



## **WORKING TOGETHER**

TO PROMOTE BRAIN RESEARCH IN EUROPE  
AND TO IMPROVE THE QUALITY OF LIFE  
OF THOSE AFFECTED BY BRAIN DISEASE



## PRESIDENT'S MESSAGE

The EBC was officially founded on 22 March 2002 in Brussels. It is a coordinating council formed by the major European societies for neurology, neurosurgery, psychiatry and basic brain research (neuroscience), as well as patient organisations and industry.

It is a unique structure that therefore encompasses a vast network of patients, doctors and scientists, working in partnership with the medical devices and pharmaceutical industries. The EBC's comprehensive scope makes it eminently suited to working closely with the European Commission, the European Parliament and the World Health Organization (WHO), as well as other decision-making bodies.

*The mission of the EBC is to promote brain research in Europe and to improve the quality of life of those affected by brain diseases.*

## WORKING IN PARTNERSHIP



**The 7th Framework Research Programme of the EU has given prominence to brain research.**

The EBC offers information and advice to European institutions in order to help ensure that the implementation of brain research is in line with the perspectives of scientists and patients and with the written text of FP7.

**These are the most widespread brain diseases in Europe and together they affect more than a quarter of the European population:**

- Anxiety
- Brain tumours
- Chronic pain
- Dementia
- Epilepsy
- Migraine and other headaches
- Mood disorders (depressive and bipolar disorders)
- Multiple sclerosis
- Parkinson's disease
- Psychotic disorders
- Stroke
- Traumatic brain injury

**These and many other brain diseases should be major priorities for European Research Policies.**

To achieve this, the EBC has a strategy involving five separate spheres of activity:

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

**Through cooperation with other European and national organisations, the EBC aims to:**

- Address fragmentation in European brain research
- Attract young people to work in brain research
- Attract more investment in brain research
- Bring science and society closer together to involve patient organisations

## PARENT ORGANISATIONS



The European Brain Council was founded by a group of distinguished researchers and patient advocates who have subsequently expanded their membership to include all the major stakeholders in European brain research.

The membership of the EBC consists of professional organisations, patient organisations and industrial partners. The EBC's ordinary members are Europe-wide organisations with an interest in the brain. They have voting rights on the Executive Board. Only one ordinary member is permitted for each major field of interest.

Any other organisation that supports the aims of the EBC can apply to become an associate member. Associate members have no voting rights but otherwise share the status of ordinary members. Organisations or individuals that have contributed in an outstanding fashion to the aims of the EBC can also become honorary members.

### PROFESSIONAL ORGANISATIONS

#### THE EUROPEAN FEDERATION OF NEUROLOGICAL SOCIETIES (EFNS)

The European Federation of Neurological Societies unites and supports neurologists across the whole of Europe. Currently over 40 European national neurological societies are registered members of the EFNS.

<http://www.efns.org/>

#### THE EUROPEAN ASSOCIATION OF NEUROSURGICAL SOCIETIES (EANS)

The European Association of Neurosurgical Societies is a supranational and independent association of national European neurosurgical societies.

<http://www.eans.org/>

#### THE EUROPEAN COLLEGE OF NEUROPSYCHOPHARMACOLOGY (ECNP)

The European College of Neuropsychopharmacology, which was established in 1987 on the initiative of European scientists working in the field of neuropsychopharmacology, aims to encourage research and facilitate communication of ideas in the convergent disciplines.

<http://www.ecnp.eu>

#### THE EUROPEAN PSYCHIATRIC ASSOCIATION (EPA)

The European Psychiatric Association has members in 57 countries. Founded in 1983, the EPA was granted by the Council of Europe a consultative status in 1989 and a participating status in 2003. The mission of EPA is to improve the quality of mental health care throughout Europe.

