INTERNATIONAL FEDERATION FOR SPINA BIFIDA AND HYDROCEPHALUS

*Brussels, October 25 2025*

# Towards a United Nations-recognised International Day for SBH: World Spina Bifida and Hydrocephalus Day

## Executive Summary


Every year, hundreds of thousands of children are born with spina bifida and hydrocephalus (SBH), conditions that can shape a lifetime of medical, social, and emotional challenges. Yet with awareness, prevention, and care, these challenges can be mitigated. SBH are congenital conditions that affect the brain and spine, forming part of a group known as Neural Tube Defects, the second most common type of structural birth defects worldwide. Each year, one in every 500 children are born with SBH, most of them in countries where food is not fortified with folic acid, a simple and effective preventive measure. For families, SBH brings a lifetime of challenges: high medical costs, limited access to quality care, and ongoing social and emotional strain. Yet beyond the statistics are millions of stories of resilience, love, and determination. Too often, people living with SBH face stigma, misunderstanding, and barriers that prevent them from fully participating in their communities. Weak surveillance systems, under-resourced healthcare, and limited policy attention mean that individuals go undiagnosed, unsupported, or unheard.

A United Nations (UN)-recognised World Spina Bifida and Hydrocephalus Day (WSBHD) would be of great help to change that. It would give visibility to the millions of people and families affected, raise awareness of prevention and lifelong care, and inspire action across governments, civil society, and communities. A UN-recognised WSBHD would challenge stigma, promote inclusion, and celebrate the strength of person living with SBH. This document outlines the urgent need for a UN-recognised WSBHD and explains how individuals, communities, and governments can take action. Establishing this day would raise global awareness, emphasise the importance of prevention and lifelong care, challenge stigma, and foster collaboration among families, civil society, and healthcare systems.

By supporting a UN-recognised WSBHD, we can advocate for folic acid fortification, better access to healthcare and education, inclusive policies, and respect for the rights of person living with SBH. Declaring this day would send a strong message: every person living with SBH deserves dignity, support, and the chance to thrive.

## 1. Background

Spina bifida and hydrocephalus (SBH) are interlinked neurological conditions caused by disrupted foetal development, leading to major congenital anomalies with lifelong impact. Spina bifida, meaning “split spine”, occurs when the spinal cord fails to close properly, while hydrocephalus results from excess cerebrospinal fluid in the brain, causing pressure and damage. The causes include low maternal folic acid intake, genetic and metabolic factors, obesity, high temperatures, and certain medications[1,2].

The SBH represents a silent global crisis largely preventable yet often overlooked. One in every 500 children worldwide is born with SBH each year[3]. While high-income countries have reduced cases through folic acid fortification and early intervention, many children in low- and middle-income countries are still born with these conditions, often without access to surgery[4]. Behind every statistic is a child striving to live with dignity and families making immense sacrifices amid stigma and limited care. In many settings, lack of early diagnosis, screening, and follow-up leads to preventable disability or death, underscoring the urgent need for equitable prevention and lifelong care[5]. Beyond the immediate medical burden lies the silent pain of exclusion is children being unable to attend school due to inaccessible classrooms, and parents burdened by a constant struggle for acceptance in their communities. Beyond the medical impact lies a deep social and emotional toll. A person living with SBH often face stigma, discrimination, and exclusion from education, employment, and social participation[6].

Misconceptions about their abilities cause isolation and neglect especially among girls and women facing higher risks of abuse and limited health access. Adolescents often internalise stigma, leading to low self-esteem, while families struggle with emotional and social barriers. Yet, people with SBH show remarkable resilience and leadership when included.

> *“I guess I failed [employment interviews] because I wrote in the documents that I had bowel and bladder dysfunction and that I couldn’t stand because of the level of my spina bifida lesion --- and so I wrote that I wanted the company to equip the workplace with a chair and that I also needed a bed, so I guess I failed because I told the people at regular companies about those things”*[7]

A person living with SBH often experience social challenges linked to neurocognitive and communication difficulties. They may find it hard to interpret nonverbal cues, join group activities, or build peer relationships. Low self-esteem, poor body image, and feelings of difference can limit confidence and social participation, including fewer romantic experiences. Anxiety, depression, and emotional distress are also common.

