BAGADILICO News
December/January

INTRODUCING ANGELA

2012 sees the introduction of a new Bagadilico Coordinator, Angela Cenci-Nilsson. We took a moment to take her pulse, asking a few questions about her visions for Bagadilico.

What specific areas will you focus on to take Bagadilico to the next level?
- I’d like to promote a common vision, a culture pursuing excellence in the work, as well as synergistic effects. Particular areas that I will try and promote are the creation of study groups working on some common important themes. These groups will have regular meetings and will build a strong local competence. Secondly, I aim to revitalize our internal “pre-lunch seminars”. Also, I would like to see the further development of technical platforms, as well as giving research training opportunities matching the platforms and themes within our network.

What are the main challenges in coordinating such a large network?
- One challenge is to get everyone on board with the vision of Bagadilico as a truly common effort beyond personal gains, that we all strive towards a shared goal across research groups and disciplines. This should allow us to successfully build a strong environment in a collegial spirit of support. I am quite convinced that this is the winning policy in the long-term. And we shall see that “a high tide raises all boats”.

What will be Bagadilico’s legacy when we take stock in 2018?
- I hope that we will be able to look back and feel proud of all the progress that we’ve made, in terms of both research results and professional and human development of our researchers. And, if there will be a call for similar centre-of-excellence grants in 2018, we should be qualified enough to get a Bagadilico 2!

NEWS IN BRIEF

SHANE GREALISH DEFENDS HIS THESIS
On January 27th, Shane Grealish successfully defended his thesis and became a doctor in neurobiology. His thesis, “Cell Replacement Therapy for Parkinson’s Disease: The importance of neuronal subtype, cell source and connectivity for functional recovery”, discusses what factors affect the functionality of transplanted dopamine neurons from the midbrain.

He looks at where the neurons are placed, what neurons are responsible for cell recovery and what cells are used. One important finding from mouse studies tells us that dopamine cells that are transplanted into their site of origin, the midbrain, can make functional connections to the striatum placed several millimeters away.

Another discovery explains the key importance of certain dopamine neurons that are needed to achieve motor recovery after transplantation. Finally, an experiment showed that dopamine neurons generated from human embryonic stem cells can closely match the performance of their fetal counterparts by surviving transplantation, not generating tumours and provide functional benefits.

NEW CREW AT M/S BAGADILICO

The deckchairs on the M/S Bagadilico has been rearranged for 2012. Besides from the switch at the helm where Angela and Cecilia changed places Oskar Hansson was selected to the board where he replaces Peter Hagell as well as to the executive group where he takes the place of the departed Patrik Brundin.

Oskar brings exciting expertise in biomarkers for Parkinson’s disease and related neurodegenerative disorders. His overarching research goal is to develop new biomarkers that will offer early and secure diagnosis of neurodegenerative disorders, spanning from Parkinson’s disease to Alzheimer’s disease. If effective biomarkers are able to catch the diseases at a much earlier stage, new treatments may be able to be put in before cell death has progressed to a state were patients begin to show symptoms.

GRANTS FOR BAGADILICANS

The Bachmann-Strauss Dystonia & Parkinson Foundation has awarded Angela Cenci-Nilsson research group a 65 000 USD grant. This is the first grant form this foundation that goes to a Swedish-based research effort. The funds will go towards the project “Neurovascular coupling and flow-metabolism dissociation in L-DOPA-induced dyskinesia”. The research is based on findings from Elisabeth Olins thesis.

Åsa Petersén’s research group has received a 3 000.000 SEK grant from the Ragnar Söderberg Foundation. The Foundation is handing out a total of 129 million SEK for 2012. The project that the Translational Neuroendocrine Research Unit will be working on is entitled; “Huntingtons sjukdom – i det molekylära gränslandet mellan depression och övervikt”.

NESU member Ulrika Nordström has been awarded a 200.000 SEK grant from Konung Gustaf V:s och Drottning Victorias Frimurarestiftelse. The grant will be used within the project “Novel progressive models for translational research of Parkinson’s Disease”.

