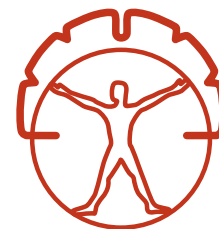


MOVING ALONG



International Parkinson and
Movement Disorder Society

Editor, Antonio Strafella, MD, PhD, FRCPC



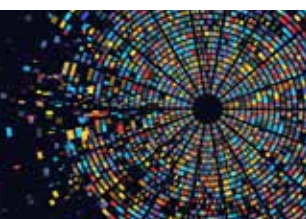
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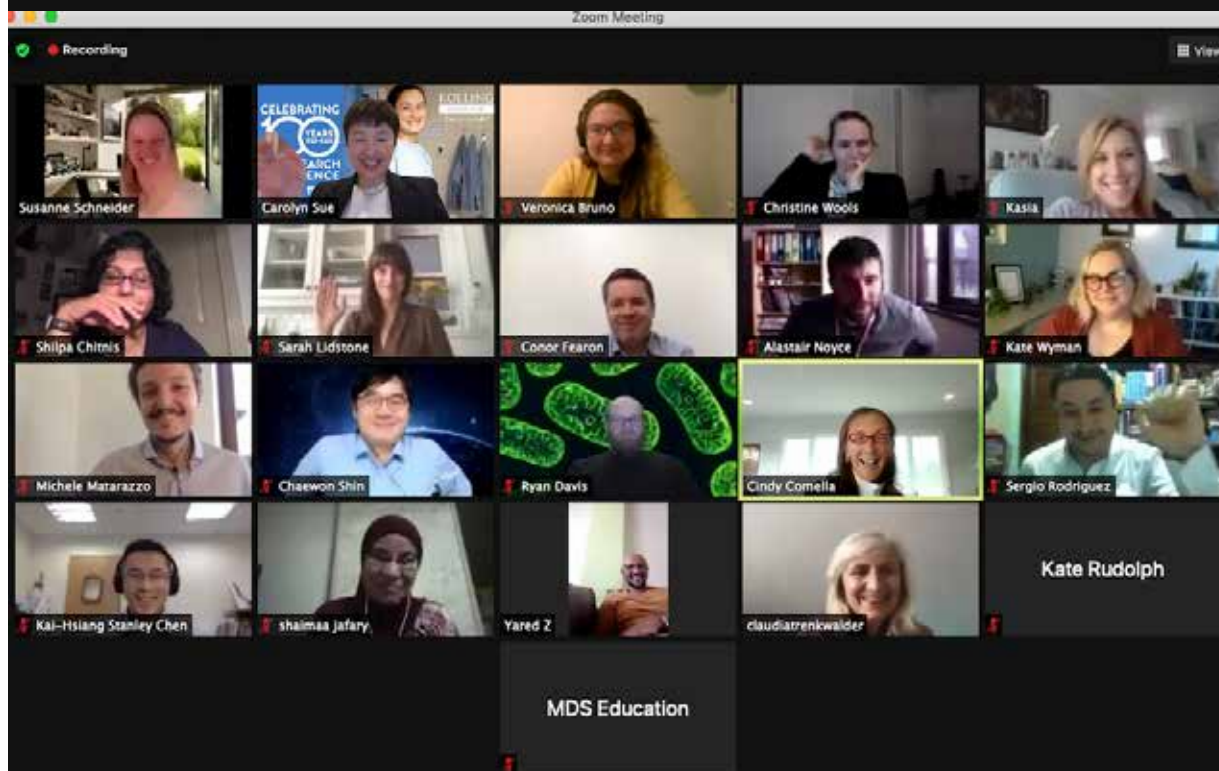
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Letters to the Editor *Your comments and questions are always welcome.*

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 members continue to be healthy and safe during this challenging time of the COVID-19 pandemic.

We again would like to thank the entire MDS community for the enthusiasm demonstrated in contributing to this new issue of *Moving Along* during these challenging times.

For this first issue of 2021, the Editorial Board worked tirelessly to pull together new exciting material for our readers. The newest member of the Editorial Board, Dr. Shaimaa El-Jaafary, has contributed two interviews for this issue. We have selected her interview with the MDS LEAP faculty and fellow 2020 class participants to be the cover story. In addition, she also contributed a very informative discussion with MDS-Africa Chair and winner of the 2020 MDS Presidential Distinguished Service Award, Prof. Njideka Okubadejo. This issue also features updates from various MDS groups and programs, new MDS rating scales, and several recent important developments in the field of Movement Disorders. And once again, the "President's Corner", by Prof. Claudia Trenkwalder, highlights future strategic change for the Society, while continuing to introduce young members to our MDS community.

Once again, 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 each issue possible, particularly through the challenges of the past year. 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

It is hard to believe it has been over a year now since the COVID-19 pandemic has completely changed the way we live and work. But a year later there is now much more hope than when we started, particularly with progress in vaccine distribution, which is skyrocketing in many countries. While there is daily progress being made, it is still a continuum, with second or third waves impacting some parts of the world while some areas are relatively good with fewer hotspots. No matter how you read or interpret it, the situation remains unpredictable.

Despite the continued uncertainty, MDS continues to make progress through virtual meetings and educational events. Most recently, the MDS Officers once again met in a virtual format to make strategic decisions for the future of the Society. I want to share the highlights of some of them with you here:

- You may recall earlier last year that MDS released an updated [Statement on Diversity and Inclusion](#). This subject remains important to the Society and we will continue to work to be more inclusive and diverse in our representation of members, leaders and committees across all MDS Regional Sections. We are working on a more detailed statement regarding these inclusion efforts and how MDS will ensure it is followed moving forward.
- We are pleased to be expanding our portfolio of assessments into the digital world, including the development of an e-diary and restructuring of the existing MDS Rating Scales Program. This new MDS **Clinical Outcome Assessments Program** will first need to establish a special Task Force to focus on data, particularly in relation to AI and machine learning. We will be seeking interested participants to serve on this Task Force and help guide these assessments in the coming months.
- The Society has been working hard to develop and build a new personalized website experience and learning management system. Thanks to the efforts of Oscar Gershanik, Brandon Barton and Brian Berman, the new and improved **MDS Education Roadmap will be ready to launch in June 2021**. Watch for more information on this exciting initiative in the coming months.
- Given the increased presence of digital information, the MDS Officers discussed the proposal of our President-Elect, Francisco Cardoso, to establish a new **Communications Oversight Committee**, which would oversee the various MDS communications platforms, including the Society website and social media. On a related note, I am pleased to announce the addition of the new **MDS Women in Movement Disorders Special Interest Group (SIG)**. More information about the goals and objectives of the SIG can be found on the [MDS website](#).

In looking ahead to more 2021 virtual events, the first **Virtual AOPMC** is coming up quickly, June 4-6, 2021. The planning committees have promised to deliver the best quality education, with innovative networking and educational opportunities supported by virtual technologies. You also will not want to miss the Welcome Ceremony, where they will announce the new AOPMC mascot and contest winner. I encourage all members in the MDS-AOS region to register for no fee on the website, www.aopmc.org - members from other regions are welcome, too!

For the 2021 **MDS Virtual Congress**, I am pleased to announce that we received over 1,400 abstract submissions this year. We have new possibilities for you to engage with presenters and to participate actively. Once again, we look forward to welcoming you to the 2021 Virtual Congress, **September 17-22, for no fee (complimentary)**.

Lastly, I will conclude this message with the introduction of two more members who are active in the MDS Young Members Group on page 5.

Sincerely,



Claudia Trenkwald, MD
MDS President, 2019-2021



President's Corner, continued from p. 4



Katarzyna Smilowska, MD, PhD
Sosnowiec, Katowice, Poland & Kiel, Germany

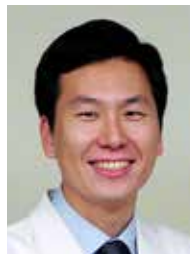
I am currently completing my residency in Neurology at the Regional Hospital in Sosnowiec, Poland. Additionally, I continue my research activities at the Christian-Albrechts University, Kiel, Germany, under supervision of Prof. Günther Deuschl. I received my PhD from the Medical

University of Silesia in Katowice, Poland in 2017. Following that, I was awarded with an EAN research fellowship at the Department of Neurology, Radboud University Medical Center in Nijmegen, under supervision of Prof. Bastiaan Bloem. Shortly after, I undertook a fellowship at the National Hospital for Neurology and Neurosurgery, at the Clinical Movement Disorders Group, led by Prof. Kailash Bhatia. I am part of the LEAP Class of 2020 and I serve as a member of numerous MDS committees, namely: the MDS-ES Education Committee, the MDS Rating Scales Translation Committee, and the MDS Web-Based Learning Sub-Committee Meeting. I am also involved in the MDS Normal Pressure Hydrocephalus Study Group and MDS Task Force on Early Onset Parkinson's Disease. My research is mainly focused on Parkinson's disease, dystonia and genetics in rare movement disorders.

I was privileged to take part in the MDS-ES Summer School for Young Neurologist at the Queens Square, London. During this school, I developed a passion for movement disorders. Since then, MDS provided me with tremendous opportunities to increase both my clinical and research skills and to learn from experienced leaders in the movement disorders field. I am very grateful that MDS created this unique community where young neurologists are taught how to be creative and innovative researchers. Most importantly, they learn how to become an attentive clinician, as well as to observe and classify phenomena in order to make a diagnosis. The strong support of the network and mentors enables fruitful discussions and further development.

I am looking forward to becoming even more active in the International Parkinson and Movement Disorder Society. I strongly believe I can share my enthusiasm with young neurologists in Poland, leading to an increase in the number of MDS members in my home country, including neurologists, students, fellows, residents, nurses and allied health professionals. I believe that this will have a direct impact on the quality of care delivered to Polish patients.

Outside of academic work, I have three amazing kids (Piotr, Hania and Zuzia), who help me to keep the work-life balance. I enjoy skiing, cycling, reading and dancing.



Jinyoung Youn, MD, PhD
Seoul, Republic of Korea

I am Jinyoung Youn, associate professor in the Movement Disorders Division, Department of Neurology at Samsung Medical Center, Sungkyunkwan University, Seoul, Korea. I am working as a vice-director of neuromodulation team and director of a gait lab. Even from the

resident training, I gained various experiences in movement disorders under the late professor Won Yong Lee, and finished my fellowship in movement disorders under professor Jin Whan Cho at the same hospital. I also had opportunities to visit world-leading centers in deep brain stimulation, including Juntendo University Hospital in Tokyo, Japan, and University of Florida in Gainesville, FL, USA. Since September 2020, I am spending my sabbatical year at Toronto Western Hospital in Toronto, ON, Canada. My research topic is clinically focused on freezing of gait and other gait disorders, which are disabling and refractory to treatments. Additionally, I am interested in various neuromodulation including deep brain stimulation and non-invasive brain stimulation as a technique. My academic goal is to develop the treatment modalities for freezing of gait and other gait disorders with a combination of these two research interests.

I was privileged to attend the International Congress of Parkinson's Disease and Movement Disorders during my residency. The first one was the International Congress in New Orleans, LA, USA, in 2005. These opportunities led me to the fellowship in movement disorders, and I have been an MDS member since my fellowship. I graduated in the MDS LEAP Class of 2018 and this experience really motivated me to get involved with MDS. For the connection to the young neurologists, MDS has leadership programs to motivate young neurologists, and also supports study groups and special interest groups for academic networking. I have had a great opportunity to participate in LEAP mentor/mentee projects as a mentor for the MDS Young Members Group. MDS has constructed user-friendly formats like the new webpage, podcast, and social networks, which are more accessible for young neurologists. Additionally, MDS should suggest the standard for the future of medicine. MDS has already developed various MDS-owned or recommended scales to improve the clinical practice, and also concentrates on telemedicine or technologies to apply cutting-edge techniques in the real practice. Since graduating from the LEAP program, I continue to serve as a member of Rating Scales Electronic Development Committee. I am also joining the MDS Normal Pressure Hydrocephalus Study Group, Telemedicine Study Group and Neurosurgery Special Interest Group. Thanks to these activities in MDS, I have met many of friends and colleagues. I love to travel all around the world, and I am really looking forward to seeing them all in person soon.

MDS Virtual Congress 2020: Highlights from 2020 - Looking Toward 2021

Highlights from 2020: Basic Science of Parkinson's Disease

— Ryosuke Takahashi, MD, PhD, Department of Neurology, Kyoto University Graduate School of Medicine, Japan



In the past year, a number of interesting papers were published from the basic science field on Parkinson's disease (PD), some of which were introduced as 'Highlights from 2020' at the MDS Virtual Congress in September of 2020.

