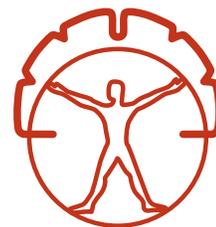


# MOVING ALONG

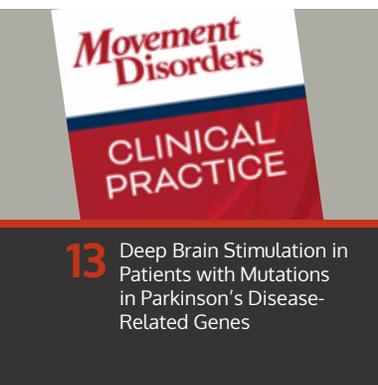
Editor, Antonio Strafella, MD, PhD, FRCPC



International Parkinson and  
Movement Disorder Society



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## An Interview with Claudia Trenkwalder : The New MDS President

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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.

### Address your communications to:

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## Editorial

In the last few months, the editorial board has worked tirelessly to collect exciting content and material for this new issue of *Moving Along* in order to engage the MDS community at large. In 2019, we have created a more dynamic format for the newsletter, informing the international MDS community on new and exciting developments in the field of Movement Disorders in a more timely fashion. We have implemented the release of "Early View" articles on the MDS website and shared through the MDS social media channels on a rolling basis. I encourage you to follow these articles at #MDSMovingAlong.

As we move to a new year and decade, I am pleased to announce that this is the first electronic-only issue, as we now will cease printing and mailing copies of *Moving Along*. This will allow for faster more efficient and environmentally friendly distribution to MDS members. This final



Members of the Moving Along Editorial Board in Nice, France

issue of 2019 takes a look at the latest events and highlights of our Society through several MDS activities happening throughout the world. We have highlighted many of the activities from the latest International Congress in Nice. We have created a new "President's Corner", where President Prof. Claudia Trenkwalder will be introducing young members to our MDS membership. With this issue, we have also initiated a new series of interviews to our members and leaders.



With these changes, we want to provide a forum to discuss the many controversial issues raised by scientific progress and to highlight recent advances in basic and clinical research. We have a variety of research and clinical activities conducted by our MDS members, making our MDS community an important component of the new format of *Moving Along*.

We would like to thank the MDS Officers, International Executive Committee, Regional Section leadership, and all of the MDS staff for their amazing support in making this possible.

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

Warm regards,

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

## 2019-2021 Moving Along Editorial Board



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## President's Corner

When I was a resident, my former boss at the Max-Planck Institute of Psychiatry in Munich regularly showed me the World Federation of Neurology newsletter in highly-polished print edition. The conversation always started with "MY WIFE AND I...", and he described the many interesting travels of Sir Walton, the former and late President of the World Federation of Neurology, and his wife to educate different parts of the world in neurology.

We wondered at that time, what the many neurology residents all over the world are like, and agreed if we ever had the opportunity to write a "President's Letter" – which we did not see as a realistic opportunity – we would want the young people, the residents of the different regions of the world to talk to us: and now, here they are, the talented, enthusiastic young members of our Society! I want to introduce you to our Young Members Group\* all over the world, so that you can network with them and so that they become a voice of our Society!

Sincerely,



Claudia Trenkwalder, MD  
MDS President, 2019-2021



*\*I would like to add that I did not feature Margherita Fabbri, Chair of the MDS Young Members Group, only because you will find a complete interview with her on page 15 of this issue.*



**Miryam Carecchio, MD, PhD**  
Padua, Italy

My name is Miryam Carecchio and I am currently working as Assistant Professor of Neurology at the Department of Neuroscience of Padua University, Italy. My main research interest is in rare genetic movement disorders, including pediatric disorders which were the topic of my PhD thesis.

I have been a member of MDS since the first edition of the MDS-ES Summer School for Young Neurologists, which took place in 2008. At that time I was 26 and movement disorders were already my passion! I love teaching students and residents - maybe because I had the privilege to come across outstanding professors who left an indelible signature in my career, personality and way of working.

I am an active member of MDS, serving on the steering committee of the Young Members Group, as well as a member of the MDS-ES Education Committee and Membership & Public Relations Committee. My hope is that the Society will be able to reach and educate as many professionals as possible in the world, and increase the number of active young members. We have a lot of fun when we meet up together!



**Tomás de la Riestra, MD**  
Rosario, Argentina

I currently work as Coordinator of the Movement Disorder Department at INECO Neurociencias Oroño, Rosario, Argentina. I got involved with MDS during my participation at the MDS-PAS Summer School in Santiago de Chile in 2013. There I was introduced to Dr. Irene Litvan and I was accepted to be her foreign

fellow at MDC-UCSD. When I was in San Diego, I was invited to be one of the co-founders of the MDS Young Members Group (at that time we used to call the group: MDS-Alumni). Now I am the Co-Chair and I collaborate in two other committees (Web-Based Learning and Social Media).

About my own career, I wish to complete my PhD and to keep developing the Movement Disorder Department with important scientific research, while remaining on top of the new innovations and treatments in the field; but never forget our main focus...our patients, and to put forth this effort and achievement for them.

In my personal life I am happy to have a beautiful family, composed by my wife Florencia and my two children, Inés who is five years old and Nicolás, who is two years old. They support me and my professional career like nobody else. We enjoy an active social life, with many friends. At the same time, Florence and I belong to large families with several brothers and many nephews, and our children enjoy their grandparents. As I indicate always to my patients, I exercise four times per week. And in our free time we enjoy being with family and, if possible, traveling together and being at the beach and the sea – our favorite place.

I hope to be involved with the MDS LEAP Program and then become a leader in the MDS-PAS to position MDS as the most important scientific society in the field.

## 2019 International Congress: Controversies Session

### Early Deep Brain Stimulation in Parkinson's Disease

— Beomseok Jeon, MD, PhD, Department of Neurology and Movement Disorder Center, College of Medicine, Seoul National University, Seoul, South Korea

Recently, the U.S. Food and Drug Administration approved deep brain stimulation (DBS) in Parkinson's disease (PD) of at least four years duration and with recent onset of motor complications, not necessarily with motor complications that cannot be adequately managed by medical treatment. I would agree that early DBS offers more benefit than best medical therapy (BMT) as shown in EARLYSIM study. However, I would argue that more benefit from DBS than BMT in the early stage of PD as a group is not enough to recommend early DBS as would be justified in the utility theory. Here, we need to consider human nature of risk aversion and the risks of early surgery.

