



The need for a Global Neurology Alliance



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ABSTRACT

Background: With increasing rapidity of advances in neuroscience and widening gaps in the accessibility to quality neurological care the risks of unpreparedness are growing.

Method: To summarise the potential risks to the equal provision of neurological care and the resources available to improve the ability to plan and respond to the unexpected.

Results: To describe three examples of cooperative effort involving the World Federation of Neurology acting in concert with other neurological organisations.

Conclusion: A global alliance of neurological organisations meeting and communicating regularly and willing to act rapidly and in concert is an essential prerequisite to managing emergent crises.

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1. Introduction

In recent times there has been an explosion of health awareness recognised by individuals, nations, and the global community. The decade of the brain was followed by the human genome project accompanied by the near eradication of malaria and polio to mention a few. Yet we now stand at the threshold of even more rapid advances on many fronts. 3-D printing of the human heart is being utilised in planning cardiac surgery, Next-Genome Sequencing is now revolutionising old concepts of disease, gene therapy shows success in some inherited neuropathies (spinal muscular atrophy [SMA]) and myopathies (Duchenne), Precision medicine is no longer an aspiration in some diseases and countries and the ability to utilise publicly accessible data via expanding cloud technologies is yielding unexpected information and the repurposing of medications. Conversely the cost of drug development, especially in bringing them to market, is becoming prohibitive, exacerbating the accessibility of therapies in many countries.

For the thoughtful and the less fortunate it is also obvious that the developing progress, while exciting and to be celebrated, is creating problems that need to be addressed. The increasing burden of non-communicable diseases (NCD) which includes mental (neurological) and substance abuse disorders; musculoskeletal disorders; and neurodegenerative conditions such as dementia, stroke and Parkinson's disease; as well as poor lifestyle choices in diet and exercise, and the effects of unhealthy environments [1] together with the changing demographic of ageing populations in so-called developed countries, all add up to what can only be viewed as a potential tsunami for the economies of the world.

Those people and countries least able to afford the advances and/or to mobilise services to adjust to them will see a widening gap, not only in these areas of disease but also in their ability to respond to the periodic recrudescence of infectious disease as was seen with the outbreaks of Ebola, MERS, SARS, and most recently the Zika emergency. It is not by chance either that the recent waves of mass migration have occurred as much because peoples seek better lifestyles (and health services) as fleeing armed conflict.

It is in this environment that those in the neurological fraternity need to mobilise and to prepare measures at a number of different levels which will mitigate the consequences of these changes. To begin, a look at the magnitude of the problems facing us is useful, followed by an overview of the resources we have available, and finally, three illustrations of how those resources can be optimised to provide the organisational readiness for rapid and effective action as well as long term planning on a national, regional, and global scale.

2. The problem

The global burden of neurological disease (GBND) figures as a relatively small fraction of the global burden of all disease (GBD) for a range of reasons [2]. Although not included in the WHO 2014 Global status report on NCDs [3], stroke and dementia are of major concern to clinicians and national health systems. The annual stroke toll is approximately 15 million, with a third being fatal and another third permanently disabling. Indeed, stroke mortality is double that due to HIV/AIDS, malaria, and tuberculosis combined, emphasising the rising burden of brain NCDs. With rates of dementia estimated to triple from 47.5 million to 115 million worldwide by 2050 [4] it is clear that the world faces a rising impost on resources. Currently the total burden of mental, neurological, and substance abuse (MNS) is now reckoned to

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be 258 million disability adjusted life years (DALYs)—a measure of overall disease burden, expressed as the number of years lost due to ill-health, disability or early death, up from 182 million in 1990 which has been equated to a loss of economic value of US\$8.5 trillion now and which will increase again by a factor of two by 2030 [5]. With the addition of other NCDs to stroke and dementia such as age-related Parkinson's disease and other chronic neurodegenerative disease, perinatal injury largely due to asphyxia, childhood developmental and degenerative disease, schizophrenia, high levels of traumatic brain disease, all causes of epilepsy, substance and alcohol abuse and rising neuroinflammatory disease of the brain and spinal cord, it is clear that the world neurological fraternity must act in concert and alert governments.

While world neurological expertise has been steadily advancing in part in parallel with the recognition of the increasing challenges on the horizon and in part with the advances in medical science, it is far from equitably distributed. When the widening gap between well-developed countries with comprehensive health care and those less developed populations and health care systems is appreciated, the likelihood for an emergency is evident [6].

