Anette Margrethe Storstein – Chair of the Board, Norwegian Brain Council

> Norway has unfulfilled innovation potential. There is a lot to be gained from an environment where pharmaceutical companies, research groups and clinicians can interact

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Anette Margrethe Storstein MD PhD of the Norwegian Brain Council introduces the burden of neurodegenerative disease in Norway today, the ongoing impact of the country's National Brain Plan, and Norway's untapped potential in neuroscience R&D.

Could you begin by giving us an introduction to your background and expertise in neurodegenerative diseases?

I have been a neurologist for almost 25 years. I work as a senior consultant at the University Hospital Haukeland, mostly with neurodegenerative disorders and neuro-oncology. My scientific activity is in neuro-immunology and neuro-oncology.

My full-time job is as a clinician with research activities on the side and for the last five years, I have been on the board of the Norwegian Brain Council, with the last two years as chair.

Can you introduce the Norwegian Brain Council and your key priorities since taking over as chair of the board in 2019?

The Norwegian Brain Council was the second such organisation established in Europe in 2007 and from the beginning aimed to promote the health of the brain and the nervous system among the entire Norwegian population – an ambitious goal! The broad spectrum of our statutes includes working for improved diagnostics, prevention, treatment and follow-up, and draws on patients and caregivers' experiences. We are involved in research promotion, and increasingly, we have become more of a lobby organisation, giving statements to the authorities and arranging meetings between various stakeholders.

Our role is to be a facilitator. We publicise the impact of brain disease in both social and traditional media, and through meeting with politicians. This is an important task, given the gap between the social impact of brain disease and the amount of money invested in prevention and research. We work for continued brain research at the highest level possible.

In 2015 our primary target was to establish a national brain health strategy, which was launched three years ago by the Minister of Health. The follow-up and operationalisation of this strategy still represent a major task for us. We also work on informing the public about brain health in general as well as the prevention of brain disease and its costs, through social media platforms.

What is the Norwegian Brain Council's level of alignment with the European Brain Council?

The European Brain Council is the EU umbrella organisation, but since Norway is not a member of the EU, we only have observer status. Although slightly complicated by this, we have an active and collaborative approach and attend meetings, correspond regularly, and try to contribute at the European level.

What is your membership base?

We do not have individual membership in the Brain Council, only organisations. These 61 member organisations are split into three different categories: research groups and institutes; organisations for professionals such as neurologists, neurosurgeons and specialised nurses; and organisations for patients and caregivers, which each make up a third of our total membership.

An ageing population such as that of Norway brings with it a rise in diseases such as Alzheimer's and Parkinson's. How do you assess the burden of brain disease in Norway today and how do you see it evolving?

We are actively using the statistics from the Global Burden of Disease Project to create an accurate assessment of this disease burden. Professor Lars-Jacob Stovner at NTNU in Trondheim is collaborating with the GBD project, and has aided in the interpretation of the Norwegian data. The GBD data are very useful to our purpose, really showing the impact of brain disease.

Brain disease is classified into different ICD-10 categories; for instance, stroke has so far been included in the group of cardiovascular disease. Thus, disease classification does not correctlyshow the total burden of brain disease.

The main burden of disease will be in neurodegenerative disorders, in particular dementia. By 2040, we estimate that there will be maybe 200,0000 people with dementia in Norway, twice the number of affected persons today. These numbers are very useful in our efforts to raise awareness of brain disease, as we want to use facts and not hyperbole.

This will make the most important impact but of course, several other brain diseases are increasing in prevalence as well, as people live longer.

What progress has been made since the rollout of the Norwegian Brain Plan in 2017?

We are of course impatient as to the progress of concrete measures, and keep up the pressure to ensure that the aims of the Brain Plan are fulfilled. One positive development was a large allocation of funds to establish a national centre for clinical research in neurodegenerative diseases and MS, one year ago. Also, we are participating in a partnership with the Directorate of Health where the Brain Council is represented. This partnership is going to run until 2024 to facilitate various tasks, one of which is to improve the care of headache patients on a national, multi-layer level. We also work for a national strategy to improve good critical care of acute brain disease.

Another major victory from the strategy is the fact that ‘brain health’ has become a term in general use among politicians, in the population, and among health professionals. We are very eager to promote an understanding of the brain as a whole, including both mental and physical symptoms.

Finally, allocation of funding to research in brain science is on the rise, thanks to a number of highly competent scientific environments and collaborations. We wish to promote the recruitment of young scientists and successful and clinically relevant neuroscience now and in the future.

What changes are you advocating for right now as part of the Brain Plan?

A very pressing issue is to ensure that patients with acute and chronic disease receive predictable and geographically equivalent health services, covering the whole course of the disease from diagnosis through therapeutics, rehabilitation, collaboration and coping of patients and caregivers. Our aim is to ensure that all patients have a pre-destined course with a personalised approach.

Professor Bastiaan Bloem developed a model for multidisciplinary follow-up for Dutch patients with Parkinson’s disease, ParkinsonNet. We are currently establishing a Norwegian version, for patients with Parkinson’s disease. Eventually, we would like to have modified models of care for all chronic diseases of the brain, to ensure that patients receive optimal treatment, follow-up and social services.

What work is currently being done in terms of neurodegenerative research in Norway today?

Norway has unfulfilled innovation potential. There is a lot to be gained from an environment where pharmaceutical companies, research groups and clinicians can interact. Logistics will be important in promoting these interactions and the Brain Council is very keen to help facilitate this wherever it can. Establishing a forum where people can meet on quite an informal level to exchange ideas and network would be a good start.

One of the most serious, yet often underplayed threats to come from the COVID-19 crisis is the rise of loneliness, depression, and lack of sleep and their consequent effect on brain health. What kind of response would you like to see to stem this looming mental health crisis?

Collaboration with patient organisations is crucial. One positive development that we have seen during the pandemic is that the patient organisations have been very active, interacting with their members, setting up helplines, creating digital platforms, and making short videos with good advice for the maintenance of brain health. Patient organisations are major stakeholders in the prevention of these illnesses.

This is especially true for groups supporting patients with chronic brain disease, who easily become isolated if shielding and refraining from their regular activities. The same is true for patients with psychiatric disorders, brain tumours, immunosuppressed people and so on. This has been an extremely challenging time, but close collaboration with patient organisations can be a major cornerstone for the future.

What are your motivations to continue to work in neurology and brain diseases?

I have always been fascinated by the brain. Brain disease is fundamental and affects the patient on so many levels as well as affecting caregivers and society as a whole. There is also a lot we do not know about the brain in health and disease, meaning that it is an incredibly interesting field for research. Finally, I enjoy working with people over time, to aid and interact with my patients and their families.

What are your predictions for the future of neurology?

Looking back ten to 20 years, neurology was at a completely different place. So much has happened since then. I expect the whole field of brain disease treatment, both neurological and psychiatric, to change in the future decades.

We are standing at a crossroads and considering the progress we have made in genetic, molecular and radiological diagnostics, we are bound to see major breakthroughs in the near future. These are exciting times and the potential is huge!

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