Movement disorder specialists probably meet many patients with advanced PD who are hesitant to undergo DBS even when operation is clearly indicated. In our survey, fear of complications was the most important reason for hesitating surgery. Under risk, we behave or make decisions differently from what the utility theory would suggest. The prospect theory was developed as a model of decision making

under risk by Daniel Kahneman, a psychologist and Nobel prize winner in Economics. There are three key ideas in this theory: 1) Risk aversion, people prefer smaller variance in outcomes; 2) Loss aversion, everyone prefers gains over losses and losses are felt more intensely than gains of the equal magnitude; and 3) Endowment effect, things you own are intrinsically valued more highly. Therefore, people give more weight on loss than on gain of the same magnitude. Thus, the question is whether the gain in early DBS is large enough to outweigh the weight of the loss, the complications.

Another issue is that as Niels Bohr said "It's difficult to make predictions, especially about the future. One of the arguments for early DBS is to prolong the duration of the DBS benefit. In early DBS, however, there is a risk of not being able to exclude MSA-P who may not get expected long-term benefit even with the best DBS. There is also a higher risk of including patients who may not need DBS. For example, dyskinesias may not necessarily become troublesome, meaning that not all patients with dyskinesias will need DBS.

Surgery involves risks even in qualified centers. To justify such risks, patients should be, at least, moderately disabled despite adequate trials of available PD medications. And mere presence of motor complications would not justify such risks.

It was Jeremy Bentham, the pioneer of the utility theory, who said "It is the greatest happiness of the greatest number that is the measure of right and wrong". But Jeremy Bentham, older and perhaps wiser, said "It is vain to talk of the interest of the community, without understanding what is the interest of the individual". Like the shepherd who worries over one lost sheep, we worry over one bad result. DBS is good. But we need to cogitate over time in order to best serve each patient by considering DBS only when necessary and not by prediction, thus avoid cases that will turn out to be poorly-advised and cases who we will never know unnecessary.

2019 International Congress Controversies Session, continued from p.6

## Early Subthalamic Nucleus Deep Brain Stimulation

— Patricia Limousin, MD, PhD, Department of Clinical & Motor Neurosciences, UCL Queen Square Institute of Neurology, London, United Kingdom

Ten to twenty percent of patients with Parkinson's disease (PD) start having symptoms before the age of 50 and therefore will need treatments over a long period of time. Dopaminergic therapies are very effective in most patients for a number of years but over time most patients will develop motor fluctuations and dyskinesias. In addition, adverse effects of medications such as impulse control disorders are common and can be devastating. As consequence, patients have early loss employment, reduction in quality of life and loss of independence. Apomorphine and Intraduodenal levodopa pumps can be useful to reduce motor fluctuations and dyskinesias but lack practicality, particularly in active young patients. All other advanced treatments such as growth factor, cells therapy or gene therapy are still experimental. Therefore, there is a need for better treatment for PD.

Subthalamic nucleus deep brain stimulation (STN DBS) was first applied to treat patients with advanced PD in 1993, following research in MPTP primates. The early reports<sup>1</sup> were followed by larger series and randomized control trials against best medical treatment (BMT) providing level I evidence of superiority of STN DBS to improve motor fluctuations, dyskinesias and quality of life with a low risk of serious adverse events in experienced teams<sup>2,3</sup>.

The application of STN DBS earlier in the course of the disease has demonstrated its superiority to BMT in a pilot study in 20 patients followed up to 18 months<sup>4</sup>. This was confirmed by a

large multicenter study, Early Stim, including 251 patients with idiopathic PD. The main inclusion criterias were age between 18 and 60 years (mean 52.6), Hoehn & Yahr  $\leq$  2.5 during best on (mild bilateral disease, recovery on pull test), disease duration  $>$  4 years (mean 7.5), fluctuations and/or dyskinesias  $<$  3 years and activities of daily living impairment (5). Patients were randomized to STN DBS or BMT and followed up to two years. STN DBS was superior to BMT to improve quality of life up to two years, in all domains except social support and communication<sup>5</sup>. In addition this study has shown an improvement of UPDRS III off medication of 53% in the DBS group at two years, with 16.4 points difference with BMT and this was confirmed by blinded video assessment. There was a reduction in motor fluctuations and dyskinesias, the later probably largely related to the reduction in Levodopa dose equivalent. Postural instability and gait were also improved at two years in the DBS group<sup>6</sup>. Non motor fluctuations were also reduced<sup>7</sup>. The number of adverse events did not differ between the two groups. Unfortunately three deaths occurred by suicide, two in the DBS group and one in the BMT group<sup>5</sup>. It has also been demonstrated that STN DBS is cost effective in patients under 61<sup>8</sup>.

There is a lack of very long term comparative data between DBS and BMT. Yet long-term cohorts have shown evidence of sustained improvement with STN DBS in many respects<sup>9</sup>. Nevertheless it is important to stress that 'early DBS' means offering DBS earlier in

selected patients who start developing motor fluctuations or dyskinesias or impairment in quality of life and have low risk factors, it should not be considered when patients are stable on medical treatment. It is important to collect more long-term data and identify predictive factors of long standing improvement with STN DBS to support patient selection.

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## 2019 International Congress: President's Distinguished Service Award, Bruno Dubois, MD, PhD

At the 2019 International Congress of Parkinson's Disease and Movement Disorders, in Nice, France, President Christopher G. Goetz, MD, delivered the President's Distinguished Service Award during the opening ceremony on September 22, 2019. This award is given annually to a scientist or clinician of exceptional stature who has served the Society with particular distinction. The 2019 recipient award was Bruno Dubois, MD, PhD, Professor of Neurology at the Neurological Institute of the Salpêtrière University Hospital in Paris, France and Director of the Behavioral Neurology and Dementia Research Center of the University of Paris (Pierre et Marie Curie).



