

## The European Brain Council's Weekly External Environment Update

Week of 27<sup>th</sup> June 2011

### Quote of the week

*"It's incredibly disappointing that people still aren't getting the treatment they deserve and that referrals aren't happening quickly enough. Too often people don't even go to their GP and the symptoms are ignored or simply put down to a 'funny turn'"*

Joe Korner of The Stroke Association reflecting on a report by the Royal College of Physicians and the Vascular Society, see articles of interest for further details

### Agenda Watch

- i) Please note that presentations and notes from The **FP7 Health - Open Information Day & Partnering Event** in Brussels, including contributions from Máire Geoghegan-Quinn, Commissioner for Research, Science and Innovation, are now available to view online [here](#).
- ii) Over one hundred progressive European political representatives have co-signed a roadmap called the 'Barcelona Appeal', which is designed to canvass political strength ahead of the 2014 European elections and is penned by The Progressive Alliance of Socialists & Democrats in the European Parliament. (S&D).  
Amongst pledges to create jobs, sustain the welfare state and increase participation in the democratic system, the roadmap focuses specifically on the need to promote **inclusion** and **integration** in the face of xenophobia and populism.  
S&D Group leader Martin Schulz said: "Our socialist values are needed now more than ever: a fair distribution of wealth and a state capable of protecting and giving opportunities to those (who are) weaker. We should all work together for Europe. Mr. Sarkozy and Ms Merkel cannot just act alone and decide for all the rest."

### Institution Watch

- i) The European Union (EU) has published an integrated eighteen-month programme of planned activity. Its public health section highlights a pledge to focus on addressing the challenges to the healthcare system posed by non-communicable diseases and an increasingly ageing population. Emphasis will be given to health from early childhood, as a prerequisite and integral part of a healthy ageing process. Work on

specific proposals regarding information to the general public on medicinal products for human use subject to medical prescription will also continue

- ii) **Horizon 2020** has been announced as winner of the **You Name it** online competition to name the future EU-funding programme for research and innovation. The competition, launched by the European Commission, is linked to the ongoing stakeholder consultation on the Commission's Green Paper on the new programme, a core element of the **Innovation Union initiative** and the **Europe 2020 Strategy**
- iii) In reply to an earlier response from Mr. Dalli (EC) highlighting that there is currently no strategy dedicated to the treatment and awareness of epilepsy, David Casa (PPE) questioned the criteria applied to ensuring frameworks for other medical conditions are established and why epilepsy didn't meet this. Mr. Dalli responded by stating that the Seventh Framework Programme for Research and Technological Development (FP7) has specifically allocated €24 million for research into epilepsy. One example is project **NEMO**, which evaluates the efficacy and safety of bumetanide as off-patent treatment of neonatal seizures, as well as the active encouragement of civil society to take part in research projects, in order to increase awareness
- iv) The World Health Organisation (WHO) has published an enlightening study on the public health impacts of headaches called the **Atlas of headache disorders and resources in the world 2011**. Please click on the following links to access elements of the publication:
- [Complete publication](#)
  - [Executive summary](#)
  - [Introduction and methods](#)
  - [Results](#)
  - [The way forward and references](#)
- v) The European Commission has published an important document called **European forward-looking activities: Building the future of 'Innovation Union' and ERA**. Please click [here](#) to access this
- vi) Last Thursday, The European parliament held a conference hosted by MEP Professor Maria da Graça Carvalho on how research and technology organisations strengthen the research and innovation base in Europe

## Key updates this week

### WHO report highlights that mental health problems face maximum discrimination

The World Health Organization's (WHO) **World Report on Disability** has revealed the shocking and dangerous levels of prejudice directed to those experiencing mental health difficulties.

Many people with mental health difficulties have been denied effective treatment despite resources being in abundance. Additionally, the WHO report found that mental health sufferers are more likely to develop chronic health problems earlier than the general population, as well as dying sooner after diagnosis.

Up to half the sufferers in developed countries, and over two thirds of those in developing nations had received no care during the year before the reports' release. WHO states that health inequalities largely resulted from social deprivation, with mental health sufferers being at high risk of poverty. Other barriers to care cited include fear and mistrust on both sides of the service, unequal treatment and lack of service promotion.

From a career perspective, the report also revealed that mental health sufferers and those with intellectual impairments experienced greater difficulties at both the selection stage and whilst in employment. This, states the report, mainly results from incorrect assumptions about the abilities of those with disabilities and a lack in knowledge of how to create work programmes tailored to the needs of disadvantaged groups.

Mental Health Europe is pressing policy makers to make mental health a key element of a European strategy on health inequalities, due to its direct link to understanding and addressing wider health and social issues.

### Scientists find link between master gene and neurodegenerative disorders

An international team of scientists (partly funded by a European Research Council – ERC - grant under the EU's Seventh Framework Programme - FP7) has identified a master gene that controls lysosomes, which break up debris produced by cells that can potentially cause neurodegenerative disorders like Parkinson's as well as pediatric genetic diseases.

"The master gene (transcription factor EB or TEFB) controls the function of lysosomes (organelles in the cell that break down waste and cellular debris) and controls the function of autophagosomes [cellular compartments]," explains Dr Andrea Ballabio of the Telethon Institute of Genetics and Medicine (TIGEM) in Naples, Italy, a professor of molecular and human genetics at Baylor College of Medicine (BCM) and the Texas Children's Neurological Research Institute (NRI) in the United States and senior author of the study.

“Defects in this process are also implicated in neurodegenerative disorders such as Alzheimer's and Parkinson's diseases.”

The findings, which researchers from the Cambridge Institute for Medical Research of the University of Cambridge also contributed to, was cited in the journal *Science* and could lead the way for new ways to fight these diseases.

#### *A joined up approach*

The European Research Area Committee has published its summarised conclusions of the **15th meeting of the High Level Group for Joint Programming (GPC)**, held in Brussels in May. Please click on the following link to view these:

<http://register.consilium.europa.eu/pdf/en/11/st01/st01302.en11.pdf>

#### **Articles of interest**

*The Daily Telegraph*, Faster access to stroke surgery could help over 1000

<http://www.telegraph.co.uk/health/8586516/Faster-access-to-stroke-surgery-could-help-over-1000.html>

*The West Australian*, New centre to boost brain research opens

<http://au.news.yahoo.com/thewest/a/-/national/9699793/new-centre-to-boost-brain-research-opens/>

*The Independent*, Common drugs could prove fatal to elderly

<http://www.independent.co.uk/life-style/health-and-families/health-news/common-drugs-could-prove-fatal-to-elderly-2302128.html>

*BBC News*, Brain research's golden age

<http://www.bbc.co.uk/news/science-environment-13874585>

#### **Dates for your diary**

Meeting of National Brain Councils and National Action Groups, Brussels, October 3<sup>rd</sup> 2011

Launch of the Cost Study to the European Parliament, Brussels, October 4<sup>th</sup> 2011

Board meeting and general assembly, Brussels, October 5<sup>th</sup> 2011

EBC Board Meeting November, Warsaw, November 17<sup>th</sup> 2011

EBC Polish Presidency Meeting, Warsaw, November 18<sup>th</sup> 2011