# EBC Manifesto for 2014 European Elections





## The European Brain Council Manifesto for the 2014 European Union elections

Brain disorders, including developmental, pain, psychiatric and neurodegenerative diseases, represent an enormous disease burden in terms of human suffering and economic cost.

The European Brain Council speaks with one voice on behalf of one third of the European population affected by these disorders. We represent a vast network of patients and their care-givers, doctors, scientists and industries. By bringing together science and society we strive to improve lives of those affected by brain disorders.

Every five years European citizens have a say on what is important to them when they take part in the European Parliament elections. In 2014 these elections coincide with electing new European Commission leaders. Both institutions have already contributed in many ways to improve the quality of lives of those affected by brain disorders. Nevertheless, we are still facing enormous medical and societal challenges in this field. These challenges need the right level of priority, and a lot will depend on newly elected EU Officials and we are calling them to commit to the following priorities:



## 1. Brain research requires more attention and funding

Costs of brain related disorders – 800 billion EUR per year



Brain-related disorders are expected to affect at least one in three persons during their lifetime – 165 million people in Europe, costing some €800 billion every year. The cost is comparable to that of cardiovascular diseases, cancer, and diabetes put together. As society ages, these numbers will increase further.

According to WHO brain disorders account for 35% of the burden of all diseases in Europe. They may become the major medical need of the 21st century.

Return on investment in brain research far exceeds the return from any other branch of research.

#### EBC's call for action

There are severe deficiencies in available effective treatments and service provision is insufficient, together causing sufferings to patients and families.

The European Commission and national governments should make brain disorders a top priority topic. They should strengthen existing program initiatives and incentivize innovation in this field.

# 2. Complexity of brain requires interdisciplinary approach

Modern neuroscience has been enormously productive but unsystematic.



Fragmentation of brain research and lack of systematized data are making it difficult to understand how the brain works.

There are more neurons in the brain than there are stars in the galaxy. Human brain forms more than 1 million new connections among the neurons each day. Because of the complexity of brain, it takes up to 35% longer to develop drugs for brain disorders than other drugs.

#### EBC's call for action

There is a need to move beyond isolated studies of individual disorders and investigate brain diseases systematically. Interdisciplinary research approaches should be particularly encouraged, e.g. by bringing fields such as information technologies, social, environmental and educational sciences, economics, law and humanities together with traditional brain sciences disciplines.



## 3. The role of patients and caregivers has to increase

Patients play increasingly active roles in the "triangle from research and policy to practice".



The patients' role in healthcare has transformed over years from being passive recipients to becoming active and responsible actors in their own health management. Quality of care depends a lot on skills of patients for the day-to-day management of their disease. Reliable, accurate and comprehensive information for patients, their families and carers became absolutely crucial.

#### EBC's call for action

Patients and caregivers should be actively involved in the planning of research approaches, execution of services and maintenance of standards of healthcare practice. Efficient implementation of "eHealth" solutions can help create a health sector that is more safe and friendly for patients and caregivers.

## 4. Clinical trial rules need major revision

More efficient Clinical Trials will boost competitiveness and improve access to innovative treatments.



Getting a drug to market takes hundreds millions of Euros. The number of failures in clinical trials is high. Many patients are overlooked (e.g. fewer than 10% of Parkinson's patients ever take part in trials), despite overwhelming interest in working with scientists to help speed treatment breakthroughs.

#### EBC's call for action

Innovative and more relevant approaches to clinical development have to be taken. This requires changes in the regulatory landscape. Relevant population groups such as children and elderly, and those with comorbidity must be better integrated in the process. Patients need to be recruited early.

# 5. Brain drain from Europe should be tackled with more vigour

European policy makers have to take all necessary steps to reverse the trend.



The pharmaceutical industry is moving out of Europe for administrative and economic reasons such as lack of a single European patent and time consuming and expensive registration procedures. Movement away from research in brain is even more serious. To a large extent the move is politically determined because of stricter regulations for some drugs with an effect on the brain.

#### EBC's call for action

European policy makers should take all necessary steps to encourage and incentivize industry and investors to engage in brain research. Political action can include improving regulatory policies, development of financial and tax incentives, simplification of procedures and reducing bureaucracy.



## 6. Coordinated national strategies can make all the difference

No single European country has the resources to achieve the required scale and quality of research.