<http://www.aep.lu/>

### **THE FEDERATION OF EUROPEAN NEUROSCIENCE SOCIETIES (FENS)**

The Federation of European Neuroscience Societies represents a large number of national European neuroscience societies and several monodisciplinary societies. FENS was founded in 1998 at the Forum of European Neuroscience in Berlin and is the successor organisation of ENA, the European Neuroscience Association.

<http://www.fens.org/>

### **THE EUROPEAN ACCREDITATION COMMITTEE IN CNS (EACIC)**

The European Accreditation Committee in CNS promotes and encourages the development of Continuing Medical Education in CNS, mainly psychiatry and neuropsychopharmacology, throughout Europe.

<http://www.eacic.org>

### **THE FEDERATION OF EUROPEAN PSYCHOPHYSIOLOGY AND COGNITIVE NEUROSCIENCE SOCIETIES (FEPSCO)**

The Federation of European Psychophysiology and Cognitive Neuroscience Societies promotes research and teaching in psychophysiology throughout Europe.

<http://www.fepsco.eu>

### **THE BRAINS FOR BRAIN FOUNDATION (B4B)**

The Brains for Brain Foundation is dedicated to the study of neurodegenerative lysosomal storage diseases. The Foundation was created in 2008 from a European task force of experts in these diseases.

<http://www.brains4brain.eu>

## PARENT ORGANISATIONS



### PATIENT ORGANISATIONS

#### THE EUROPEAN FEDERATION OF NEUROLOGICAL ASSOCIATIONS (EFNA)

The European Federation of Neurological Associations brings together European umbrella organisations of neurological patient advocacy groups to work with other associations in the field of neurology, including the European Federation of Neurological Societies (EFNS). It has been termed a “Partnership for Progress”.

<http://www.efna.net/>

#### THE GLOBAL ALLIANCE OF MENTAL ILLNESS ADVOCACY NETWORKS-EUROPE (GAMIAN-EUROPE)

The Global Alliance of Mental Illness Advocacy Networks – Europe is a federation comprising users and consumers, family members, carers, healthcare professionals, representatives of government bodies and agencies, and other parties who support or are interested in issues affecting those who suffer from a mental illness.

<http://www.gamian.eu>

### INDUSTRIAL PARTNERS

The pharmaceutical industry in Europe does not have a representative body for research on treatments for brain diseases. The EBC has therefore created a panel of industrial partners from the pharmaceutical and other sectors.

**The EBC has more than 20 industrial partners from all different EU countries ranging from small to large companies.**

### OBSERVERS

EBC Board has Observers representing the World Health Organization (WHO), the European Federation of Associations of Families of People with Mental Illness (EUFAMI), the Federation of the European Societies of Neuropsychology (ESN) and the Network of National Brain Councils and National Action Groups.

### THE EXECUTIVE BOARD

The ordinary member organisations each provide two delegates to the Executive Board. The Executive Board delegates are appointed by their member organisations.

The industrial partners collectively elect four industrial representatives to the EBC Executive Board, two from the pharmaceutical industry and the others from the medical devices sector.

These delegates are prominent figures in their respective fields and drawn from several different European organisations. They provide the EBC with a unique perspective that is truly European in scope.

**Details of the membership of the EBC Executive Board members, Observers and Administrative Staff can be found in the pocket at the back of this document.**



## OUR PROJECTS



The EBC endeavours to involve all its member organisations in its projects so far as is possible. The EBC leadership appoints members of project groups, often after advice from member organisations. This way of working allows the EBC to find the best-suited experts throughout Europe be they doctors, basic scientists or expert patients.

Publications from our projects are available to be downloaded from our website [www.europeanbraincouncil.org/publications](http://www.europeanbraincouncil.org/publications)

### **COST OF DISORDERS OF THE BRAIN IN EUROPE (CDBE)**

On 26 April 2005, the EBC announced the results of a pan-European project it conducted in partnership with Stockholm Health Economics to analyse for the first time the cost of all brain disorders in Europe.