*Christopher Goetz and Bruno Dubois*

In envisioning the prototypic credentials for this award, Dr. Goetz turned to the historic words of the first neurologist of international stature, Jean-Martin Charcot who also taught at the Salpêtrière Hospital and reminded his students and peers in 1888:

**"To me, the practice of our specialty has no real autonomy; it exists by borrowing and making new applications of ideas from other disciplines. Without a constant re-infusion from other scientific domains, our work would soon become an outmoded routine."**

With this historical background, Dr. Goetz looked beyond colleagues directly involved in Parkinson's disease and other movement disorders for this award. As a world-celebrated cognitive neurologist, Dr. Dubois has made seminal contributions in the distinction between dementias typified by cortical pathology (Alzheimer's disease as a prototype) and dementias anchored in sub-cortical pathology as in Parkinson's disease and several other parkinsonian syndromes. He has been particularly active in the defining Mild Cognitive Impairment as it applies to patients without dementia, but with developing cognitive impairments of distinctive character. Sharing his expertise with MDS members, he served on the Task Force to develop the MDS-UPDRS and the Task Force on Cognitive Impairment and Dementia in Parkinson's Disease. His infusion of knowledge and scientific approach has guided the discipline and research efforts relative to several non-motor aspects of Parkinson's disease.

"This award rightly follows the Charcot tradition", announced Dr. Goetz, "as our field of movement disorders has borrowed from and been enriched by so many other disciplines, genetics, robotics, new microbiological insights, and proteomics to name just a few. But, the major advancements in our appreciation of non-motor complications of Parkinson's disease and related illnesses comes from our Cognitive Neurology and Neurobiology colleagues, much of the effort led by Bruno Dubois over his distinguished international career."

Dr. Goetz introduced Dr. Dubois to the audience with both professional and personal reflections. As young neuroscientists, both worked in Paris in the 1980's, Dr. Goetz at the Collège de France under the celebrated French pharmacologist, Jacques Glowinski and Dr. Dubois at the Salpêtrière Hospital under the equally famed Professor of Movement Disorders and Parkinson's Disease, Yves Agid. Friendship and scientific collaboration developed side by side over their two careers even after Dr. Goetz returned to the United States. They embarked on collaborative research efforts, participated in teaching opportunities and fostered programs that enriched US-based (American Academy of Neurology and American Neurological Association) and French-based (Académie Nationale de Médecine, Société Française de Neurologie) activities. Young colleagues from each service traveled to work in the other's laboratory or clinical program as well to create an ongoing cross-fertilization at the international level.

Dr. Dubois stands beside prior luminaries who have received this award, including Esther Cubo (Spain, 2014), Roongroj Bhidayasiri and Louis Tan (Thailand and Singapore, 2015), Matthew Stern (USA, 2016), Christine Klein and Francisco Cardoso (Germany and Brazil, 2017) and Yoshikuni Mizuno (Japan, 2018).

## 2019 International Congress: Stanley Fahn Lecture

### In Our Own Words: Traveling the Career Path in Movement Disorders

— Cynthia Comella, MD, FAAN, FASM, FANA, Professor Emeritus, Neurological Sciences, Rush University Medical Center, Chicago, IL, USA

When I was invited to present the Stanley Fahn Presidential Lecture, I was deeply honored and humbled. At first, and for several weeks, I grappled with choosing the topic for this presentation, but with careful reflection, it became clear. Stanley Fahn is one of the great leaders in Movement Disorders. He served as founder and President of MDS, President of AAN and has been in leadership roles in many societies. He received numerous prestigious awards for his leadership as well as his scientific achievements. With his mentorship, many have achieved difficult goals and become leaders themselves. He has touched the lives of all of us.

With these reflections, I decided that Leadership and Mentorship as experienced by Stan and other leaders of the MDS would be my topic. Being actively involved in leadership educational programs, including MDS-LEAP, I understood this topic and felt prepared to deliver such a lecture to my colleagues. Further, I believe that with the proper tools and education, many young MDS members could be the future leaders of the Society, and therefore a formal lecture before the entire membership of the MDS would resonate... Susanne Schneider, a LEAP graduate in 2015, and I recently edited and published "Leadership in Movement Disorders" featuring the leadership stories as told by MDS leaders.



*Christopher Goetz, Cynthia Comella, and Claudia Trenkwalder*

Their words reflected many of the principles of successful leadership and mentorship. In helping to organize this effort, I read their varied stories and created countless slides presenting so many memorable quotes. With the mentorship of Christopher Goetz and Carlie Tanner, I was able to focus the presentation.

Looking out from the podium at the large audience, although daunting, was the highlight of my career. I will forever treasure this award and the privilege of being selected to present. And as you can tell from my story, the need for mentorship is never ending no matter how advanced you are in your career.

## An Interview with Claudia Trenkwalder: The New MDS President

Bettina Balint, a member of the *Moving Along* Editorial Board, sat down with MDS President Claudia Trenkwalder at the 2019 MDS International Congress in Nice, France. In this interview, Prof. Trenkwalder discusses her vision for the Society, particularly for young members and female members, as well as current and future challenges in the field.

**Bettina:** Thank you very much for agreeing to this interview and congratulations on your presidency. As the new president, what is your vision for MDS?

**Claudia:** My vision for MDS is that as a global society, we can improve outreach into areas where there's currently almost no education on movement disorders, and that we go in even the smallest parts of the world to improve education. We should also strengthen the existing regions, both for education and for increasing their membership.

**Bettina:** And do you have any concrete projects in mind in this regard?

**Claudia:** For the globalization, there are specific areas to target and this would be, for example, central Asia. The Asian and Oceanian section has already identified experts in that area who are able to distribute knowledge and set up courses. Another ongoing project in the MDS-AOS is the Middle East Working Group. Dr. Jawad Bajwa has done a nice job in collecting lots of members in that area and they are working on a variety of projects.

A further area is setting up an African section. Currently it's an African Steering Committee, which has identified more than 600 members in Africa within the last two years, so I think they are really making progress and we hope that in 2021 we can start an African section. Another goal for me is to enhance MDS as the premier leader in the field on scientific and clinical issues. This goes along with our strategic plan and means that we want to establish a committee in our society and with our experts for defining diseases, agreeing on classification, and giving recommendation for diagnosis and treatment. We already started with this many years ago, and in the last years the PSP definition criteria were added and currently an expert group on MSA group is working on new definition criteria.

