

## EBC ANNUAL REPORTS 2012 and 2013

## This report covers the period from October 2011 to October 2013

# The European Brain Council - 10 years of meeting the needs of Science and Society

2012 marked the tenth anniversary of the European Brain Council. The anniversary closed an exciting and significant first decade for the European Brain Council and opened the next phase of its journey towards the full appreciation of our most vital and precious asset which is our brain.

One of EBC's most significant achievements has been the role it played in the increase in EU brain related research funding during the past ten years. In the four years prior to the formation of the European Brain Council EU funding of brain research was €85 million; now the EU research funding for brain and brain related research exceeds one billion Euros.

Since its formation the EBC's membership has continued to grow. It now represents all areas involved in brain disorders ranging from science to society and industry. This broad range of knowledge and support is one of the organisation's most valuable assets; something the EC and EP as well as national governments throughout Europe recognise.

Maire Geoghegan Quinn, the EU Commissioner for Research, Innovation and Science said: "During the first decade of its life the European Brain Council has played a key role in the area of neurosciences in Europe. It has helped raise the awareness on the importance of supporting brain research and addressing brain related issues.

"It has also mobilised all stakeholders from researchers to clinicians, from industries to patients, rallying national and European administrations and political forces. And very importantly the European Brain Council has been a valued interlocutor for the European Commission."

Despite these significant achievements there is still a great deal which needs to be achieved. Determined to become the leading and most respected organisation in the field of brain disorders EBC intends to continue its political focus ensuring that brain disorders become a priority funding area in the EU.

#### **Publications**

# New and Updated Costs Document

The updated <u>Cost of Disorders of the Brain in Europe</u> study was completed based on 2010 data and was published in early October in the ECNP journal European Neuropsychopharmacology.

A major launch event was held in the European Parliament on October 4<sup>th</sup> 2011with significant attendance from MEPs and Commission officials.



Extensive media coverage was generated (including the article published in <u>Nature</u>) as a result of London Science Media Briefing, setting up interviews across the EU and distribution of press release globally.

The study was also distributed to all EBC Member Societies, at Members annual meetings, as well as the European Commission and in the European Parliament where all 750 MEPs received a copy.

The <u>count up</u> was set up on the EBC webpage demonstrating the every second growing costs of brain disorders. It is displayed on every page of the website.

Following the release of <u>Cost of Disorders of the Brain in Europe 2010</u>, national papers covering the data are being developed. EBC identified potential authors in 27 countries included in the European study and provided them with country specific figures and tables. EBC has also developed a template paper to facilitate writing groups in preparing country related papers.

## The size and burden of mental disorders and other disorders of the brain in Europe 2010

A major landmark study was released by the European College of Neuropsychopharmacology (ECNP). The study finds revealed that mental disorders have become Europe's largest health challenge in the 21st century.

This paper was prepared in the framework of ECNP and EBC Task Force project on the Size and Burden and Cost of Disorders of the Brain in Europe 2010, supported by funds of ECNP, the EBC and Lundbeck.

## **Project work**

# PARADISE project (2010 - 2013

<u>PARADISE – Psychosocial Factors Relevant to Brain Disorders in Europe</u> is a Coordinated Action financed by the EC within the FP7. EBC is responsible for creating and maintaining the project's website, dissemination activities and organizing stakeholders' conference at the end of the project.

On March 2012 EBC submitted an interim report covering dissemination activities as well as financial data. The project results were disseminated at many congresses and meetings e.g. EPA, EFNS and FENS.

The annual project meetings took place in Munich, Germany in 2011 and Warsaw, Poland in 2012. EBC co-organized the project's final conference that took place in Brussels at the University Foundation on February 20<sup>th</sup>, 2013.

EBC produced a detailed financial and activities report at the end of the project. The project was concluded on the 31 June 2013.

## EBC involvement in new projects:

#### **Advance HTA**



# MARATONE - Mental Health Training through Research Network in Europe

NERRI - Neuro-Enhancement: Responsible Research and Innovation

OxPAQ - The Oxford Participation and Activities Questionnaire Initiative

Other and additional projects are being considered.

**Advance HTA**, an EC funded project, seeks to advance and strengthen the methodological tools and practices relating to the application and implementation of HTA.

**Ox PAQ** is an initiative shared with Oxford University. Several meetings have already been held and the kick-off meeting was held in Oxford before the summer break of 2013.

**MARATONE** is an EC funded Marie Skłodowska Curie Initial Training Network project. It will help to train young researchers in interdisciplinary research on brain disorders. EBC is an associate partner.

