



## Working towards a Finnish Brain Council

A meeting to discuss the formation of a Finnish Brain Council (FBC) was held on 08 March 2011 in the Biomedicum Helsinki. Delegates of sixteen interested organisations attended the meeting.

1	Anne Teisseire	Uniliitto's assistant
2	Prof. Asla Pitkanen	Past Secretary General of FENS University of Kuopio, A.I. Virtanen Institute for Molecular Sciences, Department of Neurobiology
3	Prof. Eija Kalso	Pain Research and Management, University of Helsinki
4	Helena Noroila	CEO, The Finnish Parkinson Association
5	Hilkka Kettinen	Board Member of the Finnish Migraine Association
6	Prof. Irma Holopainen	Brain Research Society of Finland, President, Department of Pharmacology, Drug Development and Therapeutics, University of Turku
7	Prof. Jyrki Korkeila	President, Finnish Psychiatric Association
8	Prof. Juha Öhman	President, Finnish Neurosurgical Society
9	Prof. Markku Kaste	Helsinki University Central Hospital, Department of Neurology
10	Merja Rekola	Finnish Brain Foundation
11	Pentti Fri	Finish delegate of the International Restless Legs Syndrome Study Group
12	Prof. Pentti Tienari	Department of Neurology Biomedicum Helsinki, University of Helsinki
13	Prof. Reetta Kälviäinen	Chairman; Finnish Neurological Association; President, Finnish Epilepsy Association,
14	Prof. Reijo Salonen	Orion-Pharma
15	Riku Kivisaari	Neurosurgeon, Radiologist, University of Helsinki
16	Prof. Tuula Tamminen	President, European Society for Child and Adolescent Psychiatry, University and University Hospital of Tampere Child Psychiatry
17	Dr. Alastair Benbow	EBC Executive Director
18	Tadeusz Hawrot	EBC Project Manager



The following agenda was discussed:

Morning session:

- Participants introduction.
- European Brain Council: Background and aims, National Action Groups and National Brain Councils.

Afternoon session:

- The situation of brain research and patients affected by brain diseases in Finland - open discussion.
- Conclusions and way forward.

Tadeusz Hawrot (TH) opened the meeting and welcomed all. He explained its aims and structure. He thanked AP and MK for their invaluable input making the meeting possible. He also thanked RS, Orion-Pharma, for the financial contribution to the meeting.

Asla Pitkänen (AP) explained her role in meeting preparations.

Alastair Benbow (AB) was called in and presented. Presentation of all the participants followed. AB gave a presentation on the EBC, its aims, projects, focusing especially on the plans to have 2014 designated as the European Year of the Brain (EYOB).

Subsequently, TH presented the concept of National Brain Councils and National Action Groups and invited all to take part in the discussion on the specific Finnish issues that could be addressed by the Finnish Brain Council (FBC) and if such a council is needed at all.

Hilka Kettinen (HK) remarked that stimulating research constitutes a large part of EBC's activities and asked about the public health dimension of EBC's work. Tadeusz Hawrot referred to EYOB plans in which EBC would like to be very inclusive, making research just one of many themes to be addressed. Similarly, EBC has been paying increasing attention to other aspects of brain and public health.

AB added that when EBC was formed there was a need to increase modest resources allocation to brain research, however with time EBC has broadened its sphere of activities to many more areas such as patient access and education.

Markku Kaste (MK) listed mental disorders, Alzheimer disease and stroke as the most common brain diseases in Finland. Due to an ageing society it is very important emphasizing prevention in order to avoid future major economic problems.

According to Jyrki Korkeila (JK) the changing age structure will lead to increasing clinical and research interests among neurologists and psychiatrists. The elderly will be increasingly diagnosed with both psychiatric and neurological conditions.

TH welcomed the notion of closing the gap between neurologists and psychiatrists who in some other cases can also be competitive towards each other.



Pentti Fri would like to see a close cooperation of psychiatrists and neurologists, focusing on brain disorders.

Reetta Kälviäinen (RK) pointed out that Finland, being a small country, has many organizations related to brain in one way or the other so it might be a challenge to create FBC. At the same time it is important for the Finnish brain community to speak with one voice. The EYOB would be a good opportunity for FBC to get active.

AP added that while lobbying for particular brain diseases is important, it is even more important to lobby for the brain as a whole, if there will be no funds for overall brain research, there will be no funds for specific brain diseases either. Therefore, one of the main missions for the FBC would be to get the message across about the need to increase funding for brain research.

Also EK emphasized the importance of showing that FBC is not meant to focus on specific diseases but rather the brain as the centre and combining factor.

Further to this, according to MK, no member societies will lose their identity as the FBC is supposed to become an added value and an opportunity to work together, to be stronger and more influential.

TH complemented that the same rule applies to funding – the aim of FBC is not to take funding from its member organizations but to increase the overall funding for brain research.

HK brought to the attention of the participants that in addition to health and prevention, rehabilitation is very important and often overlooked in Finland.

There is also a need to take a good care of “Finnish brains” to be more competitive in the future, e.g. it will help with jobs that are becoming more demanding with time.

Juha Öhman (JÖ) called to pay more attention to children. Although the numbers are small when compared to diseases like stroke or Alzheimer’s disease, there are many pediatric conditions that are very often life-long lasting. Therefore, it is important not to forget about children and adolescents.