3. Resources

There are a number of valuable resources available. These include measures of the GBD and specific problem areas such as the NCDs, BNCs and MNS as well as the WHO monitoring for more acute challenges to health through national health departments and the regional structural organisation of the WHO. (The WHO regional organisation mirrors approximately that of the WFN). The periodic assessments of the GBD by the WHO and the Atlas of Neurology (a joint WHO and WFN project) provide the broad sweep, big picture view of resources and needs.

The WFN itself plays an important and growing role in the equalisation of access to neurological care both through regional organisation support and neurological education. The establishment of the African Academy of Neurology (AFAN) and its first meeting in Tunis this year are illustrative and join the expanding roles of other WFN regional organisations such as the Pan American Federation of Neurological Societies (PAFNS) and the Australasian and Oceanian Association of Neurology (AOAN) and the well-established Pan Arab Union of Neurological Societies (PAUNS), the American Academy of Neurology (AAN) and the European Academy of Neurology (EAN).

Neurological training, the improvement in access to neurological care, and an increasing awareness of the importance of brain health in the general population are furthered by the World Brain Day (WBD) [7] and the biennial World Congress of Neurology (WCN). The WFN, in partnership with AFAN, has followed the World Federation of Neurosurgical Societies (WFNS) program to train young African specialists. The WFN plans on having four regional training centres in Africa, two each for the francophone and anglophone regions. Additional emphasis of WFN involvement at a global level was given by WFN President Raad Shakir as chair of the Neurosciences Topic Advisory Group for the WHO-sponsored International Classification of Disease (ICD-11) due for release in 2018.

More generally, other areas are developing which will enhance the ability to respond to challenges. Increasingly rapid communication through electronic media, including social media, draws attention rapidly to emerging problems. The maturation and expanding expertise of neurological subspecialties and their involvement in wider educational activities (e.g. the International League Against Epilepsy, the World Stroke Organisation, and the Movement Disorders Society, to mention a few) as well as the added interest of the larger regional neurological organisations like the AAN and EAN provide a rich resource of intellectual and monetary capital if properly applied.

Over the last few years, the WFN has provided a focal point for those involved in the medical care of neurological disease through two similar

though importantly different groups. The first is the World Brain Alliance (WBA). Originally chaired by Vladimir Hachinski in his role as the then President of the WFN, it is now chaired by Raad Shakir, the current WFN President. The WBA members comprise in addition to the WFN, global organisations that are usually not neurologists such as the World Federation of Neurosurgical Societies (WFNS), the International Brain Research Organisation (IBRO), the World Psychiatric Association (WPA), the International Child Neurology Association (ICNA), and the World Federation of Neurorehabilitation (WFNR). The second is the Global Neurology Network (GNN) for which the WFN is the current convenor and whose members comprise mainly global neurological disease-specific organisations. Many were originally part of the WFN but have grown to independent organisations. They include the World Stroke Organisation (WSO), the International League Against Epilepsy (ILAE), Multiple Sclerosis International Federation (MSIF) and the Treatment and Research in Multiple Sclerosis (TRIMS) group, Alzheimers Disease International, the Movement Disorder Society, the International Headache Society, the International Society for Clinical Neurophysiology, the Peripheral Nerve Society, and the Tropical Disease group, to mention a few. Closely associated with this category of disease-specific organisations are both large regional organisations supporting all neurological subspecialties such as the AAN and the EAN and the smaller WFN affiliated regional organisations like the AOAN, PAUNS, PAFNS, and AFAN.

Together these two groups comprise an impressive global alliance of neurological expertise. It is an alliance appropriately suited to provide global disease specific advice to international organisations such as the WHO and the UN and to advocate with these organisations and national governments. It is an alliance worthy of the term the Global Neurology Alliance.

4. Recent examples of united action

The most critical function of a global alliance of neurological organisations is the ability to formulate, organise, and execute rapid and effective policy or reaction. A powerful advocacy initiative that can mobilise governments and NGOs is of enormous value to those under threat and it is the rapidity of communication and the common understanding of the advocating group that empowers these initiatives as a force for good.

Underlying this ability are two fundamentals. The first is an intimate understanding by the subspecialty organisation in the national, regional, and global spheres of all matters affecting practitioners and patients. The second is the intercommunication between the various subspecialty organisations facilitated by the GNN. Regular meetings, updates on activities, and a common understanding of the means to reach their constituencies contributes to the effectiveness of the network.

