

15 June 2020

Open letter

To: European Commissioner for Health and Food Safety Stella Kyriakides
Cc'ed to: European Commission President Ursula von der Leyen
European Commission Vice President Margaritis Schinas
European Parliament President Roberto Sassoli
European Parliament, ENVI Chair, V-Chairs and coordinators
European Parliament, EU4Health rapporteur and shadow rapporteurs

Dear Commissioner Kyriakides,

It has never been clearer that good health is our most important value, both in the European Union and beyond. This unequivocal fact must be reflected in the appropriate level of attention and priority that the EU awards to public health - the Covid-19 crisis has opened our eyes to its real significance.

Against this backdrop, the European Federation of Neurological Associations and the European Academy of Neurology:

- Welcome the recent announcement of the new, standalone EU4Health Programme, with a substantially increased financial envelope of 9.4 billion Euros. We are convinced that this can truly set the stage for a Union that does more in the field of public health. *The State of Health EU 2019* published by the European Commission shows that health promotion and disease prevention clearly matter.
- Hope that EU Member States will consider giving the EU more health powers; understanding that this would directly contribute to healthier populations, more resilient and future-proofed healthcare systems and stronger economies in their respective countries.
- Appreciate that the EU4Health programme recognises the impact of non-communicable diseases. We concur that they are amongst the biggest challenges facing EU health systems.

At the same time, we are concerned that DG SANTE has not integrated neurological health into its NCD response and does not seem to have any plans to do so. This was confirmed in the [answer to the Parliamentary written question](#) provided in April 2020.

This is difficult to understand given the evidence on the immense prevalence and burden of neurological illnesses, not just on healthcare systems but also socio-economically. Many of these disorders affect those of working age, not only our ageing populations. In fact, neurological disorders are the leading cause of disability worldwide, and the second leading cause of mortality. Amongst NCDs, brain disorders account for the greatest burden in Europe. And, worryingly, the numbers are increasing. ***(More details are provided in the Appendix below the logos.)***

However, the SANTE website, strategic documents and, now, details on the EU4Health programme repeatedly state that cardiovascular diseases, cancer, chronic respiratory diseases and diabetes, represent major causes of disability, ill-health, health-related retirement and premature death in the Union. Whilst this is true, it is not the full picture. Therefore, it is with conviction that we need to complete this narrative and it is with concern that we note how the Commission has not taken note of critical developments in global health priorities where the UN and WHO have added neurological disorders to the 5 priority NCDs – alongside mental health.

This emphasis on neurological health was underlined by the recent consolidated report of the WHO Director General to the World Health Assembly, which stated:

“existing high-level commitments – such as the SDGs agenda, NCDs and UHC policies have not afforded neurological conditions the political priority on national agendas that they require and fall short on tangible global commitments specific to reducing the burden of neurological disorders”.

Therefore, we believe that the European Commission should create strategic linkages between neurological health and global high-level commitments that would result in an integrated approach to all neurological disorders. An illustration of this is given in the recent WHO report, which stated:

“...in order to achieve universal health coverage as part of the Sustainable Development Goals, synergies are needed in addressing neurological conditions in order to understand their common denominators (risk and protective factors), burden and shared challenges.”

We believe that this can be effectively carried out through a specific strand of work within the EU4Health programme.

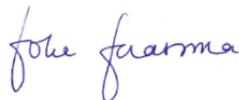
Therefore, we call on the Commission to acknowledge the full burden of neurological disorders and to take concrete steps to fully integrate neurological health into its main priority areas in the field of NCDs.

This is particularly important as we move into the post-pandemic recovery phase, which negatively affected the neurological health of many of those already living with these disorders – as well as creating neurological complications for some of those diagnosed with Covid-19. Yet the focus has been on people living with other NCDs. We need to ensure the voices of these patients – at least 1 in 3 people across Europe! – are heard in the shaping of the post-pandemic recovery and the future health planning and programme delivery.

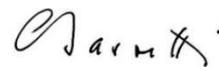
We remain at the disposal of the Commission services to further discuss and assist in driving this agenda forward. We offer our expertise, including experience of people living with neurological disorders.

