

EBC Progress Report January – April 2010

The EBC's 2010 Work Plan focuses on the priority areas in the diagram below, linked by the overarching theme of the European Year of the Brain in 2013. Progress on these themes will be reported every 4 months.

Ian Ragan/Evelyn Sipido/Tadeusz Hawrot



Consensus document revision

targeting FP7 and FP8 funding

Cost of brain disorders revision

targeting FP8 and member state priorities

Psychosocial factors relevant to brain disorders in Europe (PARADISE)

FP7 research project

establishing role of EBC as partner for dissemination

European Brain Policy Forum

gaining broad exposure to policy makers and media

building relationships with patients and patient groups

National Action Groups and National Brain Councils

helping build member state support

targeting Presidential priorities

establishing influence in European Parliament

UNIFYING THEME
EYOB 2013

European Year of the Brain 2013

The first part of this year has been spent in getting information and gathering support for EYOB 2013. The proposal was formally adopted at the EBC Board Meeting in February following discussions at the end of 2009 to focus on the Polish EU Presidency in the second half of 2011 to gain formal approval for the idea.

The outline timetable calls for a Commission proposal to be approved by a co-decision of the Parliament and Council in 2011, followed by planning in 2012 and launch, perhaps during the Irish Presidency, in 2013. The proposal was discussed with Eschel Alpermann, Team Leader Internal Policies, Cabinet of the President of the European Parliament, Jerzy Buzek, and a further visit will take place in May.

Meetings have been taking place between the EBC and the Professor Grzegorz Opala (Polish Brain Council) and with the Deputy Minister, Ministry of Science and Higher Education in Poland, Professor Jerzy Szwed. President Buzek has reiterated to Prof. Szwed and Prof. Opala his full support for the EBC initiative to declare EYOB 2013 and confirmed that issues related to brain diseases and brain research will be included in the Polish priorities. Subsequently, the Polish Ministry of Health has included a reference to the need to increase research in relation to neurodegenerative diseases in the Social Policy and Health section of their draft Presidential priorities.

In addition, there has been considerable discussion about holding a conference, the 4th European Brain Policy Forum, in Warsaw, during the EU Presidential term. Working with the Polish Brain Council, we have tentatively agreed on the topic – a one day meeting on stroke with an emphasis on rehabilitation and the social and economic consequences. Contacts have been made with the Polish Ministries of Research and Health.

Hungary has the EU Presidency in the first half of 2011 and we are delighted that they are including neuropsychiatric disorders as a priority. There will be a planning Workshop in Budapest in early May. We hope also to gain Hungarian support for the EYOB 2013. In addition, we have discussed the idea with Irena Szendrak, Director of the Hungarian Academy of Sciences Contact Office to the EU (HunASCO) and Secretary of IGLO - an informal association of Brussels-based non-profit R&D Liaison Offices.

We have been building support and awareness amongst European Parliamentarians, including Professor Antonio Correia de Campo, MEP, who is a former minister of Health in Portugal and currently a member of the ITRE Committee, and Paul Rubig, MEP, the chair of STOA and also an ITRE committee member. In May, we will meet the chair of ITRE, Herbert Reul.

Of vital importance to the campaign is gaining the support of the European Commission. The appointment of the new Commissioners has meant the loss of some of our old supporters and delayed our progress. However, a good start was made recently when Mary Baker (Vice President, EBC) and John Bowis (Honorary Member, EBC) met the Commissioner for Research, Maire Geoghegan-Quinn, to ask for her support for EYOB 2013. The meeting was constructive and positive, and the Commissioner has promised to look into what is involved and to bring the idea to the attention of her fellow Commissioners.

Consensus Document Revision

The Consensus Document for Brain Research in Europe has been one of the most influential of the EBC's projects. Published in 2006 (*J. Neurol. Neurosurg. Psychiatry* 2006;77(Suppl I):i1–i49), the paper contained 45 research themes in seven chapters covering the agreed views of authors across Europe on the priorities for brain research. The document has been used extensively by the European Commission to select topics for funding in the 7th Framework Programme (FP7) and has also been influential at member state level in setting national priorities.

Research moves on, and a revision of the document was urgently needed in order to help the Commission in the later years of FP7 and also in FP8. The revision started in late 2009 and is now well underway.

During the first quarter, the list of writers of the seven chapters and themes was updated with the help of the EBC member organisations. New names were added to the existing writing groups where needed. By the end of the first quarter, around 60% of the revised themes had been received and we have set a deadline of 1st May for receipt of the remainder.

This revised document will be a major achievement for the EBC in 2010 and we propose to launch it during the FENS Forum in Amsterdam in the first week of July.

Cost Document Revision

The study on the cost of brain disorders in Europe, published by the EBC in 2005, has also been critically important to the success of the EBC's campaign. This was a landmark study which resulted in over 40 publications of European, national and disease-specific data and has been widely used and cited. Most importantly, it was instrumental in having brain research specifically highlighted in FP7, contributing to the huge increase in brain research funding in FP7 compared with previous programmes.

