a candidate profile or refer a colleague, please visit the [Nominations webpage](#).



International Parkinson and Movement Disorder Society

MDS Statement on Diversity and Inclusion

The International Parkinson and Movement Disorder Society (MDS) is committed to creating and nurturing a diverse community of individuals dedicated to promoting excellence and leadership in medicine and science through education, research, clinical care and service.

As an international society we are committed to working across all continents and being inclusive of all colleagues to achieve our goals. The following values are intrinsic to everything that we do, and will guide our decision making at all levels.

- We celebrate the multiple dimensions of diversity that each member of our society offers, including, but not limited to, race, religion, ethnicity, sex, gender identity, sexual orientation, socioeconomic circumstance, nationality, geographic background, ability and disability, political ideology, and age.
- We strive to provide a safe environment where all members of our society are encouraged to engage in dialogue, question, learn and contribute to their fullest potential.
- We respect the dignity of all members of our society and aspire to ensure that all feel valued and supported
- We endeavor to offer education and training that emphasizes respect for differences in culture, language and life experience.

We will continuously monitor and encourage our diversity and inclusion efforts to ensure that the outcomes bring MDS closer to reflecting the diversity found in our patients, community and world.

The Non-Motor Parkinson's Disease Study Group: Almost 10 Years and Where Are We?

— Prof. K. Ray Chaudhuri; Chair, MDS Non-Motor Parkinson's Disease Study Group
 — Prof. Per Odin, MD, PhD; Vice-Chair, MDS Non-Motor Parkinson's Disease Study Group
 — Prof. Anette Schrag; Vice-Chair, MDS Non-Motor Parkinson's Disease Study Group
 — Dr. Valentina Leta; Coordinator, MDS Non-Motor Parkinson's Disease Study Group
 — Dr. Daniel van Wamelen; Coordinator, MDS Non-Motor Parkinson's Disease Study Group

The Non-Motor Parkinson's Disease Study Group (NM-PD-SG), led by Prof. K. Ray Chaudhuri, was proposed to the International Parkinson and Movement Disorder Society (MDS) in 2010 and subsequently became the first MDS study group, serving as a roadmap for the development of other study groups within the Society. The NM-PD-SG is based on the principles of the MDS being global, gender and ethnicity balanced, as well as a global network of research members, who are key opinion leaders.

The NM-PD-SG has led several initiatives on advancing non-motor Parkinson's disease research across a broad range of areas, such as non-motor outcomes with deep brain stimulation, infusion therapies, non-motor endophenotypes, biomarkers and non-pharmacological research, including exercise, dance and acupuncture. A key project has been the Society commissioned global development of the [MDS Non-Motor Rating Scale \(MDS-NMS\)](#), an updated, improved, and refined version of the existing Non-Motor Symptoms Scale (NMSS), with a recent publication of the United Kingdom and USA validation. A new MDS webinar, "[The MDS Non-Motor Rating Scale \(MDS-NMS\): A new measure for non-motor Parkinson's disease](#)," is also available. The MDS-NMS will now undergo a global translation program and is likely to become a companion tool for motor assessments in clinical trials and clinical research. The process will further champion formal measurement of the burden of non-motor symptoms in Parkinson's in real life and the long overdue recognition of the impact of non-motor symptoms by policymakers around the world.

We have also started highly popular short presentations during the annual study group meetings from key Industry partners who are developing treatments or trials addressing non-motor symptoms in PD. These slots have proven very successful for all stakeholders and are also extremely informative for the committee and allows discussion on future evolution of treatments for non-motor symptoms in PD.



In addition, in order to engage junior researchers in non-motor PD research, the NM-PD-SG has created a trainee research subgroup of theme-led research initiatives. In total, 12 themed subgroups (Table) addressing a broad range of non-motor symptoms have been created, with two subgroups taking on a crosscutting role (on artificial intelligence in non-motor symptoms and statistical/analytical support). The groups range from non-motor outcomes and interventions, such as DBS, infusion and other therapies for PD, to clinical subtyping, and personalised medicine, driven by specific non-motor symptoms, such as sleep, fatigue, pain and cognition, and will be led by a range of gender-balanced and diverse junior researchers selected by NM-PD-SG committee members. The aims in the short term are to produce high-quality reviews and pragmatic real-life practice/case based guidelines complementing the MDS evidence-based guidelines task force initiatives. As an example, the

The 12 Newly Formed Themed Subgroups

Pain and sensory symptoms	Complementary therapies for NMS
Sleep dysfunction	Pharmacology and basic neuroscience of NMS
Advanced therapies	Artificial intelligence as applied to NMS
Depression, anxiety, and psychosis	Biomarkers for NMS
Professional occupation and links to NMS	Autonomic and gastrointestinal dysfunction
Cognition and apathy	Cross-cutting analytical subgroup

Acknowledgments: We acknowledge the contributions from the international steering group as well as all standing members of the MDS NM-PD-SG.

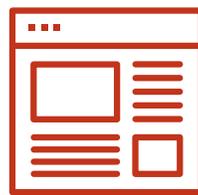
The Non-Motor Parkinson's Disease Study Group: Almost 10 Years and Where Are We?, continued on p. 10

The Non-Motor Parkinson's Disease Study Group: Almost 10 Years and Where Are We?, *continued from p. 9*

artificial intelligence group will explore home monitoring, wearables, and other technologies, which may indirectly monitor non-motor symptoms and to develop a traffic-light-system for non-motor monitoring in Parkinson's disease. To ensure statistical and methodological robustness of all data generated through the subgroups, Dr. Carmen Rodriguez-Blazquez and Dr. Joao Forjaz, from Madrid, Spain, will provide oversight across the subgroups.

Special initiatives are the role of complementary therapies, nutrition and effects on non-motor symptoms in Parkinson's as well as the impact on occupation, lifestyle and income related to non-motor symptoms. This collaborative effort will involve interdisciplinary working across neurology, movement disorders, and allied health specialists, and will mark a novel foray in non-motor research in PD. In the years to come we therefore hope the work from the trainee led research subthemes of the NM-PD-SG will enrich many unmet needs related to non-motor symptoms of PD.