The CDBE study took into account healthcare costs (including hospital care, ambulatory care and drugs), private and public costs outside the medical sector (including nursing home costs and services or goods for private homes) and indirect costs (including limits on work capability, absenteeism and early retirement). It found that across 28 European countries (the EU plus Iceland, Norway and Switzerland) with a total population of 466 million, 127 million people or 27% are affected by at least one brain disease.

The total cost of brain diseases amounts to €386 billion per annum, or €829 per European inhabitant.

**We are currently updating the previous study and expanding it to include six major diseases that were not part of the original work. This major effort will be completed in 2012.**

**The cost of brain diseases will grow dramatically in the years to come. The ageing European population will increase the number of patients and the need for resources. At the same time, demographic change will lead to a serious lack of carers to look after patients.**

The brain diseases included in the study were:

- Addiction
- Anxiety disorders
- Brain tumours
- Dementia
- Epilepsy
- Migraine
- Mood disorders (depressive and bipolar disorders)
- Multiple sclerosis
- Parkinson's disease
- Psychotic disorders
- Stroke
- Traumatic brain injury

**Citizens of the European Union deserve a policy for brain health which is based on research aimed at improving the quality of life for those who live with a brain illness.**

## RESOURCE ALLOCATION TO BRAIN RESEARCH IN EUROPE (RABRE)

The EBC has worked with Stockholm Health Economics to review the current level of resource allocation to brain research in the EU. Partly funded by the EC, RABRE sought to build on the EBC's previous finding that brain diseases represent 35% of the burden of all diseases in Europe. RABRE analysed both private and public funding of brain research in Europe, and funding sources were categorised according to both function and disease target.

A cross-country comparison of results for Europe was made, and compared with results for the US which is considered the leader in brain research. RABRE also assessed the potential benefits that further funding of brain research in Europe would bring, relative to costs. It drew on the results of the CDBE study for comparative purposes. Studies of this nature are unprecedented in Europe, making RABRE a pioneering project in an area that is receiving increasing attention from both the research community and European policy makers.

The full European report of RABRE was published in 2006 and currently authors from different countries are working on national versions, as part of the campaign to increase awareness of research needs at national level.

## CONSENSUS DOCUMENT ON EUROPEAN BRAIN RESEARCH

The EBC has prepared a green paper that outlines what EBC members from all our stakeholder groups believe are key brain research themes in Europe for the next decade.

This Consensus Document, which was published in March 2006 in the *Journal of Neurology, Neurosurgery & Psychiatry*, provides an overview of 45 thematic areas covering brain research from "man to molecule", that is, from clinical science to translational and basic science.

The EBC wants to see increased commitment to brain research at the European level, and was pleased to note that brain research was specifically mentioned in the EC's Seventh Framework Programme (FP7).

We have used the Consensus Document to explain the positions of scientists and patients on research needs, and to provide advice to policy makers at European and national level on the best way to allocate resources.

**This advice has helped produce a substantial increase in brain research funding in FP7 compared with FP6. In order to help sustain this welcome improvement, the EBC is revising and updating the document. The new version will be published in 2010.**





## PATIENT ACCELERATED ACCESS

A major impediment in European healthcare systems is the time it takes until patients get access to innovative treatments for seriously debilitating and life-threatening illnesses.

Patients' access to the latest innovations requires many years and varies widely across European countries due to gaps in research but also due to delays in the time to approval, time to reimbursement and clinical implementation.

A core team of European decision-makers from the pharmaceutical and healthcare industry as well as key regulatory institutions, the EBC and our member organisation representing patients with neurological disorders, EFNA, have been meeting to discuss how to accelerate access. From an exploratory workshop, an analysis of all the impediments was undertaken, eventually focussing on three critical areas to take forward.

These three projects range from creating a European-wide research consortium to accelerating drug development and establishing CNS diseases as a high priority in the EU member states.

