

# EVENT REPORT

## Brain health as a global priority – time for the EU to act now!

Co-organised by EFNA, EAN and EBC

Hosted by Mr Jaroslaw Duda MEP

Chaired by Mr Frédéric Destrebecq, Executive Director EBC

18 February 2020

The event was attended by more than 100 participants from leading organisations in the field of brain health. It brought together policymakers, clinicians, scientists, healthcare companies, patient advocates and carers to share knowledge and perspectives on brain health and urge the EU to act on this issue.

The event was hosted by MEP Jaroslaw Duda, under the patronage of five members of the European Parliament across five different political groups:

- **Ewa Kopacz**, Vice President of the EP, European People's Party [EPP]
- **Miriam Dalli**, Vice-Chair, Group of the Progressive Alliance of Socialists and Democrats [S&D]
- **Frédérique Ries**, Vice-Chair, Renew Europe [Renew]
- **Kateřina Konečná**, European United Left–Nordic Green Left [GUE/NGL]
- **Tilly Metz**, Group of the Greens/European Free Alliance [Greens - EFA]

**Mr Jaroslaw Duda MEP** introduced the event emphasizing that brain is the most amazing structure in the body, the 'engine of progress' in our society but also sensitive to disorders.

Mr Duda highlighted that the growing burden of brain disorders is not only due to ageing, but that we are also seeing more mental and neurological disorders across the spectrum.

**Ms Joke Jaarsma and Prof Claudio Bassetti, respectively President of European Federation of Neurological associations (EFNA) and President of the European Academy of Neurology (EAN)**, welcomed the participation of many key stakeholders from both EU and global levels.

With more than a third of the population affected by a brain disorder, Prof Bassetti stressed the urgency for the EU to act now, or the incidence will continue to increase. Some brain disorders are very frequent such as migraine, others are less frequent but devastating said Prof Bassetti who insisted on the need to apply science and increase awareness.

Ms Jaarsma indicated that mental health and neurological disorders were both included in recent UN Declaration's on Non-Communicable Disease and Universal Health Coverage. This was an important milestone for neurology. It is now essential to make sure that this progress can be translated both at EU and EU Member States level, said Ms Jaarsma.

**Ms Ewa Kopacz MEP** explained that brain disorders are responsible for 27% of the burden of non-communicable diseases in Europe, but that these can be prevented, in some case, by inexpensive means. She also insisted on the importance of addressing stigma, discrimination and inequitable access to healthcare, as well as the need for more investment in research. This was highlighted by

several speakers during the event. She also suggested that the effort on the cancer mission and the EU's 'Europe's Beating Cancer Plan' could be used as a blueprint for brain disorders.

### Session 1: Brain health as a global priority – why now and what now?

Introducing the series of presentations under the theme of 'Brain Health as a Global Priority: Why Now and What Now?', **Prof Guenther Deuschl, Past President of the European Academy of Neurology**, indicated that the prevalence of neurological diseases is very high in the EU 28, representing 16% of the total European disease burden. The data showed significant differences in the distribution of neurological diseases between European regions. He added that these figures should, however, be interpreted bearing in mind that some patients – particularly the elderly – have double or triple diagnoses.

Prof Deuschl shared data, extrapolated from the database of the Institute for Health Metrics Evaluation, University of Washington, USA to show that the prevalence, disability and mortality in relation to neurological diseases is growing.

Stroke is main contributor to DALYs in the EU-28 with 35%, followed by dementia (25%) and headache (23%).

However, he said that the burden per patient could be decreased as the tools and therapies exist in many cases. The problem is in the structure of healthcare systems, availability of the healthcare workforce i.e. neurologists and access to treatment, services and supports.

He drew attention to the EBC Value of Treatment projects which provide a number of evidence-based solutions for pressing healthcare issues in brain disorders.

**Dr Francesca Sofia, member of the European Regional Executive Committee of the International Bureau for Epilepsy**, shared her perspective as the mother of a daughter with severe epilepsy, but also an active patient advocate

She indicated that 30% of patients do not respond to epilepsy treatment.

Advancements in research can be made thanks to new research models, coupled with meaningful patient engagement. Innovative approaches are on the way and big data opens new possibilities.

