The 30th International Conference On
Spina Bifida & Hydrocephalus

Organised by:
Spina Bifida & Hydrocephalus Association Malaysia
IFSBH International Federation for Spina Bifida and Hydrocephalus

Supported by:
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Bridging The Healthcare And Prevention Gaps - A Multidisciplinary Team Approach With The Community At Heart

24 - 26 October 2024 I AVANTÉ Hotel, Petaling Jaya, Selangor Darul Ehsan, Malaysia
www.sbhconference2024.com

Kuala Lumpur Declaration

Preamble

Neural Tube Defects (NTDs) are congenital malformations affecting the brain and spinal cord during early pregnancy, often occurring before pregnancy is detected. These defects arise when the neural tube fails to close properly, leading to malformations of varying severity. Spina bifida is the most common NTD and, in many cases, children with spina bifida also develop hydrocephalus, a condition in which cerebrospinal fluid accumulates in the brain. Person affected by these complex health conditions can experience lifelong disabilities affecting for instance mobility, bowel and bladder control, and cognitive challenges[1]. Consequently, numerous health challenges and additional barriers to the full participation in life's opportunities must be addressed. Therefore, ongoing medical care and comprehensive support are indispensable for improving quality of life.

From October 24th to 26th, the 30th International Conference on Spina Bifida and Hydrocephalus[2] was convened in Kuala Lumpur (Petaling Jaya, Selangor), organized by the Spina Bifida and Hydrocephalus Association of Malaysia (SIBIAM) in collaboration with the International Federation for Spina Bifida and Hydrocephalus (IF). For the first time, this 30th international conference builds a new bridge between health professionals, researchers, individuals living with spina bifida and/or hydrocephalus (SBH), their families, and emerging scholars to discuss strategies for addressing gaps in healthcare and prevention, while promoting a multidisciplinary approach that places community at its core. Contributions were received from across the globe, representing a wide array of perspectives and shared experiences.

Declaration

During the 30th International Conference on Spina Bifida and Hydrocephalus, it was highlighted that health constitutes an important form of social inclusion, understood as both physical and mental wellbeing, enabling full participation in social and economic life. Equitable access to quality healthcare, preventive services, rehabilitation and psychological support is essential to ensuring that every individual, regardless of health conditions or disabilities, can lead an active, inclusive and dignified life. Key elements of health as means of social inclusion involve equitable access to healthcare, prevention and rehabilitation services[3], the protection of mental health[4] and a multidisciplinary approach to care[5].

It is essential to recognize that multidisciplinary care is crucial for all age groups, not only for children. All too often, integrated multidisciplinary services are available exclusively to children, neglecting the critical transition from childhood and adolescence into adulthood. Additionally, the new important findings derived from medical research have also been analyzed, such us the significance of genetics in a genomics era for improvement of communications of diagnosis and treatment options.

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)[6] recognizes in Article 25 that persons with disabilities have the right to the highest attainable standard of health without discrimination. Prevention and access to multidisciplinary care for individuals with SBH are fundamental to upholding this right. Moreover, Article 19 of the UNCRPD protects the right of persons with disabilities to live independently and be included in their communities.

To ensure the protection of these rights, dynamic collaboration among all stakeholders is essential, encompassing public, private, and civil sectors. In fact, the involvement and collaboration among a broad spectrum of actors, ranging from SBH associations and other professional organizations representing the civic domain, to private sector entities (such us millers, flour product companies), as well as public agencies on national, regional and international levels (such us non-governmental organizations and academic organizations) is imperative in addressing socio-economic determinants of health, which impact maternal nutrition and overall health, and in ensuring that individuals, irrespective of their socio-economic background, have access to high-quality prevention and care services, including rehabilitation.

The active participation of SBH community and their families is critical to ensuring that policies not only reduce neural tube defects (NTDs) prevalence but also combat the stigma often associated with disability. This aligns with SDGs[7] and Article 8(b) of the UNCRPD, which calls for combating stereotypes, prejudices, and harmful practices relating to persons with disabilities, including those based on gender and age, in all spheres of life.

The primary prevention of neural tube defects (NTDs) is of paramount importance in reducing the prevalence of spina bifida and other related malformations. Mandatory fortification of staple foods with vitamin B9 (folic acid)[8] has proven to be the most effective and cost-efficient method for preventing NTDs, especially in low- and middle-income countries where NTDs prevalence is higher and access to healthcare services is more limited[9]. However, many nations have yet to adopt mandatory fortification with vitamin B9, despite the compelling evidence supporting this policy and also despite the World Health Organization's adoption in May 2023 of Resolution WHA76.19[10], which calls for the safe and effective fortification of foods to prevent micronutrient deficiencies and their consequences. This resolution adopts a holistic approach, to address a severe public health crisis integrating perspectives from the fields of disability rights, healthcare and nutrition.

