



'Brain Health for Neurology: Opportunities and Risks'

MEETING REPORT FROM THE ROUNDTABLE DISCUSSION

Monday, December 5th 2022, 14.00-15.30hrs CET.

BACKGROUND TO THE EVENT

Neurology is, now more than ever before, in a strong political position following the adoption in May of this year of the World Health Organization's (WHO) 10-year *Intersectoral global action plan on epilepsy and other neurological disorders* and with the NCD (Non-Communicable Diseases) Healthier Together Initiative strand on mental health and neurological disorders.

It is time to prioritise neurology and speak with one voice on issues such as stigma, isolation and discrimination together with those facing the same issues in the mental health community. This can be achieved within the brain health context. The brain health momentum across Europe and indeed the globe provides an opportunity to address many public health issues and to encourage research for both neurology and mental health. We are stronger together.

However, in recent months there has been confusion among patient groups, researchers, industry and even policymakers about what the drive towards brain health means to them. Will neurology as a whole be included in discussions around brain health? Will some neurology sectors be excluded under this context? Does brain health only include neurology when linked to mental health? Are brain health, mental health and neurology three separate entities? The current state of play for many, in one word, is 'confusion'.

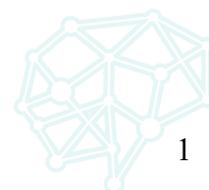
For EFNA, use of the term 'brain health' only makes sense when all of neurology is included; either independent of any mental health conditions or in combination with them.

EFNA will advocate to ensure neurology as a whole progresses through discussions, programs and frameworks under the context of brain health.

MEETING REPORT

The meeting was opened by EFNA's Executive Director, **Dr. Orla Galvin**, who welcomed representatives of EFNA's membership, industry partners and other stakeholders.

Prof. Paul Boon, President of the European Academy of Neurology (EAN), was due to share a presentation on the EAN's Brain Health Strategy but regrettably was unable to attend at the last moment. Fortunately, Orla was able to present the slides on his behalf.



Orla began by saying that the EAN is an ally of EFNA, particularly when it comes to advocating for neurology under the context of brain health. THE EAN strive to support the patient community through continuously advancing neurological therapy and care across Europe.

Prof. Boon's slides first take us through some important statistics. In terms of prevalence of neurological conditions we know that one in three are affected by neurological conditions in their life course and that these conditions cause the highest socioeconomic burden of all NCDs. On average in Europe there is only one neurologist to serve every approximately 15,000 people and for every million inhabitants of Europe there are on average only 10 neurological in-patient facilities.

The EAN take a holistic approach to defining brain health. They recognise that healthy brains mean fewer neurological conditions and happier people. Promoting good brain health in Europe will lead to lower prevalence of neurological conditions, a reduction in Disability Adjust Life Years (DALYs) and increased life expectancy. Enhanced treatment, diagnosis and care is crucial to the EAN Brain Health Strategy. Under the EAN's Brain Health Strategy a number of challenges and gaps have been identified:

- treatment breakthroughs for many neurological conditions are still insufficient
- the neurological workforce is insufficient
- funding for brain and neurological research is still limited
- determinants and assessment of brain health are unclear
- scientific evidence for the prevention of neurological disorders is limited
- awareness about neurological disorders and brain health is insufficient

The EAN will take a three-strand approach to tackling brain health determinants: Preserve, Protect and prevent, and Plan. Preservation includes encouraging mental and physical activity, healthy diet, good quality sleep etc. Protection and prevention includes avoidance of excessive alcohol, not smoking, reducing sugar intake and lowering cholesterol levels. Hypertension, excessive weight, depression, diabetes, hearing impairments and cataracts are also factors which can have significant impact on brain health. Finally, planning: factors which must be addressed by policy makers include access to education, environmental factors such as air pollution, political situation, research strategies and socio-economic conditions. There are Five Pillars to EAN's Brain Health Strategy:

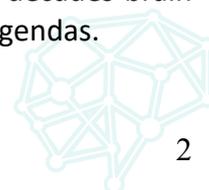
1. Contributing to a global and international Brain Health Approach
2. Support International and National policy making
3. Fostering research
4. Promoting education
5. Raising public awareness

Orla finished by thanking the EAN once again for sharing their slides with us and encouraged attendees to learn more about the organisation's activities via their website (www.ean.org) or by following @EANeurology on social media.

Tadeusz Hawrot, EFNA's Senior Policy Advisor, then led us through the policy developments that have been made in recent years regarding both neurology and brain health.

