



European Brain Council

Dialogue

Projects

Policies

**MAKE 2013 THE EUROPEAN  
YEAR OF THE BRAIN**

## European Brain Council Work Plan 2010- 12

### 1. The mission statement of the EBC

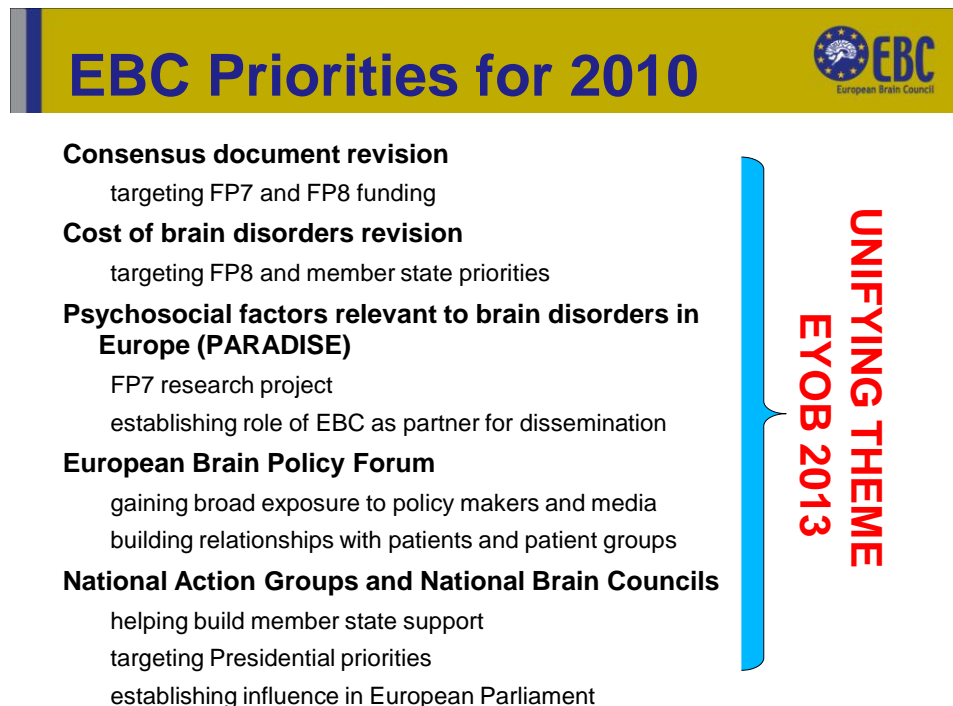
“To promote brain research in Europe and to improve the quality of life of those affected by brain diseases”.

This will be achieved by:

- Collaborating with our member organisations
- Interacting with the European Commission, European Parliament and other relevant EU and international organisations
- Promoting education in brain related topics
- Disseminating information about brain research and brain diseases in Europe
- Promoting dialogue between scientists and society

### 2. Priorities for 2010

This figure summarises the five main priority areas for 2010 and the unifying theme of the European Year of the Brain in 2013

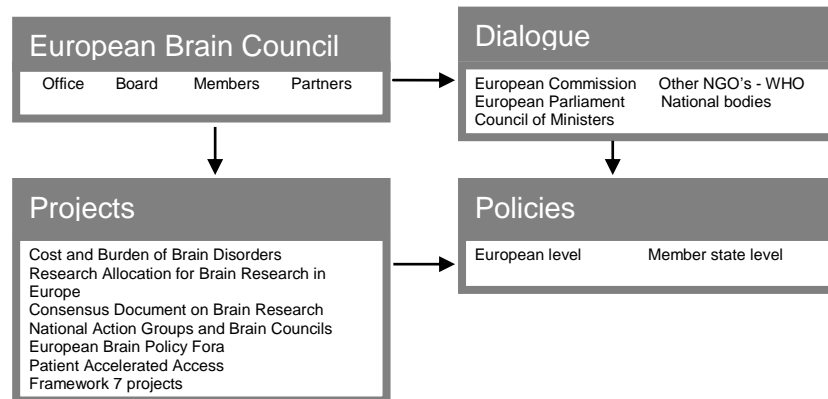


### 3. How the plan will aid the mission

#### 3.1 Dialogue

During 2009, the plan to link activities in the member states to our own work in Brussels really gathered momentum, and gained focus as the National Brain Councils (NBC's) and National Action Groups (NAG's) began to work with the EBC to drive home our messages. The year 2009 was an important one for the European Union with the creation of a new Parliament and a new Commission whose work has really only just started, and the implementation of the Lisbon Treaty. The EBC therefore has much to do to re-establish links and open dialogue with the many new faces on the European political scene. We are encouraged by the information published by the European Commission on the funding of brain research in the first