Irma Holopainen (IH) pointed out that the medical curriculum on basic brain diseases’ education at some Finnish universities is not on a sufficiently high level. One of the important tasks of the FBC would be to improve the awareness of brain diseases and education.

The level of neuroscience research in Helsinki is high but good units should also be created in smaller cities further from the capital.

Many instruments are already available but they need to be better seen and used, added Eija Kalso (EK). Complementary to lobbying for particular brain diseases, there should be activities to represent brain in general.

Reijo Salonen (RS) shared his experience of being involved for many years in EBC activities. He emphasized the need for common factors that can unite everyone. For EBC these were two major projects: the Cost of Disorders of the Brain in Europe study published in 2005 as well as the Consensus Document on European Brain Research published in 2006.



There has to be a tangible and concrete element combining everything that deals with brain, not only neurology, psychiatry etc. This is why it is also important that board members represent not themselves but their societies.

He added that EBC was created to respond to the European Institutions need to be able to speak with one institution representing academia, clinicians and patients involved in brain related research and other matters. At present, whenever EC is in need for general information concerning brain, it turns to EBC as it is much easier to deal with one organization rather than consulting a big number of organisations.

JK agreed there has to be a common goal and project identified to work on.

Merja Rekola (MR) saw “improving the quality of life” as a theme that unifies everyone. FBC can also enhance the cooperation between different groups.

MK added that in view of upcoming Finnish parliamentary elections FBC could try influencing the new government before financial plans for its term are made.

TH reiterated the importance of concrete data when speaking with politicians.

MK suggested encouraging Nokia to cooperate and announce ‘brain price of the year’.

A point was made about the need to learn more about lobbying activities from other organizations, e.g. in the area of stroke, Parkinson disease. This experience would benefit all different disciplines and brain as a whole.

MK said that brain disorders are more difficult to treat, are much more expensive, often cause early retirement and significantly decrease the quality of life of those living with brain diseases.

Education could be also an important field for FBC.

TH referred to the Belgian Brain Council that conducts regularly awareness campaigns among students in Belgium, recent one concerned addictions.

JÖ informed the participants that in Finland 15-20 thousand head injuries are registered every year. An element that should be taken into account as well.

AP seconded this observation adding that, being familiar with this area, there is a lot to do when compared to the US.

AP asked about the most costly brain diseases in Finland and expressed her interest in the cost study.

MK added that a lot of data are available yet as Finland has traditionally paid a lot of attention to gathering objective data.

EK expressed her concern that it is sometimes difficult to compare costs as different methodologies are applied in different countries.

Pentti Tienari (PT) emphasized importance of speaking with one voice, to focus on how the brain functions and at the same time not to lose interest in the bigger picture.



After the lunch break, TH gave a short presentation on the administrative aspects of the Belgian Brain Council. He also gave examples on concrete tasks identified as a result of similar kick off meetings in different countries.

AP asked who would be in favor of setting up a FBC as a legally constituted organization, as opposed to a NAG. The great majority of participants preferred to officially constitute a FBC.

MK stressed the importance of setting up a task force/steering committee which will effectively form the nucleus of the FBC. The committee should have no more than 6-8 members. He asked for candidates from the group.

HK asked if there is a need for the steering committee to be formed merely by presidents of national societies. TH explained that in some countries societies appoint substitutes.

MK agreed that it is not crucial to have presidents as long as there is a representative that reports to the president. He reiterated the importance of setting up a task force at the current meeting in order ensure continuity to this initiative, adding that it would be beneficial to achieve concrete actions before summer break.

He raised the issue of FBC bylaws. EBC bylaws and constitution will be provided to help writing the FBC's.

PT remarked that there is the Finish Brain Research Society and suggested it could be expanded instead of creating a new body.

According to AP this organization typically represents basic research whereas it is important to have a balance between all different brain disciplines and groups.

RS saw industry's participation as important but suggested that the participation of an industry delegate in the FBC's steering committee should be discussed. Participation of an industry delegate will be discussed by a committee.

Patients' organizations participation was discussed and AP stressed the importance of their involvement. RK pointed out that while thinking of involving patient organizations, FBC has to be something more than merely an organization lobbying for more funds to brain research.

AP suggested drawing up a list of organizations that should be involved.

The leadership of the Steering Committee was discussed. AP's name was put forward as she presently holds a neutral position.

MK remarked that it is important to ensure continuity in leadership as the simultaneous overturn of a majority of steering committee members very often results as counterproductive.

TH suggested that the creation of a FBC would be a good occasion to issue a news release to the national media. This will create an opportunity to actively involve major Finnish societies having expertise in working with the local media.

MK added that brain ambassadors could be a fast track to the media and that this kind of action can be very useful at a later stage.

TH was asked to send the slides presented at the meeting.



RS offered to host the next working meeting of the group in one of the Orion Pharma offices.

The following persons were discussed in the context of the steering committee and will be present during the next meeting that will take place on the 28<sup>th</sup> March:

Asla Pitkänen (coordinator of the meeting)

Brain Research Society of Finland    Irma Holopainen

Finnish Neurosurgical Society        Juha Öhman

Finnish Neurological Society         Reetta Kälviäinen

Finnish Psychiatric Society            Jyrki Korkeila

Representative of Pharma Industry from Orion

Representative from a patient organization for psychiatric diseases - Tiina Johansson

Representative from a patient organization for neurological diseases - Sari Tervonen

TH