Regarding disease mechanisms, the latest NMR analysis reconfirmed the importance of molecular chaperones for α -synuclein (aS). Chaperones inhibit the localization of aS to mitochondria and concomitant aggregate formation, and the phosphorylation of Tyr39 (a target of Abelson tyrosine kinase, c-Abl) and oxidation of aS inhibit the interaction between aS and chaperones¹. The role of heterozygous mutation of *Glucocerebrosidase* (*GBA*), the most important genetic risk factor for idiopathic PD, has long been a mystery, but *GBA* protein was shown to play an important role, especially in the minimum pathology of aS aggregates in the very early stage, and accelerates the progression after the initiation of pathology². Microglia have been attracting attention as disease modifiers and therapeutic targets, and their differing involvement in different stages of the disease was revealed. A selective autophagy termed 'synucleinphagy' that requires p62 upregulation through the NF- κ B signaling pathway but not through the TLR4 pathway is important for aS clearance³. aS aggregates in the exosomes released from microglia are involved in the propagation of the aS pathology⁴. Regarding animal models for PD, an aS propagation model in non-human primates⁵ and a prodromal mouse model exhibiting RBD, hyposmia and mild dopaminergic (DA) cell loss⁶ were added to the list of promising nonclinical animal models.

We have also seen substantial progress in the development of therapeutics for PD. In the transplantation of human stem cell grafts, late viral delivery of glial cell line-derived neurotrophic factor (GDNF) after the transplantation but not early delivery before the transplantation was shown to improve the functional integration of the grafts of DA progenitors⁷. As a striking achievement of regenerative medicine, knockdown of PTB, which suppresses a neuronal induction loop, converted astrocytes to neurons *in vivo* and improved the phenotype in a PD mouse model. In this model, astrocytes were converted into tyrosine hydroxylase (TH)-positive neurons in the milieu of the substantia nigra and functionally targeted the striatum⁸. L-type voltage-gated Ca²⁺ channels (VGCCs), whose blocker is isradipine, have been attracting attention as targets of dopaminergic neuroprotection. Knockdown of the R-type VGCC (Cav2.3) was also reported to ameliorate the phenotype of PD model mice, and this type of VGCC can function as a target for the protection of DA neurons⁹.

Our final goal is the development of disease-modifying therapies. To make the most of the progress made through basic research on the disease mechanism and neuroprotection, molecular and imaging biomarkers in the early or even prodromal stage of PD, which are currently lacking, will be needed for the early diagnosis and early intervention.

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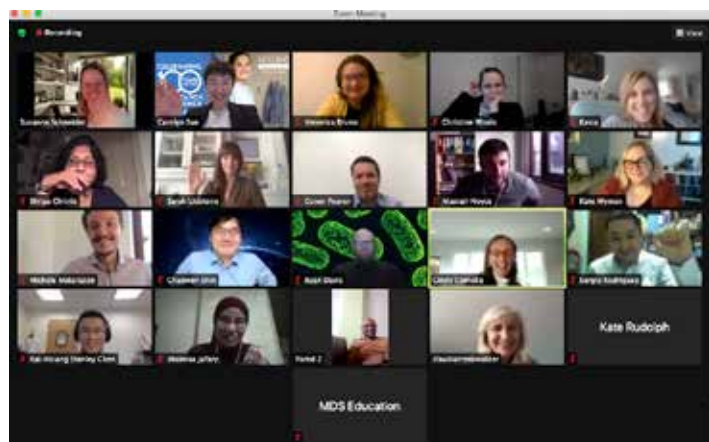
The MDS LEAP Class of 2020 Went Virtual

— Shaimaa El-Jaafary, MD, Associate Professor of Neurology, Cairo University, Egypt; Graduate, MDS LEAP Class of 2020

The MDS LEAP Program launched in 2015 to provide formal leadership training to support the growth, development, and success of outstanding, talented and passionate young members in the Society.

Each year, 14 carefully selected participants representing all MDS Regional Sections go through a well-structured 18-month program encompassing the development of leadership skills through a mentored development and didactic skills format. The two-day training workshop, which takes place immediately prior to the MDS International Congress each year is followed by a one-year hands-on training period, which includes virtual meetings with a mentor and the peers.

This year was different. In early May, the selected participants of the LEAP Class of 2020 were informed that the LEAP Steering Committee had decided to turn the LEAP program into a virtual session due to the COVID-19 pandemic. Undoubtedly, it was a difficult but reasonable decision. However, each challenge holds an opportunity. Indeed, the faculty worked hard to turn the LEAP seminar into a pearl. The seminar was special in that the participants interacted and greatly enjoyed.



Dr. Shaimaa El-Jaafary, from the MDS Africa Section, is a participant from the LEAP Class of 2020. In the following interview, she explores and reflects with the faculty and her class colleagues on the new experience and the expectations from this year's program.

LEAP Faculty:

Cynthia Comella, MD, FAAN, FASM, FANA (Program Chair)

Shilpa Chitnis, MD, PhD, FAAN, FANA

Susanne Schneider, MD

Carolyn Sue, MBBS, PhD, FRACP

What does the LEAP program mean to you?

Cynthia Comella: We started in 2015 and it's really a passion of mine because the whole goal is to have young members of the Society with developed abilities to become leaders, without taking all the side tracks

the rest of us had to. The young members in MDS are the future leaders. I love the Society, which is very dear to my heart. I would love to see it succeed moving forward and the way to ensure that success in the future is by developing new people who to take on the leadership.

Shilpa Chitnis: It's really the flagship leadership program that the MDS established in 2015 and I consider myself to be extremely fortunate to be invited to work with Dr. Comella, who's the leader, and at the same time it was a great opportunity to work with some of the leaders in the field. It was just a great honor when Dr. Comella asked me and Dr. Goldman to be the LEAP facilitators along with her. What has it meant for me? Coming along, I never realized the degree of commitment that it required. Although I think that we were more than happy to be able to take the time to provide that commitment because as a person I have spent 20 years of my career to empower young people.

For MDS, we wanted it to be the organization of people and to be open to anybody from any part of the world who could show great academic and leadership potential to be identified and picked to learn some great leadership skills. Our expectation is that these people would be the next generation leaders that will take the Society to the next level. For me, LEAP is not only a second career, but also both an honor and pleasure to make a strong friendships within MDS with people from all over the world. I have had an opportunity to learn from the young, as well as experienced mentors and professors, so I found this to be bidirectional.

Susanne Schneider: The LEAP program is a fantastic initiative, which had a great impact on my career and on my personal life. First, when I was a participant, I learned a lot about leadership and its different styles and attitudes towards it. This was reinforced when Cynthia and I put together the book on Leadership in Movement Disorders, and I had the honor to interview the leaders of our field who shared their views and experiences. Now, I am privileged that I can contribute to the success of the program by serving as faculty and on the LEAP steering committee - and there is still so much to be learned and done.

Carolyn Sue: It is just the most wonderful program to be involved in; it is a great example of how it should be helping our younger generations (future leaders) and recognizing the abilities first of all of the younger members of the Society. It also addresses some of the skills and tools that they need to become even greater later than they already have become. I like this program because it really helps to realize & extended the potentialities of the bright young stars in the Society. Everybody wants to watch people who worthwhile investing in and the LEAP program does this. We are very aligned with real love for the LEAP program, I mean Cindy is just the most amazing leader and she sets the example for us. She's picked a faculty well because again it's easier to work with like-minded people but also embrace the diversity that we can all bring to work synergistically. We are all working for a common goal and we try to complement each other with different abilities and skills, and that is another reason to love the program; meeting amazing young people and working with wonderful faculty, that I really

The MDS LEAP Class of 2020 Went Virtual, continued on p. 8

The MDS LEAP Class of 2020 Went Virtual, *continued from p. 7*

love talented people and we learn as much from each other as we do from learning from you guys as well as trying to teach skills right so and he doesn't love learning one of the best things to do is to learn.

What is the difference between this virtual LEAP and previous courses of the program?

Cynthia Comella: Prior to the pandemic-when we had to go to a virtual LEAP program-there would be a two-day session, where we would meet in person. This allowed for a little bit more networking activities with face-to-face interaction. You felt to some degree that you really got to know each individual. Virtually, in contrast we had to be a little bit more distant. It's a Zoom phenomenon where you can see people, but you can't walk out in the hall and talk to them. You are just there, and you do what you have to do. It had to be shortened; I think we included all of the important elements. Unfortunately, we could not include many of the fun activities that highlight some features of good leadership. We could not do the helium stick where there are two teams, and they compete at lifting a bamboo stick that sounds easy but challenging. We could not build the balloon tower where you had to figure out how to build the tallest tower. It was competitive. There were groups and a lot of laughing and a lot of strategies. I mean, those are the things you miss in a virtual meeting versus a real meeting, and not only that, but people do get what we may call "Zoom fatigue", when on Zoom for an extended period. So, we had to keep that in mind as we developed the program virtually.

Shilpa Chitnis: Since we started in 2015 all the way to 2019, we met in person. Nothing can compensate for personal interaction, the engagement, the bonding that comes from personal interaction. When the MDS International Congress itself went virtual, we felt that we needed the LEAP to go on and although it would be virtual that we still would not have the right to cancel and carried over to the next year because the people that were selected deserve to have the rightful training. I think the applicants that were selected, are all very wonderful, talented, and intelligent it is just a great opportunity to work with them, I also think people did their best to engage with each other despite the virtual platform. Our educational coordinator, Kate Rudolph, did a phenomenal job by creating these breakout rooms that became a little bit more intimate, it gave me an opportunity to call on people and get to know people a bit better. I think that in the virtual LEAP we have still used the technology as effectively as we possibly could to engage people and try to create some new intimate room settings where everybody would be able to share experience with 3-4 people as opposed to the whole crowd. The one thing that was very hard to do and we like to think about is the activities. The joy of presenting the principles of leadership and to be able to demonstrate them with examples through activities. Also, great vantage and friendship is hard to have in a virtual environment. The activities are fun and help to consolidate in practice what you taught in theory.

We still can have some activities and even we have some social bonding during the virtual program in the small group discussions. Yes, it has

succeeded to bring us together, though we are from different parts of the world and everyone just staying in their country, in the comfort of his/her room, but we are committed.

Susanne Schneider: The COVID-19 pandemic forced us to challenge the process and find new and innovative solutions for many things in life. For the LEAP program, we opted to offer a virtual program (rather than cancelling the course). The content of the program where we introduce the five practices of leadership is more or less the same. We do miss the overall environment and the opportunity to engage with each other in person, to chat in small groups in the corner, to go for lunch and have a fun night out. Nevertheless, I felt the vibe of the program throughout our seminar. We spent intense amazing days together and the group really bonded well.

Carolyn Sue: I don't have to spend as much time traveling to different sites. The real difference in this class is we really miss face to face teaching. There are a lot of things that we embrace; soft skills as much as the technical abilities that we all have and then face-to-face is important, so we have to rely on other things to promote the learning that's the first thing. The second thing is the activities, we must adjust and change the activities to be done virtually. So, it's not that you won't learn the skills it's just that the methods are different, and you have to adapt to the program so that it can be done virtually. I think also the timing of it at least when we're in the same place everybody's waking up at the same time we regardless of where you are in the world, so the difference between doing it virtually is that less people fall asleep. We had to change our teaching styles unfortunately Zoom doesn't allow more than one person to speak at the time and that's hard it adds a lot of enthusiasm. We really had to compromise on the length of the program because of the different time zones and trying to incorporate everybody into the same program, we did it over three days instead of two and we just let it shut for shorter time, so it was also the difference.

What are the challenges facing you as a faculty and director in running the program virtually?

Cynthia Comella: The biggest challenge is to make it feel like you are almost at the program, to impart that quality of person which is somewhat missing when you're not meeting in person. We will try to come up with ways, like breakout rooms to get a little more face and voice time with someone else. On the other hand, a virtual meeting offers accessibility for many more people; however, it is difficult to develop the person-to-person relationship in a virtual world. I wish if we could just do it as a hologram rather than just two-dimensional. The more real we can make the experience, the more it has a meaning rather than just sitting in a chair and watching your computer screen. So, what we want to do is to try to increase the in person quality of the LEAP experience. That's our challenge to make the program as interactive and as dynamic as it was regularly done. Again, I think we really worked hard, we spent days trying to figure out how to make it as real as possible, and I think we did succeed in part. I think that's what will go forward. But you just cannot capture that sense

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of being able just to talk to somebody in the whole conversation, so that's why we have to think about how we can capture, and we went through these breakout rooms. That is the element we have to work on - making it virtually as real as we possibly can.