"My trust is stronger than my fear. I see a sparkle of hope. Research can rid us of neurological disorders if scientists and stakeholders work together," she said.

**Dr Anette Storstein, Head of Board at the Norwegian Brain Council** described the significant efforts made by Norway in relation to brain health. A 'brain plan' was initiated by 4 patient organisations together with the Norwegian Brain Council and medical professionals in 2014 and a brain health strategy was adopted in 2017.

In 2018, the Directorate of Health initiated an action plan with 4 objectives: Prevention and life-long brain health; Focus on the needs of patients and caretakers; good medical care and life-long perspectives; high-quality research and innovation. Dr Storstein outlined the challenges in implementing the brain plan as: Secondary prevention in brain disease; overlap between mental and neurological disorders and investing in competence among professionals.

She informed the participants that the Norwegian Research Council has decided that the theme for 2020 will be 'brain health'.

"Brain diseases are underestimated, undervalued and underfinanced," said Dr Storstein. "Alliances between scientists, healthcare professionals, patients, carers and politicians are the most powerful to make progress."

**Ms Nina Renshaw, Director of Policy and Advocacy at the NCD Alliance** explained that the highest burden of non-communicable diseases (NCDs) like those of the brain is on people of working age (and not due to ageing) and in the EU 80% of the healthcare expenditures goes to NCD treatment.

Non communicable diseases have common risk factors. Air pollution was added to the 4 usually mentioned: unhealthy diet, tobacco use, harmful consumption of alcohol and physical inactivity.

She explained that there is huge potential in tackling comorbidities and common risk factors and to put prevention of all NCDs at the heart of the EU's cancer plan. . Despite the benefits of acting on NCDs outweighing the costs of inaction, the investment gap remains immense.

Ms Renshaw shared data showing the significant mismatch between global health funding and burden of diseases.

**Dr Dévora Kestel, Director of Mental Health and Substance Use at WHO** showed data on the disparities between low income and high-income countries in terms of policies for neurological disorders but also in terms of the neurology workforce.

WHO is developing tools for use in primary care in countries where specialised neurologists do not exist. It designed a dedicated programme for reducing the epilepsy treatment gap. It is estimated that 70% of people with epilepsy do not receive treatment.

Priority work areas for WHO's Regional Office for Europe include stroke and dementia (e.g. Global Dementia Observatory). Dr Kestel highlighted that Parkinson's Disease is growing more in European regions than globally and advised to take this into consideration for advocacy and awareness raising.

She indicated that WHO is developing a paper on integrated approaches in brain health which will require input from interested parties. It will address all neurological and brain health conditions across the life course.

She explained that during the WHO Executive Board in early February, Member States requested WHO to prepare a report on "Synergies in addressing the burden of epilepsy and other neurological disorders" for review in May 2020.

She concluded by outlining the goals of the new WHO Brain Health Unit which include to strengthening policies, health information systems and research in the area of brain health, as well as providing guidance on how to formulate an integrated approach to brain health conditions and increase investment in this area.

## Session 2: Brain health as a global priority: EU opportunities

**Mr John Ryan, Director of Public Health, Country Knowledge and Crisis Management, DG Santé.**

Mr Ryan explained that the EU will assist with the implementation of the Sustainable Development Goals (SDGs). These include important health related goals. To this end, DG SANTE brought together the Steering Group on Health Promotion and Prevention of NCDs. Unfortunately, no work has taken place in the area of neurology. Although mental health was a focus area in 2019.

The group also looks at research and public health and there will soon be a library of best practices ready to be rolled out member state level.

Reintegration of people with chronic diseases at work, is high on the EU political agenda explained Mr Ryan. He mentioned the joint action on chronic disease, Chrodis+. Here there is a work package on employment in which groups such as EFNA and EFNA are involved as collaborating partners.

He also encouraged the groups to optimise the Health Policy Platform to ensure that brain health was visible therein.

Twenty-four European Reference Networks (ERNs) are in place in the field of rare disorders, including one on rare neurological disorders.

Mr Ryan indicated that the Joint Action on Dementia has ended. Nevertheless, EU Member States continue to work together, and Alzheimer Europe has received funding from the European Commission Health Programme and supports the WHO platform on dementia.

