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

Dr. Alastair Benbow, Executive Director, EBC
Tadeusz Hawrot, Project Manager, EBC
Helsinki, 8th March, 2011
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

Cost of Brain Disorders in Europe

Size and Burden of Mental Disorders in Europe

Research Allocation for Brain Research in Europe

Consensus Document on European Brain Research
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

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<tr>
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<th>Total in FP6</th>
<th>FP7 first 3 calls</th>
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<tbody>
<tr>
<td>Brain</td>
<td>260m</td>
<td>381m</td>
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<tr>
<td>Cancer</td>
<td>485m</td>
<td>265m</td>
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<tr>
<td>Cardiovascular</td>
<td>124m</td>
<td>111m</td>
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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
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
Consensus Document Revision

- 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
Cost Study Revision

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

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 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
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
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Valmistelutoimikunta

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

Timo Peltovuori
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Irma Holopainen
Juha Öhman
Reetta Kälviäinen
Jyrki Korkeila
Reijo Salonen
Thank you