three calls of FP7. The contrast with FP6 is dramatic. Brain research funding in these calls plus that committed to the first call of the Innovative Medicines Initiative is over €400m compared with €260m in the whole of FP6. The percentage of the health budget devoted to brain research has doubled. Furthermore, the momentum created by the French Presidency has resulted in the initial planning of a European-wide project to combat Alzheimer's disease using the newly-invoked instrument of Joint Programming. If this is successful, it could become much more widely used in FP8, and the EBC hopes to become involved in the detailed planning of the project and the creation of its Strategic Research Agenda.



Clearly, then our task in 2010 with the new Commissioner for Research is to ensure that this wonderful progress is maintained (at the very least), especially as discussions get underway about the form and content of FP8. Our focus will be as it was in 2009 on the member states who ultimately decide the agenda and priorities of the European Commission, as well, of course, their own national policies. Post-Lisbon, the European Parliament has more power and we have already seen how the existence of National Action Groups and National Brain Councils helps us to gain the interest of European Parliamentarians and the Permanent Representatives of the member states in Brussels. In 2009 we focussed on those countries that held or had recently held the Presidency (France and Sweden, but also Estonia). In 2010 we will look much further ahead in the hope of influencing the priorities of future Presidential agendas. So while we will engage with Spain and Belgium through joint activities with their National Brain Councils, we will continue our discussions with Hungary and Poland for 2011, and initiate talks with Denmark, Cyprus (2012) and Ireland and Lithuania (2013). It will be our aim to ensure that all these countries have NAG's established well in advance of their Presidencies and since Poland, Hungary and Cyprus are already in place, we aim to visit Denmark and Ireland (among other countries) as high priorities in 2010. Poland is a particular focus for us since it is the first country of a new trio of Presidencies and therefore a key target for prioritising aspects of brain research.

In February 2010, the 3<sup>rd</sup> European Brain Policy Forum - A Focus on Persons with Schizophrenia and the European Society - took place in Madrid, jointly organised with the Spanish Brain Council. This was an experiment to see whether organising the meeting in the country that holds the Presidency gains greater political traction and exposure than holding it in Brussels. If this is judged a success, then during 2010 we will plan for a meeting in 2011 in either Hungary or Poland, and possibly jointly organised with both countries. ,

Looking out as far as 2013 needs a unifying theme, a goal that will sustain momentum and interest for the EBC and those whom it addresses – the patients, the scientists and the policymakers. In 2009 we started thinking about a European Year of the Brain and we have

learned during the year what a really enormous task this is. Our efforts have been delayed by the changes to the European Commission and Parliament, and therefore in 2010 our main goal will be to gain the support of major individuals and institutions in Europe, to define exactly what we wish to achieve and how it will benefit Europe, and to launch a campaign aiming at Council approval during the Polish Presidency in 2011 and implementation in 2013, the first available year. A draft plan of the campaign is included as Appendix 1.

### **3.2 Projects**

The EBC's most powerful tool for influencing policy will continue to be its project work. The EBC's unique ability to bring all stakeholders together gives great power to its voice as already shown by the influence it has had over FP7. The landmark studies that the EBC has produced on the burden and cost of brain diseases have been widely publicised and our Consensus Document on European Brain Research has been extensively used by the European Commission for setting topics for research. Therefore, to maintain this influence we must ensure our information is up to date. The revision of the Consensus Document is already in progress and as soon as it is completed, it will be passed to the Commission (who are enthusiastic to see it) to help set priorities for brain research in the 5<sup>th</sup> and later calls of FP7. A much more ambitious project is to update and expand the study on the Cost of Disorders of the Brain in Europe. This project, newly initiated through the generous support of Lundbeck and the ECNP, will take two years to complete and will contain information on six new diseases as well as an update of the previous twelve. The new data will be available for us to substantiate our arguments for a higher priority for brain research in FP8 and in the health and research policies of the member states.

Our application to the Commission for funds for a pilot field study to fill gaps in our knowledge of the cost and burden of brain diseases was unsuccessful, although ours was the highest ranked application. The possibility of the Commission reissuing the call topic is slight but we will continue to encourage them to do so. However, we had greater success as a partner in a consortium funded by DG Research to look at psychosocial aspects relevant to brain disorders in Europe. The wonderfully named PARADISE consortium has its first meeting in January 2010 and the EBC's role will be mainly concerned with dissemination activities and assisting in convening a stakeholders' conference.