**NERRI** is an EC funded project. The consortium is led by LSE. Following the suggestion by the EC, EBC has been asked to represent civil society.

# **National Brain Councils (NBCs)**

Nearly 30 countries have now formed or are in the process of forming a National Brain Council or National Action Group, These EBC replicas at the national level, work independently but their goals are aligned with those main EBC.

### 2011:

In October 2011 EBC invited delegates from all NBC and NAG to the meeting of Network of NBCs and NAGs in Brussels. The following day the participants were invited to take part in the launch of the CDBE2010 in the European Parliament. Prior to coming to Brussels all the representatives contacted MEPs in their respective countries and invited them to attend in the Cost launch meeting.

## 2012:

Two more National Brain Councils were formed in Finland in March and in Croatia in June 2012. In June 2012 a NAG has been initiated in Turkey. In September 2012 a start-up meeting took place in Serbia and in November 2012 in the Netherlands.

Three newsletters – written and prepared by EBC in cooperation with Network of NBCs/NAGs two delegates were sent to the Network providing information on the latest news both from the Network as well as EBC.

A Map of currently existing NBC/NAGs can be found here.

### 2013:

New guidelines for NBCs and NAGs as well as the expansion strategy were prepared for 2013.



Two NBCs were set up - marking the European Month of the Brain in May 2013 – in Switzerland and Ireland. A planning meeting to discuss the formation of the Macedonian Brain Council took place in Skopje, Macedonia in June 2013. Later that month the Dutch Brain Council was founded. Finally, the Polish Brain Council was launched in September 2013.

Also in 2012, three newsletters were sent out to the Network of NBCs and NAGs.

## **European Year of the Brain 2014 (EYOB)**

Despite considerable efforts, the EC President Barroso decided not to go for a year dedicated to the brain. In February 2012, following a review by the EBC Board it was decided to no longer push for the campaign to be institutionally led, but to take the project ahead together with EBC's member societies and its coalition of partners. The EC and President Barroso's cabinet were informed of this decision.

Several Commissioners confirmed their support for the campaign and EBC will continue to work closely with the EU Institutions informing them of the progress made and to ensure their involvement in our activities.

Current plans include a series of exhibitions, congresses and events.

#### **HORIZON 2020**

Horizon 2020 (H2020) will be the EC re-named future "Framework Programme". Details of the new programme have been made available by the European Commission including information on Horizon 2020's greatly increased overall budget.

However, the proportion of the overall budget dedicated to "health research" is considerably less than that in previous framework programmes. Together with many others, EBC very actively lobbied to, at least, reinstate the proportion dedicated to health as in the previous framework programme as well as to make brain a priority area, similarly to what was done in Framework Programme 7.

EBC sent a letter to 27 EU Ministers of Finance arguing that brain should remain a priority within H2020 and no reduction should be made in health budget. The letter was further promoted by EBC Members who, in turn, encouraged their members to contact their respective national governments.

In June 2012 the EBC Board met with Máire Geoghegan-Quinn, European Commissioner for Research, Innovation and Science at her offices in the EC headquarters .She illustrated H2020 as well as DG Research's plans towards the Month of the Brain in May 2013.

Jointly with ESF and FENS, EBC organised an event at the EP addressing "The Prospects of Brain Research within Horizon 2020: Responding efficiently to Europe's societal needs" The meeting was co-chaired by Prof T. Riera Madurell, one of the H2020 rapporteurs. The event was also branded European Month of the Brain (EMoB) by the European Commission.



#### **Cooperation with EBC Members**

EBC continues to cooperate with its members in a number of fields, including supporting their initiatives and meetings. In 2012 EBC delegates attended four meetings of the European Parliament Interest Group on Mental Health and Brain Disorders organised by GAMIAN - Europe.

In December 2012 EBC President Dr. Mary Baker conferred Honorary Membership to former European Parliament President, Professor Jerzy Buzek, in recognition of his outstanding contribution to the advancement of brain research in Europe and the quality of life of European citizens.

In order to better understand the needs of EBC's members, meetings with the Boards of all EBC member societies were held in the second part of 2013.