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As Patrik Brundin stepped onto the US-bound SAS flight on January fourth, contradicting emotions were running through his mind. Besides the immediate practicalities of handling two wild boys, an infant and the transportation of his precious Spanish water dog Zelma, he was filled with anticipation about the many challenges awaiting him in his new hometown of Grand Rapids, Michigan. But there was also a sense of sadness in his chest, from leaving relatives, friends and colleagues behind. After all, Lund has been home for the past 32 years, encompassing his journey from a wide-eyed young student to an internationally renowned Parkinson researcher. That journey now takes a significant turn, placing him in one of the hot seats in the American Parkinson research community, with substantial resources at his disposal. As flight SK943 took off, setting course across the Atlantic, it signaled a new direction for Patrik Brundin. But his final destination since thirty years remains the same – curing Parkinson’s disease.

Patrik Brundin’s decision to dedicate his life to Parkinson’s disease was born out of love for his father, Bertil, who got Parkinson’s when Patrik was only a teenager. The young Patrik, already a problem-solver, was determined not to see his own father defeated by the disease. At age seventeen, not long after his father’s diagnosis, he wrote a school paper on Parkinson’s disease. At that time he barely knew what a neuron was, much less what it looked like. But his resolve had now taken hold and in retrospect it seems that his fate was already sealed on that day when he handed in the paper. Patrik’s father passed away in 1995 but still remains the main driving force that motivates him today.

- That is really the case, this is what drives me still to this day… I feel sad just thinking about it, he says in a lowered voice. Evoking the memory of his father clearly brings out strong emotions. He goes on to explain how the new job reinforces the link between his career in Parkinson’s research and his late father.

- The person who donated the money for the institute, Jay van Andel, was born on the same year as my father, which I thought was a bit strange. What are the odds that I receive a job offer in someone’s name, someone who donated two billion dollars, someone who had Parkinson’s and was also born in 1924. I mean, statistically speaking, it is quite unlikely. When I heard this I somehow felt that this is something I probably should consider, there was a sense of destiny about it all. And to some extent, now that I’ve taken the job, it’s almost as if I spent the last thirty years preparing myself for this opportunity.
Breaking up is hard to do

It becomes quite clear that Patrik Brundin sees the move stateside as an adventure, an opportunity to breathe fresh air. For the past couple of years it seems that the air in his Lund working environment was often polluted by squabbling more befitting of the political arena than an academic institution. In Patrik’s opinion, which is always liberating in its honesty, the culture of consensus in Sweden often times holds back the individual. He stresses that everyone can’t and shouldn’t be treated in the same way. People have different needs and motivations.

- Sometimes Lund feels like a closed universe, where everyone is supposed to be exactly equal. Our outgoing dean recently wrote that he is satisfied that he managed to abolish the negotiating culture within the medical faculty. This of course sounds a bit bold, but in reality it translates to the abolition of the individual, a thought based on the idea that we should all be able to neatly fit into a set mold. But there will always be individuals and situations that do not fit in the preset mold, where other more creative solutions might be available “outside the box”.

- In Lund, whether one is young or old in one’s career, attracts 110 million or two million crowns in funding, one is handled and rewarded in exactly the same way. This is a culture that I don’t think is good. I don’t think that one gets the maximum from everyone, and that applies at both ends of the spectrum. A modern research and learning organization like ours should be capable of coaching and treating everyone individually, in a manner that maximizes performance and output.

Experienced in the politics of academia Patrik has developed thick skin over the years. But the uphill battle he tells me he has been fighting has taken some of the fun out of the job. This doesn’t mean that excellent science hasn’t come out of the labs at BMC. When he is asked to list achievements by the research groups in the networks he’s been involved in, he almost seems surprised himself as one positive after
another keeps popping up for the remainder of the interview. In spite of the progress made, however, he comes back to the uneasy feeling of having to swim against the current. In the end that gut feeling was what allowed his gaze to wander, making him a target for new employers. With an effective metaphor he paints a picture of the moment when he was first contacted by the Van Andel Institute.