MDS OnDemand Series



International Parkinson and
Movement Disorder Society



Webinars

Engage.

Engage by viewing webinars on current topics in Parkinson's disease and Movement Disorders, including: Telemedicine, Treating COVID-19, Gene and Immunotherapies, Device-Aided Therapies, Rating Scales, and Lectures from MDS Past-Presidents



Podcasts

Listen.

Listen to stay up-to-date with novel and clinically-relevant research findings in the field of Movement Disorders. Each podcast episode highlights results from recently published articles in the MDS journals, including interviews with the authors.



Blogs

Read.

Read blogs to obtain the latest in scientific advances, new developments and trends in the field, as well as a new series of interviews focusing on issues related to the intersection of COVID-19 and Movement Disorders.

Learn more at movementdisorders.org/ondemand

An Update from the MDS Scientific Issues Committee

— Stella Papa, MD, Chair, MDS Scientific Issues Committee

— Un Jung Kang, MD, Co-Chair, MDS Scientific Issues Committee

In recent years, the MDS Scientific Issues Committee (SIC) has initiated new activities aligned with the objective and mission of the Society, particularly in relation to advancing the science of movement disorders. One of the new activities was the production of SIC Blogs with the goal of increasing the communication of scientific information to the global movement disorder community. In addition, the SIC has launched the Scientific Panel Discussions intended to identify and communicate research directions that are deemed best candidates to advance the knowledge and treatment of movement disorders.

The SIC began producing blogs in 2016, and since then all blogs were freely accessible on the [MDS website](#). These blogs are a useful tool to disseminate scientific information and opinions of experts with differing or complementary views on an important topic that may be controversial, newly emerging, not ripe for full scientific review or viewpoint articles to wider spectrum of audiences including scientists, clinicians and other health professionals, and patients. This initiative has been a success since its inception with the first blog: "Inflammation in Parkinson's disease" written by Malu Tansey, David Sulzer and David Standaert, and edited by Michael Okun (Past-SIC Chair) and Stella Papa.

Blog topics are selected by SIC members, focusing on new clinical and scientific developments, controversial issues, theme updates, novel technologies, scientific advances, or other areas of current interest. To date, the SIC has produced 39 blogs that include a variety of categories covering the interests of our diverse readership. For example, the following blogs are a representative sample of such a diversity: "LRRK2 in idiopathic Parkinson's disease" - "Rehabilitation as a therapeutic approach for dystonia" - "Artificial intelligence in drug discovery" - "Hey Siri, do I have Parkinson's?"

Since the start, blogs appeared in the website at a monthly rate with a break usually around the annual congress. In 2019, the committee, in consultation with the Website Editorial Board, conducted an evaluation of the blogs' performance by analyzing the total page hits for each SIC blog. After computing all web traffic sources, blogs had an average hit of 1,931 with some blogs reaching 10,000 hits during the time assessed. Considering that the exposure times were variable, and too short for the latest blogs, the overall hit is highly significant. Clearly, these excerpts of the latest developments, concepts and views that often include dialogues about conflicting data and controversial views provide a unique material to the readership.

The Scientific Panel Discussions arose from an initiative of the SIC in consultation with the Society leadership to develop an activity focused on advancing research that could enhance the Society's contribution to the basic and clinical scientific community. The plan was to gather a panel of experts for a formal discussion and consensus about research needs in a particular area. This activity was designed to target areas that

have recently emerged, pose clinical/scientific challenges, or are the focus of growing research. In every topic, the panel is formed by top leaders in the field, including clinicians and scientists with the goal to critically analyze the gaps in knowledge, the past and current research, and the potential paths to make progress.

The panel discussion will be published as peer reviewed articles using an appropriate format as recommended by the editors of *Movement Disorders*. In addition, the key points of the discussion and the consensual conclusions on future research directions will be presented in a document, as MDS SIC-Research Directives. The document will provide a source of consultation for the global community, societies and foundations promoting research, and governmental and non-governmental funding organizations setting research priorities.

The first in the panel discussion series was organized this past fall, and began activities during the winter, almost overlapping with the COVID-19 outbreak. Nevertheless, progress has been made through virtual meetings and remote work, and now the panel has entered the final discussion and writing phase. It is expected that the article and accompanying research directives document will be finalized in the coming weeks.

The SIC also continues to make additional contributions as needed in our community. Early in the COVID-19 pandemic, the SIC prepared the first MDS statement and coordinated the efforts of a group of MDS members to rapidly write the viewpoint article "Impact of the COVID-19 pandemic in Parkinson's disease and movement disorders" for publication in the *Movement Disorders* journal. More recently, the SIC has completed the preparation of an updated MDS position paper on the "Use of cell-based therapies for Parkinson's disease". The paper release to the public is currently in process.

Back in 2016, we were excited about our plans to renew the committee activities, and especially about launching the SIC Blogs, and thereby contributing to spreading scientific discussions in an informal format and means widely accessible (see example on page 12). Our blogs met our expectations with a positive reception by the readership. We are again excited about the launch of the Scientific Panel Discussions, and the potential for a high impact of this MDS contribution in the scientific community. We hope our rigorous expert panel discussions become a reference worldwide for research direction priorities in movement disorders.



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An Update from the MDS Scientific Issues Committee, *continued from p. 11*

MDS SIC Blog

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MDS SIC Blog: COVID-19 and Movement Disorders: potential relationship and mechanisms + Share

Date: August 2020
Prepared by SIC Member: Alvaro Sanchez-Ferro, MD
Authors: Tiago Outeiro, PhD; Mariana HG Monje, Patrik Brundin, MD PhD
Blog Editor: Un Jung Kang, MD

The SARS-CoV-2 Pandemic represents a major global health challenge that we as movement disorders experts also have to face. Different efforts are trying to decipher the consequences that this impactful condition is having in our field. In this blog entry, two experts, Dr. Tiago Outeiro and Dr. Mariana HG Monje, addressed important open questions about the relationship of SARS-CoV-2 and movement disorders. We also had the privilege to include a final statement from Dr. Patrik Brundin outlining the key aspects about this enigmatic and impactful condition that will be studied in the history books of future generations.