With kind regards,

Joke Jaarsma, President
 European Federation of Neurological Associations



Prof. Claudio Bassetti, President
 European Academy of Neurology



ENDORSERS:

Ewa Kopacz, MEP, EPP, Vice-President of the EP

Frédérique Ries, MEP, Vice-Chair, Renew Europe

Jerzy Buzek, MEP, EPP, Former President of the EP

Miriam Dalli, MEP, S&D Vice-President

Kateřina Konečn, MEP, GUE/NGL, shadow rapporteur for the EU4Health Programme

Jarosław Duda, MEP, EPP

Tilly Metz, MEP, Greens – EFA



APPENDIX

SYNOPSIS OF RECENT DEVELOPMENTS IN THE FIELD OF NEUROLOGICAL HEALTH

- The Political Declaration on Non-Communicable Diseases, which arose from a UN High-Level Meeting in 2018, where all Governments recognized that “mental disorders and other mental health conditions, **as well as neurological disorders**, contribute to the global burden of NCDs”. ‘Mental health’ – including neurology - was added as the ‘5th NCD’, complementing global efforts to combat cancer, CVD, diabetes and pulmonary disease.

5X5

DISEASES



Cardiovascular Disease



Chronic Respiratory Diseases



Cancer

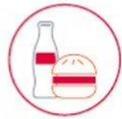


Diabetes



Mental and Neurological Conditions

RISK FACTORS



Unhealthy Diet



Tobacco Use



Harmful Use of Alcohol



Physical Inactivity



Air Pollution

Figure 1: Five major NCDs along with their risk factors, NCD Alliance

- Universal Health Coverage Political Declaration on Non-Communicable Diseases endorsed by Heads of States and Governments at the UN High-Level Meeting on UHC in 2019, which underlines the importance to “implement measures to promote and improve mental health and well-being as an essential component of universal health coverage, including by scaling up comprehensive and integrated services for the prevention, including suicide prevention, as well as treatment for people with mental disorders and other mental health conditions **as well as neurological disorders**”
- Consolidated report by the Director-General, stemming from the Decision by the WHO Executive Board 2020 (EB 146[8]) to **scale up implementation of measures to reduce the burden of neurological disorders**. The report discusses on five pages the burden of neurological disorders and suggests a number of solutions. It also notes that “**existing high-level commitments – such as the SDGs agenda, NCDs and UHC policies have not afforded neurological conditions the political priority on national agendas that they require and fall short on tangible global commitments specific to reducing the burden of neurological disorders**”. It adds that only 24% of countries have stand-alone neurological health policies.

KEY STATISTICS ON NEUROLOGICAL HEALTH

We ask the Commission to acknowledge the full burden of neurological disorders that has been captured in the following findings:

- As reported by Lancet Neurology in 2017, **neurological disorders form the world's largest cause of disability**¹
- Over the past 30 years, the absolute number of deaths due to **neurological disorders** has increased by 39%. In 2016, they accounted for 9 million deaths per year globally, making them **the second leading cause of death worldwide after cardiovascular diseases**^{2 3}
- **One in three people has a neurological disorder at some point in their lifetime worldwide**⁴ and in Europe⁵
- **Brain disorders cost Europe €800b annually, more than all major disease areas combined**⁶
- **Brain disorders constitute the most burdensome disease group among NCDs in Europe**⁷
- After sixty-two years of officially categorizing stroke as a Disease of the Circulatory System, the newly published **WHO International Classification of Diseases (ICD 11)**⁸, has classified stroke as a **Disease of the Nervous System**. Stroke affects the brain and it is evident that stroke patients should be taken care of by neurologists. We call on the European Commission to take this change into account and reflect this fact in publications such as "Causes and occurrence of deaths in the EU" by Eurostat.

¹ (Lancet Neurology. 2017;16(11):877-897).

² World Health Organization, Consolidated report by the Director-General, A73/5; 12 May 2020: 8-12

³ (Lancet Neurology. 2017;16(11):877-897).

⁴ World Health Organization, Consolidated report by the Director-General, A73/5; 12 May 2020: 8-12

⁵ The economic cost of brain disorders in Europe. Eur J Neurol. 2012; 19(1):155-62 (ISSN: 1468-1331)

⁶ The economic cost of brain disorders in Europe. Eur J Neurol. 2012; 19(1):155-62 (ISSN: 1468-1331). For comparison with other disease areas see: Economic burden of cancer across the EU: a population-based cost analysis (2009); European Cardiovascular Disease Statistics (2012); Economic Impact of Diabetes (2010)

⁷ Raggi A, Leonardi M, Burden of brain disorders in Europe in 2017 and comparison with other non-communicable disease groups, Journal of Neurology, Neurosurgery & Psychiatry

⁸ ICD-11 for Mortality and Morbidity Statistics (Version : 04 / 2019)