The study focused on 12 major diseases, whose annual cost to the European economy (€386b per annum) was estimated to be equal to that of cardiovascular disease and cancer together. However, we know that this is an underestimate for several reasons. First, several cost parameters were missing because of lack of data (for example, the indirect costs of psychotic disorders and brain trauma). Second, many diseases were missing (e.g. neuromuscular disorders, sleep disorder, developmental disorder including ASD, mental retardation, eating disorders and personality disorders). Thirdly, data on the previous 12 diseases need updating. A conservative estimate is that these factors would add €200bn per annum to the previous estimate.

The EBC has therefore undertaken to revise and expand the Cost study which is now underway thanks to generous financial support from H. Lundbeck A/S and the ECNP.

Under the leadership of Jes Olesen (Past President, EBC), Bengt Jonsson (Stockholm School of Economics) and Hans-Ulrich Wittchen (Technical University of Dresden), the project is now well advanced with the recruitment of disease experts and health economists. The first of two major meetings will be held on May 6 and 7 for approx. 40 participants.

The role of the EBC organisation and staff is administrative in 2010 and 2011, during which we will see the completion of the main study. Their role in the subsequent two years will be in the national dissemination of the results through publication in national journals.

This year the EBC has been involved in the organisation of the May meeting in Nice, including preparation of the agenda, invitations, booking of hotels and meeting facilities, and defining the reimbursement policy.

The meeting organisation is now finalised and the list of participants is complete. Last minute documents have been circulated.

PARADISE

PARADISE, Psychosocial Factors Relevant to Brain Disorders in Europe, is a new coordination action funded by the EC through FP7, having the goal, over three years, to coordinate the development of a comprehensive and cross-cutting or horizontal epidemiology of those psychosocial difficulties.

The EBC, which is one of 10 partners in the project, is responsible for creating and maintaining the PARADISE website, devising a dissemination plan and ultimately, disseminating the results. It will also organise a meeting of stakeholders whose goal will be to present those results to the scientific and policymaking communities.

The kick-off meeting for PARADISE took place in late January in Munich and established an agreed timeline for future work. It called for the early completion of two major activities for which the EBC was responsible.

The first was to create a PARADISE website. A draft of the PARADISE website was completed and approved by the project coordinator and used in discussions with various providers to employ a webmaster. A mock-up of the template design has been prepared by the webmaster, along with the detailed explanation of its operation and functionality and this has been passed to the project coordinator for comments, ahead of the required deadline.

A more challenging task has been to create the PARADISE dissemination plan. The first draft of the plan and the database for dissemination was completed in February and March. After feedback from the project coordinator, the final version was sent to the PARADISE partners on the agreed deadline.

In addition, a press release to the scientific community, and the PARADISE information brochure have been drafted. Both have been submitted to the project coordinator for comments.

European Brain Policy Forum

The beginning of the year was very busy with planning for the 3rd EBPF on A Focus on Schizophrenia and the European Society held in Madrid on February 23/24th. The EBC was responsible for the European media campaign. Working with our media consultant, a press release was circulated to the major European media (45 science journalists from 32 media in 16 countries), and we had two articles in the Parliament magazine which appeared on the day before the meeting itself. Frieda Brepoels, MEP, agreed to write a perspective on mental health from the EU perspective to complement an article on schizophrenia written by Professor Celso Arango.

The conference itself went very well with excellent talks and good quality discussion. The final session was devoted to agreeing some key points for the revision of the Consensus Document mentioned above. These were included in the EBC's March newsletter article on the EBPF and the final agreed version went to the Consensus Document writing team. The same key points were made in a final communication to the journalists summarising the output of the meeting.

Finally, the meeting report has been completed and will be put on the EBC website. We hope to publish a version in a European journal in due course.

For the future, we would like to have some kind of Brussels- based event again, but the discussions that have gone on between the EBC and Poland have resulted in a strong movement to co-organise a meeting in Poland during the Polish EU Presidency as described above under the European Year of the Brain.

National Brain Council and National Action Groups

The priority for this project is to help establish groups in those countries that will have the European Presidency in the coming years. Ireland is important because it will have the Presidency in 2013, the target year for the EYOB.

The meeting to consider launching an Irish National Action Group or National Brain Council was held in the European Union House in Dublin on the 9th March. The participants were very much interested in the EBC plans to declare the EYOB, particularly in view of the fact that it could coincide with the Irish EU Presidency. The participants agreed therefore to form an Irish Brain Council. The meeting was preceded by a conference organized by the Neurological Alliance of Ireland in the framework of Brain Awareness Week during which the EBC gave a presentation on the status of brain research at the European level.

Greece will not have the EU Presidency until the first part of 2014, but is a member of the trio of Presidencies that includes Ireland and Lithuania. Consequently, the EBC is keen for a group to form in Greece, and a kick-off meeting of the Hellenic Action Group for Brain (HAG) took place in the Athens University Club on the last day of March. After a very constructive discussion, the participants agreed on many concrete actions such as developing a press release about the formation of the HAG, drafting a series of articles and conducting several meetings with governmental representatives

The one country missing between now and 2014 is Denmark which has the EU Presidency in the first half of 2012. Contacts have been established and a list of possible invitees has been drawn up for a meeting in Copenhagen, preferably in the first half of this year.

Although these countries are our immediate priorities, we wish to visit all the remaining EU and EU-associated countries in the next two years. In this regard, Israel has expressed interest and we are in the process of identifying someone to act as a lead for a first meeting.