Question 1: Could you please comment on the relationship between Movement Disorders and COVID-19?

Dr. Outeiro: This is indeed an important question that deserves close attention, given the global scale of the COVID-19 pandemic in a time when the human population is aging.

Fortunately, there is currently no evidence that patients with movement disorders are at increased risk for COVID-19, when compared to age-matched individuals. However, since COVID-19 is such a novel disease, it is still early to rule out the possibility that COVID-19 survivors may be at increased risk of movement disorders. Therefore, it is important that clinicians stay vigilant for a possible association, especially if we consider this possible connection from a molecular perspective. Movement disorders, of which Parkinson's disease (PD) is one of the most common, are typically associated with the misfolding and accumulation of proteins in the brain. This process is known to be age-associated but is also known to be associated with the impairment of cellular pathways that are also used by viruses, such as SARS-CoV-2, during infection. Therefore, based on our current understanding of the molecular mechanisms underlying both movement disorders and COVID-19, it is wise to hypothesize that, perhaps, a relationship may emerge. This is still speculative at this point, and should not cause unwanted alarm and unsettlement, but it is a hypothesis that needs to be considered and investigated.

Dr. Monje: A broad spectrum of neurological syndromes has been progressively described associated with SARS-CoV-2 infection. Neurological manifestations vary from unspecific symptoms (i.e. headache and myalgias, present up to 66% in those patients with neurological manifestations) to stroke and neuroinflammatory syndromes (Romero-Sánchez et al. 2020). In this scenario, even in the most extensive reported series, the appearance of movement disorders in SARS-CoV2 infection is scarce (Whittaker et al. 2020). So far, the few cases reported in the literature are hyperkinetic movement disorders, mainly severe generalized myoclonus/myoclonic tremor. The Movement Disorder Society repository of "COVID-19 and movement disorders observations" and the upcoming studies would hopefully give us a better description of the movement disorders associated with COVID-19.

Question 2: In your opinion are these phenomena immune mediated or a direct effect of COVID19 on the Central Nervous System?

Dr. Outeiro: To address this, we need to consider what we know about the pathological mechanisms involved. We know that SARS-CoV-2, the virus responsible for COVID-19, enters cells by strongly interacting with the ACE2 receptor (Yan et al. 2020). This receptor is expressed by cells in the respiratory system, and this explains why they may be particularly vulnerable. However, the ACE2 receptor is also expressed in several other tissues, including in the central nervous system, suggesting it may also directly affect neuronal cells in the brain. Indeed, recent studies have identified coronaviruses in the central nervous system, including in patients with neurodegenerative disorders (Gómez-Pinedo et al. 2020). This suggests there may be direct effects of SARS-CoV-2 in the brain.

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Abstract: COVID-19 Outbreak Impact on Young Movement Disorder Experts' Work and Educational Activities

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Introduction: The severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) pandemic impacted medical training and education globally, especially in most affected countries. It was important to recognize the rapidly evolving challenges faced by hospitals and universities during the coronavirus disease 2019 (COVID-19) outbreak, upon which the structure of both the clinical and the educational activities has been obliged to be deeply changed.

The International Parkinson and Movement Disorder Society (MDS) Young Member Group (YMG) consisted of neurologists and health care professionals with interest in movement disorders and younger than 40 years and it actually represents about one third of the entire MDS community. We aimed to survey young physicians and health care professionals belonging to the MDS-YMG, to analyse the situation they are experiencing, to know how the educational system reacted to the pandemic and their satisfaction regarding the MDS virtual educational tools.

Methods: This was a web-based survey study. All MDS Young members were invited to participate through electronic mails. An online questionnaire-based survey created by the MDS Young Members Group Steering Committee and its senior chair (Bas Bloem), was conducted between June 15 and July 30, 2020. The questionnaire consisted of 23 questions, divided into three sections including demographic/professional data, impact on educational and clinical activities and satisfaction regarding the MDS e-learning tools. The questionnaire contained multiple-choice questions and one open question for suggestions and comments.

Results: 3802 members were invited to complete the survey and 288 completed it (13.2%), divided as following for each MDS section: 26.15% of the European section, 31.8% of the Pan American Section, 24.7% of the Asian and Oceanian section and 17.1% of the African section. Of note, about 30% of the answer came from US and about 10% from Brazil, that are two of the main affected countries. 72% had between 30 and 40 years, the rest between 20 and 30 years. Half of them (58.6%) were clinicians, with expertise in movement disorders. 42.8% have been involved in managing COVID-19 patients about 80% of them referred a moderate to severe impact of the pandemic to their possibility to visit patients with movement disorders. Phone calls were still the most used tool to reach

patients (82%), even if telemedicine tools were used by 24%, though with difficulties in communication with patients reported by the most part of the members (71.2%). More than half of the participants (61.6%) referred a lack of clear protocol to manage movement disorder patients during the COVID-19 outbreaks. Educational activities were largely affected (78.2%), with complete interruption of the activities for more than 4 weeks among half of the participants. Virtual teaching sessions were attended by 62% of the members, though if usually less than one a week. The MDS educational materials were used by 62% of the members and considered helpful by about 90%. Overall the used of MDS educational material is considered from moderately to extremely important.

Conclusions: Our results confirm the heavy impact that the COVID-19 outbreak had and continues to have on professional and educational activities of physicians and health care professionals interested in movement disorders, all over the world. Many young MDS members were directly involved in the management of COVID-19 patients. In spite of the recent advanced in telemedicine, progress still needs to be done to make it a widespread and feasible tool on a clinical routine setting. The survey revealed that MDS educational resources are extremely relevant, reinforcing the idea that they should be continuously implemented and advertised, especially among the young MDS community. COVID-19 pandemic continues to pose challenges in terms of clinical care organization and educational needs and it has already imposed radical and irreversible changes of academic and health care activities.



