Why IMI matters to Europe’s patients group

Dr Mary Baker, MBE
President, European Brain Council
President, European Federation of Neurological Associations
The WHO global burden of diseases

Measure of lost health – (disability-adjusted life years)

35% is Brain Disease

2004 EBC study showed that 127 million Europeans suffer from a brain disorder (27%) and costs €386 billion

2011 Study - how much has this grown?
The cost of Parkinson’s

Figure 3.8.1 Cost distribution in Parkinson’s disease

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

Source: (23).

Neurological Disorders
Public Health Challenges
WHO 2007

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The world is living longer

A baby girl born in Japan has a 50/50 chance of living 100 years
The changing 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 2011?
Provision of ‘culturally relevant care’

The challenge of migration
Time with the doctor

.....12 minutes

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Access to medication

A very uneven playing field

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Globally an estimated 2000 people die daily through Counterfeit Medicines
2008 ‘Project Medifake’ European Customs initiative discovers...

- 3 million packs captured over two months
- 4 MHRA batch recalls in 2007
- EAASM found 62% of medicines bought from internet to be fake or substandard (Counterfeit Superhighway - 2008)

EU Legislation anticipated - this will tighten supply chain
... in production

WARNING

GMP Colombian style
Ingredients include:
Boric Acid
Lead-based road paint
Shoe polish
Brick dust
Profit before patients!

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The way forward

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Launch of Innovative Medicines Initiative
IMI Achievements

- IMIDIA
- SUMMIT
- eTOX
- SAFE-T
- MARCAR
- U-BIOPRED
- Open PHACTS
- ProACTIVE
IMI Achievements

• NEWMEDS: Schizophrenia

• Database: Depression

• PHARMACOG: Alzheimers

• EUROPAIN: Chronic Pain
Delegates at the first meeting of EFNA’s initiative ‘Pain Alliance Europe’ in preparation for its launch on 29 Nov 2011 in the European Parliament
Education & Training Project

• Innovative training programmes including:
  • SafeSciMET
  • PharmaTrain
  • EU2P: Certificate & Masters courses plus new PhD programme
  • EMTRAIN

• Publications in highly respected peer-reviewed journals
Age of the Elderly

The shape of things to come:

*The world stands on the threshold of a social transformation - even a revolution - with few parallels in humanity's past.... perhaps two-thirds of all people who have ever reached the age of 65 are alive today.*

Peter G. Peterson
Clinical Trials

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Safety versus Innovation

Education of benefit/risk

Quote from cancer patient:

‘I am already in an unsafe world, a little more unsafeness doesn’t worry me’
Trust and Transparency

• Suspicion of the pharmaceutical industry

• Who is more important to them - patients or shareholders?
... from the bench to the bedside

Preclinical & clinical development
~ 8 years

New drug application & review
~ 2 years

HTA review
~ 2 years

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... from the bench to the bedside

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Moving forward

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Need Multi-disciplinary partnership

• The grand challenge of society requires co-operation and partnership from a range of stakeholders

• Creating high performing networks is essential

• European Brain Council and European Year of the Brain are examples of this in practice
The UK Health service is ‘completely unprepared’ to deliver personalised genome-based medical care....

Sir John Bell
Threats

Communicating scientific ideas to a non-scientific audience is not easy:

• Failure to plan for the future
• Lack of incentives for commercial development
• Unsuitable evaluation procedures for genetic tests
• Widespread lack of understanding of the uses of genetic testing by health care professionals
The challenge for the future

Management of long term chronic illness

- The ability to *adapt* and self manage
- To be able to participate in social activity despite all limitations
Congratulations to IMI

• Successfully tackling diseases for which there is currently no cure e.g. Alzheimers, diabetes, asthma

• Actively involving patients

• Actively communicating much needed information to the patients
What matters most

‘It is not the strongest of the species that survives nor the most intelligent that survives. It is the one that is most adaptable to change.’

Charles Darwin
1809 - 1882
Still I learn

Engraving by Goya at the end of his life