Recent examples of where this alliance has been called to mobilise and has proven its worth are the 2015 Zika virus outbreak, the WHO initiative on NCDs, and the crisis over the WHO classification of stroke as a circulatory rather than neurological disease.

The outbreak of the arthropod borne (*Aedes aegypti*) Flavi virus crisis known as Zika virus in April 2015 in Brazil was designated by the WHO in February 2016 as a public health emergency of international concern (PHEIC) [8]. Zika was first found in Uganda in 1947 and the first outbreak of disease occurred in Micronesia in 2007. The South American outbreak was much worse. The primary infection was often asymptomatic or relatively banal comprising arthromyalgia, a light rash, or a low grade fever. The major secondary effects were of brain neuronal migration injuries to the fetus of pregnant women manifesting often but not solely as microcephaly and a postinfectious neuropathy resembling Guillain Barre Syndrome. Given the unknowns with this outbreak and the urgency to gather information, together with the WFN resources through the regional organisation in South America, the expertise within the organisation, and the rapidity with which the WFN could respond to assist, a committee headed by Professor John England was

constituted assisting the global investigation of the outbreak. PHEIC status was ceased in November 2016.

The NCD initiative launched by the WHO in 2011 following the GBD report highlighting the impact of NCDs [9] concentrated on cardiovascular disease, cancer, diabetes and respiratory disease. Omitted were major illnesses central to brain health such as dementia and stroke. The omission was questioned by the global neurological fraternity. The WFN, through its role as convenor of the World Brain Alliance (WBA) and led by Dr. Raad Shakir, waged a campaign to have brain NCDs included in the initiative [5]. How did such a situation arise? It seems that because the WHO viewed stroke and dementia not to be brain diseases but rather as circulatory and mental disorders, respectively, they were not included as risks to brain health. There are historical reasons for this view which were defended by the WHO, but the ICD-11 brought this matter to a head. In doing so it also provides an illustration of the value of a global neurological alliance.

The international Classification of Diseases (ICD) is revised every decade. ICD-10 was adopted in 1990 and in 2007 its revision to constitute ICD-11 was commenced under the supervision of the Revision Steering Group which took advice from a number of Topic Advisory Groups (TAGs). The ICD-11 neurosciences TAG was constituted in 2011 under the chairmanship of Dr. Raad Shakir. Soon after this process commenced, stroke was apparently accepted as a disease of the brain. When the beta version of ICD-11 was published in 2016, the neurological and stroke fraternities were astounded to find that stroke had been reverted to a circulatory disease. Clarity as to the reason why stroke had been omitted from the NCD initiative had arrived. Stroke was not a brain disease. The decision galvanised the neurological and stroke communities. After some considerable effort it was determined that the powerful statistics group within the WHO had been at the forefront of the opposition to the change initiated by the neuroscience TAG. While the grounds for such opposition were reasonable and based on a desire to obtain the best longitudinal epidemiological data, it effectively “hid” the impact of stroke in the global community and paid little heed to the growing evidence of the contribution of cerebrovascular disease to dementia and NCDs in general. There followed initial correspondence to *Lancet* [10] by the WFN and WSO, and the formation of an ad hoc advisory group from both, the recruitment of national departments of health to voice opposition to the way stroke was handled by the WHO, a number of important face-to-face and telephone meetings as well as a review of the evidence, from the WSO perspective, why stroke should not be classified as only a circulatory disease. Through an innovation introduced in the ICD-11 version, multiple parenting was

possible and this together with the weight of argument has seen stroke, as of April 2017, classified as a cerebrovascular disease in the current beta version of ICD-11 – an event described by many as momentous [11].

5. Conclusion

It is no accident that these external initiatives of the WFN and partners have been successful. The ability to respond rapidly, to gather expertise, and to plan and then implement the agreed approach while maintaining the flexibility to adapt to developments are the prime reason. That there has been an immediate sense of shared purpose, and the acknowledgement that together we are better able to present the arguments firmly and authoritatively, has no doubt assisted. The foresight of the originators of these two groups has also to be praised as does the leadership of the current WFN President and the members of the WBA and the GNN. With the world facing continuing uncertainties, it is likely we shall see more reason to be grateful for the contributions made by these groupings and possibly for periodic joint meetings. In practice, these groups and their membership represent a truly Global Neurological Alliance.

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