The European Brain Council

Dr C. Ian Ragan, Executive Director
Dr Mary G. Baker MBE, Vice President

Committee on Industry, Research and Energy
Public Hearing on Mental Health Research:
Scientific Progress and Perspectives

European Parliament, Brussels, 17th February 2009
EBC Mission

To promote brain research in Europe

and to improve the quality of life of

those affected by brain diseases
Who is involved in the EBC?

Patient organisations
Basic neuroscientists
Clinicians
  • neurologists, neurosurgeons, psychiatrists
Industry
  • pharmaceutical, medical devices
Network of National Action Groups and National Brain Councils

More details in the folders and at www.europeanbraincouncil.org
What are the common issues?

• Increasing brain research
• Intensifying pre- and postgraduate education
• Improving diagnosis, treatment, care, prevention and living conditions for those living with brain disease
• Increasing dialogue with policy makers
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
Cost of brain disorders in Europe

All brain disorders: 386b euro
- Health care costs: 135 “
- Direct non-medical: 72 “
- Indirect costs: 178 “

Mental Disorders
295b euro
Neurological
84b euro
Neurosurgical
7b euro

Dementia 55b euro

Cost of Brain Disorders in Europe
Brain research vs other research

- 35% of the burden of all disease due to brain diseases
- 8% of EU health research funding
- 17% of NIH health research funding

Lancet Neurology 2003, 2:647
Brain research is underfunded

Figure 2: Research funding, costs and burden due to cancer compared to brain disorders in Europe (2005)

- Cancer
- Brain Disorders

<table>
<thead>
<tr>
<th>Category</th>
<th>Cancer</th>
<th>Brain Disorders</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Funding (million €)</td>
<td>€3,996m (10% 41)</td>
<td>€4,107m (41%)</td>
</tr>
<tr>
<td>Public Funding (million €)</td>
<td>€746m (18% 19)</td>
<td>€676m (19%)</td>
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<tr>
<td>Cost (million €)</td>
<td>€389m (11% 61)</td>
<td>€364m (11% 61)</td>
</tr>
<tr>
<td>Burden (DALYs lost, thousands)</td>
<td>20,502 (2%)</td>
<td>20,839 (15%)</td>
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Brain research is underfunded

The total funding of brain research p.a. is only 1% of the annual cost of brain diseases.
The burden and cost of brain diseases are twice those of cancer.
Brain research receives, per unit of cost or disability:
- 50% of the total funding of cancer research
- 25% of the public funding of cancer research
- 10% of the charity funding of cancer research

*Not a high enough priority for politicians, media or the general public*
Media analysis

Snapshot of press coverage on brain diseases compared to other major chronic diseases

Search of English-speaking media of European origin in last 3 months

- Cancer: 41,236
- Diabetes: 9,303
- Cardiovascular diseases: 9,563
- Mental health: 5,633
- Brain diseases: 82
Moving a disease up the political agenda – the cancer example

2002
Europe Against Cancer Ended

2003
Council Recommendation on Cancer Screening

2006
MEPs Against Cancer (MAC) group established

2007
European Parliament Written Declaration on Cancer

2008
Slovenian Presidency focus on Cancer (January - June) + Council Conclusions on Cancer (June)
EP Resolution on Cancer (April)
EC Report on Cancer Screening (June, December official)

2009
Communication on Cancer Launch of Cancer ‘Platform’ / partnership

EU CHANGES: New European Parliament and European Commission
Measure of lost health – (disability-adjusted life years)

35% is Brain Disease
The Cost of Parkinson’s

Figure 3.8.1 Cost distribution in Parkinson’s disease

- Uncompensated Care 18.8%
- Inpatient Care 19.9%
- Outpatient Care 7.5%
- Prescription Drugs 4.4%
- Productivity Loss 49.4%

Source: (23).

Neurological Disorders
Public Health challenges
WHO 2007
The world is living longer

...a baby girl born in Japan has a 50/50 chance of living 100 years
The role of women
In the 1920’s, a couple in their 80’s had 44 female relatives
• 14 of these did not work outside the home environment

In the year 2000, a couple in their mid 70’s had 13 female relatives
• 3 of these did not work outside the home environment

What is the situation in 2009?
Provision of cultural competent care
Time with the doctor

12 minutes
Only the patients and their families know precisely:

• how a disease can impact on daily life

• how specific treatments or management strategies can influence its quality
Caring for the Carers

A Guide for carers

Assessment of carer health status and quality of life in PD
This campaign is aimed at

• Decision makers
• Opinion leaders
• Scientists & researchers
• Healthcare professionals
• People with Brain disease and their families
• General public
Distress is not enough!

Patient advocacy groups need to:

- Establish credibility
- Collect evidence
- Contribute to discussions
- Understand health technical assessments