## EUROPEAN YEAR OF THE BRAIN

One of our important strategies to making brain diseases a high priority in all the EU member states is to campaign for the launch of a European Year of the Brain. This is a long process and one which will require the support of all the main European stakeholders. With the new European Parliament and new European Commission in place, the EBC will start its campaign in earnest in 2010 with the intention of gaining approval for the European Year of the Brain in 2011 or 2012 and its launch in 2013 or 2014.

## NATIONAL BRAIN COUNCILS (NBCs) AND NATIONAL ACTION GROUPS (NAGs)

Several EU member states have formed, or are in the process of forming, National Brain Councils which are independent but aligned with the main goals of the EBC.

Since research funds in the member states far exceed the resources available at European level, the creation of national bodies that can campaign in their respective countries is an important way for the EBC and its member organisations to achieve their goals.

Consequently, we have undertaken a project with the financial support of some of our industrial members, to encourage the formation of such groups in all EU member states.

There are now National Brain Councils or National Action Groups in over half of the member states.

**The EBC encourages the creation of National Brain Councils to promote brain research at national level. National Action Groups can be preliminary steps to the creation of National Brain Councils.**

## NATIONAL DISSEMINATION OF EBC STUDIES

As an important extension of the EBC's activities to national level, we are encouraging the publication of national versions of the key EBC studies — the Cost of Disorders of the Brain in Europe, the Consensus Document on European Brain Research and the Research Allocation to Brain Research in Europe (RABRE) study.

Authors from many countries have already used the national data in the Cost study as the basis of publications that highlight particular national issues. The same process is being pursued for the more recent RABRE data.

The effort involved in national dissemination goes hand in hand with the creation of National Action Groups and Brain Councils.

## EUROPEAN BRAIN POLICY FORUM (EBPF)

The EBC is undertaking a series of European Brain Policy Forums (EBPF) to foster debate on research policy focused each year on a different brain disease.

For the first EBPF in 2008, we chose "A Focus on Parkinson's Disease and the European Society" as the theme and for the second in 2009, "A Focus on Depression and the European Society".

The meetings brought together scientists, policy makers, healthcare providers, patients and carers to encourage communication and understanding between all the parties, and to develop policy for the future to influence decision makers and budget holders at European and national level.

The format of the conferences was a moderated and open debate, allowing only a few minutes for each presenter to introduce his or her perspective. This gave ample opportunity for all delegates to respond and engage in useful discussion with the speakers.

The 2008 and 2009 meetings were held in Brussels. In 2010, the meeting on "A Focus on Persons with Schizophrenia and the European Society" was held in Madrid during the Spanish Presidency. Reports of all meetings are on the EBC website:  
<http://www.europeanbraincouncil.org/>

## PARLIAMENTARY COLLABORATION

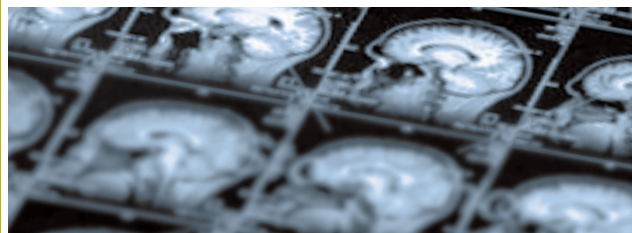
The EBC has been successful in influencing the topics for brain research to be funded by the European Commission and this will continue to be an important part of our mission.

However, at a higher level, recognition of the importance of brain research and the allocation of appropriate funding lies in the hands of the member states and their parliamentarians.

Therefore, the EBC recognises the importance of engaging the European Parliament, and those members involved in science and health policy. Working together with our member organisations and national campaigns, we will impress on policy makers the importance of brain research in tackling the major health and societal issues posed by brain disease – now and in the future.

## WHAT WE CAN BRING TO MEPS

- Expert opinion and assessment of parliamentary documents relating to brain research and brain diseases
- Effective dialogue with NBCs and NAGs
- Recent conclusions and results of our studies, seminars and conferences
- Better understanding of brain disorders
- A large network of scientific contacts





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