- You could compare your relationship with your employer to a marriage. If you are completely happy in your marriage and a stranger knocks on your shoulder in a bar, you probably won’t start chatting to them. But if you’re not quite happy you might choose to start that conversation. In my case it was an email that arrived over a year ago. Being not entirely happy at my workplace, I chose to answer that mail. If I were completely happy I may not even have read it.

The land of opportunity

In Grand Rapids, Patrik Brundin arrives to an empty canvas. Over the next five years he will recruit about 80 scientists to the Van Andel Research Institute Center for Neurodegenerative Science, which will include his own Jay Van Andel Translational Parkinson Research Lab. Five different research groups will put particular emphasis on biomarker discovery, disease modification, and the development of regenerative therapies for Parkinson’s disease.

CEO David Van Andel, son of the founder of the institute, is unmistakably excited about the their latest recruit.

- The appointment of Dr. Patrik Brundin and the maximization of the Jay Van Andel Parkinson Research Lab to its full potential are crucial pieces in our fight against this terrible disease. West Michigan is poised to become a national leader in Parkinson’s research, and the appointment of Dr. Brundin will take us to the next level.

Patrik Brundin realizes that he will have to do a lot of delegating in his new job. With a large workforce under him, micromanaging is a thing of the past. He is also determined to let the quality of research steer the direction of the projects.

- My goal is to recruit very strong researchers and then manage the bigger picture of how the research is focused. I will not sit there and say
who is going to be a graduate student, I'm more interested in excellence and to bring in researchers that are hungry to get results.

As the economic climate in the U.S. seems to be heading for yet another harsh winter the total pool of medical research funding keeps draining. The number of applications approved by the NHS has dwindled from 20-25 percent a few years ago to only around eight percent for some areas last year. However, being part of an institute with a secure cash flow, independent of national grants, allows for some wiggle room in the areas of recruitment and project funding.

- It feels like, with the resources and opportunities we have now, that we will be able to recruit some very good people. I also believe that we will get more money, because with the security provided by the endowment allowing us to take on some more risky and hopefully creative research projects, I think we will manage to pull in important external funding.

The Bagadilico legacy

Patrik Brundin is not jumping ship on Bagadilico. He will stay on as a Principal Investigator for the coming three years as he continues to manage his research group at the Neuronal Survival Unit. His input in Bagadilico affairs may be diminishing but during the formative first years he was influential in getting the sometimes cumbersome Bagadilico ship to leave port and set a steady course.

- I think Bagadilico has had a somewhat difficult journey, but things have gotten better and better and our publication rate has clearly picked up. If people would take stock of the past couple of years they would probably realize that if you take away the resources that have come from Bagadilico, they'll see that it has been an important platform for many to move on and get more money from other places, Patrik explains as he starts to name publications and projects where Bagadilico has acted as a springboard. A few minutes later Patrik Brundin starts to look quite pleased as he reflects on the long list of accomplishments connected to Bagadilico.

- What we have to focus on now is really two things. Number one, how do we get the added value from being a broad network, how do we tap that resource. Here, we still have a lot of work to do. The second key challenge is to fulfill our translational ambition, getting therapies to the clinic. This has proven to be extremely difficult. Hopefully now, with new management in place at the clinic, we will see some important change in this area.

From across the pond Patrik will stay involved with the developments in Bagadilico. Perhaps more in the role of a bench player than the go-to-guy who scores the game-winning goal. Another arena where he has literally left the playing field is the volleyball court. His team of 21 years will be without their veteran player in the coming season. A couple of times during our conversation he comes back to how much he will miss the team, not least the social aspects of exchanging high fives and the most recent gossip by the volleyball net. Workwise, it seems that he will continue to have plenty of balls in the air as he as he assumes the position of inaugural holder of the Jay van Andel Endowed Chair in Parkinson Research.
Year by year, the tentacles of the web penetrate deeper into our everyday lives. Paying bills, staying in touch with friends, getting the latest news have long been features of digital interaction. The world of medicine is, of course, no exception. As people start to share their diagnosis and genomes new communities are formed. Populous digital societies across continents, where people with a disease like Parkinson’s or Huntington’s can share information and experiences, have helped strengthen the role of the patient. With the advent of web-based companies offering direct-to-consumer genetic testing we approach a more sensitive area in professional medicine, self diagnosis. I spoke to Bagadilico’s cultural scientist Niclas Hagen about the role of digital culture in medicine today.

