



## **A meeting to consider setting up a Swiss Brain Council.**

A meeting to discuss the formation of a Swiss Brain Council (SBC) was held on 18 May 2011 at the National Science Foundation in Bern.

### List of participants

- 1 Prof. Beatrice Roth
- 2 Prof. Carmen Sandi
- 3 Prof. Christian Lüscher
- 4 Prof. Christoph Michel
- 5 Prof. Dominique Muller
- 6 Prof. Edith Holsboer-Trachsler
- 7 Prof. Jean-Marc Fritschy
- 8 Prof. Jürg Kesselring
- 9 Prof. Martin Hatzinger
- 10 Prof. Nicole Schaeren-Wiemers
- 11 Prof. Pico Caroni
- 12 Prof. Stephan Bohlhalter
- 13 Prof. Stephanie Clarke
- 14 Dr. Alastair Benbow (EBC)
- 15 Tadeusz Hawrot (EBC)

The agenda was as follows:

Chair: Dr. Alastair Benbow (EBC)

09.45 - Participants introduction

09.55 - European Brain Council: Background and aims; National Action Groups and National Brain Councils

10.40 - The situation of brain research and those affected by brain diseases in Switzerland - open discussion

11.40 - Conclusions and way forward



Alastair Benbow welcomed everyone and the introductory round of all the participants followed. Subsequently, he introduced the EBC, its main activities, goals, studies and strategy, giving a particular attention to EBC campaign to make 2014 the European Year of the Brain (EYOB).

Tadeusz Hawrot explained the concept of the National Action Groups and National Brain Councils.

Following the presentation, participants were invited to discuss if they see a need to form a Swiss Brain Council (SBC) and what could be specific issues that such an organization would address.

Participants agreed that there are a number of Swiss organizations that are already very active in the area of promoting brain research and brain diseases, especially the Swiss Society of Neuroscience. However, as much as they are involved in different spheres of activities, there are not many actions orientated at lobbying the government, as a result politicians are not giving enough attention to brain research and brain disorders.

A new law on prevention is currently being discussed in the Parliament and so far there has not been enough lobbying activities conducted in this regard.

Another advantage of establishing SBC is that it could give the opportunity to the whole brain community to speak in one voice.

Some time ago there was a somewhat similar occasion to bring together different brain related areas during the Swiss Decade of the Brain. It turned out to be a well used opportunity that created much more awareness about the brain. The EYOB could also become a promising opportunity to further increase public awareness and would create the possibility to actively involve SBC in a concrete project.

A similar process took place as well when the government requested to put together a national research programme. However, patients didn't benefit enough from this initiative. Currently politicians do not give enough priority and funds to patients and patient organizations neither.

Another issue that politicians should be addressed with is getting more government's involvement in mental health area. Most of the Swiss campaigns against depression are conducted and funded at the local (Cantonal) level. Attempts to get the government more involved have been less successful when a national campaign would be likely to be far more effective. Additionally, awareness should be raised among the policy makers so that diseases like depression or schizophrenia are actually perceived as brain disorders which is not always a case.

A question was raised how National Brain Councils are being managed in other countries and how do they use human resources. It depends from country to country. Ideally, upon the availability of funds, a dedicated person can do a part time work. In many national organizations however it is the dedication of scientist who commit some of their time and resources. The example was raised of the Belgian Brain Council where a few individuals are very actively involved in a number of campaigns. It turns out that Belgium ranks high among countries receiving international grants. Another way to be efficient is to use resources and expertise of already existing national associations that are members of a National Brain Council. It is important to add that these organizations will still mostly focus



on their particular objectives but at the same time can take it more to a general level. With a financial support from member organizations, a part time employee could be indeed hired in Switzerland.

Emphasis was also placed on the active involvement of patient groups. They are often very well organized and politicians tend to listen to them more attentively.

Industry participation has been brought up especially regarding the need to be completely independent from the industry on one hand and to show the benefits of supporting a SBC on the other. It can be done by arguments like aiming at improving the overall environment, without getting into specific diseases. For this, appropriate persons should be approached in pharmaceutical and medical devices industry, preferably not the marketing divisions but the ones who are responsible for overseeing a bigger picture. Also, it is beneficial to have many companies equally involved to avoid any imbalance and domination.

A question was asked on further interactions with the EBC and other NBCs once the SBC would be set up. Following the kick off meeting that EBC is attending, EBC also supports NBCs in various other ways such as sharing by-laws, constitutions, if needed attending further national meetings, organizing meetings of NBC/NAGs network in Brussels, inviting national organizations to attend Brain Policy Fora and National Days of the Brain. In October 2011 EBC is organizing a launch of an update of the study: Cost of Disorders of the Brain in Europe and will invite all the NBC/NAGs to attend it and to invite Members of the European Parliament from their countries (where applicable). EBC would like a Swiss representative to attend the meeting as well.

Another question was raised as to who should be a country representative. A grasp of public affairs as well as understanding science are desirable features. In practice, often it is a contact person, a coordinator, president or someone who is the most dedicated person.

In view of all these opinions participants once again agreed there is a need to create a new body in Switzerland that would tackle all these issues and to create an efficient and well balanced platform and interface between basic researchers, clinicians, patient organizations and politicians.

Following the discussion and decision to work towards setting up a Swiss Action Group/Brain Council, Prof. Jürg Kesselring offered to map patient organizations and contact them to see if they are interested to join the group, similarly with clinicians. Tadeusz Hawrot will provide Prof. Kesselring with the list of societies and persons that have been invited to the kick off meeting.

Further to that a discussion took place regarding setting up a steering group representing all the main fields. Several names were tentatively proposed and more will be investigated later. The proposed names so far were: Prof. Esther Stöckli, Prof. Pierre Magistretti, Prof. Martin Hatzinger. Prof. Kesselring was asked if he could play a coordinating role and accepted the proposal.

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