While primary prevention is crucial in reducing the prevalence of NTDs, persons with SBH require a multidisciplinary approach to ensure effective daily life management in an autonomous and independent manner. Multidisciplinary care involves collaboration among various specialists (including urologists, geneticists, neurosurgeons, orthopedists, physiotherapist, psychologists, psychiatrist, specialized nurses, rehabilitation specialists, etc.), who work in coordination to provide integrated and personalized care. This approach not only enhances clinical outcomes but also improves overall quality of life, facilitating social inclusion and fostering greater independence.

Indeed, the lack of coordination among health professionals often leads to inconsistent diagnoses and fragmented care management, with adverse effects on the wellbeing of individuals and their families. By contrast, multidisciplinary care allows for more efficient and targeted management, helping to reduce preventable comorbidities and avoid unnecessary invasive procedures[11] and optimizing resources available for healthcare. In this regard, during the conference the need for a patient registry was

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highlighted. In fact, patient registries can significantly contribute to enhancing existing knowledge and characterization of individuals with SBH, providing an important source of data for surveillance which can also inform scientific, clinical, and policy, as well as earlier access to information and care, enhancing patient well-being, empowering and preparing young people with SBH for independent lives and helping older individuals with SBH maintain their independence.

Therefore, commitments on both prevention and multidisciplinary care are essential to achieving the highest attainable standards of health without discrimination on the basis of disability, as stipulated by Article 25 of the UNCRPD and to effectively achieve the SDGs, notably SDG 2 (ending malnutrition) and SDG 3 (ensuring health and well-being for all).

Signatories' Commitments

The Spina Bifida & Hydrocephalus Association of Malaysia (SIBIAM) and the International Federation for Spina Bifida and Hydrocephalus (IF), us organizers of the 30th International Conference on Spina Bifida and Hydrocephalus facilitated discussions and collaboration on the current situation regarding gaps in healthcare and prevention, as well as the promotion of a multidisciplinary approach, concluding with the call on all relevant stakeholders to support and implement the resulting commitments:

- To support and facilitate discussions with relevant ministries and agencies on mandatory fortification programs of vitamin B9 staple food, important for safe and effective primary prevention;
- To strengthen through early education and awareness creation, the importance of prevention and integrated multidisciplinary care crucial for the lifelong support of persons affected by SBH and their families;
- To encourage knowledge sharing and understanding on the role of genetics amongst healthcare professionals, persons with SBH and families in order to better facilitate the process of communication of diagnosis, genetic counselling and the opportunities for novel therapeutic interventions;
- To encourage and support healthcare and academic institutions to design guidelines and care protocols to establish adequate standards in the management of urological, surgical and rehabilitations care;
- To work alongside ministry of health to strengthen infrastructures to improve multidisciplinary health care, evidence-based management and collection of secure patient data such as through a patient registry;
- To encourage discussions around the coordination and continuity of healthcare for optimizing transitioning from childhood to adulthood care to promote independent living.

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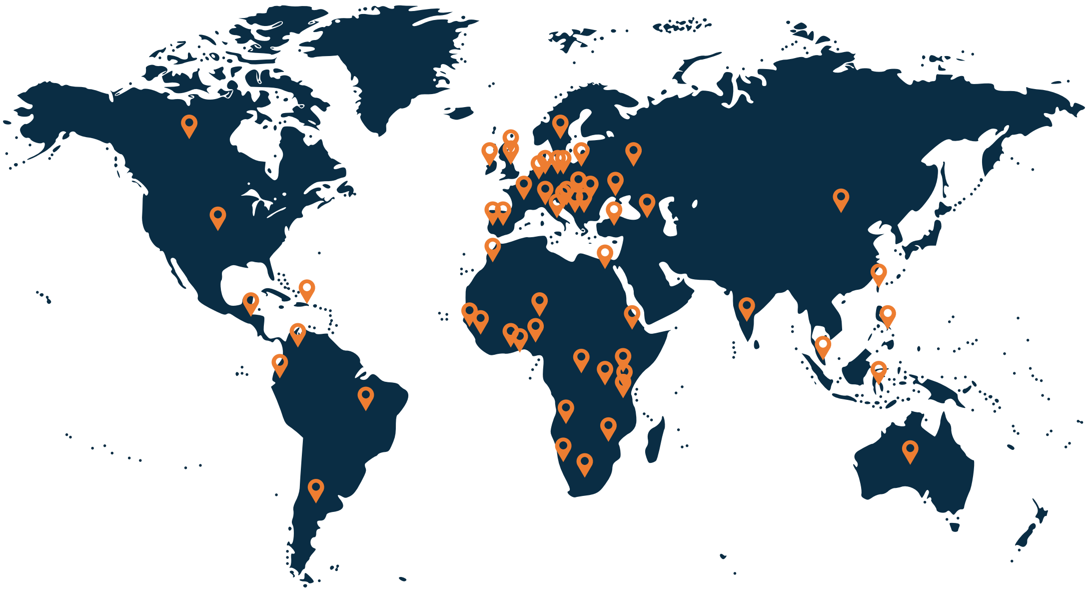

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