

# The European Brain Council

# Finnish Brain Council – a proposal from the European Brain Council

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

# EBC will achieve this by



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

# The EBC Membership



## Ordinary Members (Board members)

- EANS - European Association of Neurosurgical Societies
- ECNP - European College of Neuropsychopharmacology
- EFNA - European Federation of Neurological Associations
- EFNS - European Federation of Neurological Societies
- EPA - European Psychiatric Association
- FENS - Federation of European Neuroscience Societies
- GAMIAN Europe - Global Alliance for Mental Illness Advocacy Networks
- Representatives of pharmaceutical and medical devices industries

# The EBC Membership



## Associate Members and observers \* (non-voting)

- B4B – Brains 4 Brain
- EACIC – European Accreditation Committee in CNS
- EMSA - European Medical Students' Association \*
- EUFAMI - European Federation of Associations of Families of People with Mental Illness
- FEPS– Federation of European Physiological Societies
- ESN - Federation of the European Societies of Neuropsychology
- Network of National Action Groups and Brain Councils \*
- International League Against Epilepsy - Commission on European Affairs (ILAE – CEA) \*

# Honorary Members

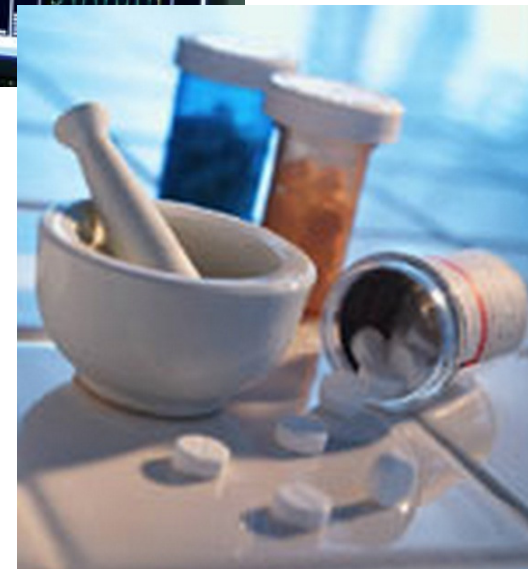
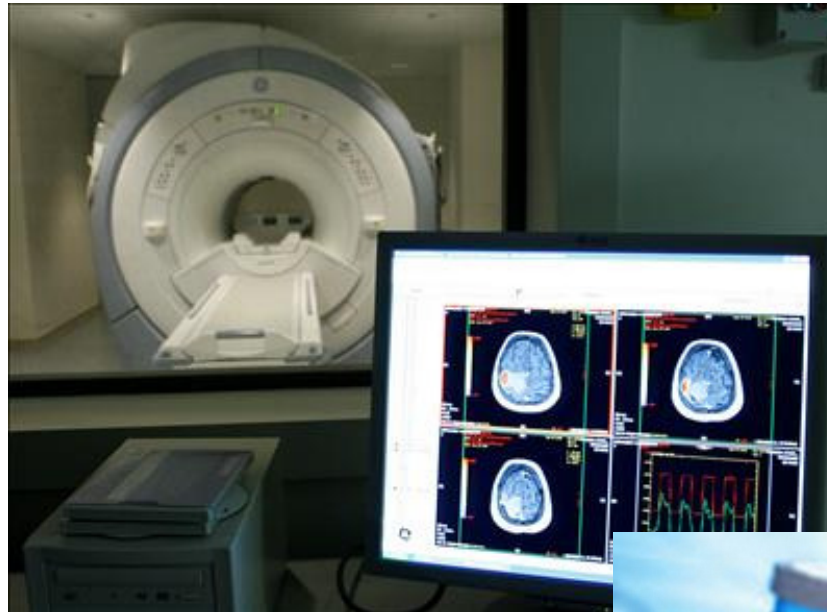


- Philippe Busquin (ex-MEP)
- John Bowis (ex-MEP)
- Jerzy Buzek (President of the European Parliament)
- Octavi Quintana Trias (ex-Health Director in DG Research)

# EBC Members



- **Abbott**
- **Actelion**
- **Astra-Zeneca**
- **Bayer Schering**
- **BMS**
- **Eisai**
- **Esteve**
- **GE Healthcare**
- **Genzyme**
- **GSK**
- **J&J**
- **Lilly**
- **Lundbeck**
- **MSD**
- **Medtronic**
- **Novartis**
- **Nycomed**
- **Orion Pharma**
- **Pfizer**
- **Roche**
- **Sanofi Aventis**
- **Schering Plough**
- **Servier**





## The Burden of Brain Diseases in Europe

- Olesen J and Leonardi M. Eur J Neurol 2003, 10:471-7.

## Cost of Brain Disorders in Europe

- Andlin-Sobocki P, Jonsson B et al. Eur J Neurol 2005, 12 Suppl 1:1-27

## Size and Burden of Mental Disorders in Europe

- Wittchen, H-U et al. Eur. Neuropsychopharmacol 2005, 15(4):355-490.