Shilpa Chitnis: We had to trim down the slide show that we traditionally use because of time restrictions. We had to edit out this class to retain the most important aspects of the unified principles that would not take away the larger message. I don't think it was that hard to use the virtual form because we all got familiar with giving virtual lectures on different virtual platforms. It is worth mentioning that Kate Rudolph made it easier for us, she managed everything beautifully especially the technical issues.

Not having activities was very disappointing, the pressure of time when using a virtual platform. I miss interacting with the leap participants in person, other challenges are how to engage them more, the different time zones, missing some informal engagement activities and as MDS is a close-knit organization we used to exchange a lot of hugs, and back slaps saying good job when somebody did really well these good vibes are really missed.

Susanne Schneider: The in person-seminar entails quite a few practical activities with hands-on leadership scenarios. These are fun and allow the group to bond. As a faculty we discussed in detail how best we can replace these. In the end, we adapted or replaced them, and I believe we were able to create the image of what the LEAP program is about. Yet, doing things in a room together feels different and we look forward to the next opportunity to meet our lively group of outstanding LEAPers in person without limitations.

Carolyn Sue: One first thing is staying up to start at midnight that was a bit tricky, I'm not sure and maybe it's better for you guys that was the first challenge. The second challenge was not being able to socialize outside of the program, for example as in coffee breaks or like before the program started or after program or even during the Congress, so talking to people around and have conversations overscheduled being harder to do virtually. A set of interactions are also harder to do in a virtual world and the extra little added social talks are missed, sometimes it's important that more than one person to talk at the same time, and I guess you can't create a different atmosphere in the virtual room, which is another challenge and how we actually cut when you're in the breakout room as the schedule is eight minutes and then it comes back so this is more prescriptive in terms of the time allocation and so that's a challenge especially if you haven't finished the conversation by the time the breakout room finished, yes it was too bad we just finished and as a faculty member you really had to watch the clock to make sure your timing is right.

How did you compensate for the physical absence of the participants in the virtually?

Cynthia Comella: You cannot really compensate insofar as the person-to-person interaction. We tried to come up with activities that one could

do on Zoom that would highlight again principles of leadership. And I like them and thank goodness we have them or we have no interactions at all. By the same token, having people in a room that can talk to each other, joke with each other or make comments which again are not as easy using Zoom. I used to think that Zoom could make up for everything, but it just can't. Hopefully, we were able to transmit our own passion and our own knowledge through the Zoom platform, but it's harder to know that. As so much is based on the expressions of peoples' faces in the room, so you can see even clearly when someone's puzzled, or they've had a Eureka moment for this. It is much more difficult to do when you see all these faces on a small screen.

Shilpa Chitnis: Nothing can compensate for the in-person interaction; we tried to do some activities, and small discussion using these breakout rooms, to be more interactive.

How difficult it is to teach skills like leadership skills in a virtual platform?

Cynthia Comella: Well, I don't think it's difficult, I mean the didactic part of it. I think you can do that didactic part and you can do some of the activities. It just doesn't have as much dynamic quality to it, should I say? You can't sit down to lunch and share ideas. You can't run out and pause for a picture. Someone has to take a Zoom picture. So I think it's doable, definitely doable and people have done leadership training virtually even prior to the LEAP.

Shilpa Chitnis: I think when we are teaching leadership skills, we present a few modules. We have a lot of time built in for interpersonal discussion. I think part of learning a leadership skill is learning by thinking and learning by doing, and so I think that that's a key element. I mean, obviously there are theoretical concepts that need to be introduced, but then to be able to consolidate these concepts and to be able to figure out how you will be using these leadership concepts in your own life and you are functioning as a leader for that, the discussions, the opinions of everybody and also the activities make a huge difference in teaching leadership skills.

How did this virtual form of the program this year enrich The LEAP Experience as a whole?

Cynthia Comella: Enrich the experience! I don't think that the virtual leap enriched the experience to be frank with you. I do think it was incredibly useful, and that's what we are hearing back that it was very helpful. But I don't think it was as enriching as an in person meeting. I mean call me old-fashioned, but there is just nothing that can replace person-to-person contact. And so hopefully when this pandemic ends we will go back to the in person sessions. We developed a short form of the program, so, we did regional programs to condense it into a day rather than two days. We didn't have all the activities, and the follow up exercises by doing the presentations of each of the characteristics of

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The MDS LEAP Class of 2020 Went Virtual, *continued from p. 9*

leadership. I think even that was more dynamic if it was done in person rather than virtual. I think the one advantage of doing things virtually is that you can get people who can't travel and yet they can be a part of it. In a way it is more global with more potential people that can participate, so you asked me about enhancing and I said it didn't, but I'll have to contradict myself in that way. It did enhance what we're able to do.

Shilpa Chitnis: For me learning more about that human spirit just has the capability to endure and to keep on going and I think that's an important lesson that I learned. Although we have this pandemic, and we had the choice to do or cancel we all decided that we're just going to do it will give it a chance. The resilience and the commitment showed by the whole faculty. The relationships that we built through 5-6 years of LEAP, truly enriched my life and I think that I was very fortunate to interact with very intelligent people, not just faculty but every single LEAP participant. I made a lot of friends and collaborative research with people whom I really know, and trust and I feel validated that I'm doing something good to help other people and contribute to the Society.

Susanne Schneider: I am grateful and fascinated by what is possible technically. We are getting connected on a virtual platform; one of us in the coldest winter, someone else in the heat; some of us still in their pajamas with an early morning coffee, the others on their way to bed after a full day. Some at work with a lab coat and a FFP2 mask, others in their home office, sometimes with children in the background. And yet, we all take the time and make the effort to attend the LEAP calls. Because they enrich us. The spirit is amazing, and I would not want to miss it!

Carolyn Sue: I think the ability to adapt from the LEAPers, the faculty and also the Secretariat to be honest with you, I think that it's inspiring to see that people could adjust so well so it restored my admiration. I think it really helped to focus on that within the messages, we really had to be very clear and efficient in getting our messages across to everybody during the virtual experience. We have to make it more efficient because we don't want to do any less and I guess we've now got a broader set of skills like everybody is involved and we are more confident that the program can be delivered by many different forms which enriches the experience of the program as a whole and finally I'll just roll in the fact that doing things virtually means we can broaden around a little bit in terms of expand the leadership programs, build resources for the Society like the leadership academy, we got more insight into how can we scale teaching these using a virtual platform which is an advantage in the program.

Is there any intention to have an online LEAP that could substitute the regular course even if the pandemic is over?

Cynthia Comella: Well, at this time, I would say no. The one advantage of the online LEAP is that you can participate without traveling so it overcomes many of the obstacles and allows accessibility to more people from all over the world easily. It has been somewhat discussed but I think we will leave the live/in-person program. I hope with the blessing of

the MDS Officers that we will leave that intact and revise it every year as we already do. Hopefully, we'll be able to reach more people by having at least some virtual programs, although not as dynamic or selective. I think it offers many advantages and so I do hope that we continue in some form with the virtual LEAP but I have to say I am really looking forward to the time when we can do the LEAP program in person, and to do it regionally so that there is more access even to the live program. We just started doing regional programs last year and then those were eliminated. By the same token, you know what would be wonderful in my eyes. It's not only to have this more or less virtually because it be more in a web and platform, but to have more regional access to a live program. So we will continue to train people to be able to facilitate LEAP.

How do you see the future of the LEAP?

Cynthia Comella: I hope it grows more in terms of the training it offers and the accessibility to as many people as possible, we are ambitious, passionate about that. We can include the virtual the regional leaps. I'd like to see it combined with perhaps some other programs as well. We have to be reasonable, but what I would like to see is that people who want access to the LEAP would have the opportunity.

Shilpa Chitnis: The future is very bright, more people are interested in the LEAP program and it's supported by the MDS leadership, so we are extending and expanding it to reach out more participants. We started already our mini one-day LEAP program at some regional meetings, as in MDS-AOS SYNERGIES, and what was planned in the ES-Summit in March 2020. So, I see the future is very promising to engage young people and train more faculty to facilitate the program.

Participants:

Shaimaa El-Jaafary: As the class participants, we enjoyed the new experience and found that it exceeded our expectations. We enjoyed the interactions, the group dynamics and the passion of the faculty, with much respect given for their commitment and continued efforts. Both the faculty and our MDS Secretariat staff liaison, Kate Rudolph, worked hard to make the program a success. As a group, we were successful in social bonding and were able to connect through a WhatsApp group with more interaction and discussions outside our class time. The mentoring aspect of the program also was adored by all participants. Here are some responses on the expectations, experiences and favorite aspects of the program in its virtual form.

What were your expectations of the course?

Sergio Rodriguez: All MDS activities are always characterized by an excellent organization, planning and scientific content of excellence and the LEAP-Course reaffirm this. My expectations with the 2020 LEAP course were to achieve global knowledge regarding leadership, learn strategies that mentors used, identify and improve my leadership skills in order to enhance my personal growth and apply it in my professional

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The MDS LEAP Class of 2020 Went Virtual, *continued from p. 10*

environment, and I am absolutely sure that the LEAP virtual course fully exceeded my expectations.

Conor Fearon: I was really honored to be selected as one of the MDS-ES participants for the MDS LEAP Class of 2020. The prospect of becoming part of a growing network of LEAP graduates will be something that I will always value - as both colleagues and friends.

Veronica Bruno: When I heard that the MDS meeting would be virtual I assumed that the LEAP activities would be canceled and postponed until 2021. I was excited when I received the email saying that we would have a "virtual" LEAP. I did not know exactly what to expect considering that I knew that the program was very interactive. I was afraid that the virtual version would not give us the opportunity to meet each other and learn from our colleagues.

Katarzyna Smilowska: MDS LEAP program is a tremendous opportunity for me to develop the leadership skills and model the way to become an advocate for advancing clinical care and research in movement disorders and to inspire young neurologists. This is a remarkable opportunity to learn from experience of a leaders in movement disorders field.

Michele Matarazzo: When I applied, I saw this as a great opportunity to learn a new set of skills that will help me in my career, and I also thought it would be nice to meet with the other LEAPers, people who will likely share some of my expectations and future goals.

Tell us about your overall experience.

Sergio Rodriguez: Since the emergence of the COVID-19 pandemic, it was established universally that the virtual way was the the method to connect with others, and the LEAP Course was not the exception. I felt so excited to participate in the first virtual version of the LEAP program, and I would summarize my experience in 4 points: The opportunity of meet, learn and share with an extraordinary MDS faculty team that delivered didactic and interesting classes and activities during the course sharing motivation and confidence; the chance to meet a great group of colleagues (LEAPers) from different parts of the world, I felt that all of us shared similar goals, aspirations and willingness to have an active role in the field of Movement Disorders locally and globally. The mentorship component that gave me the opportunity to be in contact and learn from my mentor and that constitute a valuable and great personal experience for me. And finally, an impressive course organization that let the challenge of a virtual LEAP course version was a real success.

Conor Fearon: Given that I am at a relatively earlier stage in my career than many of the other participants, I have learned an enormous amount from them and how they are navigating the early career challenges, they encounter in becoming leaders within their own institutions. The structure of the program has provided a framework and experiences which I will be able to draw upon throughout my whole career. The opportunity to engage with the LEAP faculty and mentors has been an

amazing opportunity. They have been extraordinarily generous with their time and advice and I am hugely thankful to them. I thought that the virtual format of this year's program might be more challenging, but all of the faculty and participants have really strived to make it a very personal experience and there is clearly a strong connection between all of us and we continue to keep in touch.

Veronica Bruno: The experience was a very positive surprise. The program contents are excellent. I learned a lot about myself. I also found I had many life experiences in common with my colleagues. The LEAP faculty members are amazing Movement Disorders experts with a clear passion for leadership and education. They are inspiring.

Katarzyna Smilowska: On the beginning I was disappointed that we can't meet in- person. However, the course faculty have made their best efforts to adopt and overcome this challenge and assure high standards of this course. I was impressed by the experience of both faculty and peers. I realized that despite of career advancement, previous experience and country of origin, we all share similar concerns. Discussing challenges has widened my perspective for different ways to manage problems that can arise. In addition, both the faculty and my mentor helped me to understand that leadership shouldn't be a lonely journey. I started to listen more attentively and to ask for feedback.