> *“People think that since we have spina bifida and hydrocephalus, we are mentally ill, and we do not have any sexual and reproductive health needs at all. They do not even call us for the youth meeting or even for community outreach services”*[8]

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[1]Iskandar BJ, Finnell RH. Spina bifida. *N Engl J Med.* 2022;387(5):444–450.
[2]International Federation for Spina Bifida and Hydrocephalus. *Why would we care about the genetics.* Brussels; 2025. Available from: https://ifglobal.org/publications/if-factsheet-genetics/
[3]Kancherla V, et al. Preventing birth defects, saving lives, and promoting health equity: an urgent call to action for universal mandatory food fortification with folic acid. *Lancet Glob Health.* 2022;10(7):e1053–e1057.
[4]International Federation for Spina Bifida and Hydrocephalus. *IF Statement: A call for global action to reduce the prevalence of neural tube defects worldwide.* Brussels; 2022. Available from: https://ifglobal.org/news/if-statement-a-call-for-a-global-action-to-reduce-the-prevalence-of-neural-tube-defects-worldwide/
[5]International Federation for Spina Bifida and Hydrocephalus. *IF Statement on multidisciplinary care.* Brussels; 2021. Available from: https://ifglobal.org/news/if-statement-on-multidisciplinary-care/
[6]International Federation for Spina Bifida and Hydrocephalus. *IF Statement on mental health in focus.* Brussels; 2024. Available from: https://ifglobal.org/publications/if-statement-mental-health-in-focus/
[7]Murayama S, Doering JJ, Sawin KJ. Transition to adulthood: experience of Japanese youth with spina bifida. *Health Care Transit.* 2024;2:100080.
[8]Ndekezi D, Ssemata AS, Ganshanga A, Nalugya R. Sexual and reproductive health challenges among adolescents and young people with spina bifida and hydrocephalus disability in Uganda: a qualitative study. *PLoS One.* 2025;20(5):e0308194.

## 2. Purpose of this document

Global awareness of SBH remains alarmingly low, with major disparities in public understanding, prevention, and professional knowledge. Studies show limited awareness of folic acid's preventive role and persistent misinformation in many communities. In low- and middle-income countries, weak surveillance, missing birth defect registries, cultural stigma, and low political prioritisation further hinder progress. Despite proven success in countries with food fortification, consistent education and outreach remain lacking globally. Therefore, this policy brief advocates for establishing a UN-recognised WSBHD that would create a unified global platform to raise awareness, promote prevention, and drive coordinated action for those living with SBH.

## 3. Importance of a united nation–recognised WSBHD

A UN-recognised WSBHD would have a transformative impact on awareness, advocacy, policy mobilisation, and resource allocation. By elevating SBH to global visibility, it would inspire dialogue, foster partnerships, and drive investment in prevention, care, and inclusion. Such recognition would ensure that the needs of person living with SBH remain firmly embedded within global, regional, and national agendas for health equity and disability rights.

### 3.1. Raising global awareness

A UN-recognised WSBHD would bring attention to a condition that often remains overlooked, highlighting both its preventable causes and lifelong implications. It would help reduce stigma and misconceptions, encourage empathy, and promote understanding of the physical, social, and emotional challenges faced by person living with SBH and their families. By doing so, it would stimulate dialogue among governments, civil society, and communities worldwide.

### 3.2. Mobilising action

Such recognition would act as a catalyst to galvanise governments, NGOs, and communities to move from awareness to concrete action. It could launch coordinated campaigns, policy commitments, and public initiatives that address prevention, early detection, and long-term care. This momentum would translate advocacy into measurable impact by improving services, building capacity, and strengthening inclusion.

### 3.3. Influencing policy

Aligning an SBH International Day with existing UN resolutions and global disability commitments would elevate SBH onto policy agendas at national and international levels. It would help leverage advocacy efforts, reminding decision-makers of their obligations to integrate SBH into health, education, and social policies. By keeping SBH visible within UN and national frameworks, it would support long-term policy reform and resource investment. As seen with other UN-recognised international days, such as World Diabetes Day[9], World Autism Awareness Day[10], World Duchenne Awareness Day[11], International Day of Persons with disabilities[12], official recognition catalyses awareness, mobilises policy action, and unites governments, civil society, and communities around shared commitments. UN-recognised WSBHD would likewise accelerate prevention, inclusion, and lifelong care efforts worldwide.