Another goal is definitely to promote and stimulate leadership among the young people. As you know, the LEAP program is a very successful program. We got a lot of applications there and I think it is really a good example of how young people can be integrated into the Society early. And for me personally, it's important to promote female leadership in the Society. The final message should be: Gender does not matter in this Society if you want to become a leader.



*Past-President Christopher Goetz passes the MDS gavel to Claudia Trenkwalder*

**Bettina:** I remember you once told me that you were looking also for new ideas to reach younger members. Do you have any particular projects or plans in mind?

**Claudia:** The intent of the MDS Innovation Lab was to provide a formal structure for young members to propose and implement innovative projects, and we already received several proposals that we are currently reviewing. We have identified at least two proposals that we may support. This will be a repeated call, so the young members can continue to send their proposals to the Society. For example, one of these proposals suggested is that one should learn how to do a review. There are lots of papers and the Society and our Journal Editors need qualified reviewers for all these papers, but nobody is teaching how to correctly review a paper. It is a good idea that the seniors or even previous journal editors are lecturing on this, so that could be a fruitful project.

**Bettina:** It looks like there are many opportunities indeed for young people to get involved, thank you for sharing. And when you were saying strengthening women in leadership and showing that for our society gender does not matter. What is your view on that? Can you elaborate?

**Claudia:** I hope that maybe in two or four years from now we have an equal distribution of men and women in all society activities. We have 50% female members as incoming new members, and I think we should have the same percentage for all Committee and Task Force Chairs, and also members in these groups. Currently we have a very close look on these numbers. Chris Goetz and I agreed on this strategy, and I hope that also future presidents may have a look on the gender distribution.

*An Interview with Claudia Trenkwalder: The New MDS President, continued on p.11*

An Interview with Claudia Trenkwalder: The New MDS President, *continued from p.10*

**Bettina:** And how about being the first female president of MDS - is this a bit of a challenge in terms of being a role model with maybe many expectations on you, or do you see it more as a chance, or as both?

**Claudia:** I see it as both, although I have to admit, I never felt that I am different from male presidents, but I think it is important that young women see that it is a chance and that you can achieve it. You have to work hard, as everyone has to do, in order to achieve good positions. You can still have a private life and a successful professional life.

**Bettina:** Since you are mentioning private life, how do you manage your busy schedule, your research, your clinical work to find time for the private life? How do you balance all of this?

**Claudia:** This is one of the frequently asked questions, but I think everybody has to find his or her individual way. I have a family with children and grandchildren, and it is my special pleasure to take care of my grandchildren, which I can do on weekends and on holidays and it is fun to manage that life. I have a full clinical day, I have to admit. If I am in my hospital I cannot check all the emails, but I really see the patients. There is always an evening, when I am doing a lot of my emails, reading publications and writing the papers. I try to make reservations for some weekends just for my private life, which is not always possible, but I learned from Chris Goetz, that the weekend is free and I will try to continue with this procedure.

**Bettina:** And in terms of organizing yourself and balancing all the different aspects of your work life and your private life, how do you manage with the additional responsibilities of MDS?

**Claudia:** Working with MDS means you have a professional Secretariat. You can always email them, and you get a fast, nice and a polite response. It is so helpful that you know there is someone. You may not know exactly how to address some issues or what was the rule in the past, so the Secretariat can give you background information or they can contact other colleagues or sections. We can, as a society, be only as successful as we are, because we have this real strong Secretariat. The people are absolutely devoted to what they are doing. This makes it a lot of fun.

**Bettina:** There would not be an MDS without the MDS Secretariat?

**Claudia:** At least not the same. Without EDI (MDS' Management Company), led by Kay Whalen, who has been there for as long as I can remember, this Society would not be the same. And without Jennie Socha, just a wonderful Executive Director, who always has a solution for any problem, and many other knowledgeable staff persons, there would be a different spirit in the Society.

**Bettina:** It is wonderful to have such a team. What do you see as the current or future challenges for movement disorders as a neurological specialty?

**Claudia:** Movement disorders within neurology – it is very well defined and is an especially interesting sub-specialty. There is some discussion of the role of movement disorders with the increasing importance and numbers of neurologists who are devoted to stroke. The field of Movement Disorders and neurodegeneration is, however, still very important because with our population growing older and older with an increase of neurodegenerative diseases. Treatment of neurodegeneration just became very exciting in the last years because of new immunological and tailored genetic strategies for both Parkinson's disease and Huntington's disease. I'm not convinced that we will finally find only one target and one agent to, let's say, cure some of these diseases. We may end up with a mixture of several approaches that are finally successful.

**Bettina:** One issue with these promising new treatments is that they are quite expensive. Do you think MDS as a society might have a role in starting the discussion about priorities in healthcare funding?

**Claudia:** Yeah, I think this is a very important topic and it has also been brought up by industry professionals several times. They would like MDS to act as a sort of facilitator with the authorities, with local health care providers and local or national institutes. This could be a future role of MDS, but not an easy route to take as we do not know how successful we can become with the many regions and health care systems in our Society. As you say, these treatments may become quite expensive, especially if it goes to rare diseases.

An Interview with Claudia Trenkwalder: The New MDS President, *continued on p.12*

An Interview with Claudia Trenkwald: The New MDS President, *continued from p.11*

**Bettina:** Is there anything MDS members can do in this regard to support, to help or to get involved in this?

**Claudia:** Different MDS members may have different contacts, from politicians to healthcare providers. It would be very welcome if these members identify themselves to the Society and we can work together with them to discuss and to influence the decision makers. This should happen on a regional section and /or national level.

**Bettina:** And from the regional level to a more personal level: Do you have any particularly special memories with MDS?

**Claudia:** I still remember the very first meeting of MDS, which was in Washington in 1990. It happened to be my very first Congress, when I presented a poster and we were sitting at the table for some discussion with David Marsden. And at that time, Thomas Gasser and myself, we just had started a position paid by some pharmaceutical grant in Munich. The trial, we worked on, however, was not feasible at all. Finally, we decided to tell David Marsden, who was the PI, and we thought, this would end our career. But David Marsden stepped in and said: "Ok fine, then we should stop it" - and we still received the grant.

