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The future of brain health advocacy: Recommendations of the 2023 World Congress of Neurology advocacy panel



Dear Sir

Below we share insights and recommendations on neurological advocacy emanating from two panel discussions held at the World Federation of Neurology's (WFN's) 2023 World Congress of Neurology (WCN) that took place in Montreal, Canada, in October 2023.

The first panel, titled "WHO, IGAP, and Future Prospects for Advocacy," focused on implementation of the World Health Organization's (WHO's) Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders 2022–2031 (IGAP) (1). IGAP was approved in 2022 by the World Health Assembly (WHA). The WFN closely cooperates with the WHO on IGAP and supports implementation of the toolkit. This panel reflected on the operationalization of IGAP at the individual, local, national, and global level. This panel proposed thoughts and ideas on action plans to achieve the objectives of IGAP. The second panel, titled "Advocacy Across Life," centered on brain health advocacy in all stages from pre-birth through old age. The following is a summary of recommendations resulting from both panel discussions.

- 1. Both panels proposed a succinct and impactful statement detailing the IGAP for lay people and the media. This concise description aims to effectively communicate its significance to individuals, societies, and stakeholders, both within and beyond the neurological community. Identifying stakeholders and embracing cultural values are pivotal in the implementation of the IGAP. Advocates should encompass all stakeholders, including individuals living with or without neurological diseases, ensuring a broad representation of perspectives.
- 2. Brain health is a key word for all advocacy and awareness campaigns (2,3). To champion brain health, it is crucial to emphasize the paramount significance of the brain as the body's foremost asset. Our wealth truly resides in brain health, which fundamentally underpins both physical and mental well-being. Shifting from a disease-centric approach, we should instill from early childhood the understanding that our brain stands as our most valuable resource. This shift in perception is pivotal, guiding everyone to recognize and prioritize the incredible importance of nurturing and preserving brain health.
- 3. Brain health awareness and education should be a priority for all organizations. School children should learn about brain health the same way they learn about dental health at an early age. "What can you do to keep your brain healthy?" should be a topic of awareness campaigns. This could be a part of school education. Medical students, graduates, and trainees should also be taught about brain health.
- 4. Governments need to be convinced of the importance of brain health in economic terms. When we talk about brain health as the

most valuable resource that governments have, it may be easier for them to understand why it is important to invest in it. Improving brain health must be considered an investment, not an expense.

- 5. Advocacy training and skills development is of paramount importance. There are many aspiring neurology trainees across the globe looking to be engaged in advocacy. Experts in the neurological community who aim to implement the IGAP should reach out to these trainees, including residents, fellows, students. Program directors and residency directors are the most appropriate conduit to the "learners" and can encourage the IGAP goals as an area of research, as well as advocacy activity on every level.
- 6. Data collection related to the burden and impact of neurological diseases in various parts of the world is important for the planning of neurological advocacy. One in six people around the globe, or more than one billion people, suffer from one or more neurological diseases (4).
- 7. Each member society of the WFN ought to develop a dedicated strategy for brain health as a holistic plan encompassing all neurological disorders. The American Academy of Neurology (AAN) launched its brain health plan, strategy, and definition (5). Likewise, the European Academy of Neurology (EAN) recently launched a brain health mission in Europe that is a comprehensive, inclusive effort to bring together all stakeholders that are committed to promoting brain health (6).
- 8. Partnership and collaboration are needed across the various organizations at the global, regional, and national levels so that everyone speaks with one voice. These include primary healthcare providers and policymakers. Professional societies and associations should be partnering with patient advocacy organizations. The WFN is collaborating with regional organizations, the global neurology alliance, and specialty groups for this purpose (7). This network of collaborations and partners needs expansion.
- 9. Improving epilepsy and stroke services would enhance neurology services in resource-limited countries.
- 10. The WHO has an essential medicine list (EML) (8) that is regularly updated. Many of the drugs on the EML, however, are not available in many countries of the world due to procurement, registration, logistics, inability to prescribe, and lack of affordability by individuals. The WHO strives for cost-effective, inexpensive medications, yet the lack of access to those medication is more than 95% in many of the low- and middle-income countries. Our advocacy campaign should focus on those eight hundred million patients with neurological diseases who are not getting needed medications.

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- 11. Approximately three billion people are affected by neurological disorders worldwide, which includes family members, friends, and caretakers of those diagnosed with neurological disorders. The WFN can act now to help mobilize the patient, caregiver, family, and friend community. Mobilization of a patient's families, support groups, and associations as donors, partners, and activists in awareness and advocacy campaigns may be extremely helpful in propagating the mission of the WFN across communities.
- 12. There are many professional neurological organizations working at a global level for the promotion of neurological care and advocacy, such as psychiatry, neurosurgery, rehabilitation, pediatric neurology, and subspecialty societies and organizations. Through united cooperation, coordination, and collaboration, the neurological community can raise public awareness and advocacy globally.

Panel discussion participants included: Wolfgang Grisold (President, WFN), Sheila Martins (President, World Stroke Organization), Helen Cross (President, International League Against Epilepsy), Danuta Wasserman (President, World Psychiatry Association), Volker Hoemberg (President, World Federation of Neurorehabilitation), Tarun Dua (Brain Health Unit, World Health Organization), Paul Boon (President, European Academy of Neurology), Augustina Charway Felli (President, African Academy of Neurology), Steven Lewis (Secretary General, WFN), Walter Struhal (Editor-in-Chief, eNeurologicalSci), Serefnur Ozturk (Chair Migrant and Refugees Specialty Group, WFN), Riadh Gouider (Co Opted Trustee, WFN), Guy Rulo (Vice President, WFN; Congress Chair, WCN 2023), David Dodick (Past President, World Headache Society), Mayowa Owolabi (World Stroke Organization), and Helmar Lehman (Young Neurologists Group, WFN). The Panel was moderated by Mohammad Wasay (Trustee, WFN) and Tissa Wijeratne (Co-Chair, Public Awareness and Advocacy; Co-Chair, World Brain Day, WFN).

CRediT authorship contribution statement

Mohammad Wasay: Conceptualization, Data curation, Writing – original draft, Writing – review & editing, Formal analysis. Wolfgang Grisold: Conceptualization, Data curation, Writing – review & editing,

Formal analysis, Writing – original draft. **Tissa Wijeratne:** Writing – review & editing. **Walter Struhal:** Writing – review & editing. **Safa Younis:** Writing – review & editing.

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