Christine Wools: The virtual platform has many limitations, but we are in the middle of a difficult time around the world. The main positives for me include: feeling connected to new peers from around the globe in this challenging time of the pandemic, benefiting from the lessons learned on the path trodden by our leaders, learning to lead by intent with tangible practices that are immediately available to me (although they'll require some practice), However, the virtual platform, to which I have gratitude for without which none of this was possible, but it means that we are all compromised on the time of day, attending to other competing demands off screen (interruptions etc), not having the normal social cues and relationship building experiences that come from being in the same room as our colleagues. The format is rather didactic (I think this relates to the virtual nature of the program), which was good for the introductory days of teaching, but it would be better to have a more free flowing discussion in the follow up sessions. It feels a little like an exam to me each time, but perhaps that is just that I am attending at midnight and my brain is always struggling at that time!

Michele Matarazzo: When they announced it would be done in the virtual format, I was somehow disappointed at first. Then when the entire thing started, first with my mentor and then with the course, the faculty and the rest of LEAPers, it has been a great experience. My mentor has been very present, and he has been able to help me with practical advices and to teach me things on a more general and global level, also he is a very nice person to talk to on a personal level. It was also the first time that the course was done virtually, and so it was a first-time experience for all of us, including the faculty. It turned out very nice and that part of personal touch that you lose for not meeting in person, was

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certainly gained by virtually being in the houses of one another and thanks to the professional, yet friendly attitude of the faculty.

From the point of view of the contents of the course, I think it was very informative, and certainly useful, even though I will say that the discussion and the sharing of experiences was the real learning value, which went way beyond the mere contents of the book.

What did you enjoy most in this class?


Sergio Rodriguez: There are so many moments in the course that I enjoyed so much, the small group discussion where we have the chance to hear experience, real life stories and points of view of leapers and faculties. The “create a vision” activity was so interesting for me also. I think that every moment I learned from colleagues and the faculty team. I want to express my gratitude to the staff who developed the 2020 Virtual LEAP course and I hope in the near future, I personally could meet all of this great group!

Veronica Bruno: In this program I met an inspiring group of young and enthusiastic people from all over the world that share my passion. During each one of our meetings, I am delighted to hear about their goals, their dreams, their challenges, and their achievements. I am looking forward to seeing them leading the way for all of us in the Movement Disorders world.

Katarzyna Smilowska: Those interactions, discussions and continuous challenging the process are my favorite features of the LEAP course. I think, that as a team, we have found ways to incorporate technology to build connection and overcome COVID isolation.

Michele Matarazzo: The follow up meetings with the mentor and with the faculty and the rest of LEAPers feel like getting back with old friends. I think we connected quite well, and it feels like a safe place to share experiences and opinions freely. Thanks to the faculty I think we created a very enjoyable common space of professional and personal growth.

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MDS Networking and Engagement Series: "For You, With You"

Since September 2020, the MDS Networking and Engagement Series has provided opportunities for members to virtually connect with their peers and experts from the MDS community by sharing knowledge, successes, and challenges with one another within small breakout groups. These networking sessions have allowed participants to engage through a series of purposeful topics that enhance their professional growth, which has helped to fill the gap created by COVID-19 travel and meeting restrictions. Each session of the MDS Networking Engagement Series has provided an intimate forum to highlight and discuss MDS initiatives and programs, gain MDS expert advice, and discover ways to get involved within the Society. In 2020, session topics included *How to Initiate a Movement Disorders Exam*, *How to Submit a Paper*, *Women in Movement Disorders*, and the *MDS Young Members Group*.

One of the more recent sessions in the series focused on the MDS Young Members Group. Participants learned about the Young Members Group and other young delegate offerings from the Young Members Group Steering Committee and its senior leaders. Within small groups, participants and faculty discussed the role of the Young Members Group within MDS, how to get involved in both the group and the Society, and the group's latest projects. At the end of the hour-long session, participants and faculty came back to share their top three learnings from their discussion. In total, this series session was led by 11 faculty and attended by 60 participants.

Margherita Fabbri, Chair of the MDS Young Members Group, led the session, along with Prof. Bas Bloem, and posed the following questions to him regarding this particular session and the future of the Networking and Engagement Series.

How was the format of the meeting?

Bas Bloem: The meeting started with a plenary session, chaired by Margherita Fabbri on behalf of the MDS Young Members Group, and myself. Margherita presented a PowerPoint presentation, highlighting the services and achievements of the Young Members Group. We then split up in smaller virtual sessions, always with a senior chair, with the specific aim of collecting feedback about the services of the Young Members Group, asking in particular about what was perceived as being helpful, and what could be added to the existing portfolio. All comments in each of the virtual rooms were collected and summarized by the chairman, which were then discussed in a plenary concluding session where everybody joined again.

Did the format stimulate an active interaction among participants?

Bas Bloem: The split into smaller virtual sessions was very helpful, and this really allowed everyone to raise their voice and contribute to the discussion.

MDS Networking and Engagement Series



"For you - with you"

How will the key messages/suggestions from the participants be transmitted to MDS leadership?

Bas Bloem: The leadership of the International Parkinson and Movement Disorder Society is always keen to improve its services to the membership, and is of course very interested to hear the voices of the young members, who by definition hold the future of our Society. As the current Secretary of our Society, I will personally share the summary of all suggestions and recommendations with the other Officers, while Margherita Fabbri will circulate all comments back to the leadership of the Young Members Group. Both bodies will discuss which recommendations should receive the highest priority, while also being feasible, so that we can strive to implement these in the coming years.

Have you any suggestions in terms of topics and target population for the next MDS Networking Engagement series?

Bas Bloem: Haha, I have plenty of ideas myself of course, but I think that it should really be the members of our Society that should tell us which topics we should select for the future networking engagement series.

What is the direction and final aim of the MDS Networking Engagement Series?

Bas Bloem: Our original idea was to provide an alternative to the traditional physical conferences, where particularly young members of our society could have the opportunity to meet face-to-face with more senior leadership. Such in-person events are always inspiring, and not rarely lead to new collaborations. Many young members now feel deprived of this opportunity, given that we are forced to organize only virtual conferences because of the ongoing COVID-19 crisis. The networking engagement series is now offering a virtual alternative for young members to meet more senior colleagues, to ask them questions, to express their concerns, and to identify exciting new opportunities.

MDS resumed sessions of the MDS Networking and Engagement Series in early 2021, with the MDS Basic Science Special Interest Group (SIG) session on March 25, 2021. More sessions will be added throughout the year.

An Update From the New MDS Basic Science Special Interest Group (SIG)

— Lorraine Kalia, MD, PhD, Associate Professor, Toronto Western Hospital, Toronto, ON, Canada; MDS Basic Science Special Interest Group Steering Committee



The MDS Basic Science Special Interest Group (SIG) represents research-oriented neurologists and neuroscientists interested in fundamental mechanisms underlying Movement Disorders. Although the Basic Science SIG was established in the latter half of 2020, there are already over 1,800 MDS members who have joined the group. The Steering Committee has been meeting monthly to prioritize and implement

the group's early initiatives. Important objectives for the Basic Science SIG include developing online educational materials and surveying interest in aspects of Basic Science of Movement Disorders among MDS members. Therefore, two of our initial activities are: 1) establishing an online webinar series on general scientific topics and 2) hosting our first networking and engagement event.

Online Webinar Series

We have started this series with a focus on the communication of scientific findings since it is a cornerstone of all research endeavors and necessary for effective collaboration and knowledge translation. SIG Steering Committee member, Professor Tiago Outeiro, provides instructive presentations on *Oral Communication* and *Written Communication*, in which he discusses the many facets of “what constitutes a good talk?” and “what is a good paper?”, respectively. SIG Steering Committee member, Professor Erwan Beazard, provides a practical presentation on *Peer Review Process* with useful tips for getting a paper published from the perspective of a journal editor. These presentations can be found on the [Basic Science SIG webpage](#). While these first three presentations of our online webinar series are intended to be valuable resources for Junior Members who are in the early stages of their careers, the advice provided by these senior scientists can be informative for any members looking to enhance or refine their science communication skills.



Networking and Engagement Series Event

We are excited that over 1,800 MDS members have joined the Basic Science SIG. This large membership demonstrates a high level of interest within MDS in fundamental Movement Disorders research (e.g., genetics, preclinical models, pathophysiological mechanisms, imaging) and thus the relevance of this SIG for MDS members. It also tasks the Steering Committee with ensuring the needs of its membership are met. We have recently received helpful input from the MDS Young Members Group based on their survey on what basic scientists expect from MDS and how MDS can facilitate interactions between clinicians and basic scientists. In order to gain input from other members, we hosted MDS Networking and Engagement Series event on March 25, 2021, which provided an opportunity to discuss what basic science events and resources the MDS membership is keen on seeing from the Basic Science SIG. We were pleased to welcome over 50 participants during this event and expect it to be the first of many as we work to ensure Basic Science remains integral to MDS.

MDS Basic Science Special Interest Group Leadership

Chair: Per Svenningsson

Vice-Chair: Brit Mollenhaur

Steering Committee Members: Erwan Beazard, Glenda Halliday, Lorraine Kalia, Chin-Hsien Lin, Tiago Outeiro, Mohamed Salama, David Standaert, Miquel Vila

The MDS Peer Reviewing Education and Mentoring Program

— Daniel G. Di Luca, MD, Edmond J. Safra Program in Parkinson's Disease, Rossy Program for PSP Research and the Morton and Gloria Shulman Movement Disorders Clinic, Toronto Western Hospital, Toronto, ON, Canada

— Alana Kirby, MD, PhD, Rush Parkinson's Disease and Movement Disorder Program, Department of Neurological Sciences, Rush University, Chicago, IL, USA

— Christopher G. Goetz, MD, Rush Parkinson's Disease and Movement Disorder Program, Department of Neurological Sciences, Rush University, Chicago, IL, USA



Daniel Di Luca, MD



Alana Kirby, MD, PhD



Christopher Goetz, MD

The MDS Peer Reviewing Education and Mentoring Program was launched by the International Parkinson and Movement Disorders Society (MDS) and the MDS Young Members Group in March 2020. The project was developed as part of the MDS Innovation Lab initiative, supported by the MDS Education Committee. Conducted entirely via teleconference, this program provided a formal space for trainees and young movement disorders professionals to learn the skills necessary to perform independent peer reviews.

The response from the membership was encouraging, with an impressive tally of more than 100 applicants. We selected ten early stage professionals from this outstanding array of applicants. This inaugural cohort was representative of the MDS membership, including; geographical region, representing all four regions of the global Society; background, including clinical focus; and gender. Each mentee was paired with a former Editor of one of the *Movement Disorders* family of journals.

There were two phases in the yearlong program. First, mentees and their mentors were introduced to the practice of peer review by reviewing documents about peer review, then meeting to discuss them. We compiled this online library from multiple articles and guidelines describing the basics of the peer review process, including systematic and structured approaches on how to perform a peer-review as well as ethical guidelines. Mentees then moved on to reviewing two original manuscripts and providing their reviews to their mentor. We provided appropriate manuscripts in a library assembled by the leadership team, containing anonymized previously submitted original manuscripts along with the peer review critiques of these manuscripts. In addition to this formal, hands-on experience, the mentees also benefited from the opportunity to interact with senior members of the Society and learn from their experience as former MDS Journal Editors. Each mentee had individual conferences discussing general aspects of an effective peer review, as well feedback on their previously submitted reviews.

Preliminary results suggest that the program was effective in improving their confidence and knowledge in peer reviews. Additionally, mentors and mentees generally enjoyed the program. We will provide the names of all graduates to the current editors of the MDS journals, in the hope that this training will provide a new array of qualified reviewers that reflect the diversity of our Society. We plan to follow up with our graduates over the next three years to see how the program has impacted their peer reviewing.

We are hoping to continue the program for a second year. We envision expanding the didactics by creating an online resource open to all MDS members. Other opportunities and academic exercises will also be added in order to increase the interaction between mentees and improve their peer-review skills.