Neuropalliative Care Is Not Just End-of-Life

— Janis Miyasaki, MD, MEd, FRCPC, FAAN; Director, Parkinson and Movement Disorders Program and Co-Director, the Complex Neurologic Symptoms Clinic (Neuropalliative Care); Professor, University of Alberta, Edmonton, AB, Canada



The commonest misperception about palliative care is that it concerns only the end-of-life stages. Even among healthcare professionals, a palliative care referral suggestion is often met with, “but the person isn’t at that stage yet”. The World Health Organization states that palliative care can be appropriate at any stage of illness including the earliest stages of an illness. Indeed, studies

demonstrate that early palliative care can be associated with not only improved quality of life, but prolonged survival¹.

Prior to 2007, palliative care for Parkinson disease (PD) was often reported as part of larger cohorts by geriatricians and palliative care physicians. In 2007, the Parkinson Foundation provided a grant to start a palliative care program for PD. This resulted in a cohort demonstrating that those with advanced PD (loosely defined as those with needs beyond the already multidisciplinary Movement Disorder Centre) had symptom burden similar to those with metastatic cancer².

Since that time, Neuropalliative care as a subspecialty of Neurology has burgeoned. A review of peer reviewed publications for Neuropalliative care demonstrated an increase from 15 in 2000 to 190 in 2019 (Fig 1). Publications included applying palliative care principles to Multiple System Atrophy, Progressive Supranuclear Palsy and Huntington Disease^{3,4,5}.

What has been the appeal of palliative care for healthcare teams and ultimately, the patients and families? I believe that palliative care embraces the best of medicine: that is, the desire to improve our patients’ and their families’ lives and not just to complete all the items in our Electronic Health Record or to satisfy government mandates that have been shown to be associated with burnout⁶. Physicians and other clinicians are willing to spend time to do things that improve patients’ lives.

Our recent study of ambulatory palliative care for PD and related disorders demonstrated that despite high symptom burden, those participating in ambulatory palliative care had improved quality of life⁷. Participants were diverse (Hoehn and Yahr 2-5). Those in the control group (usual care by their neurologist), experienced worsening quality of life over the 1-year study period. Caregivers had a trend towards reduced burden compared to those in the control group. An examination of caregiver burden revealed that both caregiver (caregiver depression or anxiety and caregiver perception of patient quality of life) and patient characteristics (more spiritual distress and lower health-related quality of life) were associated with higher caregiver burden. Among our patients participating in the trial, those that identified a caregiver willing to participate in research were more likely to be male and from a higher socioeconomic strata. Further, despite having higher scores on the motor UPDRS and lower MOCA scores, individuals with identified caregivers willing to participate in research had higher quality of life and reported fewer nonmotor symptoms. This speaks to the importance of caregivers to our patients. When caregivers do well, our patients do better. And the

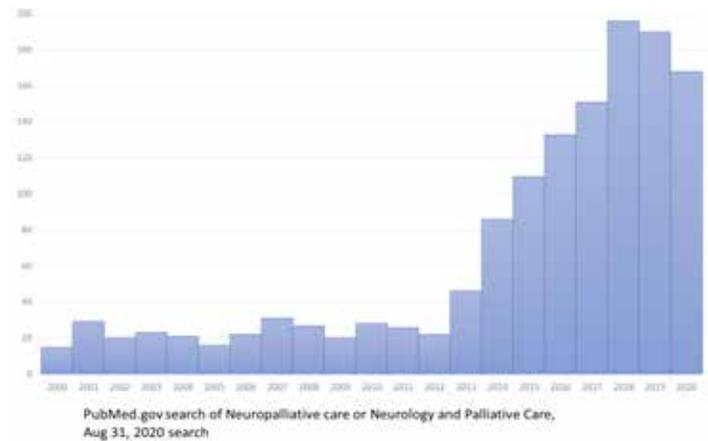


Figure 1

corollary is true: when a patient does not have a caregiver, it may be challenging to maximize quality of life outcomes for this patient. Of note, women and those with lower socioeconomic status and thus, less ability to mitigate the absence of a caregiver, were most likely to report not having someone to support their health. The palliative care philosophy of including families as our unit of care with the patient can maximize benefits to quality of life for both and provide the needed support to remain integral to our patients’ lives throughout the course of their illness.

Neuropalliative care acceptance among physicians continues to have a spectrum from those who embrace its philosophy from diagnosis to those who feel that it is only appropriate for the imminently dying. The research in 2020 demonstrates that Neuropalliative Care has significant positive impact on patients and families. The demand for Neuropalliative Care is likely to be a grassroots patient and family issue that hopefully will define excellent care delivery for movement disorders across the globe.

