



## PRESIDENT'S MESSAGE



IN THE LAST NEWSLETTER, I ANNOUNCED THAT THE EUROPEAN BRAIN COUNCIL WAS LAUNCHING A CAMPAIGN TO DECLARE A EUROPEAN YEAR OF THE BRAIN (EYOB), POSSIBLY IN 2013. SINCE THEN, WE HAVE BEEN WORKING HARD TO GATHER SUPPORT FOR THIS PROJECT, WHICH IS A MAJOR GOAL FOR THE EBC. THE SUPPORT OF THE EUROPEAN COMMISSION IS PARTICULARLY IMPORTANT TO US, AND DISCUSSIONS WITH RELEVANT EC DIRECTORATES-GENERAL HAVE ALREADY GOT UNDERWAY.

Meanwhile, we have continued our discussions with the member states who are next in line to take up the European Union Presidency. This newsletter includes the welcome news that the Hungarian Presidency will highlight neuropsychiatric diseases as its main R&D priority, organising a congress on this theme next year. The Polish government continues to support our mission and planning is underway for the 4th European Brain Policy Forum, which will take place in Warsaw during the Polish Presidency of the EU. The proposed theme of this forum is "Stroke and dementia: major health threats in Europe", and it will complement the Hungarian meeting very well. In 2011, therefore, we can look forward to two major conferences on topics central to the EBC's mission, both of which will result in EU presidential support for EYOB 2013.

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## HUNGARY TAKES ON NEUROPSYCHIATRIC ILLNESS

IN AN EXCITING DEVELOPMENT FOR THE EBC, THE HUNGARIAN GOVERNMENT HAS CHOSEN NEUROPSYCHIATRIC DISEASES AS ITS MAIN R&D THEME UNDER THE HUNGARIAN EU PRESIDENCY IN THE FIRST PART OF 2011. UNDER THE LEADERSHIP OF TAMÁS FREUND, A FORMER EBC BOARD MEMBER, A WORKSHOP WAS HELD IN BUDAPEST ON 10 MAY TO PLAN THE CENTRAL EVENT ON THIS THEME, A CONGRESS TO BE HELD OVER 18-19 MARCH 2011, DURING ANNUAL BRAIN AWARENESS WEEK.

The workshop, which was held in the magnificent Hungarian Academy of Sciences, brought together international experts to agree on the content and speakers for this important event. The EBC was represented by Ian Ragan, Executive Director, and Past President Jes Olesen. Delegates agreed that the congress will be entitled "Discovery research in neuropsychiatry: depression, anxiety and schizophrenia in focus".

The burden and cost of depression, anxiety and schizophrenia are huge, and the congress will discuss not only the current state of research into the three conditions, but also their societal impact. To that end, patients, policymakers and the media will be encouraged to contribute their views.

The EBC considers it very important that the conclusions of the congress should be



disseminated in a way that maximises their impact on research funding and secures the attention of all stakeholders, in conjunction with other, similar European initiatives. We are delighted, therefore, that the Hungarian Presidency of the EU will support and publicise our European Year of the Brain (EYOB) campaign. ||

*Ian Ragan, Executive Director, EBC*

*image right:  
Jes Olesen,  
Past President*

*image below:  
Workshop at the  
Hungarian Academy  
of Sciences, May*



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The European Parliament's Interest Group on Mental Health, the brainchild of Dolores Gauci, President of the Global Alliance of Mental Illness Advocacy Networks (GAMIAN)-Europe and an EBC Board member, was launched on 28 April, marking another big step towards raising awareness of mental health and brain diseases. The press release describing this event can be found on our website under a new heading of News Alerts. The EBC later met one of the group's co-chairs, Antonia Parvanova MEP, to make her aware of our activities, including EYOB 2013. Having also recently met the Chair of the parliament's Committee on Industry, Research and Energy, Herbert Reul MEP, the EBC can claim to have had a very successful start to its campaigning in 2010.

Finally, from now on we will publish monthly progress reports on our website. This quarterly newsletter will continue to appear, but the progress reports will provide interim updates on our activities which I hope our supporters will find interesting and informative. ||



Julien Mendlewicz  
President, EBC

## AUTISM — AN AGENDA FOR EUROPE

VERY FEW COUNTRIES HAVE AS YET DEVELOPED NATIONAL STRATEGIES FOR TACKLING AUTISM SPECTRUM DISORDER (ASD). OVER 11-12 MARCH, THE EC'S THIRD PANEL OF EXPERTS ON ASD MET IN LUXEMBOURG TO DISCUSS HOW TO CORRECT THAT OVERSIGHT, BY PUTTING IN PLACE THE FIRST STAGE OF A LONG-TERM PROJECT: THE DESIGN AND IMPLEMENTATION OF COHERENT RECOMMENDATIONS FOR AN EU-WIDE PUBLIC HEALTH POLICY ON ASD.