Discussions for the first two years of Horizon Europe are underway: "It is now the time to tell us exactly where we should be investing," said Mr Ryan. The workplan will be published in the course of this year.

He mentioned the new pharmaceutical strategy under preparation by the European Commission that will address access to innovation: "Access to innovative medicines and treatments should be in everyone's interest," he stated.

The cancer plan is a priority for the next five years. He said that this may serve as a template for brain disorders, but he also cautioned against pursuing only this approach. He mentioned work that the EC had undertaken on vaccines and AMR, and suggested that these approaches may be more relevant and replicable.

In concluding, Mr Ryan drew attention to the opportunities to flag issues on brain health in the frame of the EU Pillar of Social Rights and the European Semester process

**Miriam Dalli MEP, Vice-Chair, Group of the Progressive Alliance of Socialists and Democrats** said that brain health and mental health are underappreciated and underfunded issues: "We must raise awareness. It might be uncomfortable to speak about it - but we must do it. Every organ in your body can get ill, and so can your brain" said Dr Dalli.

She suggested that the cancer plan could perhaps be used as a template for brain health.

She shared her view that people affected can still contribute to the society and prioritising brain health should also be high on the agenda of the Member States and the regions. Dr Dalli highlighted the need to pay attention to children who are also affected.

**Tilly Metz MEP, Group of the Greens/European Free Alliance** shared her experience as chair of the Multiple Sclerosis Society of Luxembourg and raised the need to give more visibility to brain health in the political agenda at EU and global level: "The reality is that people are at risk of discrimination and social exclusion and giving the voice to patients is important," said Ms Metz.

**Mr Ortwin Schulte, Head, Health Unit, Permanent Representation of Germany to the EU**, explained that in the World Trade Organisation (WTO) and in the World Food Programme (WFP), EU is a member and not the EU Member States, while in the WHO, the EU Member States are members which is more challenging. He said that better coordination was needed amongst the EU member states at WHO. In terms of the upcoming German EU Presidency he reassured the audience that: “This topic will not be forgotten.”

**Dr Karim Berkouk, Deputy Head of Unit E2, Combatting Diseases, DG Research and Innovation** provided the EU health research perspective. He indicated that there are still opportunities to get involved in shaping the agenda of Horizon Europe, and getting involved in the ongoing Horizon 2020.

### Key points

- Norway has a brain health strategy since 2017. Norwegian Research Council has decided that the theme for 2020 will be ‘brain health’. (A. Storstein).
- Several speakers insisted on the importance to address stigma, discrimination and equal access to healthcare in addition to research.
- The highest burden of non-communicable diseases (NCDs) like those of the brain is on people of working age (and not due to ageing) and in the EU 80% of the healthcare expenditures goes to NCD treatment. (N. Renshaw).
- There is a significant mismatch between global health funding and burden of diseases. (N. Renshaw).
- Parkinson is growing more in European regions than globally. This should be taken into consideration for advocacy and awareness raising (D. Kestel).
- WHO is developing a paper on integrated approaches in brain health which will require input from interested parties. It will address all neurological and brain health conditions across the life course. (D. Kestel).
- WHO Member States requested WHO to prepare a report on “Synergies in addressing the burden of epilepsy and other neurological disorders” for review in May 2020. (D. Kestel).
- The EU will assist with the implementation of the sustainable development goals. Priority topics in the field of prevention include mental health. A library of best practices is ready to roll out at member states level. (J. Ryan).
- Discussions for the first two years of Horizon Europe are underway. It is now the time for stakeholders to say where the EU should be investing. The workplan will be published in the course of this year. (J. Ryan).
- There is a new pharmaceutical strategy under preparation by the European Commission that will address access to innovation (J. Ryan).
- The EU Pillar of Social Rights may provide opportunities to flag issues on brain health. (J. Ryan).
- Several speakers suggested to use the cancer mission/plan as a template for brain research/health. The ‘EU vaccination action plan’ and the ‘EU antimicrobial action plan’ were also mentioned as being possibly better templates.
- Germany and the three subsequent presidencies of the EU have decided to focus on public health, where brain health could be included (O. Schulte).