



**Meeting of the European Brain Council and National Action Group in Sweden.**  
5<sup>th</sup> November 2009

A meeting to discuss the formation of a Swedish National Action Group for brain was held at the office of the Sveriges Läkarförbund in Stockholm. The EBC was represented by Ian Ragan and Tadeusz Hawrot. Thirty people had been invited to the meeting, eleven of whom confirmed their participation. The meeting itself was attended by 9 people.

LP	Name	Organization
1	Aleksander A. Mathé	Prof. Karolinska Institute
2	Bengt Winblad	Prof. Karolinska Institute
3	Bo Ingemarson	CEO, Swedish Brain Foundation
4	Lars Farde	Prof. Astra-Zeneca
5	Susanna Lindvall	President, Swedish Parkinson Foundation
6	Sven Ove Ögren	Prof. Karolinska Institute
7	Torgny H Svensson	Prof. Karolinska Institute
8	Ian Ragan	Executive Director, European Brain Council
9	Tadeusz Hawrot	Project Manager, European Brain Council

Psychiatry, basic research, patients and industry were represented at the meeting that started at 10.30. The agenda was as follows:

**AGENDA**

10.30 - General introduction.

10.45 - Participants introduction.

11.00-12.00 - European Brain Council: Background and aims; what are National Action Groups and National Brain Councils and what do they do?

12.00 - Lunch

13.00-15.00 - Discussion on major fields in Sweden; Establishment of the Swedish Action Group.

15.00 - Conclusions and way forward.

Ian Ragan welcomed everyone and thanked Astra Zeneca who was represented by Lars Farde for a generous contribution to the meeting costs. Afterwards he introduced the EBC, its main activities, goals, studies and strategy. Tadeusz Hawrot presented the concept of the National Action Groups and National Brain Councils.

After the lunch break the participants discussed the status of brain research and diseases in Sweden and beyond.



Torgny Svensson proposed three points for discussion which he felt were highly relevant to brain disorders in Sweden:

1. There needs to be, in part, a shift in research priorities from neurology to psychiatry and mental health.
2. There should be greater emphasis on the major health problems such as depression, schizophrenia and addiction. Therefore, there needs to be a shift in priorities across the age range, from older people to younger ones.
3. The view of the power of genetics to solve problems in mental health is often too optimistic.

Lars Farde remarked that for patient organizations related to brain disorders, advocacy can be much more difficult, especially in conditions like schizophrenia. Patients with mental disorders are not always effective advocates for themselves and often find it impossible to be active. There is a need to overcome this situation by finding alternative routes for their advocacy. Tadeusz Hawrot mentioned EUFAMI as a good way for advocacy of people with mental illnesses.

Susanna Lindvall emphasized the importance of officially forming a Swedish Action Group in order to put brain higher on the agenda of policy makers. She added that patient organizations can be very helpful in achieving this.

There was much discussion about issues of fragmentation of research and of efforts to translate research into patient care. Aleksander Mathé illustrated that issue by discussing the way that extra funds allotted to psychiatry have been distributed to many units across the country. He concluded that there is a need for a greater effort to support basic researchers.

All the participants agreed that one of the most prevalent problems in Sweden is fragmentation of research. Even if the government is investing money in research, it is too fragmented and more bottom-up approach is needed.

Aleksander Mathé reminded the participants that in contrast to some other countries within the EC as well as Norway, universities in Sweden no longer have their own hospitals. Hospitals are run by counties and their policies may differ from county to county.

Bo Ingemarson outlined the role of the Swedish Brain Foundation that both raises awareness of brain diseases and distributes grants to all brain disciplines in Sweden. He underlined further need to raise public awareness about brain disorders. In order to achieve this and to reach the public, the message has to be translated into different, non-scientific language, and simplified.

Aleksander Mathé summed up what he saw as the three major challenges:

1. Fragmentation at all levels from research to clinical practice guidelines and trying to find a way to counteract it.
2. More focus on diseases that have onset relatively early in life, such as depression, bipolar disease and schizophrenia.
3. More focus on physiology and pharmacology.



Torgny Svensson proposed that Europe needs to create a European Institute on Mental Health modelled on the US NIMH and NIDA to raise the profile and to obtain ring-fenced funding for mental health research.

Susanna Lindvall mentioned again the importance of raising awareness. She added that media in Sweden do not avoid brain topics but they focus on diseases other than those of the brain as such.

Ian Ragan presented several slides on the cost of brain disorders versus the amount of funding at the European level. Bo Ingemarson mentioned that in Sweden costs of brain diseases are 5 times bigger than those of cancer and yet brain diseases receive 5 times smaller funding.

Lars Farde described the focus of AstraZeneca research. In neurology, there is a large emphasis on Alzheimer's disease and multiple sclerosis, and an opportunistic interest on Parkinson's disease. In the mental health area, there is research in depression, schizophrenia (especially the cognitive impairment) and ADHD.

Susanna Lindvall urged everyone to officially form a Swedish Action Group. There was unanimous agreement and Aleksander Mathé was chosen as coordinator of the group. It was decided that the participants of the meeting will contact other scientists who might be interested in the initiative. They will be also mailed a list of people who were interested in the Swedish Action Group but couldn't come to the meeting.

Ian Ragan outlined a few examples of how the Swedish Action group could start working together to give greater priority to brain issues in Sweden. Among others he suggested that at the beginning, focusing on one issue can be a good starting point – for example, a survey, a jointly authored publication or a meeting.

The meeting ended at 15.00

T. Hawrot  
I. Ragan