## Research Allocation for Brain Research in Europe

- Sobocki P et al. Eur J Neurosci 2006, 24:1-24.

## Consensus Document on European Brain Research

- Olesen J, Baker MG et al. J Neurol Neurosurg Psychiatry 2006, 77 Suppl1:i1-49.

# EBC involvement in Framework Programmes



## FP7 3rd Call

- Psycho-social factors of brain disorders
  - PARADISE

## Advising on the call topics for FP7 and planning for FP8

- Continue to push for better funding of brain research

	<b>Total in FP6</b>	<b>FP7 first 3 calls</b>
Brain	260m	381m
Cancer	485m	265m
Cardiovascular	124m	111m

# EBC Priorities for 2011



## Consensus document revision

- targeting FP7 and FP8 funding

## Cost of brain disorders revision

- targeting FP8 and member state priorities

## PARADISE

- establishing role of EBC as partner for dissemination

## European Brain Policy Forum

- gaining broad exposure to policy makers and media
- building relationships with patients and patient groups

## National Action Groups and National Brain Councils

more details in the coming slides

## European Year of the Brain 2014

- Building support in Brussels and in members states

**UNIFYING THEME**  
**EYOB 2014**

# European Year of the Brain



The European Brain Council and its member organisations launch a call for 2014 to be ‘The European Year of the Brain- to improve neurological and mental health’

Science and Society in partnership creating healthcare and economic benefits for European citizens

An opportunity to:

- Increase the profile of all brain diseases in every member state
- Increase funding for brain research through the framework programmes and in the member states
- Achieve concrete actions at local, national and European level

# What could a 2014 European Year of the Brain achieve? 1 of 2



- Increase the profile of all brain diseases in every member state
- Draw attention to the costs and impact of brain diseases now and into the future
- Increase funding for brain research through the framework programmes and in the member states
- Increase efforts to educate, inform and advise all those living with brain diseases in order to improve their quality of life
- Recognise the increasingly important role of those who care for a person living with a brain disorder

# What could a 2014 European Year of the Brain achieve? 2 of 2



- Draw attention to health inequalities in brain disease
- Develop action plans at local, national, regional and European level to address specific areas related to brain diseases
- Influence policy decisions over the next 5-10 years
- Address controversial and difficult areas
- Stimulate open debate and dialogue on brain diseases
- Show the value of partnership across all of society

# Potential themes



Research/Science

Education/Information

Patient access

Health Literacy

Economics

Brain Drain

Creating the environment  
for development of new  
treatments

And many more..

Stigma

Ethics

Health technology  
assessment

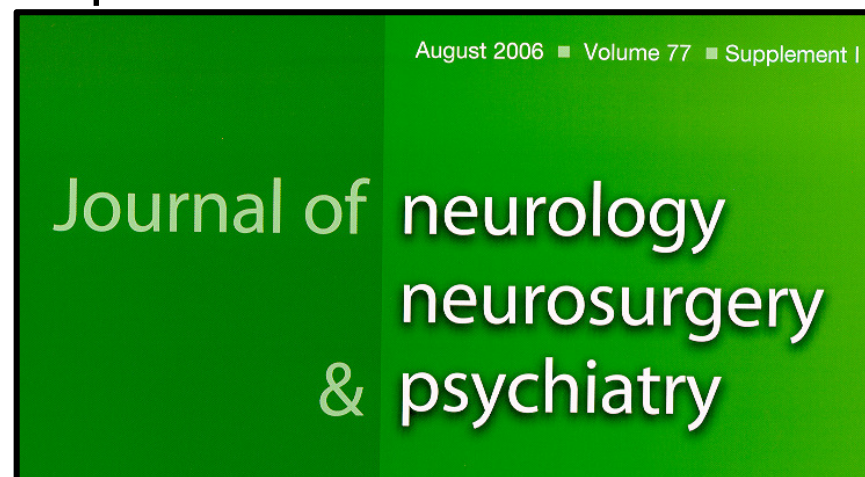
The creative brain

The healthy brain

The productive brain

Overarching psychiatry and  
neurology

- Multi-authored, multi-national collection of 45 research themes published in 2006
- Used by EC for selection of topics in first calls of FP7
- Revision of the document requested by the EC to inform later calls and FP8
  - New themes
  - Changes to authorship
  - Updating of text
- Publication in 2011





The first study of the cost of disorders of the brain in Europe reported data for 2004

- Landmark study resulting in over 40 publications of European, national and disease-specific data
- Cost of 12 diseases (€386b per annum) equal to that of cardiovascular disease and cancer together
- Instrumental in having brain research specifically highlighted in FP7

- **Psycho-social fActors Relevant to brAin DISorders in Europe**
  - Horizontal epidemiology across 9 major brain disorders of factors impinging on quality of life
  - Develop protocols and data collection strategy, make recommendations for implementation
  - EBC role in final report, stakeholder conference and communication (website, publications etc)
  - Started January 2010