**Bettina:** What a wonderful story - Do you have any role models in your early career, or maybe even now?

**Claudia:** Honestly, I have to say that Chris Goetz is for me a real role model. I have been working with him now for one and a half years, very closely in weekly calls, and he is so structured, knows the Society so well, and he is the perfect teacher. I learned an important strategy for this Society: you can have a lot of creative ideas, but you have to structure them, otherwise you cannot execute your projects.

  
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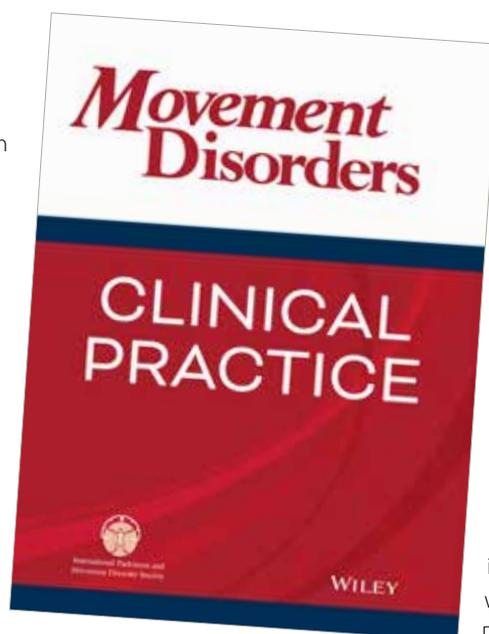
## Deep Brain Stimulation in Patients with Mutations in Parkinson's Disease-Related Genes

— Rubens Gisbert Cury, MD, PhD and Lais Machado de Oliveira, MD; Movement Disorders Center, Department of Neurology, University of São Paulo, Brazil

In the era of precision medicine - an effort to identify which approaches will be effective for which group of patients based on genetic, environmental and lifestyle factors<sup>1</sup> - the question whether genetic background should guide specific therapeutic plans in patients with mutations in Parkinson's Disease (PD)-related genes has gained increased relevance.

In this context, we systematically reviewed studies that have evaluated deep brain stimulation (DBS) motor outcome, non-motor symptoms and adverse events in patients with mutations in PD-related genes. Twenty-five studies (135 patients) with available objective motor outcomes were included in this review. To synthesize this data, we defined mean UPDRS III change of 50% or more as marked response, mean UPDRS III change of 30 to 50% as satisfactory response and less than 30% change as unsatisfactory response. Because of the variable postoperative follow-up intervals adopted by different studies, we defined shorter follow-up as mean follow-up less than two years, intermediate follow-up as mean follow-up between two and six years; and longer-term follow-up as mean follow-up of more than six years.

Parkin (PRKN), LRRK2 and GBA were the most frequent mutations in this population. At shorter-term, most patients with PRKN, LRRK2 (except for R144G) and GBA mutation had marked satisfactory response to STN-DBS; and the improvement seen in the PRKN group was similar when we excluded the single heterozygous PRKN carriers. At the intermediate follow-up, although most PRKN homozygous/compound heterozygous patients and LRRK2 patients had marked satisfactory responses after STN-DBS; in GBA patients the motor outcome varied equally among marked, satisfactory, and unsatisfactory responses. Longer-term follow-up was rarely reported. As the number of patients varied widely among groups, we emphasize these are all preliminary and exploratory findings. Unfortunately, data on GPI-DBS was scarce and precluded conclusions regarding target selection based on genetic status.



In regards to non-motor symptoms, non-systematic reporting and small sample size limited interpretation of the results. Despite these, worsening of cognition was a consistent finding in GBA patients. However, it is crucial to highlight that none of the studies describing GBA-DBS patients compared the cognitive outcome with GBA-PD patients not subjected to surgery. Higher progression to mild cognitive impairment and dementia has been shown in PD patients with GBA mutations at baseline<sup>2,3</sup>, and it is still unclear whether STN-DBS inputs an additional risk and if GPI would be a safer target in these patients.

In conclusion, our study showed that DBS results in positive outcome at shorter-term in patients with PRKN, GBA and LRRK2 (non-R144G) mutations. Despite limitations regarding a small sample size, it is possible that patients carrying GBA mutations

may be associated with higher frequency of cognitive and other non-motor symptoms after surgery. Longer and larger cohort's follow-up, with broader non-motor symptoms evaluations, will be necessary to better customize the DBS therapy in this population.

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This summary was provided by the authors of the study. The full article was published in *Movement Disorders Clinical Practice*: <https://onlinelibrary.wiley.com/doi/abs/10.1002/mdc3.12795>

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## MDS Task Force on Management of Movement Disorders: Interdisciplinary and Integrated Care

— Carsten Eggers, MD, Consultant, UKGM, Marburg, Germany; Chair, MDS Task Force on Management of Movement Disorders: Interdisciplinary and Integrated Care

Parkinson's disease (PD) is a complex disorder which affects the motor system but also mood, cognition, and behavior. PD severely impacts both the patient and the caregivers, leading to a severe reduction of quality of life (QoL) during the course of the disease.

Various approaches to an “allied health care” or an “integrated care” have been proposed. The term “multidisciplinary care” focuses primarily on the integration of experts of different specialties, including a movement disorders specialist, gerontologist, physical therapist, occupational therapist, speech therapist, clinical psychologist, neuropsychologist, non-nurse coordinator, social worker or dietician. Other approaches focus on small specialized care teams, including a PD nurse or a social worker. Different approaches of integrated or multidisciplinary care have been explored in both outpatient and in-patient settings to improve the efficacy of a team approach in PD care. However, the core components to meet the needs of patients and caregivers have not been clearly identified.

Given that MDS is an international organization and with the recognition that the needs for interdisciplinary care may vary according to cultures and regions, a Task Force within the Society with expertise in this evolving area of service and research can offer the scientific and clinical communities insights and recommendations to advance this field. This Task Force has started with a structured analysis of available resources, existing models and given evidence in this field. Currently, the Task Force is working on a meta-analysis and a systematic review in order to identify strengths and weaknesses, best practice models applicable in different countries and regions and specific problems related to interdisciplinary care approaches in PD. Ultimately, this should lead to suggestions for solutions to identified shortcomings.



