



**A consensus Statement by the *Belgian Brain Council*
(BBC)¹ for the adoption of a NATIONAL BRAIN PLAN**

¹ The *Belgian Brain Council (BBC)* is a non-political platform gathering 19 scientific societies, 25 patients associations and 24 pharmaceutical companies www.braincouncil.be.



Why do we need a National Brain Plan?

The Facts

Brain disorders hit 3.3 million Belgians - or 1 Belgian out of 3 (38.2% of the population of the EU as estimated in 2010) [1]. These diseases are multiple and include amongst others Alzheimer's disease and other dementias, schizophrenia, depression, stroke, migraines, epilepsies, Parkinson's disease, multiple sclerosis, sleep disorders, chronic pain, autism, addiction to drugs and alcohol and brain tumors. .

Their prevalence is increasing due to the increase in life expectancy but also because of a number of socio-economic, environmental and behavioral health determinants that are still poorly understood.

Their causes are heterogeneous ranging from degeneration or immune processes to developmental and functional abnormalities, and frequently implicate a complex interplay between genetic and environmental factors. A better understanding of these causes is mandatory to improve treatment and primary or secondary prevention. Most brain disorders are chronic, often associated with acute episodes during their course, and they can be accompanied by long-term, complex health problems and multi-morbidity, the impact of which tertiary prevention aims to soften.

Brain disorders are responsible for 35% of total disability due to all human diseases [2] and their cost is constantly growing, estimated in Belgium at € 18 billion per year with an increase of 42% over the last 6 years [3]. In Europe, the annual cost for brain disorders is estimated at € 798 billion of which 60% of direct and 40% of indirect costs [4].

Besides the great disability ensuing from a malfunctioning brain, we must remember that maintaining the brain in optimal operating condition affects the survival and progress of human societies. Understanding the organ that enables us to perceive, think and act is one of the greatest challenges of the twenty-first century.

The brain is our most precious patrimony and we as well as human society have the crucial obligation to maintain it in an optimal functional state. The prevalence of brain disorders is high and increases with increasing life expectancy. Brain disorders are a burden for patients and caregivers, and costly to the society.

The Needs

Some countries have addressed the challenge of increasing knowledge on the brain and decreasing disability due to brain disorders, and significantly increased their efforts to promote the neurosciences. Unfortunately, Belgium is lagging behind: the public funding of research on the brain and its disorders is barely 15% of the funds invested in medical research [2], which contrasts with 35% of global disability caused by brain disorders. While billions around the world are invested in Artificial Intelligence, more needs to be done to boost studies of the human brain that allows developing the former, after all.

Since 2010, reforms of health systems in Europe are calling for more savings and efficiency with high societal value (improving the quality of life of patients and reducing the burden related to mental and neurodegenerative diseases). The challenges are multiple because of the medical, social, and economic impact of chronic diseases, which emphasizes the need for an ambitious, more efficient, patient-empowering research policy and a transversal approach to brain disorders, including: action programs extending over the whole life course focus on prevention, "patient-centered" strategies, optimization of health care services encompassing multi-disciplinary motor, cognitive and social rehabilitation.

The proposal

With this joint statement the Belgian Brain Council wants to call for a **National Brain Plan** to be planned in consultation with the federal and decentralized entities, teams of experts in the brain and its disorders (basic and clinical neuroscientists, psychiatrists, adult and pediatric neurologists, neurosurgeons, pharmacists, physiotherapists, neuro-nurses...), patients associations and the private sector including private foundations.

This will need a pluri-annual scientific effort requiring human and financial resources. We propose the following major general objectives:

- 1) to build a comprehensive observatory of brain research activities in Belgium and explore innovative initiatives seeking to do for the neurosciences what the Human Genome Project did for genetics
- 2) to prioritize measures that aim at improving efficacy and efficiency of care for brain-diseased persons disorders such as creating a central registry for brain disorders and ongoing clinical trials, promoting bio-banks and brain excellence networks, looking at what could be mainstreamed from other current Plans (Rare Diseases Plan, Cancer Plan, ...) and involving patients' representatives in health plans.
- 3) to promote novel therapeutic approaches for brain disorders, including new technologies like 'omics' that allow for a better understanding of metabolic network process and more effective as well as more rapidly accessible therapies.

Needless to say that the project holds the potential of paving the way for advances in Artificial Intelligence (and not the other way around) and of providing, besides a medical, an economical benefit.

The growing demand for health care services and pressure on social security will continue in the future for brain disorders. The BBC calls for a **National Brain Plan** to improve efficacy and efficiency of research on the brain and its disorders as well as health care for them.

NBP strategy

The goal of the Plan is aligned with targeted efforts in providing responses towards lowering the impact of common and disabling conditions and finding solutions to tackle to huge costs represented by these disorders for our Federal/Decentralized Health Budget.

The Plan will have major returns in terms of population health, productivity and quality of life.

The goal is also to better integrate recent neurosciences progress, to strengthen the arsenal of therapeutic tools (pharmacological, non pharmacological and psychosocial interventions) to prevent and treat patients with neurological or mental illness.

A work document detailing Workpackages, Milestones, Deliverables and Fundraising is under construction and will be distributed before the end of 2016

Belgian context

Numerous across-diseases initiatives have been established by the federal government in concert with the federal entities, with a positive impact in Belgium (the chronic disease plan, the cancer plan, the "Psy107" reform of mental health care, the plan for rare diseases, the recent joint plan on integrated care for better health adopted in 2015 and currently in the implementation phase with the selection of pilot projects).