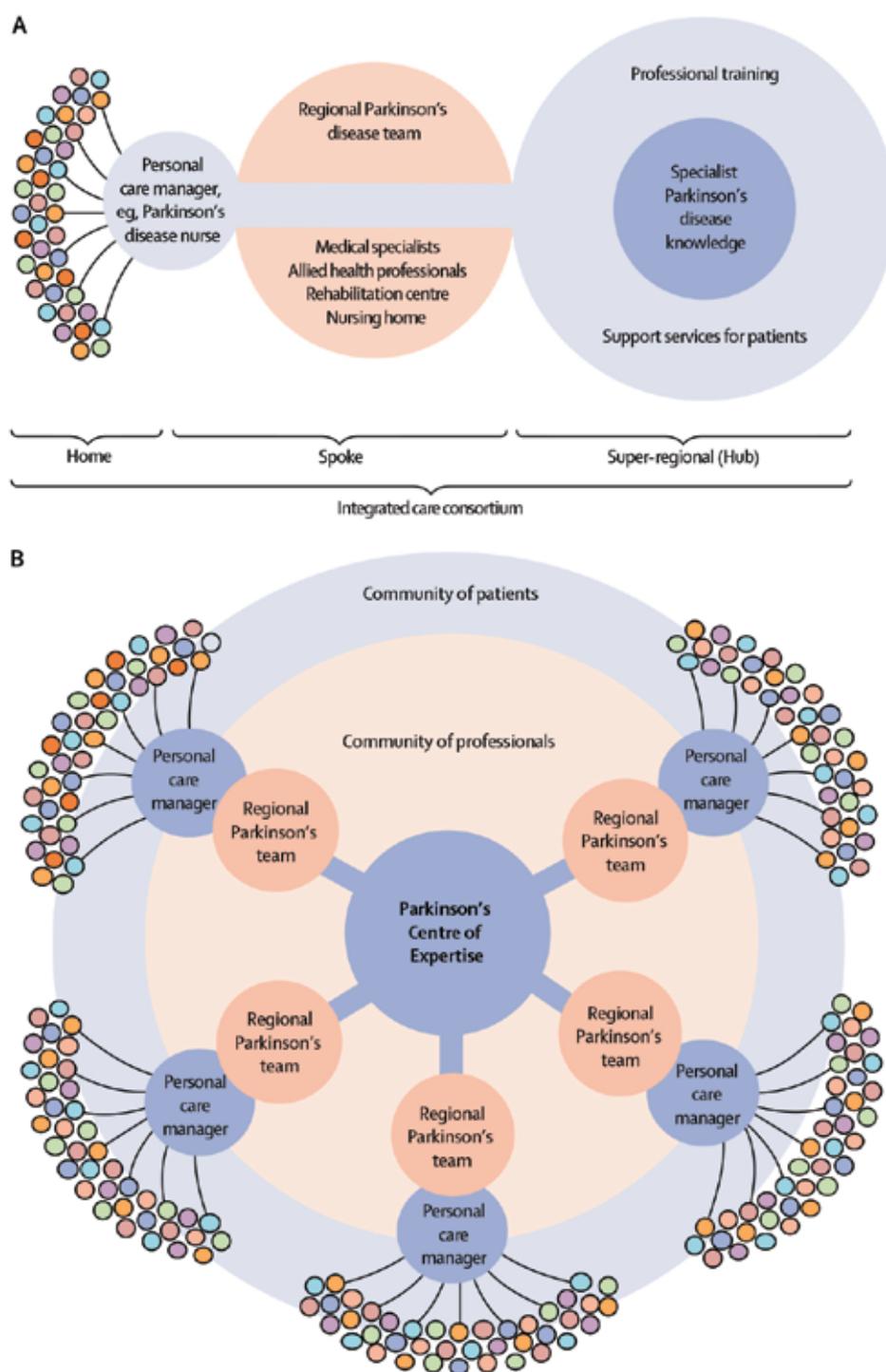
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Integrated and Patient-Centered Management of Parkinson's Disease: A Network Model for Reshaping Chronic Neurological Care

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Chronic neurological diseases are now the leading source of disability globally. Yet, our healthcare systems are not designed optimally to meet the needs of the many chronic neurological patients. Care is fragmented, with poor interdisciplinary collaboration and lack of timely access to services and therapies. Furthermore, care is typically reactive instead of taking a more proactive approach, while complex problems are managed inadequately due to lack of disease-specific expertise and insufficient use of non-pharmacological interventions. Treatment plans tend to focus on the disease rather than the individual living with it, and patients are insufficiently involved in clinical decision-making. In our new publication in *The Lancet Neurology*, we have illustrated a new integrated care concept with a patient-centred perspective that includes evidence-based solutions to tackle the limitations of current healthcare delivery for people with chronic neurological conditions. In our paper, we illustrate this by using Parkinson's disease as a model condition for other types of movement disorders as well as other chronic neurological conditions, for various reasons: Parkinson's disease may be the fastest growing neurological condition worldwide, the phenotype is characterized by a complex array of both motor and nonmotor features, and chronic care involves a wide range of professional disciplines that operate in all possible layers of healthcare. The model that we introduced is tailored around eight specific solutions. First, to monitor patients and deliver care within or close to the patient's own home environment, whenever possible. Second, to educate patients, and to support them in self-management, which relieves anxiety and alleviates pressure on the medical system. Third, to deliver proactive instead of reactive care, thereby preventing disease burden and avoiding escalation to more expensive care (including avoidance of unplanned admissions). Fourth, to support proactive care by remote



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Integrated and Patient-Centered Management of Parkinson's Disease, *continued from p. 15*

monitoring using e.g. sensors and e-diaries, allowing for timely detection of medical problems before they derail. Fifth, to deliver care according to each patient's unique sociodemographic, disease-specific and genetic factors, considered in tandem with their personal objectives and goals, following personalised "precision" approaches. Sixth, to optimize timely access to both generalists and specialists in the management of persons with PD. Seventh, to facilitate that patients can easily contact a single point of access (a personal care manager) who can directly answer simple questions, refer patients to appropriate colleagues, and coordinate the multidisciplinary team advice. Eighth, to seamlessly connect the different layers of healthcare and bundle all solutions into an integrated network, across both professional disciplines and different healthcare settings. We anticipate that this integrated care model will improve the quality of lives of patients and create an attractive working environment for professionals, whilst being affordable for future generations.

We agree that the proposed new model of integrated care holds great promise to revolutionize our approach to the chronic management of patients with Parkinson's disease, as well as those with different movement disorders or other neurological conditions. The model may be easiest to implement in well-developed and densely populated countries, but we also see definite opportunities to implement important elements of the new integrated care model in developing countries. The introduction of telemedicine (such as videoconferencing to diagnose and support patients remotely) is a prime example of this. The next step is to take this new model to the test, which is currently taking place as part of a large controlled study in the Netherlands (the PRIME project: PROactive and Integrated Management and Empowerment of people with Parkinson's disease). This experiment will yield hands-on experience with the new model in a living laboratory, and as such provide important "lessons learned" for a wider implementation elsewhere in the world.

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Parkinson's Disease in the Western Pacific (Asia Pacific) Region

— *Shen-Yang Lim, MBBS, MD, FRACP FASc, Senior Consultant Neurologist, University of Malaysia, Kuala Lumpur, Malaysia*

In the July 2020 issue of *Moving Along*, Bas Bloem, Ray Dorsey and Michael Okun highlighted the pandemic of Parkinson's disease (PD), noting that "... rates of the disease, adjusted for age, are increasing in virtually every part of the world and have doubled in China".