Most recently, integrated or multidisciplinary care trials have used quality of life as the primary outcome within the clinical study setting. However, approaches to assess the extent of integration of a dedicated care model into a health care system have not been assessed in PD. The Task Force is working together with acknowledged researchers in this field to explore and assess quantifiable integrated care measures in the field of PD and potentially other movement disorders. A survey in this field is planned within the duration of the mandate of the Task Force on Management of Movement Disorders: Interdisciplinary and Integrated Care.

The ultimate aim of the Task Force is to identify outcome measures that are useful for testing the efficacy of integrative care with consideration of cost and utilization of societal resources. Additionally we aim to develop recommendations for a necessary “Core Team” to meet the goals of interdisciplinary and comprehensive care with the identification of ancillary service and expertise that may be tailored for different needs.

Together with large existing consortiums in integrated care research (e.g. European Union funded iCare-PD or PD\_Pal consortiums), the Task Force will increase the scientific interaction and collaboration in this field and aims to emphasize education and awareness regarding various aspects of interdisciplinary care with a focus on PD.

## An Interview with Margherita Fabbri, Chair of the MDS Young Members Group

In this interview, Bettina Balint, a member of the *Moving Along* Editorial Board, discusses the mission, structure and activities of the Young Members Group with the newly elected Chair, Margherita Fabbri.



Margherita Fabbri, MD

**Apart from being a member of the *Moving Along* Editorial Board yourself, you are also the Chair of the MDS Young Members Group, so tell me - How old is the Young Members Group, and how was it born?**

The MDS Young Members Group (YMG) kick off meeting took place during the 18th International Congress of Parkinson's Disease and Movement Disorders in Stockholm, Sweden, in June of 2014. At a very preliminary stage, this group was intended to gather young alumni from the past MDS Summer/Winter Schools, who wanted to be more active within the Society. I remember that Professor Joaquim Ferreira was the senior promotor of this initial idea. In 2015, we had our first concept paper, and in 2018 we developed our first official Action Plan which defines our objectives, communications strategies and governance structure. Our principal aims are to enlarge the networking of young MDS members and improve the MDS educational tools.

**How can one apply and become part of the Young Members Group? And how do you define "young"?**

All members of MDS who are under age 40 may join the MDS Young Members Group. To join the YMG, log into your MDS Members-Only account and select My Profile. The Young Members option is located on the Professional tab under Special Interest Groups. To stay updated with our activities and on-going projects, members can visit our webpage ([www.movementdisorders.org/YMG](http://www.movementdisorders.org/YMG)) and join our Facebook Group (<https://www.facebook.com/groups/118963335392192/>).

**How many members do you currently have?**

We currently have 2,622 members, divided as follows among each MDS Section: 863 in the Pan American Section, 713 in the European Section, 761 in the Asian and Oceanian Section and 285 in the African Section. We represent around 30% of the whole MDS community.

Our Facebook group currently has over 1,000 members, from all over the world, including not only neurologists but also other health care professionals.

**You are growing rapidly - How do you coordinate such a fast growing community from all over the world?**

The YMG Steering Committee Chair and Co-Chair (maximum one two-year term for each role), appointed by the MDS Education Committee Chairs, are responsible for all projects run by the YMG. All our activities are coordinated by our Steering Committee, whose structure has been established by our recently approved Action Plan. The Steering Committee is composed of eight young members, with two young members representing each region

(MDS-PAS, MDS-ES, MDS-AOS, and continental Africa), a Chair, Co-Chair, and Past-Chair. The Steering Committee members are selected through an online application process that is open to all young members in the YMG. The Steering Committee Chairs review the applicants based on pre-defined criteria to establish a ranking and they finally present the list of selected members to the Education Committee Chairs for their approval. Our senior Chairs are currently Professor Bastiaan Bloem and Professor Charles Alder. Steering Committee members serve for a term of two years with a maximum of two terms (four years) that is in sync with the appointment of other MDS Committees and Task Forces. The YMG Steering Committee has regular teleconferences, one every two months and our Chair and Co-Chair have regular teleconferences with our senior chairs, in order to monitor on-going projects and activities. In May 2018, we had the last election of our new steering committee members. We received 162 applications and it was very difficult to select the new members. Currently I am the Chair, Tomas de la Riestra (Argentina) is our Co-Chair, Thiago Cardoso Vale (Brazil) is our past Chair and the following members form the



An Interview with Margherita Fabbri, Chair of the MDS Young Members Group, *continued on p.16*

An Interview with Margherita Fabbri, Chair of the MDS Young Members Group, *continued from p.15*

Steering Committee: Myriam Carechhio (Italy), Bruno Bergmand (Belgium), Shaimaa El-Jaafary (Egypt), Roopa Rajan (India), Nirosen Vijjaratnam (Australia), Michele Matarazzo (Canada) and Houyam Tibar (Morocco).

### **And I hear you have your own event at the International Congress?**

Yes, you are right. During each MDS International Congress, we usually have one meeting restricted only to our Steering Committee and senior chairs and three events open to all the young members: a strategic meeting, a brief MDS Pavilion presentation to present ongoing projects and receive inputs from the audience, and the Young Delegates Networking Event at night. During the last networking event in Nice, around 200 young members participated.

### **You were saying that one of your aims is improving MDS educational tools – how do you accomplish this?**

Actually we are actively collaborating in several MDS educational activities, such as the web-based learning modules, a survey on past MDS Young Summer/Winter schools and we have supported and advertised the MDS Podcast project, the Virtual Professor Program, and the Visiting Training Program.

### **And I believe you recently applied also at the MDS Innovation Lab – what was this about?**

Yes, we are very happy about this recent achievement! The project selected to the Innovation Lab 2019 is entitled "*LEAP mentorship program for young members from*

*underserved areas*." The initial idea of this project was proposed by few members from the audience during the Strategic meeting in Hong-Kong, 2018. The principal aim of this project is to offer one-year mentorship for young neurologists from underserved area. Ten LEAP participants and graduates will be invited to be the mentors of ten mentees. We have decided to open the program only to ten pairs during the first year to verify the feasibility but we hope to enlarge the number in the next years. Mentees and mentors will have regular teleconferences during the year. Career development efforts will be principally focused on guidance and advising on seeking fellowship and grant opportunities, improve networking and professional decision-making. As a secondary aim, the project could serve as a real-world educational tool for LEAP participants to utilize their mentorship and leadership expertise to benefit members from underserved areas. More details in terms of timeline and application will be soon available on our website and social media. Stay tuned!