[9]United Nations. *World Diabetes Day – 14 November.* New York: United Nations; 2006. Available from: https://www.un.org/en/observances/diabetes-day
[10]United Nations. *World Autism Awareness Day – 2 April.* New York: United Nations; 2007. Available from: https://www.un.org/en/observances/autism-day
[11]United Nations. *World Duchenne Awareness Day – 7 September.* New York: United Nations; 2021. Available from: https://www.un.org/en/observances/duchenne-awareness-day
[12]United Nations. *International Day of Persons with Disabilities – 3 December.* New York: United Nations; 1992. Available from: https://www.un.org/en/observances/day-of-persons-with-disabilities

### 3.4. Fostering solidarity

A UN-recognised WSBHD would have a transformative impact on awareness, advocacy, policy mobilisation, and resource allocation. would foster empathy and shared responsibility, reinforcing that the challenges faced by person living with SBH transcend borders. It would also foster partnerships and recognition across sectors by linking governments, academia, NGOs, and affected communities. This solidarity would strengthen global cooperation and ensure that collective solutions address SBH effectively and sustainably.

### 3.5. Empowering communities

A UN-recognised WSBHD would provide a powerful platform for person living with SBH to share their lived experiences and advocate for their rights. Storytelling and community participation would help humanise data, strengthen demands for inclusion, and enhance visibility. Empowering communities in this way would build agency, confidence, and local ownership of change efforts.

### 3.6. Sustaining momentum

By keeping SBH consistently on the global agenda, a UN-recognised WSBHD would ensure continuity in advocacy and accountability. It would help track progress, mobilise funding, and maintain political will year after year. This sustained visibility would not only prevent SBH from being overlooked but also secure long-term commitment to prevention, care, and inclusion.

## 4. Key principles, goals and agenda addressed by prioritising SBH

Addressing SBH contributes to achieving the Sustainable Development Goals (SDGs) by promoting health, education, equality, and inclusion. It supports the WHO Disability and Health Equity agenda by building inclusive health systems, leadership, and evidence for equitable care. It also advances the Convention on the Rights of Persons with Disabilities' human rights principles. Below are the details on how it contributes.

### 4.1. Sustainable development goals

The SDGs are a set of 17 global goals adopted by all UN Member States in 2015 as part of the 2030 Agenda for Sustainable Development. They aim to end poverty, protect the planet, and ensure peace and prosperity for all by 2030. Each goal addresses key global challenges, including health, education, inequality with an emphasis on leaving no one behind[13]. It is important to note that if we address the SBH, it would directly contribute to achieving several SDGs, particularly those related to health, education, reduced inequalities, and partnerships for sustainable development.

- **SDG 3**: Good Health and Well-being. Preventing SBH through folic acid supplementation, food fortification, and quality antenatal care supports SDG 3. Access to surgery, rehabilitation, and lifelong care improves health outcomes, while mental health and stigma reduction enhance overall well-being.
- **SDG 4:** Quality Education. Early intervention and supportive technologies for children with SBH reduce dropout rates and improve learning outcomes. Inclusive education fosters lifelong skills, independence, and access to decent employment, directly advancing SDG 4.

[13]United Nations. *Transforming our world: The 2030 Agenda for Sustainable Development.* New York: United Nations; 2015. Available from: https://sdgs.un.org/2030agenda

- **SDG 5:** Gender Equality. Women and girls bear unequal caregiving burdens for children with SBH. Access to reproductive health services and shared caregiving responsibilities empower women, promote equality, and protect health rights, contributing to SDG 5.
- **SDG 8:** Decent Work and Economic Growth. Inclusive workplaces for person living with SBH enable economic independence and reduce poverty. Equal access to training and employment fosters productivity, strengthens economies, and supports SDG 8.
- **SDG 10:** Reduced Inequalities. Ensuring equitable access to healthcare, education, and social services for person living with SBH promotes dignity and inclusion. Disability-inclusive policies dismantle barriers, strengthen cohesion, and advance SDG 10.
- **SDG 16:** Peace, Justice and Strong Institutions. Adopting rights-based disability approaches aligned with UNCRPD ensures equal recognition and participation. Embedding inclusion in national policies strengthens governance, accountability, and progress toward SDG 16.
- **SDG 17:** Partnerships for the Goals. Strong collaboration among governments, NGOs, academia, and communities is key to addressing SBH. Multi-stakeholder partnerships drive advocacy, research, and resource mobilisation, directly contributing to SDG 17.

