

17 September 2019

OPEN LETTER

To:

*European Commission President, Ursula von der Leyen  
Health Commissioner-Designate, Stella Kyriakides  
Commissioner-Designate for Innovation and Youth, Mariya Gabriel  
European Parliament President, David Sassoli  
European Parliament ENVI and ITRE Committee Members  
Chairs of European Parliament political groups*

One of the largest challenges our ageing societies face is the increasing prevalence and burden of non-communicable diseases. We feel that EU-level action is necessary to prevent diseases and promote healthy lifestyles, supported by a framework for tackling non-communicable diseases that will ensure equitable access to high-quality healthcare.

In the Political Declaration on Non-Communicable Diseases (NCDs), which arose from the UN's High-Level Meeting on NCDs in 2018, all Governments recognized that *'mental disorders and other mental health conditions, as well as neurological disorders, contribute to the global burden of NCDs'*. This resulted in adding 'mental health' as the '5<sup>th</sup> NCD', complementing global efforts to combat cancer, CVD, diabetes and chronic respiratory diseases.

We very much welcome this initial move – as we believe that the time is right for a significant increase of global efforts to address brain health.

According to the study conducted by the European Brain Council *Cost of Disorders of the Brain in Europe* at least 1 in 3 people will experience a brain disorder in their lifetime, with a total cost of brain ill-health in Europe alone estimated to be €800 billion each year (more than the cost of all major disease areas such as cancer, CVD and diabetes combined).

Recently, the Global Burden of Disease Study Group found that neurological disorders formed the world's largest cause of disability adjusted life years [DALYs] in 2015 (250.7 m), an increase of 7.4% from 1990. Further, in terms of mortality, the study revealed that they are the second largest cause of global death, i.e. 16.8%, with a 36.7% increase in the period 1990-2015 despite reductions in age-standardised rates (*Lancet Neurology. 2017;16(11):877-897*).

More recently, the study: *Burden of brain disorders in Europe in 2017 and comparison with other non-communicable disease groups* demonstrates that brain disorders (mental and neurological alike) constitute the most prevalent disabling and burdensome disease among NCDs in the European population.

In fact, brain disorders account for 20.8 million years lived with disability and 34.6 million DALYs. This equates to 34.5% and 26.9%, respectively, of all those associated with NCDs. They caused 1.2 million deaths: 24.3% of those associated with NCDs. The results show that brain disorders in Europe account for 26.8% of the total burden associated with NCDs.

Due to differences in methodologies, and the recent inclusion of stroke under the heading of neurology in ICD 11, these numbers are in a stark contrast to many other studies and statistics used to inform the work of the EU Institutions, such as the annual Eurostat report "Causes and occurrence of deaths in the EU", where diseases of the nervous system are seen as just a tiny fraction (4%) of all causes of deaths.

From an under-estimated, under-recognized and under-resourced group of conditions, neurological disorders are now a major challenge for health policy worldwide. To counteract this, sufficient priority and resources have to be provided for disease prevention and mitigation, management and treatment, in line with measures related to the five main risk factors related to NCDs.

Evidence shows that brain research has the highest potential in terms of return on investment, far exceeding the return in any other area (*Brain research has high returns, but Europe is lagging behind: European Journal of Neurology 2007*). Investing in prevention, early detection and diagnosis, treatment and care in neurology have also been shown, by the European Brain Council's *Value of Treatment white paper (The value of treatment policy white paper: towards optimizing research and care for brain disorders. Brussels: European Brain Council; 2017)*,

to be cost-effective. Essential to confronting these issues is a clear understanding of them by governments, health planners and systems.

Against this backdrop, we are concerned that the European Institutions and EU Member States have not adequately integrated neurological/brain health within their portfolio of work on NCDs, reflecting the enlarged scope as outlined above. This may, in part, be because the terminology used by the WHO is implicitly including neurological disorders within its internal and external texts on 'mental health' – with no explicit mention of 'neurology' or use of the more encompassing term of 'brain health'.

Despite a number of EU initiatives in this field, we feel that a broader, long-term and strategic portfolio of work in the area of neurology and brain health is urgently needed to counteract the disease burden demonstrated above.

Perhaps one channel to ensure neurology is included within the EU's work on NCDs is via the Steering Group on Health Promotion, Disease Prevention and Management of NCDs? Until now, the Steering Group has focussed on specific NCDs such as CVD, cancer and, more recently, mental health. Neurological/brain health should be considered as a distinct priority for 2020 or 2021.

Neurological/brain health should be addressed through integrated, coordinated and co-operative efforts, both at the European and national level. This could be based on best practice in other disease areas – for example, rare diseases, diabetes and cancer. In fact, whilst we commend the Commission in proposing its 'Europe's Beating Cancer Plan', we should also ensure that neurology and other NCDs are not left behind. In fact, this ambitious work on developing a cancer plan for Europe could, if successful, be seen as a template for other non-communicable diseases to follow. We would be very happy to discuss how a broader model for tackling cancer and other NCDs in Europe could be developed and rolled out, with a view to achieving SDG 3 (particularly 3.4 and 3.8) by 2030.

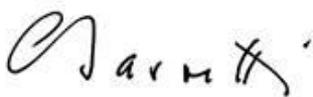
In summary, we call upon the European Commission, European Parliament and Member States to:

- Give more visibility and priority to neurological/brain health, as per the enlargement of the scope for NCDs that was adopted at the 2018 UN High Level Meeting on NCDs. This now includes mental disorders **as well as neurological disorders** as so called 5th NCD.
- Make neurological/brain health a distinctive priority for the Steering Group on Health Promotion, Disease Prevention and Management of NCDs for 2020 or 2021.
- Give more attention to improving brain health, as a whole, in European and national policy priority settings – from both the medical and socio-economic perspectives. As such, the EU should develop a unified strategy to promote brain health and curb the prevalence of brain disorders. Such action should have as one of its key components coordination and support for development of National Brain Health Plans in all EU countries – based on the 'Europe's Beating Cancer Plan'.
- Acknowledge and use data from the recent studies demonstrating the exceptionally high burden of brain disorders in terms of mortality, disability, prevalence and economic impact.

We thank you in advance for your attention and we very much hope that you will consider this data and our requests, to the benefit of millions of people who will be affected by brain ill-health at some time in their lifetime.

We, Presidents of the undersigned organisations remain at your disposal to work with you to make this happen.

Yours sincerely,



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President  
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Prof. Monica di Luca  
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Joke Jaarsma  
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European Federation of  
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