# European Brain Policy Forum



## 3<sup>RD</sup> EUROPEAN BRAIN POLICY FORUM

A FOCUS ON  
PERSONS WITH SCHIZOPHRENIA  
AND THE EUROPEAN SOCIETY



MADRID, SPAIN

FEBRUARY 23 – 24, 2010



Presidencia  
Española



2010.es

PROGRAM

**2008 – A Focus on  
Parkinson's Disease & the  
European Society**

**2009 – A Focus on  
Depression & the  
European Society**

**2010 – A Focus on Persons  
with Schizophrenia & the  
European Society**

- Attendance by patients from several EC countries
- Press, MEP's, EC officials
- Publication and policy as outcomes

# National Campaigns for Brain Research



- National Action Groups
- National Brain Councils

# National Action Groups National Brain Councils



## Multidisciplinary action groups

- Scientists, doctors, patients and industry
- NAGs could form the nuclei of NBCs in the future
- **Many countries are forming NBC's**
  - **NBCs:** BE, ES, HU, IT, NO, SL launched
  - **NAGs:** CY, CZ, DE, EE, FR, GR, IE, IL, LT, MT, PL, PT, RO, SE, SK
  - CH, LA targeted for the near future

## Share aims of the EBC but are independent

- Focus on national priorities

# Why there is a need for National Campaigns?



- **A need to increase the priority of brain research at the national level - most research funding on the national level, not by the EC.**
- **The failure of the EC to fund brain research in the way that is needed is a reflection of the lack of priority in the MS themselves.**
- **Increase public awareness of the brain.**
- **Speaking in one voice**

# What can NAG's/NBC's do?



## **Influence national research programs**

- Organise meetings to gain stakeholders support
- Campaign for national assessment of current activities
- Campaign for more resources for brain research
- Mobilise national funding bodies and decision makers
- Increase public awareness
- Alert about the impact of brain diseases
- Work for better prevention, diagnosis and treatment

**AND**

## **NBCs also have aims that are aligned with those of the EBC**

- Support EBC initiatives in Brussels
- Help with dissemination of EBC work at national level
- Organize together with the EBC policy fora in countries where the EU presidency takes place.

# What can NAG's/NBC's do?



## **GREECE**

- Meeting with the General Secretary of Research and Technology.
- Press release about the formation of the HAG – media, MEPs
- Article on the current situation of brain research
- Series of articles on different brain disorders

## **DENMARK**

- Brain package



# What can NAG's/NBC's do?



## **ISRAEL**

- Mapping of patient organizations and neuroscience, biotech companies
- Meeting in the Ministry of Health
- Series of articles on different brain disorders

## **OTHER**

- Drugs reimbursement
- Brain day/week
- Workshops, lectures
- Data comparison

# Interactions between NAG's/NBC's and EBC



## **The organisations are independent**

- The EBC has not been an umbrella group of NAG's/NBC's
- The EBC is not going to compete over the available funds.

## **EBC can help through:**

- Providing contacts
- Providing the national data on brain research and brain diseases
- Providing guidance on industrial participation
- Providing guidance from the experiences of other countries
- Providing materials, reprints, slide sets etc
- Supporting initial meetings to establish NAG's/NBC's

# Contact between NAG's/NBC's and EBC



## Closer interactions

- Network of NBC's with 2 observers on the EBC Board
- Discussion at meetings of NAG's and NBC's
- Participation in the Annual Brain Policy Forum
- Exchange of minutes and newsletters
- EBC section on NAG/NBC websites and vice versa
- Joint approaches to European and international institutions
- Joint work on dissemination of European projects and documents at national level
- AND possible closer interaction in the future

EU COUNTRIES, PRESIDENCIES		EU COUNTRIES, PRESIDENCIES	
Germany	2007 NAG	Latvia	2015 Plans for 2011
Portugal	2007 NAG	Luxembourg	2015
Slovenia	2008 NBC	Netherlands	2016
France	2008 NAG	Slovakia	2016 NAG
Czech Republic	2009 NAG	Malta	2017 NAG
Sweden	2009 NAG	United Kingdom	2017
Spain	2010 NBC	Estonia	2018 NAG
Belgium	2010 NBC	Bulgaria	2018 Plans for 2011
Hungary	2011 NBC	Austria	2019 Plans for 2011
Poland	2011 NAG	Romania	NAG
Denmark	2012 NAG, June 2010	Finland	2020 March 2011
Cyprus	2012 NAG	<b>NON EU COUNTRIES</b>	
Ireland	2013 NAG	Norway	NBC
Lithuania	2013 NAG	Israel	NAG
Greece	2014 NAG	Switzerland	May-11
Italy	2014 NBC	Turkey	Plans for 2012

# Valmistelutoimikunta



Mielenterveyden Keskusliitto  
Neurologiset Vammaisjärjestöt  
Suomen Aivotutkimusseura  
Suomen Neurokirurgiyhdistys  
Suomen Neurologinen Yhdistys  
Suomen Psykiatriyhdistys  
Teollisuuden edustaja

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Irma Holopainen  
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Reetta Kälviäinen  
Jyrki Korkeila  
Reijo Salonen

Thank you