Tadeusz explained that science is only waking up to understanding the most complex material we have discovered in the Universe – the human brain.

Collectively, brain disorders represent a global threat to individual well-being, economic productivity and intellectual capital. But this understanding has been growing only recently. For decades brain disorders had been largely absent from the global health research and public health agendas.



This is because neuroscience had been believed to be difficult to understand and, consequently, was a low priority for research investment.

However, knowledge around neurological disorders and the possibilities to treat them have made extraordinary advances in the last few decades. We can diagnose and treat more and more neurological disorders. Underpinning this, we have a growing understanding of fundamental biological mechanisms underlying many brain disorders. This is one reason why brain health is gaining popularity.

Another reason was publication of the World Bank's 1993 Report *Investing in Health* which popularised Disability Adjusted Life Years (DALYs). Before that, the global disease measurements (such as the Global Burden of Disease project – GBD) were primarily captured in terms of mortality (i.e. premature deaths). With the rise of DALYs, the importance of brain disorders became evident, accounting for approximately 28% of the global burden of disease.

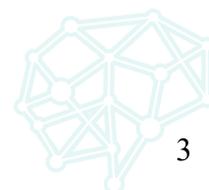
We have also seen an epidemiological transition from Communicable Diseases (CDs) to Non-Communicable Diseases (NCDs) due to changes in the patterns of mortality. NCDs became the leading cause of mortality in the world and a vast body of knowledge started accumulating on the immense opportunities for global action to control them.

In 2011 a UN meeting launched a high-level declaration, looking at four NCDs, but brain health/neurology had to wait another decade to be included. In 2018, at the 3rd high-level meeting of UN, mental health and neurological disorders were added to the NCD agenda. WHO have blurred lines by historically incorporating neurological disorders under a broader term of mental health conditions. Tadeusz reminded attendees that language used is extremely important- something EFNA has continued to raise with WHO and others.

In 2019, EFNA made a strategic decision to 'go global', understanding that in order to see proper recognition of neurology as a priority NCD in Europe, we need to first make sure it is seen as such globally (the European Commission adopts global approach to addressing NCDs). In doing so, we quickly recognised that there was a need at global level for a stronger, more coordinated and strategic voice, advocating for full recognition of neurology as a distinct discipline and advocating for the bringing together of WHO activities addressing various neurological conditions into one comprehensive framework. A global platform bringing together the voice of people and organisations representing people living with neurological conditions was needed and as a result, EFNA co-founded the OneNeurology initiative with EAN.

During the years of EFNA's global engagement, we have closely followed, co-shaped and nurtured the WHO's growing recognition that neurological conditions need a strategic and comprehensive global framework. Along the way, we have seen and endorsed their use for the first time of the term 'brain health' at the 2019 Mental Health Forum (EFNA attended this event in Geneva and participated in relevant discussions), the creation of the WHO Brain Health Unit in 2020 and the growing impetus at WHO member state level to address neurology as one, seen at the WHO Executive Board and World Health Assembly meeting. All these finally resulted, in May 2022, in the adoption of the *Intersectoral global action plan on epilepsy and other neurological disorders*, which OneNeurology contributed to. This was followed in August by publication of a position paper on 'Optimizing brain health across life'. The paper offers "a framework for understanding brain health and the importance of brain health optimization for all". It defines brain health as

"the state of brain functioning across cognitive, sensory, social-emotional, behavioural and motor domains, allowing a person to realize their full potential over their life course, irrespective of the presence or absence of disorders".



Brain health, according to WHO, spans “a continuum that can be considered to range from well-being to disorders and disability”.

In recent years, EFNA made a strategic decision to use language promoting neurological health/conditions rather than ‘brain health’. We felt that there has been a need to first strengthen neurology before coming back to the brain health umbrella. This being said, we do recognise that focusing on one or a grouping of brain diseases rather than on brain health holistically is an artificial approach that has led to unfortunate divisions. There has been a historically siloed approach to neurology and psychiatry, or division of the brain and the mind. This approach is perpetuated by long-standing institutional divisions, with progress towards a more integrated view happening largely from the bottom up, as researchers and clinicians collaborate and break down the silos.