Yet, while the Asia-Pacific region is poised to face a large brunt of the increasing burden of degenerative disorders worldwide (with China alone projected to have the majority of patients with PD), and PD heterogeneity increasingly recognized to be a crucial aspect of the disease, there has been little study comparing similarities and differences between East and West.

In conjunction with the World Parkinson Congress (WPC) in Kyoto, Japan (held for the first time in Asia), *The Lancet Neurology* published a very timely review on "Parkinson's disease in the Western Pacific Region" (the WPR being the World Health Organization's terminology for the Asia-Pacific region, minus the Indian subcontinent and a few other countries).

Some of the major highlights were:

1. Overall, a lower prevalence of PD was observed in some WPR countries such as Japan and Singapore, despite having a relatively high proportion of aged individuals. There is also a reversal of the usual male predominance of the disease in Japan and South Korea. These findings may point to important differences, e.g., in environmental risk factors, in the region.
2. There is likely to be a different weightage for PD environmental risk and protective factors in the WPR, relating to pesticide use, smoking, consumption of tea and dairy products, exercise, diabetes, and infections such as hepatitis C. For example, exposure to pesticides, solvents and metals might have contributed to the increased PD incidence in China, which has undergone rapid industrialization over the past generation. Many of these require further study and if confirmed will have important public health implications.
3. Some genetic factors underlying PD are distinctly different in WPR populations. Taking the *LRRK2* gene as the prototypical example, G2385R and R1628P (so-called "Asian variants") are seen in Asians and not Caucasians with PD, whereas the converse is true for the much more widely-known G2019S mutation.² In turn, these genetic differences may have important implications, e.g., in the basic pathogenetic mechanisms (G2019S resulting in increased kinase activity, whereas other mechanisms might be at play with the Asian variants). The more "aggressive" L444P (L483P) *GBA* mutation² appears to account for the majority of *GBA* mutations in Chinese patients. Among the autosomal recessive forms of PD, *PINK1* mutations are common in certain Asian groups. Understanding these inter-ethnic differences is vitally important as the field enters the era of genetics-based targeted therapies.^{3,4}
4. There are differences in medical management in the WPR which may partly account for substantial differences in clinical features such as



5th World Parkinson's Congress, Kyoto, Japan. Panel of plenary speakers and chairs (left to right): Shen-Yang Lim, Roger Barker, Jeffrey Kordower, Per Borghammer, Heather Kennedy and Hideki Mochizuki.

motor complications (e.g., dyskinesias) and non-motor symptoms. For example, dyskinesias occur at lower rates in this region, probably partly caused by lower levodopa dosages used, and possibly related also to the high frequency of amantadine use.⁵ These factors could potentially be exploited or addressed to improve patient symptomatology.

5. Co-morbid health conditions such as diabetes, cerebral small vessel disease and osteoporosis may be even more highly prevalent in WPR populations, with significant implications for disease causation and/or disease course. For example, diabetes and cerebral white matter disease may contribute significantly to axial motor impairment and cognitive decline. These areas are only beginning to be appreciated by the PD clinical and research communities.

6. There are major gaps in awareness and knowledge of PD. Identification of these gaps, as well as patient and caregiver perspectives and preferences will help to inform the design of educational efforts, and a more efficient allocation of healthcare resources to meet patients' and caregivers' needs and goals.^{6,7}

7. Healthcare resources are insufficient with a shortage of neurologists, PD specialists, and neurosurgeons with expertise in deep brain stimulation (DBS). For example, while the USA has 1 neurologist per 20,000 population, this ratio is 1:300,000 in Malaysia ... and around 1:1.5 million in Cambodia and Laos! Currently, there is poor or no access to potentially life-changing treatments such as dopaminergic infusions and DBS in many WPR countries, highlighting an urgent need for stakeholders (patient groups, clinicians, industry and government) to work together to improve the appropriate utilization of these therapies. These issues were also recently reviewed by Noyce and coworkers.⁸

Parkinson's Disease in the Western Pacific (Asia Pacific) Region, continued from p. 17

8. There is a paucity of PD-related clinical trials in the WPR, highlighting a major gap in PD research currently, given that there are likely to be inter-ethnic differences in drug metabolism, therapeutic responses and adverse effects. In two MDS-sponsored evidence-based reviews of trials published between 2011 and 2016, fewer than 20% of PD drug trials were conducted in this region. This disparity exists not only in PD, and there are increasing calls for drug developers across medical fields to design studies that represent more of the world's populations.⁹

9. Complementary and alternative treatments are even more widely used in the WPR (by up to three-quarters of PD patents) than in the West, reflecting many factors including cultural history, easy access, and a desire for a more holistic approach to health care. The most popular approaches include tai chi, acupuncture, and herbal preparations. There is therefore a need for these treatments to be tested in a rigorous manner as for conventional therapies, in order to provide an evidence-based, scientific rationale for their use.

10. A number of specific suggestions on how the field can move forwards in terms of further research, short and medium-term priorities for care, and opportunities for improvements in training and advocacy in the region, were discussed in this multi-authored paper. It is our sincere hope that there will be much more analysis, discussion and debate regarding the issues raised in this article.

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Breakthrough in Synucleopathies Thanks to Investigations in Nonhuman Primates

— Erwan Bezard, PhD, Director, Institute of Neurodegenerative Diseases, Bordeaux, France



Erwan Bezard, PhD

The basic problem in Parkinson's disease (PD) is loss of dopamine-producing nerve cells in a region of the brain called the substantia nigra pars compacta (SNc). Everybody has a gradual loss of these

dopamine-producing nerve cells as they age, but PD patients have lost more of them than other people. Why these cells die in PD is unclear, and the focus of much research. To answer these questions, research requires the use of a variety of animal models to study different aspects of the disease. An international group of German (B. Mollenhauer), qatari (O. El Agnaf), Spanish (M. Vila, MT Herrero, J Obeso) and French (P. Derkinderen, B. Dehay, E. Bezard) senior researchers teamed up to address fundamental questions regarding development of synucleopathies in non-human primates, a species which brain anatomy and physiology is close enough to human beings to allow direct translation.