The National Brain Council project, as explained above, has now become one very important arm of our strategy with European policymakers. However, we cannot ignore the fact that nearly half of the EU member states still do not have either NAG's or NBC's and, funding permitting, it is our intention to encourage their formation in the remaining countries and EU-associated countries within the next three years.

### **3.3 Policies**

The primary function of the EBC will continue as before to bring the results of its work to the attention of policymakers and to influence policy at European level (Framework funding, education and training needs, guidelines for best practice, inequalities in access to treatment) and at national level (national research policy and funding for brain research, access to treatment, education and training needs, adoption of best practice). Last year, our approaches to policymakers became more refined and focussed as we began to understand where our limited resources could be most effective. Our interactions with the Permanent Representations and member state Science Contact Agencies have been particularly useful and it is through them that in collaboration with the National Brain Councils and National Action Groups we hope to influence the Presidential priorities. The European Year of the Brain and its attendant policy aims and declarations will become our main rallying point during the coming three years.

## 4. Successes in 2009

The main successes and most important events of 2009 were as follows:

- New data on brain research funding in FP7 show greatly increased investment compared with FP6
- The President of the EBC, Julien Mendlewicz, and EBC staff met the President of the European Parliament, Jerzy Buzek, to discuss the European Year of the Brain and the priorities of the future Polish EU Presidency.
- EBC representatives met Commissioner Janez Potocnik, members of his Cabinet and Dr Ruxandra Draghia-Akli, the Health Director in DG Research. Several meetings were also held with other Commission staff to discuss priorities for brain research.
- EBC Staff met members of the Permanent Representations of Hungary, Poland, Spain and Sweden.
- Funding was received to start the revision of the study on the Cost of Disorders of the Brain in Europe.
- EBC Officers and Staff participated in several meetings of European organisations including the ITRE and STOA committees of the European Parliament, the European Regions Research and Innovation Network, Brains 4 Brain, the DG SANCO Panel of European Experts on Joint Programming Initiative for neurodegenerative diseases, and the Swedish Presidential Conference on European Research.
- Merck Serono and Johnson & Johnson agreed to join the industrial partners of the EBC, but because of changing priorities, UCB, Noscira and Wyeth resigned.
- The European Societies of Neuropsychology (ESN), the European Federation of Associations of Families of People with Mental Illness (EUFAMI) and the European region of the International League Against Epilepsy (ILAE) were admitted as Observers to the EBC Board.
- Philip Busquin MEP and John Bowis MEP were made Honorary Members of the EBC in recognition of their unfailing support and enthusiasm.
- The 2nd Brain Policy Forum "A Focus on Depression & the European Society" was a great success and received excellent reviews from the participants. Planning is complete for the 3<sup>rd</sup> EBPF on A Focus on Persons with Schizophrenia & the European Society to be held in Madrid.
- Meetings to set up National Action Groups were held in France, Estonia and Sweden, and the Spanish Brain Council was formally instituted two years after setting up the Spanish National Action Group.
- Delegates of the National Action Groups and National Brain Councils met in February and again in September when they formed the Network of NAG's and NBC's and elected two Observers to the EBC Board.
- Tadeusz Hawrot joined the EBC as Project Manager at the beginning of June

## 5. The Action Plan

The Action Plan is built upon the five critical areas of action in Section 1. The purpose of the plan is not only to document those activities that will be undertaken by the EBC over the next 3 years but also to show how they will contribute to the mission of the EBC and meet the aspirations of its member organisations and partners. The following sections describe activities under each of these headings.

### 5.1 Collaborating with our member organisations

#### 2010 Objectives

- The EBC will continue to look for opportunities to expand our membership and we will encourage the organisations that joined as Observers to become Associate Members where appropriate.

- The EBC will seek to expand its group of industrial partners and will implement measures to ensure better communication of EBC achievements to help attract support.
- The EBC will maintain its informal interaction and information exchange with EFPIA.
- The EBC website will continue to change incrementally with addition of new pages and information, including a new Alerting Service, in order to improve communication to our members about EBC activities. The EBC Wikipedia webpage will be put online.
- The EBC will continue to participate in the main meetings of our member organisations and welcomes invitations. In 2010, the EBC will organise joint symposia with the EPA at the EPA Congress in Munich and with FENS at the 7<sup>th</sup> FENS Forum in Amsterdam. The EBC will organise a one day meeting in the EP with B4B on rare neurological diseases of childhood.
- The EBC will build on its successes in encouraging the establishment of National Action Groups (NAG's) and National Brain Councils (NBC's) and will target Denmark, Greece, Finland, Ireland, Switzerland, and the Netherlands for creation of NAG's, and Poland for transforming its NAG into an NBC. The number of countries approached will depend on the level of sponsorship received. The most important are those that will hold the EU Presidency in the near future; Denmark and Ireland.
- The EBC will host an Annual Meeting of the Network of NBC's and NAG's.