When it comes to Direct-to-Consumer Genetic Testing (DTC), how would you map out the moral grey areas in this industry?

- Apart from the issue of the pros and cons of commercialization itself, which is more of an ideological issue, one major issue in relation to DTC is that we do not know that much about how people react to the information given in the tests. Then it is the issue of the actual utility of the information given, both in terms of the scientific and clinical utility. What do these tests actually tell us about the potential of developing this and that disease, and what value does this info have for the individuals who take these tests?

If DTC becomes more commonplace in a few years, how might this development affect future regulations of a person’s ability to access their genetic data?

- A greater amount of companies that operate in the sector of personalized genetics mean that they might become a more powerful stake-holder, in terms of their ability to organize themselves internally and coordinate their actions towards regulative bodies such as the US Food and Drug Administration. We also need to consider that new players might enter the scene in just a few years, as whole genome sequencing will become cheaper and readily available. All in all, this development probably means that there will be a greater access for individuals when it comes to getting hold of their genetic data. However, it is another question if they will go to the web in order to get info about their genome.

What is your view on the cooperation between private DTC-companies and the research community? For example, 23andMe, the most aggressive DTC-company in your opinion, is today collaborating with the Michael J. Fox Foundation.

- One interesting issue in relation to this kind of scientific cooperation concerns the role given to the individuals who take part in the project and who donate their DNA for research. In what role do they participate in this kind of research, as a customer or as a research subject? What kind of obligations do this cooperation give rise to for the involved stake-holders?
Is there a moral obligation to inform the participants on their own results, for example of a total genome sequencing, in order to provide feedback and transparency to the research? And what are the implications of this for the way science is produced within these joint projects?

Connected to the growing DTC-services provided on the internet is the development of the consumer from a user to a producer of science. Would you say that this is problematic or perhaps democratic?

- I think one major change from this development concerns a shift from the public to the private realm. Genetic information accessed through the internet, upon a commercialized technological platform where you are both a customer and a producer of knowledge, creates a possibility for a “short-cut”. A chance to bypass the channels of communication and decision-making that the society have relied upon for taking decisions about how, when, and to what extent genetic tests are to be used within our society. Yes, this might be seen as a democratic turn, as this gives more power to the individual to decide for themselves. But it also means that various forms of professional and institutional bodies might be left out on important issues. So, the democratic issue is a tricky one which we are looking into at the moment.

You have also detected a true positive of the cyber revolution. That is the development of a social digital culture where patients with a similar diagnosis can share their experiences.

What are the main consequences of this phenomenon?

- For individuals who are affected by rare diseases, like Huntington’s disease, online social media such as Facebook enables them to get in touch with people who share their situation. They can also form disease identities through these online communities that will help them share information and take common positions on issues related to their disease. Research performed indicates that this has positive effects for the affected individuals who can reach out to a far greater amount of people through the internet.

This could perhaps turn what used to be passive patients into active agents of change, giving them a sense of purpose that might improve quality of life. Long term, could these online communities possibly inform how science is being produced?

- Within the context of Huntington’s disease there is an ongoing initiative that tries to do something like that, the HD-Buzz website. Here, scientists write about research on HD on the HD-Buzz website. So, there are possibilities to get through to the affected individuals through the internet and online social media. I think HD-Buzz is a good example of the way the scientific community can interact with affected individuals. So yes, I think that different forms of online communities can provide information on science, and I think that we can see examples of this already today.