Why Everyone with a Movement Disorders Interest Should Be a Member of MDS: A Membership Committee Update

— K. Ray Chaudhuri, MD, FRCP, DSc, Wohl Clinical Neuroscience Institute, King's College, London, United Kingdom; Chair, MDS Membership Committee

— Huifang Shang, MD, Vice Director, Department of Neurology, West China Hospital of SiChuan University, ChengDu; Co-Chair, MDS Membership Committee

— Prashanth L. Kukkle (LK), DM, Neurologist & Movement Disorder Specialist, Vikram Hospital, Bangalore, India; Member, MDS Membership Committee

The International Parkinson and Movement Disorder Society (MDS) Membership Committee serves to invite new members to the Society and ensure that all members are properly registered, while making suggestions to the MDS International Executive Committee (IEC) about other classes of membership (i.e. those for allied health professionals, basic scientists and trainees). In addition, the committee is mandated to help the dissemination of knowledge about movement disorders, by close liaison with the education committees, as well as supporting marketing resources to encourage interest and participation with MDS. The membership of the current committee also reflects the overarching principles of the Society, including equality, gender balance and inclusivity in membership without any racial, sociopolitical and geographical barriers.

The work the committee has now achieved draws on the foresights of the succession of MDS Presidents and past committee Chairs such as Alberto Espay, Joachim Ferreira, Shilpa Chitnis to name a few, as well as the multitude of members who have advised on the strategies as well as invaluable support from the MDS Secretariat. The success of the committee work as it stands now has been considerable and is evident in the current membership number, which has risen to 11,720 members across 145 countries globally reflecting a 23.6% growth in membership since December 2019. Over 3,900 subjects became new members of the Society in 2020 and from 2019, there has been a steady rise in membership from the African and Pan American regions, now representing 6.2% and 36.6% of the total membership respectively.

New initiatives have included 'No Fee' memberships for basic scientists, with a substantial number of new membership requests to the Society due to the successful completion of a recent MDS-ES course on basic science, as well as promotion of the Society by Prof. Shang (Co-Chair). In addition, we have brought in a specific "Financial Hardship Policy" related to the current sweeping COVID-19 pandemic, which has negatively affected many healthcare professionals, as well as medical practices, requiring some MDS members to ask or request a dues waiver for the upcoming dues cycle. In addition, the committee has been particularly interested to engage in the issues related to diversity among the MDS membership, and are working on a process to ensure there is a reasonable minority and gender-based representation in the membership, as well as targeting hard to reach communities and countries for membership with the Society. Proposed tactics to support this initiative will include a new poster campaign, in addition to a promotional video with short statements from all segments of membership, ranging from the top leaders and President to trainee student members articulating the benefits of MDS membership.

Our key message to all intending to become a member is the ability to engage in a global voice to enrich the lives of millions of people around the world afflicted with a range of movement disorders and most notably Parkinson's disease (PD). Global numbers of PD are projected to double by 2040 with a massive societal and healthcare burden that will be felt acutely in many developing countries where people are living longer. A global increase in the MDS membership will allow the Society to be visible and audible in policymaking bodies around the world, where decisions on treatment and management of PD and other movement disorders are made.

Acknowledgment: We acknowledge all current members of the MDS Membership Committee and Brandon Hamilton, MDS Secretariat staff liaison.

2019-2021 MDS Membership Committee:



K. Ray Chaudhuri, Chair



Elen Monteiro



Huifang Shang, Co-Chair



Edward Poluyi



Miryam Carecchio



Konstantin Senkevich



Alex Medina



Alexander Storch



Prashanth L. Kukkle



Indu Subramanian

Not pictured: Adrian Mugeny

Movement Disorders in Asia Task Force

— Priya Jagota, MD, Movement Disorders Consultant Neurologist, Chulalongkorn Center of Excellence for Parkinson Disease and Related Disorders, Bangkok, Thailand; Chair, Movement Disorders in Asia Task Force



Asia consists of half of the world population. Despite that, access to care is far lower than in Western countries. Asian population is quite heterogeneous in itself, with different ethnic groups and wide socioeconomic disparity. Many Asian countries do not have movement disorders specialists and a low number of allied health care. Some countries have minimal access to Parkinson's disease treatment.

On the other hand, movement disorders in different regions and ethnic groups have different concerns. Patients' concerns about their disease in Asia are different from those in Europe and America.¹ There have been many studies showing differences between Asian and Western patients – in terms of prevalence,² motor and non-motor symptoms³ and genetic heterogeneity.⁴ An example is the genetic variability in LRRK2 mutations – Gly2019Ser mutation is common in white patients, Ashkenazi Jews and some Arab population, while Gly2385Arg is common in some other Asian population.⁵ These contribute to phenotypic and disease progression differences, impacting treatment. Additionally, there are several movement disorders that are more prevalent in Asia.

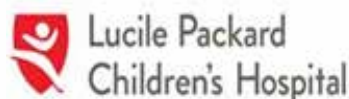
With the above in mind, the Movement Disorders in Asia Task Force was formed in June 2020 as a part of the MDS-AOS strategic plan. The objective is to be a platform for physicians and basic scientists to come together and study movement disorders that are unique or of importance and interest to the Asian population. The Task Force is unique in that it is confined to the MDS-AOS, it is expected to be an on-going Task Force and the Chair, Co-Chair and members will be nominated/elected every two years.

For this first term, Priya Jagota is the Chair and Roongroj Bhidayasiri is the Co-Chair of the Task Force. There are four advisors – Shen-Yang Lim, Yoshikazu Ugawa, Pramod Pal and Beomseok Jeon; and a mixture of ten mid-level and senior movement disorders neurologists as working members – Jee-Young Lee, Huifang Shang, Onanong Phokaewvarangkul, Cid Diesta, Zakayah Aldaajani, Prashanth Lk, Cholpon Shambetova, Shinsuke Fujioka, Chin-Hsien Lin and Norlinah Ibrahim.

For the first two years, our task would be to review the movement disorders that are unique and highly prevalent in Asia and conduct a regional online course on this topic, which is expected to be in November this year. With these, we hope that we would have built the foundation for future work and collaboration to increase research and studies in the region for the betterment of patients' health, treatment and quality of life.

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Thank you,

Cynthia Campen & Research Team

Questions for the Research Team? Contact us at peds_neuro_case@stanford.edu or 650-736-0885.

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An Interview with Njideka Okubadejo, MBChB, FMCP, FAAN: Recipient of the 2020 MDS President's Distinguished Service Award



Shaimaa El-Jafaary, a member of the *Moving Along* Editorial Board, recently sat down for a virtual interview with Njideka Okubadejo, Chair of the MDS Africa Section and winner of the 2020 MDS President's Distinguished Service Award, which was presented by MDS President, Claudia Trenkwalder, at the 2020 Virtual Congress Opening Ceremony on September 11, 2020.

Shaimaa: Thank you very much for accepting our invitation to have this interview for *Moving Along*. First, our congratulations to you on the 2020 MDS President's Distinguished Service Award.

As the Chair of the MDS Africa Section, I know you have been honored before from the Society of Neuroscientists of Africa, SONA, and you have the Women in Science Award from the International Brain Research Organization IBRO, so it is not your first time to have an internationally recognized award. I would like to know what this award specifically means to you.

Njideka Okubadejo: Thank you, Shaimaa. This award was a real honor for me to receive. Movement disorders is an area of neurology that has been very dear to my heart. Over the course of my career, I focused first on myself gaining additional education and training in movement disorders not only to serve my patients better, but also to expand the knowledge regarding movement disorders in Africa, starting with my own institution and of course, my own country.

So, it was really a great pleasure and an honor that to recognize the efforts made by me and others in order to expand both the understanding of movement disorders, as well as the care provided for people with movement disorders in Africa. I must say it is definitely the best award that I have ever received in the course of my career. I really appreciate the president of MDS, Claudia Trenkwalder, and others who found me worthy to have received this award.

Shaimaa: Thank you. Let's move to a question that you have touched already, when did you become interested in movement disorders, and how did you become interested?

Njideka Okubadejo: I think it was a serendipity; the structure of neurology training in my country is that, first you enter for an internal medicine residency and after the first two years or 36 months, then you choose a sub-specialty. I found myself in neurology primarily because my training institution needed someone to be a senior registrar in neurology because there was nobody pursuing a career in neurology. You know that many people run away from neurology. So, I was specialized in neurology. I conducted my dissertation on Parkinson's disease to obtain

the Neurology fellowship. The topic was suggested by my mentor. To be honest, when I started my neurology training, I did not pay much attention to movement disorders because the patients were very few as far as I knew.

My mentor suggested that when you begin to focus on an apparently uncommon neurologic disorder, is that you identify more and more patients with the condition. So, as part of the efforts to ensure that I completed my dissertation, I started focusing on the patients with movement disorders in the clinic, particularly Parkinson's disease. In that way I was able to accumulate my first cohort of patients. I also had the opportunity of giving the added care that they needed. And that is how it started.

As my career advanced and I became more focused, I realized that we actually had patients with different kinds of movement disorders at the clinic. I then asked for permission from my department to set up a movement disorders clinic. Finally, a couple of years ago, we set up the first movement disorders clinic in my institution as well as in the country.

In our set up, we mainly focused on three aspects. One was to ensure that the patients with Parkinson's disease and other movement disorders had access to neurologists that had special interest in movement disorders. Secondly, it would also help us to train neurology residents to focus on the aspects of their competency that related to movement disorders.

And then thirdly, it would also be an opportunity for us to conduct clinical research and other research in that field since if you look at the literature, for many years, there was hardly anything published on movement disorders from Africa. So that is how the journey has been. And I can report that many other colleagues have taken up an interest in movement disorders and the opportunities have continued to grow.

Shaimaa: This is great, and this is very interesting and exciting. So, the second question is what excites you about your work?

Njideka Okubadejo: The first thing I find very exciting is that I would say the more you know, the more you see. I think that might be the experience of many movement disorders specialists. When you cannot recognize phenomenology, much of movement disorders can look very strange and very unusual. However, your eye is trained to recognize movement disorders, it is very exciting because much of your diagnostic evaluation, you can complete clinically. Movement disorders is an area of neurology that you can do quite a lot of your diagnostic ascertainment clinically just by virtue of what you can recognize from history from physical examination. In a developing country where we do not have a lot of access to technology, I find that practicing is very important as you can begin to offer your patients treatments that can meaningfully improve their quality of life. That is the most exciting aspect of it.

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An Interview with Njideka Okubadejo, MBChB, FMCP, FAAN, *continued from p. 18*

In general, I think I just find that I am excited and fascinated by movement disorders with that love for everything related to either diagnosing, discussing, treating, or researching it. Really all these aspects are very exciting to me.

Shaimaa: Great. The coming question is about the MDS-African Section. When it was founded and what is the history behind the founding the MDS-Africa Section?

Njideka Okubadejo: It was about 10 years ago, I attended one for MDS meetings and I met up with a colleague at the time, Richard Walker. We talked about the specific challenges that were peculiar to movement disorders and Parkinson's disease in Sub-Saharan Africa. These challenges, of course, included the low MDS membership from Sub-Saharan Africa, together with the rudimentary researches from Africa in that field with respect to the knowledge and treatments. Then, we talked about the possibility of having a MDS Special Interest Group to look at these peculiar challenges.

Together with Richard, we then approached MDS and they accepted to set up first with the Special Interest Group, and then it became a task force for Africa, and from the task force, we then metamorphosed into the Africa Section Steering Committee. So it has been a fairly long journey. I must recognize the role that people like Richard Walker played and the role that other members of the Special Interest Group and the task force played up until when the Africa Section Steering Committee was formed.

I also want to highlight the role that the African Academy of Neurology (AFAN) has played really because during the tenure of Christopher Goetz as president of MDS, it became clear that the African members of the task force needed to take the wheel, so to speak, in steering the affairs of the Section. At that time also the African Academy of Neurology had been formed as the society recognized to be the umbrella body for neurological societies in all of Africa. The MDS did approach the African Academy of Neurology to recommend a way in which movement disorders could be represented all across the regions represented by AFAN. So, we have North Africa, South Africa, East Africa, West Africa, Central Africa according to the United Nations Regional Distribution. The AFAN also made recommendations, and that's how the new task force was reformed, and I was selected to chair that new task force. That is how the journey has been so far.

Shaimaa: Would you please give us an overview about the different activities of the MDS Africa Section?

Njideka Okubadejo: Okay. So, thank you. I can subdivide the activities of the African Section. One major activity is that related to membership, another one is related to training, the third one is related to administration. Those are the three major areas.