### **Very impressive, so many projects and activities - Any more to come?**

We are preparing a survey for basic science MDS members in order to obtain further information on their educational needs. We really would like to strengthen our bond with basic science members. However, as I have said, we are open to new proposals from young members from all over the world. Any young member who would like to propose a new project should send a very brief synopsis of the project to our Steering Committee and we will be very happy to discuss the proposal and suggestion.



## An Interview with Cynthia Comella About MDS-LEAP

Bettina Balint, a member of the *Moving Along* Editorial Board and past participant of LEAP, sat down with MDS-PAS Chair, Cynthia Comella. Dr. Comella is credited for starting the MDS leadership program, LEAP. In this interview, they discuss the current and future activities of the program.



*Cynthia Comella and Bettina Balint*

**Bettina:** To start off, how was LEAP born?

**Cynthia:** LEAP came about as the idea originally of Matt Stern and Oscar Gershanik. They knew I was interested in leadership and I had worked in leadership in the American Academy of Neurology, so they asked me if we could organize a program for young movement disorder specialists. Of course, I said, "Yes, I think that's a fabulous idea." So with their support and the subsequent support of Oscar Gershanik, who then became president of MDS, we designed a course that was specifically directed toward young movement disorder specialists. The faculty at that time included Jennifer Goldman, Shilpa Chitnis, and myself. Subsequently, we were fortunate to be able to add Carolyn Sue from Australia and Susanne Schneider as the most recent faculty addition and graduate of the 2015 LEAP class. Both have been excellent and enthusiastic faculty. We started in 2015. This was the first time we had actually taught leadership. This was after intensive training at the Leadership Challenge course in California. Following months of preparation, we launched LEAP. Young Movement Disorder Specialists would apply to each of the sections of MDS, and the sections would recommend individuals for the training. From their recommendations, we would select four individuals from each of the sections to complete the class each year. I laud the 2015 LEAP participants who were the first group. They were enthusiastic and responsive despite our "learning curve." We have revised the course every year in order to make it more relevant for each upcoming group, and more appropriate for the MDS. Each year we have had 12 people who have graduated from LEAP, four from each section, and this past year in the class of 2019, we were fortunate to have two people from Africa. We look forward to continuing the course as so many want to participate.

**Bettina:** Could you expand on what is the vision of LEAP?

**Cynthia:** The vision of LEAP is to teach leadership skills to young movement disorder specialists who are starting out or are early in their career so that they have the tools they need to be able to take on bigger and bigger types of endeavors. We wanted them to have the tools to take leadership to the next step, rather than the "trial and error" technique used by most of us in the past. MDS is committed to the young leaders, and wants them to have a head start in their careers. So the idea is to transform young physicians into leaders, and to offer them leadership opportunities in the Society.

**Bettina:** How did developing leadership and teaching leadership skills affect your professional life?

**Cynthia:** Taking the leadership training was life-changing. When I first realized that leadership is a skill that one can acquire, it was a revelation to me. I have used the tools that we have been teaching in LEAP in my own life and career. I feel that it's made a huge difference in how I approach what I do, what I say, and how I lead.

**Bettina:** How has LEAP changed and developed since the first course?

**Cynthia:** When we did our first course, it was a challenge. Although we were trained in leadership skills, the first course was new to us and we wanted to personalize it to MDS. So what better way to do that than to have the sections; Pan-American, Asian and Oceanian, and European sections, select the people that they felt would benefit by this training? In addition, each section would choose a mentor for each participant. The section would select a mentor that they felt would be very beneficial to the participant and introduce the mentor and the mentee. The mentor was to focus on the leadership and career building aspects, and not necessarily on research. So the mentees were able to get personalized guidance regarding the challenges they faced and possible ways to address them. We have some of the most fantastic people who have been willing to give their time as mentors to improve the life and the quality of leadership of the individuals who are participating.

*An Interview with Cynthia Comella About MDS-LEAP, continued on p.18*

An Interview with Cynthia Comella About MDS-LEAP, continued from p.17

**Bettina:** The LEAP course itself is very didactic, with many hands-on exercises which often also have an element of humor. What do you think when you watch us go through the program?

**Cynthia:** When you add in the humor aspect and you add in this networking of people, the program becomes very dynamic. Over the course of a couple of days, the participants transform from individuals from separate sections into a unified group. By the end, there is a network established where each participant supports the work of the entire group. They continue to network beyond the course. I think that may be one of the important aspects of the LEAP course. In addition to acquiring the nuts and bolts of leadership, I think the LEAP program provides the opportunity to meet others from varied backgrounds. The course introduces people to each other. And I think it informs them that you can make connections just through reaching out and talking to others. For some, this is a lifelong network that started with a small activity. And you find that just because you're from a different region of the world, many of the challenges are the same. So there's a lot of commonality. For the participants of one section to learn from the participants from another and vice versa promotes the global unity of the MDS. In the LEAP program, you are able to find the common ground and also the differences of each of the sections. This is the other important element that LEAP provides that is hard to get elsewhere.

**Bettina:** For people who are interested in developing leadership skills and who are not participants of the LEAP program, what can they do?

**Cynthia:** We are developing regional LEAP programs that will be a shortened version of the LEAP program as it is now. Currently, LEAP can only accommodate 12-14 participants. These new regional programs will be one day courses where leadership skills are introduced. We will be doing this in each of the sections and associate it with another activity that the section is doing. We want to reach out to as many young physicians as we can. We have three planned already. One in Europe associated with the ES Summit, one in the PAS associated with the PAS Congress and one in the AOS associated with the Synergies program.



