IN FOCUS

On September 27th Erika Elgstrand Wettergren had her dissertation on ‘Specific Genetic Modifications in the CNS.’ The thesis presents a couple of novel ways to find disease-specific promoters to be used in gene therapy solutions for Parkinson’s disease.

The promoter typically controls the expression of the transgene delivered in the viral vector. In one study presented in the thesis a method is laid out for picking relevant promotors for specific neurons that play a key role in the development of Parkinson’s disease.

The research presented also details a way to limit transgene expression, here in microglia, by adding a sequence complementary to a micro-RNA. The technique allows for singling out microglia to study its role in neurodegenerative diseases.

The second part of the thesis focuses on gene therapy solutions for controlling the release of the GABA neurotransmitter. Aberrant signalling of GABA is present in many diseases of the brain, for example Parkinson’s and Huntington’s disease.

The target in Erika’s research is here directed towards the enzyme GAD67 which controls the pace of the GABA synthesis. The thesis presents two different approaches to regulate the expression of this enzyme in order to normalize the release of GABA in the brain.

For further info, CLICK HERE
On paper Bagadilico is a shining example of multidisciplinarity. In reality, fusing ethnologists with neuroscientists is not always a smooth ride. Fitting a cultural scholar into the world of experimental medical science may sometimes require the metaphorical shoehorn. Niclas Hagen’s journey over the past couple of years does not necessarily challenge this premise. The road towards his dissertation on October 4th has been one of trial and error. Breaking new ground is, however, never easy and in this case the pay off is a piece of true interdisciplinary research, materialized in the thesis Modern Genes – Body Rationality and Ambivalence.

Working side-by-side with HD expert Åsa Petersén, Niclas has challenged traditional scientific boundaries in an effort to understand how patients and their families relate to the often abstract scientific information provided them in the context of a Huntington’s disease diagnosis. How does the genetic specifics of the disease affect the patients’ views of their own bodies? How does one build a new identity around such an elusive concept as a single gene mutation?

- I was interested in how people who have no real prior knowledge of genetics or neuroscience take in this knowledge coming from laboratories. These are pretty abstract ideas to the general public. The information
is also often at odds with how we perceive our own bodies. I know, from science, that there are genes in my body but it is not a part of how I experience things when I’m out running example.

It is here, in the clash between the individual’s own experiences and the hard facts provided by hard science, that Niclas Hagen’s thesis takes place. The project is based on qualitative interviews with HD patients and their families. The choice of HD seemed an obvious one considering the overriding genetic component that defines the disease. Sitting down with these people Niclas expected them to have plenty of thoughts about the biology of genetics and how it shapes us as human beings. And sure, they did. But there was another theme that kept dominating conversations, the health care system.

I expected them to talk about the pros and cons of presymptomatic testing for example, a hot debate in past years. Instead they talked a lot about health care and the welfare system. They expressed feelings of being misunderstood or not getting the help they felt they needed, personal assistants for example. This surprised me a little.

The clash between the patient’s life-world and the hard science seemed to be matched here by an equal clash between how patients perceived their own situation and the services offered by the welfare state. In both cases there appeared to be a communication gap that was yet to be bridged. In the case of the health care system the rules and regulations set by the state were perceived as difficult to navigate, often resulting in a feeling of powerlessness.

In some cases patients dealt with this by engaging in the ‘language’ set by the authorities. Becoming well versed in the law texts dictating the health care system was one way towards empowerment, taking control of your situation. Since the system was sometimes ill-equipped to deal with the emotional situation of the patient other routes of communications ultimately became a necessity. These collisions between the life-world of the individual and broader cultural systems in society runs like a common thread throughout the thesis.

- If we are not thinking about how science is manifested in society there is likely to be a clash between the scientific system and the people who are the actual target group of the research, that is, the patients. As citizens we can often take on this knowledge intellectually, but it must also fit into people’s emotional reality, for example how we perceive our own body in everyday life.

**THE DIGITAL SQUARE**

One way for patients and their relatives to deal with the situation is to engage in different arenas related to HD. In the rapidly evolving age of Facebook and other digital communities people can now connect their life stories and find a platform for sharing and building new identities. For someone experiencing the ambivalence of a presymptomatic HD diagnosis it is hard to overestimate the importance of such an outlet.

- When it comes to digital media one can imagine two scenarios. One is that that Facebook, for example, is a tool, like patient organizations, towards consolidating a common voice that can be an actor in relation to the scientific community and the health...

Niclas Hagen nailed his thesis on September 4th at Kulturana- tomen.

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care system. But it can also work solely at the grassroots level, as a platform for individuals, across the world, to make direct contact with each other outside of a traditional organization.

**BEING BAGADILICO**

Being part of Bagadilico has been a learning curve, explains Niclas. It has forced him to challenge his ways of formulating a research problem. Meeting and presenting for medical scientists has given him a rare opportunity to look at his own research from the outside, with fresh eyes. It has also required him to boil down his message to the bare essentials, to the extent that it is possible. There will always be dividing lines between the clear-cut causalities of the natural sciences and the ‘softer’ studies represented in the social sciences.

- It has been fascinating to get an insight into scientific excellence on the molecular level. Without Bagadilico it would have been almost impossible to get this collaboration going. Writing articles together with Åsa, for example, has been so valuable. Conversely, I believe that natural scientists can, through us, learn to systematize a broader cultural context, to look upon society from above, a bird’s eye view if you will.

The thesis has now led to a post-doc position with Åsa Petersén and Deniz Kirik. Niclas will be part of a project that aims to develop an informed consent document for volunteer HD patients who want to participate in medical studies. In part, the model document will relate back to the thesis, taking into account the emotional life-world of the patients. In practice, this means that the patients will be a key part of the process in formulating the document.

If successful the project will be a true manifestation of interdisciplinary research with real results in the clinic. The clash between the life-world of the patient and the health care system, as proposed in the thesis, may be a little less of a clash as a result.

Niclas Hagen’s research reflects the disciplinary mosaic that has developed within the walls of Bagadilico. At the time of the research network’s inception some skeptics may have suggested the accomplishment a far-fetched idea.

The communication of research advances in genetic science is of key importance, believes Niclas Hagen. For Huntington’s disease patients the science behind their diagnosis is often experienced as abstract and difficult to relate to.