So, let me start with the membership. One of the mandates of the African Section is to increase the representation of Africa within the MDS. So, one

of the things that the MDS did for us was to encourage a merge of the Sub-Saharan Africa the North Africa membership. So, the African Section as it stands now is representing the whole of Africa. In addition to that, to boost membership of the MDS we expanded it to include not only neurologists, but other people in the neurosciences representing all five regions of Africa. The strategies have been different. The educational programming that has reached out to not just neurologists, but also to basic scientists has also been instrumental in helping us boosting the membership.

We have reached out to people that we know, we have reached out to neurological societies directly, and the attendees of the different educational programs that have taken place and ensured that at each opportunity we have, people are invited to become members of the MDS. And we are hoping that in the coming years, we will continue to expand on this membership.

So, right now we have keyed into the MDS program of having affiliate societies who become affiliated to the Section. So, we have the Egyptian network for neurodegenerative disorders, and the neurological society from Morocco. We also have almost a dozen other societies that are completing the process of the affiliation. The good thing about that is that the members of those associations automatically are often a membership of the MDS.

The no-fee membership of the MDS, which is what it is now called, is open to all members from Africa. It is also something that has encouraged boosting the membership even more.

something that has helped was the virtual format of the last MDS Congress in that many more people from all over the world, including Africa, had access for the first time. And we are hoping that we can gain from that also that they become members of the MDS.

The second area is education and training. So, as you know and as you are a part of it and have been engaged in it, a lot of educational activities have gone on taking advantage of the different programs that the MDS has in place. So, the Developing World Education Program, the Virtual Professor Program, and other formats. So, the idea is that hand-in-hand with increasing the understanding of movement disorders amongst neurologists is also creating opportunities for people in the neurosciences in Africa to become more aware of new movement disorders, how they can engage in their research, and how they can network with others. So, those educational programs have really helped both in increasing our training and so forth.

The administrative aspects is another aspect that the African Section is engaged in, particularly the Steering Committee members. That includes helping out with structuring courses, helping out with making selections for things like the LEAP Program, making selections for the training programs that we had.

Also, the MDS has the short courses that are sponsored for the Visiting Trainee Program that enables trainees go to other sites to have training. Although in 2020, it was interrupted because of the COVID pandemic,

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An Interview with Njideka Okubadejo, MBChB, FMCP, FAAN, *continued from p. 19*

so people could not physically visit the sites that they were supposed to. But that's another area where there's training and where we help to administer by identifying suitable candidates for those programs. So basically, that's what we do as the African Section.

I really wanted to emphasize the key role that the Education Committee of the MDS-Africa Section plays. The Education Committee is key to all of those training and educational programming that takes place. So, it is mirrored like the broader Education Committee of the MDS. It is chaired by Professor Ali Shalash. There are members from across the African Section so that they work together as a team led by Professor Shalash and Professor Jonathan Carr to plan the programs, to help the course directors, to format the programs properly and so forth. So, I really wanted to mention them.

Shaimaa: Is there any official training or fellowships program about movement disorders in Africa apart from the exchange program or Visiting Trainee Fellowship offered by the MDS? Is there a formal training for movement disorders in Africa, in Nigeria or other African countries?

Njideka Okubadejo: There is no formal movement disorders training program in Africa that I am aware of. There are sites that have special interests in movement disorders. I am aware that in Egypt, for instance, in South Africa, in Nigeria. However, I mean, you will notice that the number of neurologists in Africa is not that large. And so many countries don't have the opportunity of a formal sub-specialization in movement disorders for now.

The opportunities that the MDS provides are essential because they enable our people to grow alongside their normal professional development, then they can take the opportunity and continue to improve themselves in the area of movement disorders. But we hope that at some point we'll be able to put our resources together and have these types of formal training for movement disorders.

Shaimaa: What are the available services for patients with movement disorders in Africa? And what are the challenges for this patient to have access for, for example, advanced treatment for health educational programs and so on? How can we improve these services?

Njideka Okubadejo: So, thank you very much. That is a very important question. So, with respect to the resources available for diagnosis, the truth is that across all the African regions, there are very few places where you can get treatment or a clinic that is focused entirely on movement disorders.

So, what exists in most sites where there's a neurologist is that the neurologist has additional interest, or the neurologist, even the general neurologist is the one that's providing this care. Now, it will be difficult for that to change quickly just because of the manpower limitations. So, the

number of neurologists to the general population is low.

And I think that one of the key things therefore that we can gain is by ensuring that every neurologist is trained specially in movement disorders so that while we're trying to build specialists in the area over time, we're showing that at least when patients come in contact with neurologists, they get that added benefit.

The other advantage that we can take on is also to look in the area of just people who have internal medicine training, or even general practitioners to get them interested in gaining the skills required at least for primary care of movement disorders. That will really be helpful in terms of treatment and access to treatment, which is also an area that deserves a lot of work to be done.

Accessibility includes the concept of affordability, availability, accessibility of medications, and so forth. So, for most of Africa, the medications that are required, even basic medications required for the treatment of Parkinson's disease and most movement disorders are largely unavailable. Where the medications are available, they are also hardly affordable because for many countries, a large chunk of the population may be living below the poverty line.

And the health systems are not well-developed so that many countries still have people who pay out of pocket for medications which makes it more difficult. Even in some countries where there's health coverage, you may find that the coverage is incomplete, or the coverage does not include medications that are not manufactured locally. So, for most African countries, for instance, Levodopa or Carbidopa is important, but the governments may not be able to cover it even if they had the intention to do so.

Again, the cost of medication and the availability are difficult. Then to add to that, because of the COVID pandemic, the importation of medications was severely hampered.

And I know that many times during the epidemic there were patients that would reach out and say they couldn't buy their medication because even if they had the money to buy it, they couldn't find the medication because the pharmacists who import them had not been able to access them because of the lockdown.

With respect to advanced treatments for Parkinson disease, there are hardly available in very few locations I know that some sites in North Africa and in South Africa are able to offer some of these therapies. But for most of the rest of Africa, there's no access at all to DBS or to other advanced therapies.

Physical therapy, I must say, which is an emerging area that has shown promise in people with movement disorders, including Parkinson's, is largely available. But I think what is lacking, where there's a gap really, is in the training of physical therapists and speech therapists in deploying modalities that have been found to be useful in the treatment of people with Parkinson's disease.

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An Interview with Njideka Okubadejo, MBChB, FMCP, FAAN, *continued from p. 20*

MDS has made some advances in that regard because we have held some educational programs for physiotherapists or supported such training. I think that it is an area in which we can also continue to improve because we have quite a large number of physiotherapists who can be trained to support the treatment of people with Parkinson's disease.

Speech therapists are few, and in many countries, it is either the nurses or the physiotherapists that double as speech therapists. And there's a gap there that can be filled. Again, the training of nurse specialists is also an area that the MDS-African Section has contributed to. But there are opportunities to do much more in that area because we also have more nurses than physicians. So, if we can task shifts or task share, it would really be helpful in reaching out more to the population with movement disorders.

With respect to patient support groups, however, it is also an area where we are struggling. I think that the burden of providing care to people with movement disorders and being the one who's doing the training and being the one who's seeing the patients and doing the research. So, many people are having multiple roles. And so many physicians are not able to engage in promoting support groups. So, it's really an area where help is needed with volunteers who can be trained and who have a passion for Parkinson's disease to help build support groups.

So, there are a few support groups for people with Parkinson's disease within Africa. I know that there is a strong support group in Kenya, there are one or two in Ghana, I think there's one in Nigeria and in South Africa. There are a few, but certainly, there's room for improvement in expanding the support for people with Parkinson's disease so that they realize they're not alone in their journey of the disease. And they also learn life skills and other skills that can help them cope better with the disease.

Shaimaa: Moving to another area, which is the research of movement disorders in Africa, how do you view the research in Africa and how it could be improved?

Njideka Okubadejo: Thank you. With respect to the research, well, to be honest, in comparison of course with other continents, we are still lagging behind. But I must say that in the past decade or so, more research groups with interest in Parkinson's disease and movement disorders have begun to spring up across Africa. So, in North Africa, in South Africa, in West Africa, and in other areas.

In addition to that, we have begun to connect with each other. So, rather than just have isolated research groups, particularly through the opportunity that the MDS has given us to network, we are connecting with each other to see how we can work collaboratively. Hopefully, in the coming years we will see much more research coming out of Africa.

How can this be improved? I think networking more with each other and benefiting from each other's prior experience can also be helpful. So, those with the strength in the clinical aspects can support those with strength with, for instance, genetic studies or studies that have to do with

biomarkers or radiological features and other basic science areas. So, I think it will help us if we work collaboratively to promote the research.

Shaimaa: I know about your interest in the genetics and in the neurology of Parkinson's disease in Africa. And I would like to know about the genetics of African population, it is peculiar for the Africans and why it is important to promote research about genetics of movement disorders, especially Parkinson's disease in Africa.

Njideka Okubadejo: Thank you very much. Yes, I do have an interest in the genetics of Parkinson's disease. The simple reason is that Parkinson's disease is a complexly inherited disorder. We need to understand better why the disease occurs and what can be done to treat it. So, understanding the underlying mechanisms and what can be done to prevent it are what spurred my interest in that area.

The African population offers a unique opportunity for us to understand various aspects, including the clinical aspects and the genetic aspects. I mean, we are familiar with the fact that we say that the Black African, for instance are the population represents the genetic origins of man based on the Out of Africa theory. That can give us an opportunity to conduct research that identify the origins of the changes in a genetic makeup that resulted in Parkinson's disease.

In addition to that, as we have seen the North African population has given us a real eye-opener as to how, for instance, LRRK2 mutations cause Parkinson's disease. That knowledge helped us not just to understand the monogenic inherited forms of Parkinson's disease, but also the apparently sporadic forms of the disease.

The study of the environmental influences in Parkinson's disease in Africa can also help us understand how environmental exposure can lead to Parkinson's disease. I think that the African population really gives us a great opportunity to first of all understand the big genetic basis of Parkinson's disease and other movement disorders, but also to give us clues and insight into how the disease may be prevented. Clues and insights that may not be apparent in other populations, like in Caucasian populations.

Shaimaa: How do you see the future of movement disorders in Africa?

Njideka Okubadejo: I am excited because it is clear that people with movement disorders are present in Africa. You just need to look around and you will see them. I am excited that these people will have the opportunity in the coming years of having physicians trained in recognizing the diseases that they have, offering them treatments and improving their quality of life.

For many of the people with movement disorders, the diseases are poorly recognized or diagnosed, there is also a lot of misinterpretation or misconception about what causes them, misconception about what

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can be done in terms of treatment. So, I believe that with all the effort that MDS is putting in with the educational programs created, that in the coming years, patients with movement disorders in Africa will be diagnosed earlier and will also receive the much-needed care to improve their quality of life.

Shaimaa: Touching on your personal life, I would like to ask, who is your role model?

Njideka Okubadejo: Wow. Who are my role models? I will start with my mother. First, my mother was as a strong influencer in my life. My children say that I am like my mother in terms of her attitude towards life of never giving up. Always looking for opportunities to improve yourself irrespective of anything that is going on in the environment in which you work, and just believing even that there are no ceilings, which you cannot break through. So, she is my role model in life.

Shaimaa: How do you find time for your personal life? I know you have very busy schedules in clinical science and research. How could you find time for your personal life and activities?

Njideka Okubadejo: I think I am a little freer now because I am an empty nest. My four girls are not at home, so I have a bit more time now. I think I have not always been able to balance my work-life balance very well, but I have learned a couple of things. First thing is to not procrastinate. So, if I have a task, to just do it as quickly as I can because I realized that, well, other tasks are going to come that will have their own deadline. The earlier I do tasks that I have the better.

The second thing I have learned is to have me-time. That time when I set aside and just do nothing. Even if it is just an hour or two in my day, or every other day, or once a week. But to ensure that I have those times when I can just close my eyes, not sleeping, not reading, and just rest and do nothing.

I have also tried to prioritize. I find that as my schedule has changed, I do not have as much time for clinical work as I would like to have. I have tried to as much as possible build that structure for myself. A lot of times for clinical work, and times for my research work, and times for admin work, so that all my responsibilities I am able to meet up with them. But increasingly, I find that you can't have it all. I cannot be the 100% available clinician and the 100% available researcher and 100% available administrator. So, I have to prioritize. And that has helped me as well. You have to micromanage your time yourself.

Shaimaa: So, what are your hobbies?

Njideka Okubadejo: My hobby is watching light TV shows and series. I like comedy and romance. I cannot watch tragedy where somebody dies or something like that. I avoid those entirely trying to keep my bubble and mental health intact. I play a word game every day to enhance my memory. So, I make sure that I play something that makes me unscramble words and things like that just to show that I am not losing my mind.