There is a need to develop or refine national strategies on brain research within an overarching European context. Successful examples of national strategies in other research areas, such as cancer, already exist in Europe. What is clearly required is a coordinated policy covering disorders of the brain in general, mental and neurological alike, because together they constitute by far the biggest health problem in the EU.

#### EBC's call for action

National policies in each European country should adopt national plans addressing brain diseases according to the specific situation in their country. This will help promote health of the citizens and limit the immense and expanding cost of brain disorders. More coordination should be taking place between member states and the EU.

## 7. Europe's investment in health needs to increase

European research and development investments in health have stagnated.



The healthcare sector accounts for 8% of the total European workforce and 10% of the EU's GDP. It is the basis for a strong life industry of pharmaceuticals, sciences biotechnology and medical devices. Yet, European research and development investments in health have stagnated since 2010, for the first time after decades of annual increases. The findings are worrying in the light of Europe's increasing disease burden and ageing population, as well as the millions of people whose health cannot be improved without health new care approaches.

#### EBC's call for action

Europe's R&D investment in health needs to increase. This will have a number of positive effects including improved health that leads to better productivity among the working population. Health R&D investments also have the potential to provide high economic yields, both in terms of return on investment and in producing and deploying a highly educated workforce with technical skills.



## 8. A strategy is required to reduce harm caused by alcohol

Alcohol consumption is one of society's biggest health and economic challenges.



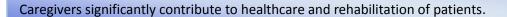
Within the EU, 14.6 million people are affected by alcohol dependence, and 195.000 premature deaths are caused by excessive use of alcohol. It is estimated that alcohol consumption causes up to 60 different diseases.

Alcohol dependence does not only come with great personal consequences, it also represents a huge burden to society and has immense consequences to the families of those suffering from an alcohol-use-disorder.

#### EBC's call for action

An integrated and comprehensive strategy is required to reduce the health and social burden caused by harmful alcohol consumption. Political regulation on e.g. pricing and availability of alcohol should be coupled to secondary prevention measures such as early diagnostics, and interventions as well as screening problem drinkers.

## 9. Caregivers have to receive adequate attention and support





During the past 50 years, a shift towards community care and de-institutionalisation of psychiatric patients took place, often transferring the responsibility of patient-care to informal caregivers. Caregivers significantly contribute to healthcare and rehabilitation of patients and a good example is schizophrenia: According to a study of caregiving, they spend an average of 6–9 hours per day providing care. This places a significant burden on caregivers, who can experience adverse health effects, such as stress and depression.

#### EBC's call for action

Despite caregivers' good intentions and hard work, they do not always have the knowledge and skills to support the patient and themselves in the best way. Timely and adequate support and education for caregivers will therefore not only benefit the patients, but also remove a significant burden from caregivers and improve the issues of both.



## 10. An epidemic of depression requires urgent measures

More than 350 million people of all ages suffer from depression worldwide.



Depression is a common, serious and in some cases life-threatening condition and more than 350 million people of all ages suffer from depression worldwide. According to the WHO depression is the leading cause of disability. It is also the most predominant mental health problem among working-age patients, which is why depression in the workplace is a leading cause of lost work productivity, sick leave and early retirement.

#### EBC's call for action

National legislations should provide for prevention, screening and early diagnosis of depression in the workplace. Thanks to this work productivity will not be lost due to absenteeism or presenteeism.

There is a need for adequate treatment – a crucial factor in reducing symptoms and improving employment prospects for people with depression. Depression-related stigma remains a major concern for patients: efforts must be made to tackle it so those afflicted are able to come forward and seek treatment.

## 11. Dementia needs to remain a high public health priority

The total number of people with dementia is projected to almost double every 20 years.



Dementia and in particular Alzheimer's disease have considerable social and economic implications. There is no treatment currently available to cure dementia or to alter its progressive course. Dementia is overwhelming for the families of affected people and for their caregivers. Physical, emotional and economic pressures can cause great stress to families and caregivers, and support is required from the health, social, financial and legal systems.

#### EBC's call for action

Despite no treatment currently available to cure dementia, much can be done to support and improve the lives of patients, their families and caregivers. An appropriate and supportive legislative environment is required to ensure the highest quality of service provision to those affected by dementia and public and private efforts need to be strengthen to improve care and support for people with dementia.