*EBC Requirements for item 4.1:*

*Core funding for its staff, office and operational costs*

*Sponsorship of the establishment of National Action Groups and Brain Councils*

*Sponsorship of the Annual Meeting of the Network of NBC's and NAG's*

## **5.2 Interactions with the European Commission, European Parliament and other policy makers**

### 2010 Objectives

- The EBC will continue to campaign at multiple levels for an increase in the proportion of research funding allocated to brain research and brain disease. Meetings will be arranged with the new Commissioners for Research and for Health as the highest priority.
- The EBC will continue the involvement of our members in SANCO activities e.g. the Expert Panels on Alzheimer's disease and Autism Spectrum Disorders and the Thematic Conferences on Mental Health.
- The EBC will host a lunch meeting in the EP between the leaders of the Network of NAG's and NBC's and their MEPs to launch the revised Consensus Document on European Brain Research.
- The EBC will continue its parliamentary campaign through meetings with MEPs, in particular members of the ENVI and ITRE Committees and the STOA Panel.
- The EBC will continue its discussions with the Scientific Counsellors of the Permanent Representations in Brussels, and the Science Agencies of the member states and regions.
- The EBC will prepare position papers on issues important to the European institutions and our members.
- The EBC will develop its strategy to launch a European Year of the Brain in 2013/14 focussing on Hungary and Poland as the key countries to support a co-decision in 2011.
- The EBC will initiate a strategy to make brain research a priority in FP8.
- The EBC will hold a dinner or dinners to award three new Honorary Memberships of the EBC.

### 2011 Objectives

- The EBC will aim to have brain research as a priority of the Hungarian and Polish Presidencies.
- The EBC will seek co-decision of the EP and Council to declare a European Year of the Brain.

#### 2012 Objectives

- Planning and preparation for the European Year of the Brain.

#### *EBC Requirements in 2010 for item 4.2:*

*Core funding as for item 4.1.*

*Sponsorship of EP lunch for the Network of NAG's and NBC's*

*Sponsorship of dinners for new Honorary Members*

*Sponsorship of activities related to the EYOB*

### **5.3 Promoting brain health and brain-related education**

#### 2010 Objectives

- The EBC will plan a workshop with EMSA and other student organisations to plan an application to the Life Long Learning Programme of DG Education and Culture for an e-learning project.

#### 2011 Objectives

- A future project will analyse best models of clinical care and research centres
- The EBC plans to initiate a project on ethics of brain research (possible collaboration with the King Baudouin Foundation)

#### *EBC Requirements in 2010 for item 4.3:*

*Core funding as for item 4.1*

*Sponsorship of the workshop on e-learning*

### **5.4 Disseminating information about brain research and brain diseases in Europe**

#### 2010 Objectives

- Expansion of the website as a data source and communication medium will continue.
- The EBC will complete updating the Consensus Document on European Brain Research.
- The EBC will participate in the revision and expansion of the study of the Cost of Disorders of the Brain in Europe.
- The EBC will publish an analysis of brain research funding in FP7.
- The EBC will participate in the PARADISE project (psycho-social aspects relevant to brain disorders in Europe)
- The EBC will revise and reprint its publicity materials as necessary.

#### 2011/12 Objectives

- Completion and dissemination of the revised Cost study.

#### *EBC Requirements in 2010 for item 4.4*

*Core funding as for item 4.1:*

*Sponsorship of the revision and dissemination of the Cost study*

*Sponsorship through Framework funding of PARADISE*

*Sponsorship of the revision and reprinting of publicity materials*

### **5.5 Promoting dialogue between scientists and society**

#### 2010 Objectives

- The EBC will continue its European Brain Policy Fora on this theme. The third such meeting - A Focus on Persons with Schizophrenia and the European Society - was held in Madrid in Feb 2010 for 100 participants drawn from the entire community of the EBC's members (scientists, medics, patients and industrialists) and with the participation of policy makers and the media.

2011 Objectives

- The EC will consider organising the 4<sup>th</sup> European Brain Policy Forum in Hungary or Poland, perhaps jointly with both countries. A possible topic under discussion is Brain Rehabilitation in Stroke.

*EBC Requirements in 2010 for item 4.5:*

*Core costs as for item 4.1*

*Sponsorship of the European media campaign for the 3<sup>rd</sup> EBPF and dissemination of the outcomes*