ASD is a complex neurodevelopmental disorder that affects approximately 1 in 110 individuals in a population, according to 2009 data from the US Centers for Disease Control and Prevention. The spectrum ranges from severe autism to the more subtle but still challenging behaviours of Asperger syndrome and pervasive developmental disorder — not otherwise specified (PDDnos). It affects not only the individual and his or her family, but also society at large. One estimate suggests that ASD has a direct impact on about five per cent of any population. It is also expensive. The annual cost to the British economy of ASD has been estimated at €32 billion, for example.

Fourteen European countries were represented at the meeting in March, as were basic scientists, clinicians, patient groups, epidemiologists and policymakers. They discussed strengths and weaknesses, needs and priorities, in five areas: research, services, policy, advocacy/awareness and surveillance/monitoring. Among their recommendations were the following:

- **Research:** inclusion of biomarkers in intervention research and review of cost-effectiveness of early diagnosis programmes
- **Services:** diagnosis of adults with autism and improved training for parents and carers
- **Policy:** coordination of policy between agencies and dissemination of models of good practice
- **Advocacy:** recognition of the importance of self-advocacy and creation of EU-wide lobby groups
- **Surveillance:** introduction of a unique code for ASD in national registries, and standardisation of databases

The full report of the meeting, which is still in draft form but will be published on the EBC website as soon as it has been finalised, will provide the basis for further regional conferences in eastern and western Europe to be held in September. A strategic public health plan for ASD will then be presented at a meeting in Dublin in November. ||

## IN BRIEF

### EBC HONOURS

Jerzy Buzek, President of the European Parliament, and Octavi Quintana Trias, former Director of Health at the EC's Research Directorate-General, have both accepted Honorary Membership of the EBC. ||

### EU-COMPASS

EU-Compass is a tool set up by the EC for sharing information on mental health situations and wellbeing. Containing information on the five priority issues in the European Pact for Mental Health and Wellbeing — prevention of depression and suicide, mental health in youth and education, mental health in workplace settings, mental health in older people, and combating stigma and social exclusion — it will be developed in parallel with the pact conferences on these issues. Those wishing to add good practices and policies to the EU-Compass database can do so at: [http://ec.europa.eu/health/mental\\_health/eu\\_compass/](http://ec.europa.eu/health/mental_health/eu_compass/) or by writing to the following address to request the relevant templates: [EC-MentalHealthProcess@gencat.cat](mailto:EC-MentalHealthProcess@gencat.cat) ||



Delegates at a kick-off meeting for a Hellenic Action Group, Athens, March

## IRELAND AND GREECE MOBILISE FOR BRAIN RESEARCH

A MEETING TO DISCUSS THE FORMATION OF AN IRISH NATIONAL BODY TO REPRESENT BRAIN RESEARCH WAS HELD IN DUBLIN ON 9 MARCH. AMONG THE CONCERNS ADDRESSED WERE THE FRAGMENTATION OF BRAIN RESEARCH IN IRELAND, AND THE FACT THAT MANY PHARMACEUTICAL FIRMS ARE WITHDRAWING THEIR FUNDING FOR IT.

Delegates finally agreed to declare the creation of an Irish Brain Council, one of whose first joint initiatives with the EBC will be to reach a consensus regarding the European Year of the Brain. EYOB is planned for 2013 and will therefore coincide with the Irish Presidency of the EU.

On the other side of Europe, in Athens, a meeting was held on 31 March to discuss launching a Hellenic Action Group (HAG) for the brain. As at the Irish meeting, the EBC was represented by Ian Ragan, Executive Director, and Project Manager Tadeusz

Hawrot. Ian Ragan talked about the need for patients and scientists to speak with one voice and discussed the availability of data indicating the cost and burden of brain diseases. He emphasised that presenting such data to policymakers could have an appreciable effect on investment in brain research.

Delegates at the Greek meeting discussed the lack of a national body having responsibility for the funding of brain research, and their hope that an HAG could stimulate the creation of one. They agreed that organisations with

an interest in brain research should cooperate with organisations in other scientific fields and with industry, to advocate the creation of such a body. However, they warned, in light of the current economic climate in Greece, some realism was required and the appropriate way forward might be to launch the HAG as an unofficial organisation that might, in time, become a legal entity. ||

*Tadeusz Hawrot, Project Manager, EBC  
Ian Ragan, Executive Director, EBC*



## B4B TAKES ON CHILDHOOD NEURODEGENERATION

BRAINS FOR BRAIN (B4B), A EUROPEAN FOUNDATION WHOSE AIM IS TO ENCOURAGE A EUROPE-WIDE RESEARCH EFFORT INTO RESTORATIVE THERAPY FOR LYSOSOMAL STORAGE DISEASES (LSD), HAS RECENTLY RECEIVED FUNDING FROM THE EUROPEAN SCIENCE FOUNDATION FOR RESEARCH INTO PAEDIATRIC NEURODEGENERATIVE DISORDERS.