Shaimaa: At the end of our interview, what is your advice for the young neurologists in Africa?

Njideka Okubadejo: My advice to them is that neurology is an exciting and fulfilling subspecialty. It's a subspecialty where fulfillment can be found if you commit yourself and your time to your training and as well as the service to your patients and your institution.

There will be challenges along the way just like in any other specialty. However, I can ensure you that there are a lot of opportunities out there for you to build yourself career-wise in whatever direction that you choose.

And because many aspects of neurology you can get away with clinical ascertainment and then offer your patients some treatment based on that, it can be rewarding if you're practicing in an area where resources are limited. So, I want to encourage them to try and take up a career in neurology, and it's very rewarding.

Non-Motor Fluctuations in Parkinson's Disease: Validation of the Non-Motor Fluctuation Assessment (NoMoFA) Questionnaire; A New MDS-Owned Rating Scale

— Galit Kleiner, MD, Medical Director, Jeff and Diane Ross Movement Disorders Clinic; Medical Director Assistive Technology Clinic; Baycrest Health Sciences, Toronto, ON, Canada



Non-motor fluctuations (NMF) in PD are a subset of non-motor symptoms (NMS) that fluctuate in a manner similar to motor fluctuations¹, and are believed to be dopaminergically-mediated, though the exact pathophysiology has not been confirmed. Like motor fluctuations, they may be amenable to treatment, though to date there has not been an instrument to capture and quantify them, limiting the ability to determine

effective interventions.

The Non-Motor Fluctuation Assessment (NoMoFA) questionnaire was developed by my colleagues and me, as part of the Parkinson Study Group (PSG) NoMoFA Study Group, following the FDA Guidance for development of patient-reported outcome instruments.

The NoMoFA is the first valid and reliable comprehensive patient-derived and patient-administered questionnaire that captures and quantifies NMF. It has been created through a methodologically rigorous process² with focus group and cognitive interviewing input, Delphi panel deliberations, and two large scale validations, to produce a final survey of static and fluctuating NMS.

This second validation of the penultimate questionnaire was the subject of the recent study: *Non-Motor Fluctuations in Parkinson's Disease: Validation of the Non-Motor Fluctuation Assessment Questionnaire*, now published in MDJ³. The study was performed in 200 subjects in 5 Centers across US and Canada.

In creating the NoMoFA questionnaire, there was deliberate intention to integrate patient input in the development of the scale from its inception, to include items relevant to patients' own functional abilities and not necessarily easily rated by outside observers. The self-rated framework was aimed at reducing the burden of administration as well to provide a questionnaire that could be accessed remotely in an era where both clinical care and research are increasingly shifting to remote applications with the assistance of technology.

An additional priority when conceptualizing the NoMoFA, was to be able to identify the proportion of NMS that fluctuate ('true' NMF) as well as the proportion of those NMS that do not fluctuate ('static' NMS). By providing a comprehensive survey of an individual's complete experience with NMS both static and in the ON and OFF states, NoMoFA has relevant application for measuring the effect of therapeutic interventions designed to reduce both NMS and NMF.

Integration of the NoMoFA into clinical practice and research protocols is anticipated to facilitate efficient and effective customization of treatment strategies and augment the value of future research endeavors particularly for therapies that may improve NMS/NMF. Additional studies, already in progress, will include determination of the minimal clinically important difference in NoMoFA scores and its sensitivity to change (responsivity) with interventions. Future application of the NoMoFA will inform our understanding of the natural history of NMF, its relationship to other symptoms, and its impact on quality of life.

The NoMoFA is under the management of the International Parkinson and Movement Disorder Society (MDS) and is now an MDS-owned scale and available on the MDS website (<https://www.movementdisorders.org/MDS/MDS-Rating-Scales/NoMoFA.htm>). Please contact MDS for questions regarding licensing and translations.

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The Modified Progressive Supranuclear Palsy Rating Scale (mPSPRS): A Measure to Quantify Status and Progression of Patient-Relevant Disease Milestones

— Gesine Respondek, MD, and Günter Höglinger, MD, Department of Neurology, Hannover Medical School, Hannover, Germany



Gesine Respondek, MD

The modified Progressive Supranuclear Palsy Rating Scale (mPSPRS) has been conceptualized to measure clinically meaningful disease progression in patients with progressive supranuclear palsy (PSP). It was published online on January 29, 2021, in the *Movement Disorders Journal*.¹

The mPSPRS was derived from the original Progressive Supranuclear Palsy Rating Scale (PSPRS),² which is a well-established clinical tool, comprising 28 items to quantify the presence and progression of disease-specific symptoms in PSP in the domains “daily activities”, “mentation”, “bulbar”, “ocular motor”, “limb motor”, and “gait/midline examination”. The PSPRS is frequently applied in clinical routine and served as primary outcome measure in numerous observational and interventional studies with PSP patients. The PSPRS is highly appreciated in the scientific community, since it captures a

broad spectrum of signs and symptoms associated with PSP and reliably provides reproducible annual progression rates, enabling therapeutic trials of reasonable size. However, not all items of the PSPRS may reflect milestones that are equally relevant for the patients with regard to quality of life, functionality in daily activities and mortality. Not all items appear to be equally sensitive to detect change with disease progression. Moreover, the PSPRS requires approximately 14 minutes for completion,³ which can be too laborious in certain settings.

Therefore, members of the Movement Disorder Society-endorsed PSP study group set out to generate a modified version of the PSPRS, which would only contain items representing clinically meaningful disease milestones for PSP patients, and at the same time be sensitive to change within one year of disease progression. The process involved the following steps:

- (1) Each PSPRS item was evaluated semi quantitatively by 16 PSP experts from the Movement Disorder Society-European Section with regard to its relevance for the patients’ quality of life, functionality and mortality.
- (2) Items that did not represent severe milestones were eliminated.

- (3) Response categories of the items were re-calibrated to a uniform ordinal system against to the experts’ milestone rating.
- (4) Items with low sensitivity to change over a period of 12-months were eliminated, as determined by natural history data from prior clinical studies.
- (5) Finally, conceptually redundant items were eliminated.

The final mPSPRS¹ contains 14 items, all of which capture relevant disease milestones, spanning a broad spectrum of domains including “daily activities”, “mentation”, “bulbar”, “ocular motor”, and “gait/midline examination”. All mPSPRS items offer 3 response categories, ranging from 0 to 2 points, resulting in an mPSPRS score range from 0 (best) to 28 (worst).¹

The mPSPRS demonstrated good sensitivity to change within one year, with a similar effect size as the original PSPRS. A number as low as 41 PSP patients per treatment arm appears sufficient to identify a 50%-slowing of disease progression in an interventional trial with a power of 80% at a significance level of 5%, when using the mPSPRS as outcome measure.

Of particular relevance: A survey among patients evaluating their perception of the clinical meaningfulness of each mPSPRS item indicated a good correlation between the patients’ and the experts’ ratings,¹ supporting the appropriateness of the mPSPRS items as patient-relevant outcome measure.

In summary, the mPSPRS is not a novel scale, but a refined version of the successful PSPRS. Whereas the full version of the PSPRS may be preferred to comprehensively describe the clinical status and change of PSP patients, the mPSPRS is geared to focus clinically meaningful disease milestones with good sensitivity to change. The mPSPRS pays particular attention to patient-relevant parameters, which are increasingly requested for outcome variables in interventional clinical trials. The mPSPRS may therefore prove to be helpful for cross-sectional and longitudinal analyses in clinical care and research.

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MDS Moving Along Cochrane Corners

Introductory note



João Costa, MD, PhD
Coordinating Editor

Cochrane (previously known as the Cochrane Collaboration) is an international organization formed to organize medical research findings. It is aimed at facilitating evidence-based choices

about health interventions for health professionals, patients and policy makers. It includes 53 review groups based at research institutions worldwide and has approximately 30,000 volunteer experts from around the world.

Cochrane Movement Disorders focuses on conditions such as Parkinson's disease, progressive supranuclear palsy, multiple system atrophy and other akinetic-rigid syndromes, Huntington's disease, dystonia, tremor, and tic disorders. The group conducts systematic reviews of health-care interventions, published in the Cochrane Database of Systematic Reviews (IF: 7.89).



Moving Along Cochrane Corners seek to bring visibility to our reviews, and to involve and engage the MDS membership in the evidenced-based medicine initiatives promoted by our group. Currently we have seven ongoing protocols, six ongoing reviews, 20 published protocols and 70 published reviews. Our reviews and protocols can be found at: <https://tinyurl.com/CochraneMDG>.



Filipe B Rodrigues, MD, MSc
Assistant Coordinating Editor

Iron for the Treatment of Restless Legs Syndrome

—Prepared by Filipe B. Rodrigues, MD, MSc, Margherita Fabbri, MD, and João Costa, MD, PhD

This summary is based on a Cochrane Review previously published in the *Cochrane Database of Systematic Reviews* 2019, Issue 1, DOI: 10.1002/14651858.CD007834 (see www.cochranelibrary.com for information). Cochrane Reviews are regularly updated as new evidence emerges and in response to feedback, and *Cochrane Database of Systematic Reviews* should be consulted for the most recent version of the review.

Review in context

Restless legs syndrome (RLS) is a prevalent condition characterised by an urge to move the legs, transiently relieved by movement, that worsens with rest, and with a predilection to occur during the evening and night. It is more common in females and incidence increases with age. Long suspected to have a genetic predisposition, recent genome-wide association studies have identified several genes associated with increased risk. Despite these advances, the RLS pathophysiology is only partly understood. Recent hypothesis postulate dopamine dysregulation mediated through deficiencies in the central nervous system iron may play an important role. Iron supplementation exists in different posologies, formulations and routes of administration, and has been widely used for people with RLS with and without iron deficiency. This review aimed at evaluating the effects of oral or parenteral iron for RLS treatment.

Review findings

Authors identified 10 controlled studies (428 adult participants, 2 to 16 weeks of follow-up). Nine compared iron (7 intravenous and 2 oral) to placebo and one study compared oral iron to a dopamine agonist (pramipexole). Iron probably improves RLS symptoms when compared with placebo (International RLS Scale [IRLS, range: 0 - 40] mean difference at 2 to 12 weeks of -3.78, 95%CI -6.25 to -1.31; 7 studies, 345 participants). Authors were uncertain whether iron improves quality of life. Subgroup analyses suggested more benefit in dialysis patients, and did not find differences associated with ferritin levels or administration route (oral vs intravenous). The safety profile probably wasn't different from placebo (risk ratio of 1.48, 95% CI 0.97 to 2.25, 6 studies, 298 participants).

Implications for clinical practice

The studies showed that iron is better than placebo at reducing the severity of RLS symptoms, although the benefit was low to moderate. Iron was helpful even if blood iron levels were normal at the start of the study. Conclusions are largely based on studies using intravenous rather than oral formulations, and long-term controlled data is lacking. High-quality studies are still needed to investigate: 1) the effects on quality-of-life and sleep quality; 2) predictive patient characteristics for therapeutic response; 3) ideal posology, formulation and route of administration; 4) comparison with other interventions; 5) and the effects of combination therapy.