In the first study published in May 2020 in *Science Advances*¹, they show that dopaminergic neurodegeneration can be induced in non-human primates by both, small and large aggregates of α -synuclein. In contrast, experiments in rodents, used in 85% of studies, show that small α -synuclein aggregates do not induce neurodegeneration.

The so-called protein, α -synuclein, has a central role in the development of PD. In 2014, the same team, composed of the Spanish and French researchers, showed that pathological forms of the α -synuclein protein present in the brain of deceased PD patients were capable of initiating a Parkinsonian-like pathological process in mice and primates². Using the same human aggregates, they now characterized the synucleinopathy in non-human primates, by comparing these human aggregates with fractions containing soluble and smaller α -synuclein aggregates. To their

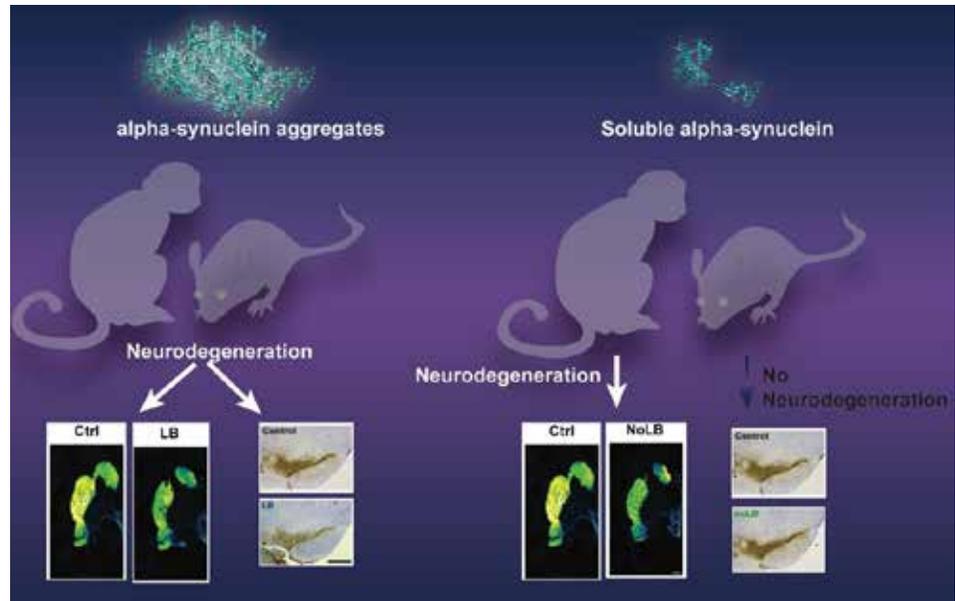


Figure 1: In non-human primates, both large and small α -synuclein aggregates, induce neurodegeneration via distinct pathogenic mechanisms while only large aggregates do so in mice. This has dramatic impact upon search for disease modifying therapies.

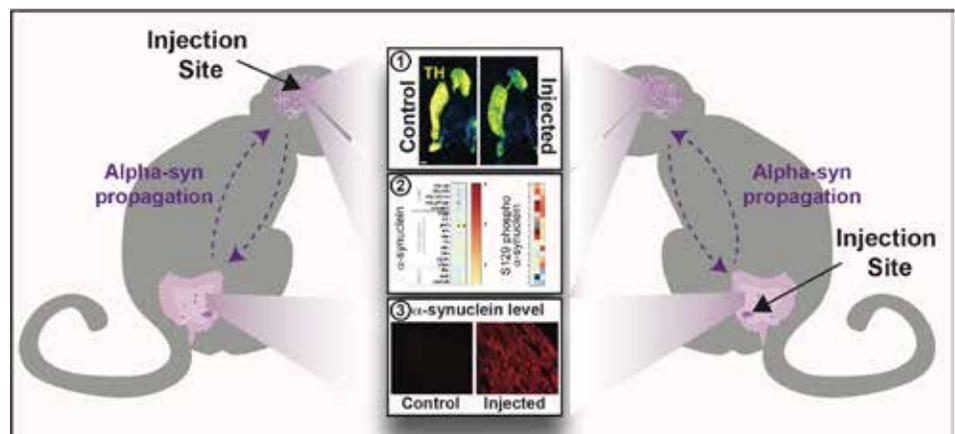


Figure 2: Both brain and gut injections of enriched fraction containing human α -synuclein aggregates induce : 1) nigrostriatal degeneration, 2) α -synuclein pathology in the central nervous system and 3) α -synuclein pathology in the enteric nervous system.

biggest surprise, while these small α -synuclein aggregates did not produce any neuronal cell death in mice, non-human primates showed neurodegeneration after small aggregates injection; to the same extent of big aggregates (Fig. 1). For the authors, these findings provide new information on how the disease is initiated and amplified, and shows that, in non-human

primates, a small amount of singular α -synuclein aggregates is as toxic as larger amyloid fibrils, reinforcing the need for preclinical research in non-human primates (Fig. 1). These results have dramatic impact upon search for disease modifying therapies as focusing upon rodent species only in our therapy development programs may simply ignore the diversity of

Breakthrough in Synucleopathies Thanks to Investigations in Nonhuman Primates, *continued from p. 19*

synucleopathy-causing mechanisms.

The origin of misfolding trigger signal of α -synuclein remains a mystery. The research about the gut-brain axis emerged in 2003 when a neuroanatomists team led by [Heiko Braak](#) spotted α -synuclein inclusions within the enteric nervous system of people who had died with PD. They proposed a staging scheme in which α -synuclein pathology spread from the gut to the brain. However, the intestinal origin of PD has not been proved in nonhuman primates and the bidirectional travel of α -synuclein is still under investigation.

The very same international team included that key question into their thorough investigations and have found additional evidence that brain alpha-synuclein can also travels down to the gut. The [study](#), described in the May 2020 issue of *Brain*, offers a new invaluable primate data exploring the role of the gut-brain axis in the initiation and propagation of PD pathology³.

The authors now show that extracted α -synuclein aggregates of brains of dead patients have the ability to initiate and extend the neurodegenerative process that typifies PD in mice and primates. Using the same human aggregates, this study shows that, not only α -synuclein spreads from the gut to the brain, but also travels from the brain to the gut (Fig. 2). Understanding how the disease develops over time should open the door to the development and testing of new therapeutic approaches.

