IN FOCUS

SCANDMODIS SCANDINAVIAN MEETING GOES TO STOCKHOLM

The current - and so far only - president of ScandModis Per Odin, is gearing up for an intensive calendar year for the Scandinavian umbrella organization for movement disorders. In mid-May the annual Scandinavian Meeting will be held in Stockholm and in June the organization hosts the International Congress of the global Movement Disorders Society, also taking place in the Swedish capital.

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The Scandinavian Meeting, March 14-15, gathers close to 200 physicians and scientists to cover the latest developments in education and research. It’s a time to network, keep abreast of new scientific advances and to set joint Scandinavian guidelines for education and treatments.

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The international Congress in June will spotlight a Swedish strong suit, experimental Parkinson’s research.
BRIDGING THE GAP:
PUTTING PATIENT PARTICIPATION ON THE AGENDA

TEXT: JENS PERSSON

On an unusually bright day in the dead of Swedish winter the speakers of Patient Participation in Parkinson’s (PPP) converged in Lund to give their personal takes on what patient participation can and should be. Moderator Cristin Lind kicked of proceedings with the story of how her son Gabriel’s diagnosis with a unusual genetic disease set her on an unexpected journey from a passive recipient of health care to working on a national level in the U.S. with providers, researchers and politicians to break down silos, giving a stronger voice to patients and families.

“When that young future doctor followed me and my son around, one exhausting medical appointment after another, you could see that he was affected and by the end of the day I think perhaps something had changed in him.” The words belong to Cristin Lind, mother of two and a pioneer in advancing partnerships between patients, families and healthcare professionals. Closing the perception gap between the very real but different experiences of patients, health care providers and researchers is at the core of the fast-growing, yet sprawling global patient participation movement. The BAGADILICO event Patient Participation in Parkinson’s on February 4th presented an opportunity to help bridge that gap.
"I am not alone here", says Cristin Lind. "Thousands of patients are becoming embedded in teams around the globe. The collaboration is taking place on many levels within the system — during clinical visits, in the design and governance of hospitals, in research and in policy."

"On whatever level of health improvement and research they participate, patients provide a relevancy, a reality check, an authenticity and a sense of urgency. But to make this work, we all need to engage. In this new way of working together, we are all equal partners. Our areas of expertise differ, but we are all experts in some essential knowledge."

**TAKING “A SEAT AT THE TABLE”**

Next up on stage was Sara Riggare, an engineer by training who experienced her first symptoms of Parkinson’s disease around 1984, at age 13, but wasn’t diagnosed until twenty years later. Sara has never fit the bill of the submissive patient. Her talk, delivered in characteristic energetic fashion, showcased how she has worked tirelessly to give PD patients “a seat at the table”, helping them become partners in creating their own health. As a founding member of the Parkinson Movement, an ambassador for the World Parkinson Congress and now also a doctoral student in health informatics she has truly taken matters into her own hands.

Part of her studies involve developing digital tools for self-monitoring. One such example is an app where a simple tapping exercise gives patients a chance to map the fluctuations in symptoms related to their medicine intake schedule.

The potential benefits of self-monitoring was illustrated with a simple graph showing the short amount of time patients actually spend in the company of health care professionals in one year, making the point that self-management will be a necessary component in creating the complete “health package” of the future. Quite simply, for all purposes patients need to start to be viewed as a partner and a resource.

"Engaged patients have, in most cases, shown to be cost-effective. We know that traditional health care systems cannot support all the needs of patients, the resources are simply not there. This is where we, as active partners in creating our own health, can step in and start complete the puzzle”, concluded Sara before exiting the stage.

The following speaker, Peter Hagell, discussed the inherent difficulty in measuring the outcomes of different therapies. For all the uncertainty of what will never be an exact science - based on the subjective experiences of patients, and health care workers - one thing became very clear. Up until now, what dictates the focus of new treatments is not to a satisfyingly degree centered on the real everyday experiences of people with PD. Peter Hagell has long been a innovator in this area and is currently developing new outcome measurement models where the views of health care professionals and patients are integrated to better map out new guidelines for evaluating and informing new therapies.

**THE DUTCH EXPERIENCE**

One example of patient-driven care in PD comes from the Netherlands.
In 2004 ParkinsonNet was founded, a central organization acting as a hub for regional care communities of healthcare professionals specialized in PD. The participating professionals are selected, trained in use of evidence-based guidelines and supported in their communication and collaboration. Persons with Parkinson’s disease are able to find the specialized health professionals through a search engine on the ParkinsonNet website.

Marjan Faber, a health scientist and leader of the Patient Empowerment research at IQ health care, has been an integral part in the rolling out of the ParkinsonNet over the past decade. She talked about how the strengthening of communication between patients and professionals has been substantial in the growing ParkinsonNet experience, revealing that a culture of best practice is now developing PD care throughout the Netherlands. Interestingly, the focus is also beginning to shift even further to where patients are becoming actual partners, getting involved in decision-making processes.

“I want to help empower patients through for example provider choice after referral, translating patient experiences into national policy, empowerment through e-health and patient activation by means of shared decision making in different ways.”

BOUNCING BACK

Last to take the stage was Jon Stamford, a trained neuroscientist with a specific focus on PD who himself was diagnosed with early onset Parkinson’s in 2006. With a distinctive dry tone of self-deprecating sarcasm he told his own story, from a curious young scientist to his diagnosis and the disillusionment that followed. After the initial blow of the news delivered by his neurologist, a blow that took two years to recover from, he bounced back and became an active voice in the PD community as a blogger, writer and co-founder of the Parkinson Movement, of which he is now the director. The story of the Parkinson Movement is also one of falling and getting up, repeatedly. Jon admitted how naïve the original goals of the movement now looked in retrospect and how the founding members hadn’t clearly defined the purpose of the organization at the outset. However, in a growth process, growing pains will typically follow and as the Parkinson Movement is now moving into its fourth year in existence the lessons learned have helped hone the vision of the organization going forward. A new quarterly magazine, a clearly defined role for its ambassadors and a more aggressive social media approach are all parts of the new strategy.

THE TWITTERSPHERE ABUZZ

The evening concluded with a panel Q & A where the in-house audience - as well as people in front of their computers the world over - were encouraged to take part. Social media wizard and neurologist-in-training Paul de Roos fed the panel questions and comments from a lively twitter feed.

A couple of snippets from the web Q & A:

What skills are missing in health care providers and researchers to really be able to engage in patient participation?

Peter Hagell: “I believe in my own basic training there was a real lack of focus on engaging with patients in an authentic dialogue. Regardless of our respective fields of expertise I think communication skills have to be more emphasized in the overall education of health care professionals. There’s no way around it, it’s a culture shift that is needed. But things are happening”

On the internet, patients get information of varying quality. How can we address this and help patients?

Jon Stamford: “Actually, through the Parkinson Movement we are now planning to set up something called AidPark, which is a broader assessment of the resources available to patients, gathered from all over. On the subject of sleep, for example, we will pick out the best literature, assessed by a panel of patients. This approach will be applied across the board, subject-by-subject, starting in about two months time.”

In her closing remarks Cristin Lind echoed the sentiment of Jon Stamford and the continued reinvention of his Parkinson Movement.

“I think we all have a shared feeling that we’re just in the beginning here. Very few events have even been held on this topic before. I think it will take some time before we can set into perspective where this movement is at this point in time. Personally, I believe we’re seeing the first signs of a broader paradigm shift that is clearly picking up speed year by year.”