NICLAS HAGEN - BAGADILICO'S PIONEER BLOGGER

The number of science blogs on the internet have exploded over the past couple of years. Suspicion has turned into curiosity and many scientists have now begun to see the upside of social media - being able to start a dialogue with peers and laymen about the scientific process, not only the results. This month Niclas Hagen became Bagadilico’s pioneer blogger with his blog ‘Bioculture(s)’.

Why a blog Niclas?
I am interested in new social media and I thought it would be a great idea to increase my knowledge by becoming a blogger myself. I would like the blog to communicate my research and my thoughts on various aspects concerning my field of research, not least in relation to interdisciplinary science.

Why is it called Bioculture(s)?
I am interested in the relationship between science and the rest of society and our culture. What impact will the knowledge produced within Bagadilico, and neuroscience in general, have on how we see ourselves, our society and our culture? On the other hand, what kind of social and cultural frameworks structure the way the public sees science and disease, and ultimately how they might utilize the knowledge produced within science? As a social/cultural scientist with a background in molecular genetics I always shift between different scientific cultures, between medicine, biology and social/cultural science, and I thought the name bioculture(s) captured these aspects.

Who's blog would you like to read?
I would like to follow a blog from one of the top researchers out there. I would like to see the actual research taking shape, all the ups and downs, as a way to see the actual process. Very often, at least in my opinion, you come across research when it is packaged and published and that doesn't give you a picture of all the hard work, the successes and disappointments that is part of being a scientist.

Find out more on ‘Bioculture(s)’ - Click here

NEWS IN BRIEF

BAGADILICO’S CAREER PROGRAM UNDERWAY
Bagadilico’s new Career Program got off to a flying start on the first day. The themes - leadership and communication - are important parts when building an academic career. Guest lecturer Dr. Rhiannon Sanders, an expert in career development, inspired the participants to see new opportunities.

Find out more about the Career Program - Click here

ÅSA PETERSÉN AND MARIA BJÖRKQVIST ELECTED IN PRAGUE
Åsa Petersén and Maria Björkqvist were elected members of the Scientific and Bioethics Advisory Committee at the European Huntington’s Disease Network meeting in Prague 3-6 September. Sofia Hult won the prestigious poster award at the same event.

PATRIK BRUNDIN EDITOR-IN-CHIEF OF NEW PD JOURNAL
Patrik Brundin has agreed to become editor-in-chief together with Bill Langston for the new ‘Journal of Parkinson’s Disease’. The journal will be published by IOS Press and cover both original basic and translational science as well as clinical medicine within the Parkinson field.

Link to Journal of Parkinson’s Disease - Click here

BAGADILICO IN SOCIAL MEDIA
As we rapidly move further into the information technology era it’s high time for Bagadilico to catch up with the front runners in science communication. In September we launched our very own YouTube channel and our first science blog

A few pointers for all Bagadilico members:

YOUTUBE – This month we have seen the birth of the Bagadilico YouTube Channel. Since we haven't produced any videos of our own yet we are initially using it to link to clips that are related to Bagadilico but also to our broader research areas. If you have a video that you think might be relevant for Bagadilico's channel, send me the link and I will post it for you.

Bagadilico’s YouTube Channel - Click here

FACEBOOK – As most of you might already know, Bagadilico has a facebook page. Please try to use it to post interesting links to Bagadilico events or publications as well as links or comments to subjects of general interest in related fields of research.

Bagadilico’s Facebook Page - Click here

BLOGS – This month Niclas Hagen became Bagadilico’s first blogger kicking off his own science blog. Today many top scientists use the blog as a tool for speaking directly with the public, as well as communicating with fellow scientists. If you have an interest in starting your own blog, contact me and I will help you get started.

Find out more on ‘Bioculture(s)’ - Click here
A rare opportunity to discuss directly with leading scientists attracted around 50 curious visitors to Bagadili-co’s first ever Huntington Café. The topics ranged from everyday clinical situations to the very latest in cutting-edge research.

Many had long expressed a need for an open forum to meet and discuss the statistically rare disease. Patients, relatives and assistants were now given an opportunity to share experiences and ask questions to experts in the field of Huntington’s disease.

- It gives you so much to get the information directly from the researchers themselves. To have the opportunity to follow up with questions and create a personal dialogue is very important. Here were people today who have never even heard a professional researcher speak about Huntington’s.

Therese Persson carries the defective gene for Huntington’s herself, and devotes much of her spare time to raise public awareness about the disease. Unusual diseases often carry with them a stigma, simply based on the lack of knowledge among the general public. This is why Therese sees the Huntington café as an important initiative in line with her own ambitions - to encourage dialogue and raise public awareness about Huntington’s disease.

- There are far too few of these kinds of occasions, actually there are barely none at all. Today’s event has shown us that there is a great need for forums like this. Hopefully even more people will dare to attend next time around - I think today’s experience gives us hope that they will.

**Everyday clinical reality and frontline research**

Håkan Widner, Professor and Director of the Neurology Clinic at Skåne University, got the Café underway with a lecture on clinical perspectives in the treatment of Huntington’s. Åsa Petersén, MD and Associate Professor at Skåne University, brought with her two fresh reports from international Huntington conferences and informed an all-ears audience on the latest developments in the field of Huntington research.

Particularly one of the new research findings raised a number of questions. It concerned a method that aims to “turn off” the Huntington gene. The goal is to, at an early stage, stop the defective gene from producing the proteins that clump together and eventually kill the nerve cells. Clinical trials are now expected for the new technology that attacks the core of the disease process in Huntington’s.

- If we can stop the defective gene, we will also eliminate the problem. Today many researchers and companies are interested in this technique. Hopefully the first clinical trials will start taking place in North America next year, Åsa Petersén told an inquisitive audience who wondered when the
treatment could possibly reach the patients.

- In the coming years we will know how well this method might work. Personally, I think it is the most promising development we are seeing today in the research that is directly targeted towards preventing disease development.

Ethics and genetics in Huntington’s disease

Many questions dealt with issues concerning the genetic tests that show if someone is carrying the defective Huntington gene. Because Huntington’s disease is controlled by a single gene it is often central to the broader ethics debate relating to genetics and privacy, for example concerning individual insurance matters.

Håkan Widner was firm in his statements about protecting patient privacy as far as is legally possible.

- If we examine you here at the neurology clinic and see that you are carrying the defective gene, you are technically - according to our lawyers - not necessarily a patient with us. In this case, you’re here to receive information. That means that you are not required to state in your health declaration that you have been here and that you’ve taken a genetic test and is a healthy carrier. However, if you’re showing clear symptoms of the disease the situation becomes more complicated.

Before the Huntington Café drew to a close Therese Persson informed about her newly started blue ribbon campaign. The call is to - on the first day of each month - wear a blue ribbon to raise public awareness for Huntington’s disease. Only a few blue ribbons have been sold so far and the account balance for the total amount collected still lacked some desired zeros. The money will later be donated to Åsa Petersén’s research team.

- In this context, it is the activity that is so important, not the money. The information will spread slowly and one way or another it will end up on the desk of someone with authority over research grants. Of course it will take time but the ripple effect is extremely significant, said Håkan Widner, ending the first Huntington café on a hopeful note.