Although further experiments are necessary, the study also suggests that the transmission of α -synuclein pathology does not go through the vagus nerve as it was previously suggested. Instead, the results suggest a possible systemic mechanism, in which the general circulation would act as a route for long-distance bidirectional transmission of endogenous α -synuclein, strengthening the predictive role of α -synuclein as a biomarker.

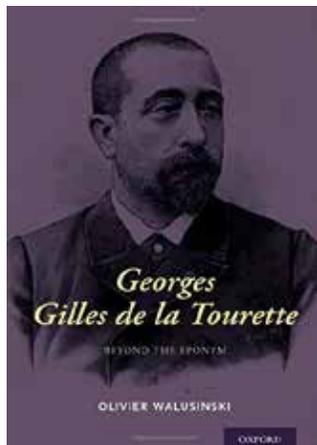
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Book Review: Georges Gilles de la Tourette. Beyond the Eponym, by Olivier Walusinski, MD

— Christos Ganos, MD, Department of Neurology, Charité University Medicine Berlin, Berlin, Germany

Only recently was I informed that a new work was published on Georges Gilles de la Tourette's life and works by Dr. Olivier Walusinski, an expert medical historian with incredible knowledge on J.M. Charcot's legacy in neurology. Although I immediately placed my order for *George Gilles de la Tourette. Beyond the Eponym* (Walusinski, 2019), I was uncertain whether I would be able to distill new information both on the syndrome, but also on the person whose name it bears. Indeed, and until this publication, most of the historical knowledge I had acquired on the syndrome of Gilles de la Tourette sourced from Howard I. Kushner's remarkable *A Cursing Brain* (Kushner, 1999).



Already from the first pages, I realized that my hesitations had been ungrounded. I was fascinated by the meticulousness of historical information that Dr. Walusinski graciously offers and felt abundantly ignorant on numerous facts. The book begins, for example, by presenting the genealogy of Georges Gilles de la Tourette, to make a point that the original family name is actually "Gilles", with the toponymic reference of "de la Tourette" being added on the 18th century. On this note, Dr. Walusinski poignantly adds that if a simplification is needed, "Gilles" instead of "Tourette" would be the historically preferable one. The book continues by documenting Gilles de la Tourette's education and early career, the academic struggles of the time – to be noted, not very

different from the ones in place today – and his successful medical path earning him the Legion of Honor rank. Special mention is made with regard to the assassination attempt against his life in 1883 by Rose Kemper - who did not have tics -, and also on the historical circumstances that lead to the publication of his work on the syndrome that now bears his name. A large segment of the book also focuses on the incredible productivity and diversity of Georges Gilles de la Tourette's scientific interests, including his doctoral thesis on gait studies, the development and practical usage of new medical devices to treat disorders such as "locomotor ataxia", and his works on hypnosis and hysteria. A detailed account is also provided on his interest in writing and communicating different aspects of human behavior and life to the public. Finally, a chapter focuses on his "*Sad End*" following the diagnosis of neurosyphillisis and his incarceration in the Bois-de-Cery asylum in Lucerne until his death on May 22, 1904.

The depth and meticulousness of Dr. Walusinski's *George Gilles de la Tourette. Beyond the Eponym* urges me to recommend it to any contemporary clinician-scientist interested in disorders of human behavior. It does not only serve as an archive of the past both for tic disorders and the entire Parisian school of neurology, but also as an important reference point, which allows to place contemporary practice within the wider context of clinico-scientific progress in modernity.

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The Era of Virtual Learning: The Movement Disorders Society of India (MDSI) Webinars

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The outbreak of COVID-19 has led to dramatic changes worldwide, affecting not only the health care requirements, but also disrupting changes in the classical methods of teaching and learning. This sea of changes can be seen from the schools to colleges and societal conferences worldwide. It has brought its own merits and limitations associated with this virtual world. The disadvantage of social world contacts is dramatically replaced with the ease of listening to 'best of the world' in the comfort of the home. The Movement Disorders Society of India (MDSI) was quick to react when the COVID-19 lockdown started in India. Prof. Vinay Goyal, President of the Society, along with the Prof. U. Meenakshisundaram, Secretary, initiated the MDSI webinar program. The primary objective was to get best of the lectures with the ease of being at home. Prof. Rupam Borgohain, President-elect of the Society, is the chair of this webinar series. The program consists of weekly didactic lectures from the leaders in the field from across the globe, latest scientific research in India as well as interesting learning case presentations by the residents/fellows. These weekend webinars are very abuzz with audience from not only across India, but also from many other countries worldwide. The exhilarating activity in these webinars do indicate that they have achieved their primary goal of getting knowledge from the masters to the comforts of the home; and these are going to stay for years to come.



MDSI Webinar didactic talks included:

- Anthony Lang (Clinical Trials Targeting α -Synuclein)
- Kapil Sethi (Movement Disorders Video Session)
- Kailash Bhatia (Movement Disorders Potpourri),
- Kallol Ray Chaudhuri (Non-Motor symptoms in Movement Disorders),
- Dag Aarsland (PD Dementia)
- Dan Weintraub (ICD and PD)
- David Shprecher (Tic and Tourette Syndrome)
- Steven Frucht (Focal Dystonia and Musician's Dystonia)
- Ruth Walker (Approach to a patient with Chorea)
- Mandar Jog (Q&A for Movement Disorders)
- Niall Quinn (Young onset Parkinson's disease and Juvenile Parkinsonism revisited)
- Alfonso Fasano (Recent Advances in Deep Brain Stimulation)
- Antonio Strafella (Neuroimaging Biomarkers in Parkinson's Disease and Atypical Parkinsonisms)
- Susan Fox (Drug Repurposing for Parkinson's Disease)
- Tuhin Virmani (Freezing of gait in PD)
- Sean Pittock (Paraneoplastic syndromes)
- Savica Rodolfo (Dementia with Lewy Bodies – Clinical Features, Imaging and Management)
- Alberto Espay (Epileptic Movement Disorders)