

CALENDAR PICKS

- 1. November 4th, Invited Lecture Series.** Jörgen Kjems - MicroRNA and Circular RNA in Control of Neuronal Development and Disease. 16.00, Segerfalksalen.
- 2. November 7th, BAG Young Investigator Talks.** Torgny Roxå - Challenges and productive principles in expert presentations - the audience as co-creators.
- 3. November 15th, Parkinson Research Foundation Deadline** Calls for PRF applications expire.
- 4. November 20th, Workshop for the Future of BAG -** How do we create identity: strategic discussions for the future of BAGADILICO.

BAG NEWS PICKS

- 1. New BAGADILICO Videos**
On BAG's YouTube Channel you can now find a number of new researcher presentations.
- 2. Parkinsonfonden Jackpot**
A host of Bagadilicans were recently awarded prestigious grants from Parkinsonfonden.
- 3. Londos New Associate Member**
As of mid-October BAGADILICO welcomes Elisabeth Londos as a new Associate Member.
- 4. Career Coaching Opportunity**
The Medical Faculty has just appointed its first ever Career Coach, Pernilla Carlsson.

IN FOCUS



EU GRANT HIGHLIGHTS LATE STAGE PARKINSONISM

Together with a group of international applicants Per Odin recently was awarded an EU grant for evaluating the needs of patients with late stage parkinsonism. The Lund piece of the pie this time around is 1,4 M SEK. The three-year program will kick off on January 1st.

The study, funded by the EU Joint Programme for Neurodegenerative Disease Research (JPND), will aim to evaluate the needs and provision of care for patients in the late stages of Parkinsonism and their carers. This will be done through an in-depth assessment of patients and carers, interrogation of national and regional databases, and assessment and outcome of management strategies in six European countries.

- We hope to map the experiences

of the the most gravely affected Parkinson's patients in different European health care systems and examine whether an intervention, including for example a more specialized neurologist, may improve their situation, says Per Odin.

Researchers will also compare the effectiveness and cost of different health and social care systems, and carry out a trial comparing assessment by a specialist with management suggestions, guidance and access to telephone advice to that of usual care of this late disease phase.

- I think perhaps our project was singled out because it focuses on a group of very ill patients that are sometimes forgotten, concludes Per Odin.



WPC PAVING THE WAY

TEXT: JENS PERSSON

For all the extraordinary advances made in Parkinson's research over the past fifty years, great challenges remain. Few, if any, will contest this premise. So, what are the next big trends in PD research? What or who will push us towards better therapies and hopefully someday, a cure? If the recent World Parkinson Congress bears any indication as to where we are heading, patient participation might just be the way of the future. Some would argue that patient-driven research is still a virtually untapped resource. A potential Klondyke waiting to happen.

In the world of commerce the customer may not always be right but they tend to play a key role in product development. So should the health care consumer, says the Parkinson's patient community with a voice that is only getting louder. If you think about it, it's just good business.

-On October 1st people with Parkinson's disease, health care professionals and researchers converged in the heart of French Canada for the triennial WPC in Montreal. Over 3000 delegates from 70 countries took part in what has become the truly global hub for PD, a place where all stakeholders get a seat at the table.

In Montreal, Parkinson's patient and mul-

tiple BAGADILICO collaborator Sara Riggare shouldered the responsibility of WPC ambassador for the first time. Besides the obvious positives of a congress program designed to give voice to patients she felt “something different in the air” this time around, a new atmosphere.

- It really felt like a meeting place where all parties could discuss on an equal footing. Partly because people with PD had such a key role in setting up themes and subjects at the event. I think this gave a new legitimacy to our point of view. And also, there has been a broader shift in the view of the patient’s role in recent years and I believe we are reaching a tipping point where patients are starting to act without asking first. Thankfully a lot of health care professionals and scientists are on board. But not all of them.

STRIKING A BALANCE

A telling example from the new generation of neurologists comes with a quote from a young Iranian doctor, a WPC volunteer doing his PhD at Karolinska Institutet. Excited to meet all the patients he said “I would have to work in the hospital for decades to get the opportunity to meet and speak to this many patients in such a positive setting.” An attitude instilling hope for the future.

All participants were perhaps not as straightforwardly positive about patients taking charge.

Snippets from a conversation overheard between neurologists.

- There really are a lot of patients here this year.

- Yes, but it seems the program is so good it’s still worth coming.

These comments perhaps show that we have a way to go.

However, Sara Riggare is the first to admit that striking the balance between patients, health care professionals and researchers is a difficult one. Patients taking over the show is not the point here. Honest dialogue is.

- I know for a fact that we would have wanted more neurologists at WPC this year. We strive to get a fair balance to foster a conversation that is as constructive as possible. That’s the goal. And it’s really not just the younger generation that holds a new perspective

on patient participation. My feeling is that a lot of senior researchers have a more progressive view on this than they did a decade ago.

BAG IN MONTREAL

Making the trip to Montreal were also a number of Bagadilicans. One of the young scientists taking part was Veronica Francardo. Asked about her experience she conveys a level of excitement seldom associated with conferences.

- That was the best congress I’ve ever been to! There was a lot of interaction, not only with scientists, but with patients as well. The patients were coming to the lectures asking a lot of questions and telling us about their own personal experiences. There was an intimacy to the event that I haven’t experienced before.

As the only forum of its kind today, Veronica believes that WPC plays a key role in promoting patient participation. Not least as a reminder and motivator of why the research is so important.

- Sometimes researchers might be a little bit detached from reality but seeing the patients and talking to them was so inspiring. For me, researching on dyskinesia for example, I got to meet patients with these symptoms and it’s so valuable to listen to their experiences. My science becomes real, you know!

- Patients were really anxious to share their experiences. I was a little bit surprised by this. Sometimes patients don’t want to reveal their disease or show to be suffering. But here, they told stories from their everyday lives, and also telling us not to give up. It was very emotional.

As Veronica Francardo returns to her lab with a new spring in her step WPC’s Executive Director Eli Pollard is already setting course towards 2016 when the event will be held in Portland, Oregon, U.S. It is probably safe to say that with the ongoing e-patient boom, where patients are becoming more empowered and more informed, the Portland experience will be one where the envelope is pushed even further, recognizing people with Parkinson’s as proactive partners in the development of their own care.

- I think more and more people are realizing that the existing structures within health care cannot serve all the needs of the patient. The resources are simply not there. That’s where we come in. And we are a resource, not a threat, concludes Sara Riggare.