



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. And 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.

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.



Christopher Goetz and Claudia Trenkwalder

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.

Bettina: And how about being the first female president of the 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 so 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 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.

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.