Other initiatives, such as the currently ongoing reform of hospital financing, the e-health plan, the reform of the Royal Decree 78 related to the health professions, and the 2014 Royal Decree on "unmet medical need", the 2015 agreement with the pharmaceutical industry for a better harmonization of prices, and the legislation formally recognizing informal caregivers should also be mentioned among others as to serve the improvement of the quality of life of patients, optimization of health care and cost rationalization.

Proposals of the Belgian Brain Council for innovative interventions and objectives of the Brain Plan

To unite and to mobilize all stakeholders in biological, cognitive and clinical neuroscience, to grant them the necessary resources, to benefit from more flexible arrangements, to establish more fertile bridges between the public and private sectors in research, to get closer to the patients and their families, to work together with patients' associations but also to further spread knowledge, these are the main objectives of the Brain Plan and of the Belgian Brain Council [5].

The national research effort, both in financial and human terms, will only be effective if it is part of a long-term strategic vision to lead in the national and European context", as stipulated by the European Brain Council in its "Call for Action 2015" [6].

The birth of an ambitious, long-term National Brain Plan is a major public health priority in our country. This initiative is promoted internationally since the World Health Organization (WHO) and the European Commission support the adoption of such a plan [7,8].

The Brain Plan also aims at improving the national and international visibility of our research system and our work in neuroscience and at boosting exchanges. Essentially, the proposals in this Brain Plan are devoted to different aspects of research including, if possible, and according to the therapeutic progress, the following pillars: 1) prevention, diagnosis and information to the patient; 2) optimization of care; 3) knowledge and clinical information, 4) governance and sustainability.

The analysis of the inventory (report to come) will treat/analyze more in depth the strengths and weaknesses of what exists now (by conducting a SWOT analysis and a needs assessment):

- Audits by a Committee of Experts (to be established) will be needed to assess rigorously the research efforts in neuroscience in the broad sense: in research organizations, universities / university hospitals and general hospitals.

Twenty to thirty people (representative of Belgian society) should be contacted to participate in the work of the mission and to ensure the feasibility of the proposed actions. All will join the main conclusions of this statement with rapid developments particularly through the implementation of prioritized measures and a significant increase in resources.

- This Brain Plan could also have the justified ambition to improve the policy of care in neurology, neurosurgery, and psychiatry. This second complementary and indispensable step, which will require the contributions of other experts, should be considered without delay, especially in the field of psychiatry, neurology, and neurosurgery, but also in the field of pediatrics, geriatrics, paramedics in anticipation of aspects of integrated care (currently the engine of any initiative) and the social and economic situations which we will soon face.

Task force, experts and advisors

The BBC Working Committee (Task Force) includes for now already 7 people (N. Beugnier-cabinet Ministre Bacquelaire, F. Destrebecq-EBC, T. Hawrot-EBC, V. Quoidbach-consultant, R. Pochet-BBC, L. Le Roy BBC, J. Schoenen-BBC) and should be completed.

This group could also be expanded into more specific meetings on very specific subjects.

References

- [1] Cost of disorders of the brain in Europe 2010. Gustavsson A et al. Eur Neuropsychopharmacol. 2011 Oct;21(10):718-79
- [2] http://www.belgianbraincouncil.be/fr/archives/bbad_2015.html
- [3] Cost estimates of brain disorders in Belgium. Schoenen J., Franco G., Schretlen L. and Sobocki P. Acta Neurologica Belgica 2006, 106: 208-214
- [4] The economic cost of brain disorders in Europe. Olesen J et al. Eur J Neurol. 2012 Jan; 19(1):155-62.
- [5] TEN GOOD REASONS TO INVEST IN THE BELGIAN BRAIN COUNCIL ...AND THE BRAIN !. Schoenen J and Pochet R (2016). Front. Aging Neurosci. Conference Abstract: 6th Belgian Brain Congress. doi: 10.3389/conf.fnagi.2016.03.00001 or http://www.frontiersin.org/events/6th_Belgian_Brain_Congress/3500/abstracts
- [6] <http://www.braincouncil.eu/activities/news/value-of-treatment-project-report-from-2016-first-semester/>
- [7] **WHO Global action plan** for the prevention and control of NCDs 2013-2020 : <http://www.who.int/nmh/publications/ncd-action-plan/en/> , **WHO Global action plan** on mental health 2013-2020 http://www.who.int/mental_health/action_plan_2013/en/ , **WHO Regional Office for Europe** : The European Mental Health Action Plan 2013–2020 , <http://www.euro.who.int/en/publications/abstracts/european-mental-health-action-plan-20132020-the> **WHO World Health Assembly** adopted resolution on Epilepsy, May 2015 <http://www.who.int/mediacentre/news/releases/2015/wha-26-may-2015/en/>
- WHO Executive Board** (Jan 2016) adopted a decision requesting the WHO Director-General to develop a Global Action Plan on Dementia http://apps.who.int/gb/ebwha/pdf_files/WHA69/A69_Jour1-en.pdf?ua=1

WHO World Health Assembly adopted resolution resolution on the global strategy and action plan on ageing and health 2016-2020 <http://www.who.int/mediacentre/news/releases/2016/wha69-26-may-2016/en/>

[8] EU Joint Action on Mental Health and Well Being 2013-2016, see final report :

[http://www.mentalhealthandwellbeing.eu/assets/docs/publications/Framework%20for%20action_19jan%20\(1\)-20160119192639.pdf](http://www.mentalhealthandwellbeing.eu/assets/docs/publications/Framework%20for%20action_19jan%20(1)-20160119192639.pdf) **EU Joint programme** on Neurodegenerative Diseases :

<http://www.neurodegenerationresearch.eu/> **EU Joint Action** on Chronic diseases and healthy ageing

CHRODIS : <http://www.chrodis.eu/> **EU Framework** for Research and Innovation Horizon 2020

<https://ec.europa.eu/programmes/horizon2020/>