At the 4th B4B workshop in Frankfurt in March, Tim Cox of Cambridge University presented new findings on the childhood genetic disorder, Tay-Sachs disease. One of the major challenges in the area of LSDs is transporting lysosomal enzymes across the blood-brain barrier (BBB). In one session of the workshop, the discovery, design and development of therapeutic molecules that

can cross the BBB efficiently were reviewed. In another, special session, at which both the EBC and major biotech companies were represented, delegates discussed possible European collaborations and funding opportunities for tackling paediatric neurodegenerative diseases. Francesca Peri of the European Molecular Biology Laboratory in Heidelberg closed the meeting with her

exciting findings on microglial phagocytosis in zebrafish, including an in vivo movie of microglial phagocytosis in action.

A full report of the workshop can be found at: [www.brains4brain.eu](http://www.brains4brain.eu) ||

*Maurizio Scarpa, Co-founder, B4B*

# PROGRESS UPDATES

## CONSENSUS

The 2006 Consensus Document on European Brain Research is one of the most influential of the EBC's projects, having been used by the EC to select topics for funding under the 7th Framework Programme for research (FP7) and by member states for setting national priorities.

The document needed updating to be relevant to the last years of FP7 and to FP8, and its revision, which began late last year, is now nearing completion. The EBC hopes to launch it during the 7th Forum of European Neuroscience in Amsterdam in early July. ||

*image below:  
Partners in PARADISE*



## COST

The EBC's 2005 Cost of Disorders of the Brain in Europe (CDBE) study revealed that brain diseases were more costly than other types of disease, and was instrumental in persuading the EC to nominate brain research for special attention under FP7.

Since the cost of brain diseases in Europe is expected to have increased by between 30 and 50 per cent since 2005, this research also needs updating.

Lack of data meant that certain important diseases — developmental and sleep disorders, for example — were left out of the original CDBE study, as were important dimensions of the cost of others, such as the indirect or non-healthcare-related costs of psychosis. More data are now available in these areas, and preliminary estimates of the revised, total cost of brain diseases in Europe will be presented at a meeting in January 2011.

The new CDBE study is funded by unrestricted grants from the pharmaceutical company H. Lundbeck A/S and the European College of Neuropsychopharmacology. ||

*Evelyn Sipido, Liaison Officer and Administrator, EBC*

## PARADISE

PARADISE, Psychosocial Factors Relevant to Brain Disorders in Europe, is a new Coordination Action funded by the EC through FP7, that was launched in January and aims to coordinate the development of a cross-cutting or horizontal epidemiology of the psychosocial difficulties experienced by people with brain diseases in Europe.

The EBC, one of 10 partners in the project, has now devised a dissemination plan for the data that will be gathered under the project, as well as a project brochure, a distribution list comprising EBC partners, media organisations and other stakeholders, and a list of major project-related conferences that will take place over the next two years. The EBC has also designed the PARADISE website, which can now be accessed at: [www.paradiseproject.eu](http://www.paradiseproject.eu) ||

*Tadeusz Hawrot, Project Manager, EBC*

## CONFERENCES AND EVENTS

**7th FENS Forum of European Neuroscience**  
Amsterdam,  
The Netherlands  
3-7 July 2010  
<http://fens2010.neurosciences.asso.fr>

**23rd European College of Neuropsychopharmacology Congress**  
Amsterdam,  
The Netherlands  
28 August-1 September 2010  
[www.ecnp.eu](http://www.ecnp.eu)

**14th European Federation of Neurological Societies Congress**  
Geneva, Switzerland  
25-28 September 2010  
[www.efns.org](http://www.efns.org)

**GAMIAN-Europe Annual Convention**  
Lisbon, Portugal  
21-24 October 2010  
*For more information please contact GAMIAN-Europe Information and Communication Officer, Dorothy Micallief: [dorothy@richmond.org.mt](mailto:dorothy@richmond.org.mt)*

**19th European Congress of Psychiatry**  
Vienna, Austria  
12-15 March 2011  
[www.europsy.net](http://www.europsy.net)

**4th World Congress on Women's Mental Health**  
Madrid, Spain  
16-19 March 2011  
[www.iawmh2011.com](http://www.iawmh2011.com)

**14th European Congress of Neurosurgery**  
Rome, Italy  
9-14 October 2011  
[www2.kenes.com/eans/Pages/home.aspx](http://www2.kenes.com/eans/Pages/home.aspx)