#### **European Month of the Brain 2013**

As a direct result of EBC's lobbying, the EC – Commissioner M. Geoghegan-Quinn of DG RTD designated May 2013 the <u>European Month of the Brain</u>, highlighting the outcomes of EC funded projects as well as future EC plans for brain related research. EBC was very actively involved in promoting the initiative. The EFNA President sat on the scientific committee for the conferences and the EBC President as well as other EBC eminent Board members were speakers at the two major conferences the EC organised. These meetings were held in <u>Brussels on 13 May</u> - <u>European Brain Research</u>

<u>Successes and Next Challenges</u> and <u>Dublin on 27-28 May</u> - <u>Healthy brain: healthy Europe. A new horizon for brain research and health care.</u>

EBC has been very actively promoting the EMoB among its Members. As a result of this work, over 100 events happened across Europe, many of which generated through EBC's efforts.

EBC was also involved in a kick of event of the EMoB organized by <u>EP STOA Panel</u> in the EP in later April 2013.

EBC received special thanks from Mr Philippe Cupers, Head of Neuroscience in DG RTD, for its help in ensuring the success of the conferences. More specifically he thanked EBC for promoting the initiative of the EMoB and contributing to its great success.

## **Meetings**

#### Danish Presidency Jan-June 2012

EBC participated through the EBC President and others in a number of Presidency meetings highlighting the needs for more brain research.

High Level Conference "EU Health Programmes: results and perspectives" EBC was given a stand to promote its work.

#### Cypriot Presidency July-Dec 2012

EBC is a member of the Steering Group for the major Cypriot Presidency Conference on Innovation that was held in Larnaca on 12-13<sup>th</sup> October, 2012. EBC co-lead on the education and Nutrition work-



streams and presented and led the Education session of the conference which was attended by the Commissioners for Research and Innovation and Health and Consumer Protection, as well as the Cypriot Minister for Health Dr. Stavros Malas - a neuroscientist - and other important stakeholders.

## Irish Presidency Jan-June 2013

Within the <u>European Month of the Brain</u> the Irish Presidency organized a conference <u>Healthy brain:</u> <u>healthy Europe.</u> A new horizon for brain research and health care in Dublin on 27-28 May. EBC was involved in the preparations EFNA President sat in the organizing committee and EBC President was a speaker.

<u>Lithuanian (July – December 2013), Greek (January – June 2014) and Italian (July – December 2014)</u> Presidencies

Discussions are at an early stage with all three Governments, critical to maximize the impact of 'The Year of the Brain'

#### Interactions with the EC and other EU institutions

The number of invitations for EBC to participate in Commission led activities/ other stakeholder initiatives is increasing, demonstrating thus our increasing influence in the EU sphere. Regular interventions/presentations are being made at both national and regional level.

# Membership

New industry members Shire, Britannia, EHIMA, UCB joined the EBC Industry Board.

Several other potential members both from European scientific societies and industry have approached EBC: ESR — European Society of Radiology, ESO - European Stroke Organisation and EURO-CNS.

The membership requests of ESR and ESO were officially accepted by the Board and will be presented to the General Assembly in October 2013.

#### **Communications**

Two major pieces of media communications have been produced with very broad coverage related to:

- 1. The launch of the Cost of Brain Disorders
- 2. The 10 year anniversary press release, interview with Commissioner M. Geoghegan Quinn and several interviews that can be seen <a href="here">here</a>.

Two publications were created:

- 1. The European Brain Council Annual Review 2011
- 2. EBC celebrating 10 years brochure.

A weekly External Environment Report (EER) and EU Research Update (CORDIS reports) continue to be produced and circulated to all members and feedback on its' usefulness has been excellent.



These weekly reports will continue to monitor the areas in which we work and key agendas and meetings as well as key publications. The EERs can be found <a href="https://example.com/here">here</a>.

The website has undergone a major overhaul with broader video usage, news sections better availability of resources, slide sets, publications, meetings and so on.

EBC logo was amended and subsequently trademarked.

A new section was added called "President's Corner" featuring President's message and activities.

## **EBC News**

The official newsletter of the European Brain Council – <u>EBC News</u> was launched in May 2013. First issue featured interviews with the former European Parliament President Prof. Jerzy Buzek and DG Research Commissioner Máire Geoghegan-Quinn. The EBC News was distributed extensively to EBC Members, MEPs, EU Officials and other relevant organisations and individuals.

In May EBC registered in the Transparency Register operated by the European Parliament and the European Commission. The register provides policy makers and citizens with a direct and single access to information about who is engaged in activities aiming at influencing the EU decision making process, which interests are being pursued and what level of resources are invested in these activities.

#### Staff

Alastair Benbow left EBC on 31 December 2012.

Eveline Sipido and Tadeusz Hawrot continued to provide EBC with support and expertise in line with their roles in EBC.

Nick Deeming joined EBC as acting Executive Director in April 2013

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