Erna Roque, BSc
Managing Editor

Unraveling the "Dark Genome" of Parkinson's Disease

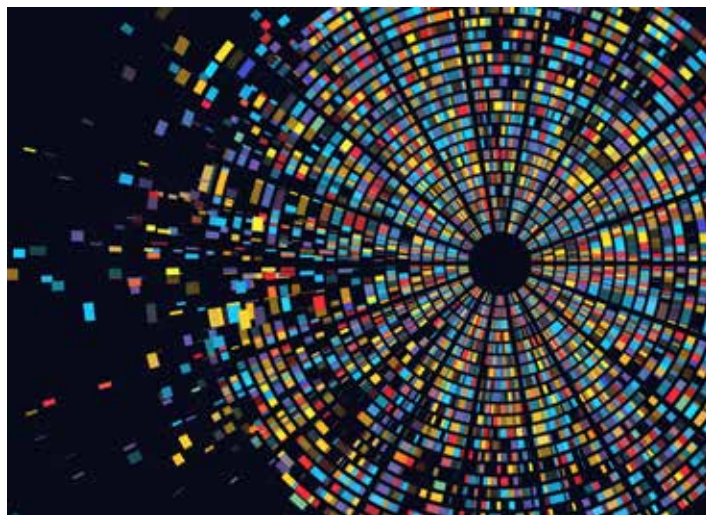
— Ziv Gan-Or, MD, PhD, Leader of the Neurodegenerative Disorders Research Group, The Neuro (Montreal Neurological Institute-Hospital), McGill University, Montreal, Quebec, Canada



In 1938, a case report described a Gaucher disease patient who developed extrapyramidal rigidity. The following decades saw additional scattered reports of Gaucher disease patients with Parkinson's disease (PD). In 2004, first genetic studies confirmed that genetic variants in *GBA*, the gene causing Gaucher disease when mutated, are important risk factors for PD. a decade and a half later, we have multiple clinical

trials directly targeting *GBA* and patients with *GBA* mutations, demonstrating the strength of human genetics in driving therapeutics development. At the same period of time, technological advances in genetics have allowed for much larger and more comprehensive genetic studies, such as genome-wide association studies (GWAS). While GWASs have many advantages, they also have some limitations. GWASs can robustly identify genetic loci associated with a disease, but in most cases, they cannot identify the specific gene or genetic variants within these loci that drive the association with the disease. In the case of PD, we call these loci in which we do not know which gene is associated with the disease "the dark PD genome". Currently, genetic and molecular studies are mainly focused on a handful of genes, while most of the dark PD genome remains understudied. Identifying the genes and genetic variants that drive the associations in each of the GWAS loci is crucial to understand the biology of PD, to be able to stratify patients according to their genetic risk and underlying mechanisms, and to identify targets for future drug development.

In our paper recently published in *Brain* and led by our graduate student Uladzislau Rudakou, we fully sequenced 32 genes from different PD GWAS loci with the aim of pinpointing the genetic variants and genes that drive some of these associations. This paper is the fruit of a collaboration between groups in Canada, France, Israel and the US, all contributing samples to the genetic analysis done at McGill University. A total of 2,657 patients and 3,647 controls were sequenced using targeted next generation sequencing with molecular inversion probes. We then analyzed the genetic data and separately examined the role of common or rare variants in the analyzed genes.



The strongest and most interesting finding of the study is the involvement of a gene called *SYT11*, encoding the protein Synaptotagmin 11. The *SYT11* gene is located on chromosome 1, not far from *GBA* (Fig. 1), and previous studies have suggested that the entire association is driven by genetic variants in *GBA*. To address this possibility, we further excluded all patients and controls who carry *GBA* variants and repeated the analysis. After this exclusion, the association of *SYT11*, mainly driven by variants in its 3' untranslated region, remained strong. These results suggest that the association of *SYT11* with PD is independent of that of *GBA*. Synaptotagmin 11 has previously been shown to be involved in neurotransmission, in particular in dopaminergic neurons. Our results therefore make *SYT11* an important target for future basic and translational studies.

Other important findings in our paper highlight rare variants in the genes *FGF20*, potentially involved in the development of dopaminergic neurons, and *GCH1*, involved in dopamine synthesis, and in other neurological disorders such as dopamine-responsive dystonia and hereditary spastic paraplegia. In addition, our analysis of common variants implicated the genes *PM20D1*, *BST1* and *GPNMB*.

This study is a proof-of-concept for fine-mapping of genomic regions in PD, and much larger studies are still needed to further map and unravel the dark PD genome.

Recent Advances toward Objective Diagnosis of Dystonia

— Kristina Simonyan, MD, PhD, Dr med, Massachusetts Eye and Ear, Massachusetts General Hospital, Harvard Medical School, Boston, MA, USA



As the third most common movement disorder after essential tremor and Parkinson's disease, isolated dystonia is estimated to affect over 300,000 people in the United States, with an incidence of up to 35.1 per 100,000 in the general population worldwide¹. Its exact incidence, however, remains unclear because up to half of the dystonia cases go misdiagnosed². Except for only a minority of patients who are carriers of DYT

gene mutations, the current diagnostic recommendations are formulated purely on clinical symptom characteristics. As such, dystonia diagnostic workup is impacted by phenotypical variability of the disorder, the circumstances of evaluation, the clinician's experience and expertise, the psychological status of the patient, and non-neurological conditions that mimic dystonic symptoms^{3,4}. Considerable variability in diagnostic accuracy between clinicians led to the estimates that only about 5% of patients receive an accurate diagnosis at the symptom onset⁵, with the diagnostic delay extending up to 10.1 years⁶⁻¹². Besides the negative impact of the delayed diagnosis on the patient's quality of life, the current diagnostic workup of dystonia amounts to the continuous healthcare costs from repeated office visits, redundant assessments, and professional disability. Diagnostic imprecisions also impact the stratification of patients for research studies, including clinical trials of new therapeutics.

The lack of objective diagnostic options for dystonia has been long rooted in a poor understanding of the disorder's pathophysiology. Traditionally, dystonia has been considered a basal ganglia disorder due to the predilection for striatal lesions to trigger dystonic symptoms¹³. However, recent advances in brain imaging methodologies and analytical techniques allowed the identification of widespread alterations of brain structure and function, involving the basal ganglia, cerebellum, and higher-order motor and associative cortical regions¹⁴⁻¹⁶. This knowledge critically shifted our understanding of dystonia pathophysiology toward a large-scale neural network disorder. It made, at last, attainable the formulation of novel approaches to the development of biomarker-based diagnostic tests for objective evaluation of these patients.

Initial studies in the field attempted to harness the potential of machine learning (ML) for objective diagnosis of dystonia based on selected neuroimaging alterations. Linear discriminant analysis (LDA) with resting-state abnormalities in sensorimotor and frontoparietal networks achieved up to 81% accuracy in diagnosing laryngeal dystonia¹⁷. Similarly, a support vector machine (SVM) with resting-state alterations succeeded in the diagnosis of cervical dystonia with 90.6% accuracy¹⁸. While these studies provided promising results, their outcomes were limited by testing only a subset of neuroimaging abnormalities in relatively small

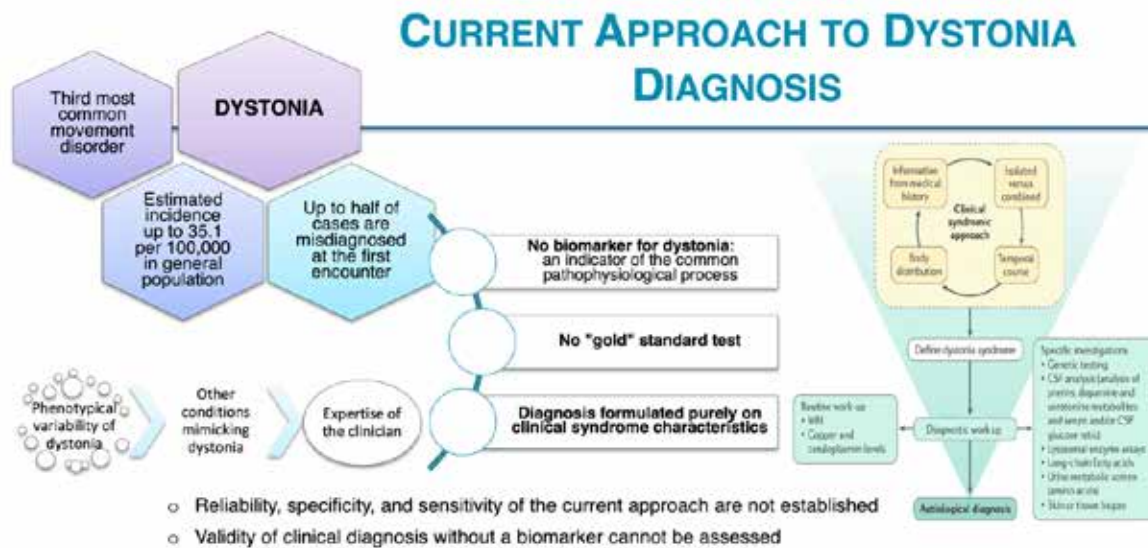
patient cohorts. Moreover, the necessity for extensive preprocessing of imaging data prior to their use with ML algorithms significantly reduced their translational potential.

There are several critical features to consider when developing translational ML algorithms. It is important to *train* ML algorithms on a well-characterized, balanced, homogeneous, large dataset to develop a robust model. It is equally important to *test* the algorithm's performance on the independent, heterogeneous, large dataset to validate the robustness of its performance across the phenotypical spectrum of the disorder. This is especially important for rare diseases, such as dystonia, which lack an established biomarker. The *translational potential* of a diagnostic ML algorithm lies in its applicability to the individual rather than the group level based on streamlined, robust, explainable, and generalizable performance compared to the current standard of care. Its *implementation* in the clinical setting necessitates an automated, fast, and cost-effective performance that is built on a user-friendly interface and minimizes clinician's involvement with the processing of input data.

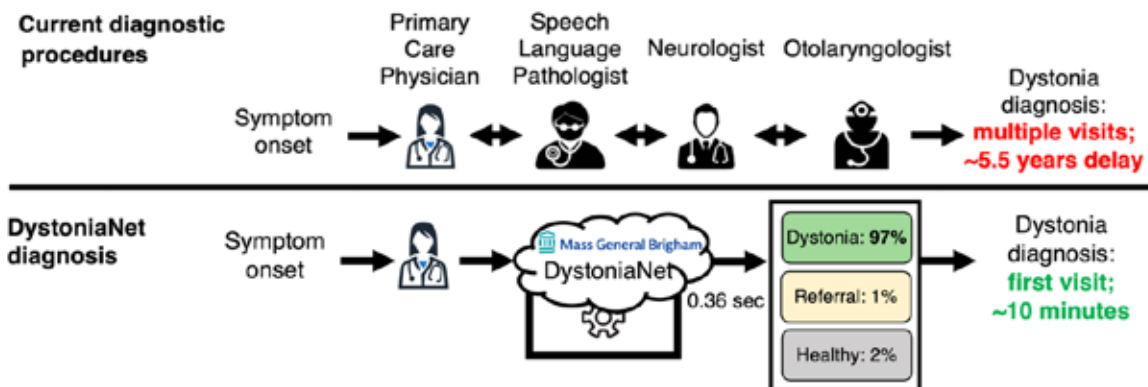
Following these principles, a recently developed deep-learning algorithm, DystoniaNet, employed a fully automated, data-driven approach to identify a microstructural neural network biomarker of significant diagnostic potential from raw structural brain images of 392 patients and 1,700 healthy controls¹⁹. The biomarker components are pathophysiologically relevant as they reflect well-known structural and functional abnormalities across the dystonia spectrum, including laryngeal dystonia, focal hand dystonia, blepharospasm, cervical dystonia, musician's dystonia, DYT1 and DYT6 dystonias, as well as post-stroke lingual dystonia and X-linked dystonia-parkinsonism²⁰⁻²⁶. DystoniaNet achieves an overall accuracy of 98.8% in diagnosing laryngeal dystonia, cervical dystonia, and blepharospasm, with a referral of 3.5% of cases due to diagnostic uncertainty. DystoniaNet-based diagnosis is computed in 0.36 sec per case. Its performance does not depend on the MRI scanner vendor, magnetic field strength, scanner hardware, acquisition sequence, or acquisition site, making it easily implemented in various clinical settings. In benchmark comparisons, DystoniaNet significantly outperforms other machine-learning algorithms (including LDA, SVM, one-layer artificial neural network), showing over a 20% increase in its diagnostic performance.

As a web-based ML platform, DystoniaNet has the potential to aid clinical decision-making for dystonia diagnosis by reducing the rate of misdiagnosis and time-to-diagnosis. Follow-up studies are warranted for DystoniaNet testing in the multicenter clinical setting. Equally important, future research should focus on the extensions of DystoniaNet for comprehensive differential diagnosis of dystonia from other movement disorders and non-neurological conditions mimicking dystonia.

Recent Advances toward Objective Diagnosis of Dystonia, *continued from p. 27*



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Recent Advances toward Objective Diagnosis of Dystonia, *continued from p. 28*

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The graphic features a central white circle with an orange border. Inside the circle is the MDS logo (a stylized figure with arms raised) and the text "International Parkinson and Movement Disorder Society". Below the logo, the text "MDS *Virtual Congress* 2021" is displayed in a large, bold font, with "MDS" in black and "Virtual Congress" in orange. Underneath, the dates "SEPTEMBER 17-22, 2021" and the website "www.mdscongress.org" are listed. The background of the graphic is a vibrant orange-red color with a network of white lines connecting various icons, including a cityscape at night and several human silhouettes.

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