LEAP Class of 2019 in Nice, France

**Bettina:** What are the future perspectives for LEAP?

**Cynthia:** I think LEAP has to grow. I think we should provide more access to young MDS physicians as well as Allied Health professionals. Currently, it is a program that has limited capacity. So despite the 60-80 excellent applications we receive each year, we are forced to only invite 12-14 participants. This means we have to say no to people who obviously thirst for leadership skills. We always encourage those who cannot participate to apply again. And now with the regional LEAP courses, we may be able to reach many more.

**Bettina:** If there is a scope for something like online learning, do you think there is something which could be done in this regard?

**Cynthia:** The LEAP participants have come up with a variety of online modalities to learn or to teach leadership. So there will be that online resource available to everyone. These online resources are innovating in their presentation and incorporate humor and originality reflecting the abilities of past LEAP participants to interpret the leadership skills they have learned. But there may be more to do....

**Bettina:** Perfect. Thank you so much for agreeing to the interview, but even more so for doing LEAP, because I think this is really a life's work you can be proud of - and we, the LEAPers, are very thankful to you and consider what we have learned and what we have been given a true gift.

**Cynthia:** On behalf of the faculty and the MDS leadership, I want to thank the people that take part in LEAP. Without participants, without people energetic and willing to devote themselves to the program, there would be no LEAP.

## MDS Rare Movement Disorders Study Group - Global Genetic Testing Survey: Exploring the Unmet Needs

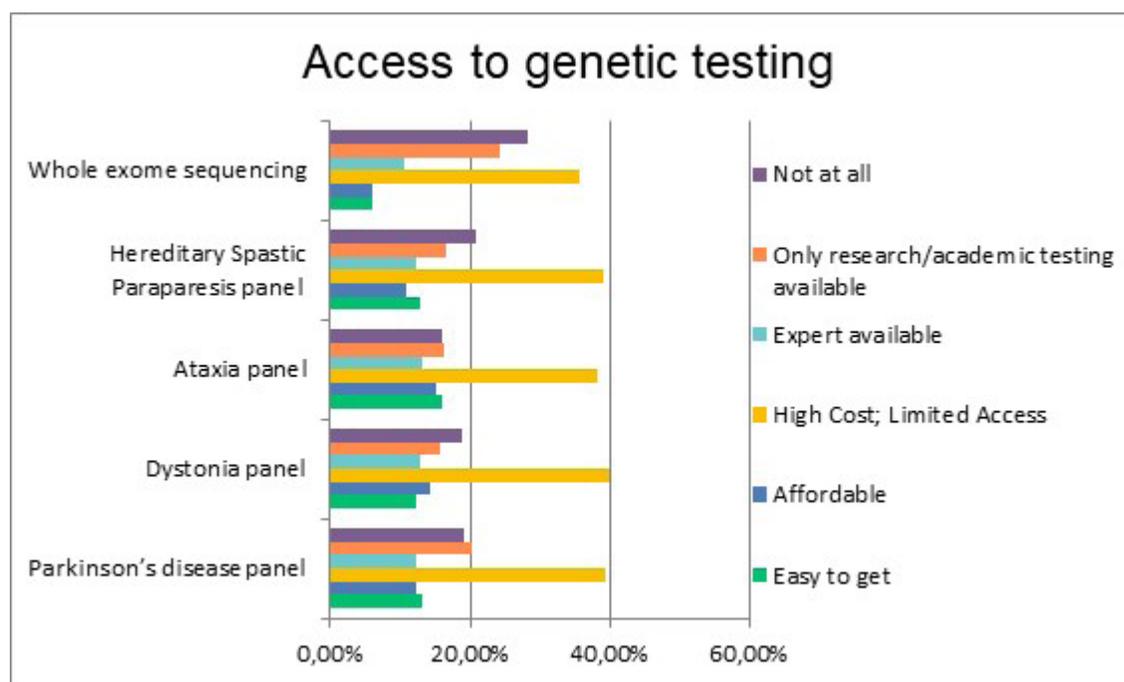
— Emilia Gatto, MD, FAAN, Chairman, Department of Neurology, Sanatorio Trinidad Mitre, Buenos Aires, Argentina; Chair, MDS Rare Movement Disorders Study Group

One of the aims of the Rare Movement Disorders Study Group (RMDSG) of the International Parkinson and Movement Disorder Society (MDS) is to improve the diagnosis of rare movement disorders. The emergence of new gene testing technologies constituted a tremendous advance in the field of rare diseases. These advances have enormously increased our knowledge on mechanisms and new promising therapeutic pathways, and at the same time expanded the genotype/ phenotype spectrum of rare diseases. Although, in the last years, next-generation sequencing (NGS) has enabled a cheap genetic diagnosis, the availability and accessibility to genetic tests remains a great challenge and account for enormous healthcare worldwide.

Members of the RMDSG designed a 21-question online survey which was electronically mailed to all members affiliated with MDS. The main objective of this survey was to better understand the access to genetic testing in different regions of the world. This survey was sent to 7,815 affiliated members of MDS who were invited to complete the survey 1,269 (93% fully completed) from 109 countries responded. 53.8% of respondents reported >10 years in clinical practice and 45.4% identified themselves as movement disorders specialists or consultants. Furthermore, 39.4% practiced in a university setting, 26.3% in a combined

(private practice + university setting), 20.7% in a government setting, 9.9% in private practice, and 3.7% in another setting. Almost 90% were primarily involved in clinical care. Movement disorders specialists or pediatric neurologists were ten-fold less accessible than general physicians, whereas genetic specialists were 25-33-fold less accessible. Access to specific tests (whole exome sequencing and genetic panels for parkinsonism, dystonia, ataxia and other disorders) were limited and considered “expensive” for 35-40% of respondents. Genetic tests for Huntington’s disease and ataxias were the most commonly available tests at the respondents’ home institutions (available to 43%-40%). For other than these tests the average availability was 26%. University and academic centers (52.8%), provided the major genetic tests, followed by private institutions (40.8%), and by government or public institutions (36%). A national network for genetic testing was reported in only 36.7% of respondents. Despite some limitations, this survey highlights the major global challenges and disparities for access to movement disorders specialists, genetic clinics and for genetic testing availability.

These preliminary results encourage the RMDSG to increase the educational efforts and to promote the creation of networks that contribute to reduce the gap among different regions worldwide.





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