The conceptualisation of brain health is also attracting increasing attention from outside the traditional health sector. The best example of this trend might be efforts led by the Organization for Economic Co-operation and Development, better known as OECD. Its Neuroscience-inspired Policy Initiative which gave birth to the Brain Capital Grand Strategy stems from an understanding of brain health not only as key to improving health and quality of life but also as “a pathway to understanding the new economic and social reality”. As such, it argues that “in our brain economy, investments in brain health and brain skills are critical for post-COVID economic renewal, re-imagination, and long-term economic resilience”.

Regrettably, the EU Commission has been maintaining to the narrative that the main NCDs are cardiovascular, respiratory and diabetes, while failing to show neurological disorders as the high priority area they are. Neurology and brain health have been a blind spot. For this reason, EFNA has tried to raise awareness by calling on the European Commission for a brain health strategy. EFNA has launched calls to action, sent memos, letters and shared policy recommendations. Ultimately the Commission has had to listen and have now added mental health & neurological disorders to their NCD Initiative as a priority strand.

Tadeusz closed by looking to the future. From 2025, it is hoped that we will see a Brain Health Partnership run by DG Research, where significant resources will be invested into improving our understanding of the brain and ultimately improving our brain health.

Following Tadeusz’s presentation we moved to **our short poll**. The first question posed to the group was:

In your opinion, does the current momentum around brain health present an opportunity or risk to your community?

Encouragingly, 100% of respondents see this as an opportunity.

Our second question, with results shown to the right, was:

Which of the following do you believe to be most true?:

- Brain health encompasses primarily neurology – 8%
- Brain health encompasses primarily mental health – 0%
- Brain health encompasses both neurology and mental health – 85%
- Brain health, mental health and neurology are three separate entities – 8%

Our third question was:

In your opinion, are peripheral nervous systems included in the context of brain health?

Results here were not so clear-cut, with 36% saying yes, 14% saying no and 50% unsure.



Finally we asked:

Do you feel that you have an opportunity to influence action under the context of brain health conversation?

We were pleased to see that 92% of our attendees feel they do have that opportunity.

Following our polling we moved to a presentation by **Prof. Mayowa Owolabi**, OneNeurology Ambassador. OneNeurology is the only global partnership where patients, clinicians, and researchers come together to advocate for neurological conditions as ONE.

Prof. Owolabi has defined brain health as

“..the complete functioning of the brain across the life course to support the physical, mental, social and spiritual wellbeing and quality of life of an individual towards attaining and maintaining the epitome of a meaningful, impactful, purposeful and productive life.”

Without brain health it's impossible to have good physical/mental health, says Prof. Owolabi. Brain health is important to every sphere of health. The brain is the controller of our central nervous system and our peripheral nervous systems, meaning that both these things come under brain health.

Prof. Owolabi feels that given the recent policy progression, we have entered 'The neurology revolution'. He led the recent publication of a paper of this title in The Lancet Neurology. He states that protecting and promoting brain health adds years to life, adds life to years, adds meaning to life, and therefore is necessary to bring people toward self-actualisation. Brain capital consists of knowledge and creative skills that allows people to realise their potential as productive members of society. Brain health is a component of this.

Prof. Owolabi has developed 'The Brain Quadrangle' to represent the need for a synergistic approach to brain health across the life course. Through this he calls for (i) establishment of a framework for research and surveillance at local, national and International levels, (ii) implementation of integrated population-wide prevention strategies, (iii) acute care services, including workforce training and (iv) rehabilitation- promotion of access to interdisciplinary care, training for caregivers and capacity building of community health workers.

Prof. Owolabi concluded by speaking on the importance of collaboration. He shared an African proverb: *“If you want to go fast, go alone. If you want to go far, go together”*.

We were then honoured to be joined by **MEP Kateřina Konečná**, a Czech MEP and member of the Left Group in the European Parliament. Ms. Konečná has been a longstanding supporter in the European Parliament of both neurological and mental health.

Two years ago, she worked with EFNA to campaign for neurological disorders to be listed amongst the priority non-communicable diseases in the EU4Health programme text. Ms. Konečná suggested to her MEP colleagues several amendments recognising neurological conditions as a priority NCD area and spoke in support of their inclusion at the hearing of the Parliament committee on health and environment. This was successful. As a result, we now have a EU non-communicable diseases initiative Health Together which has mental and neurological disorders as one of the priority strands.

A few weeks ago, at the Parliament plenary debate, Ms. Konečná called upon the EU to create a comprehensive long-term strategy for mental health, mirroring the EU Plan to fight cancer. In fact,



she believes that what Europe needs is a brain health strategy, bringing together mental and neurological health. She said this is because millions of EU citizens are affected by brain disorders and member states will only be able to take on the challenge if they work together.

Similar existing and successful initiatives show that even if health remains a national responsibility, it is clear that joint European action can create considerable added value by confronting the major challenges in brain health in a more efficient way, helping to avoid ineffective action or the duplication of roles, as well as encouraging better use of available resources.

“Brain health is our most vital asset and healthy brains need to be put right at the heart of Europe health policies”.

Ms. Konečná concluded by saying that she will continue to support EFNA’s work to the end of her mandate and that she hopes we can achieve many good things together in 2023.

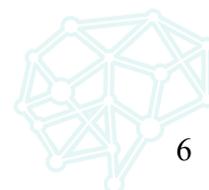
Following MEP Konečná’s intervention, Orla asked a question of **Frédéric Destrebecq**, Executive Director at the European Brain Council (EBC). Given that the EBC represents both neurology and mental health communities they have had long-term involvement in the discussions on the definition of brain health. Do they see a risk here, or synergies and opportunities for both communities? Fred responded that EBC’s approach to brain health is to hold neurology and mental health on equal footing and said he was glad to see that that approach was shared by the majority of attendants at the meeting. He believes that neurology and mental health are intimately connected and therefore EBC will strive in a collective fashion to drive common advocacy. “We don’t see any value in starting to fragment the community or fragment the narrative” he says; something that would lead to a degree of duplication. The EBC instead aims to build a common understanding of what the collective priorities for the future are, in terms of brain research.

During the open discussion section of the meeting a number of EFNA’s member representatives and industry partners shared their thoughts:

Arlene Wilkie, Director General at Stroke Alliance for Europe (SAFE) raised a problem that affects many of EFNA’s members- a lack of resources. It is difficult for a group to know how best to prioritise their work and how to advocate for brain health, when they are so limited already in the disease-specific activities they can undertake.

Sebastian Winter, Head of Policy and Research at the International Bureau for Epilepsy (IBE), said more needs to be done to bring psychiatry, neurosurgery, neuropediatrics and anaesthesiology on board; to really shape the message that brain health, as such an overarching term, can be shaped by these disciplines. He also suggests that more needs to be done to disentangle the problem of brain health encompassing peripheral nervous system diseases because there are conditions such as diabetic neuropathy affecting 30 million people worldwide- something that could also come under brain health awareness. There is work to be done to ensure that everyone is on the same page and to make sure that brain health truly encompasses these peripheral and neuromuscular disorders.

Stephanie Ludwig, Global Patient Partnership Chapter Lead in Neuroscience at Roche, commented on the complexity of brain health and asks how to we can progress most quickly? Her concern is not the group attending today, but rather the wider community. She mentions Brain Awareness Week (March) and asks whether that is a moment when we can work together to raise awareness.



Orla responded that EFNA are indeed making plans for this and will be in touch with all partners on the topic very soon.

Vanessa Pott, Patient Engagement Lead at Boehringer Ingelheim, explained that while their focus as a company is primarily on psychiatry, value is seen in recognising one community and one voice under brain health and then acting individually when that is appropriate.

“For me it's clear we have a lot to gain from working together but also there might be areas where we don't want to water things down too much”, she said.

Mark Sterckel, Sr. Patient Engagement Director at Alexion, says Alexion has launched a multi-stakeholder working group, in which both EFNA and EBC are represented. The group that is looking at setting priorities and at areas where we can work together. He issued an invitation to other groups, particularly other industry partners, to join the initiative.

Arabela Acalinei, President of the European Association of Neuromuscular Disorders (EAMDA), sees brain health as very important. Arabela lives with Charcot-Marie Tooth (CMT) syndrome and has a child with epilepsy. EAMDA are working to strengthen efforts in brain health advocacy, particularly relating to neuromuscular disorders. Arabela would like to be kept updated on EFNA's work in this area and is very glad to see that EFNA is not leaving peripheral nervous systems to one side. “Together we can have the best impact at European and national level” she said.

To conclude the meeting, we heard from EFNA's President, **Joke Jaarsma** who felt that the slide in Prof. Boon's presentation, showing challenges and gaps, painfully illustrates the position neurology is in, with the recurrence of the word 'insufficient'. Joke concluded by saying

“Today has strengthened our view that for us at EFNA, it is of the utmost importance to see neurology as the driving force in brain health actions. We will continue our engagement in the discussion on how to prevent illness and how to restore and optimise brain health.”

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