### 4.2. WHO disability and health equity agenda

Prioritising and addressing SBH directly supports the WHO Disability and Health Equity agenda by tackling systemic inequities faced by people with disabilities. It strengthens leadership for health equity through national advocacy and cross-sectoral collaboration. Integrating SBH prevention, care, and rehabilitation into mainstream health services helps create disability-inclusive health systems. By elevating SBH within policy discussions, countries make health equity a political priority, ensuring sustained investment and accountability. Finally, systematic data collection and research on SBH enhance monitoring and evidence generation, informing equitable and evidence-based health policies[14].

### 4.3. Convention on the rights of persons with disabilities

Focusing on SBH aligns with the UN Convention on the Rights of Persons with Disabilities (CRPD) by upholding dignity, autonomy, and full participation in society. It shifts the narrative from charity to rights, ensuring access to healthcare, education, and social inclusion. Embedding human rights principles in SBH policies reinforces equality, non-discrimination, and accountability, in line with UN human rights frameworks[15].

## 5. WSBHD as a catalyst for global awareness and action

A UN-recognised WSBHD offers a unique opportunity to translate awareness into concrete action. Building on existing evidence and past IF declarations[16], IF urge all Governments, UN agencies, civil society, and healthcare institutions can use this platform to implement evidence-based policies and improve the lives of person living with SBH. Therefore, we call upon all governments, UN agencies, civil society, and healthcare institutions on the following actions.

[14]World Health Organization. *Health equity for persons with disabilities: Guide for action.* Geneva: WHO; 2024. Available from: https://www.who.int/publications/i/item/9789240101517

[15]United Nations. *Convention on the Rights of Persons with Disabilities.* New York: United Nations; 2006. Available from: https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf

[16]International Federation for Spina Bifida and Hydrocephalus & Spina Bifida and Hydrocephalus Association of Malaysia. *Kuala Lumpur Declaration.* Brussels; 2024. Available from: https://ifglobal.org/news/the-30th-international-conference-on-spina-bifida-and-hydrocephalus-kuala-lumpur-declaration/

### 5.1. Raising awareness

- Highlight SBH as a preventable and manageable condition through timely folic acid intake, early diagnosis, and lifelong multidisciplinary care.
- Promote mandatory folic acid fortification in staple foods, supported by strong monitoring systems and sustained community education.
- Promote understanding of genetics among healthcare professionals, individuals with SBH, and their families, supporting effective communication, genetic counselling, and new therapeutic opportunities.
- Reduce stigma and misconceptions by amplifying lived experiences and showcasing resilience of people living with SBH and their families.

### 5.2. Mobilising policy and action

- Encourage governments to integrate SBH prevention, care, and inclusion into national health, education, and social protection policies.
- Strengthen data collection, birth-defect registries, and monitoring systems to inform evidence-based planning and policy decisions.
- Expand access to essential medicines, assistive devices, and rehabilitation services, ensuring affordability and equity.
- Establish sustainable funding mechanisms and partnerships between governments, donors, and private sector actors to advance prevention and lifelong care.

### 5.3. Empowering communities and inclusion

- Create platforms for people living with SBH and their families to participate in policy dialogue, advocacy, and awareness campaigns.
- Promote inclusive education, employment, and social participation through accessible infrastructure and supportive workplace and school policies.
- Foster local and global networks of collaboration, innovation, and solidarity among healthcare providers, civil society, and patient organisations.

### 5.4. Sustaining global momentum

- Institutionalise an annual global observance such as UN-recognised WSBHD to maintain visibility and accountability.
- Ensure that awareness translates into measurable improvements in prevention, care quality, inclusion, and protection of rights.

## 6. Next steps: translating recognition into action

Declaring a UN-recognised WSBHD would be more than symbolic. It would create a global platform to raise awareness, combat stigma, and promote inclusive policies that ensure prevention, lifelong care, and independent living. By amplifying the voices of person living with SBH, such a day would strengthen commitments across governments, civil society, and international organisations. Above all, it would affirm that dignity, equality, and opportunity must be upheld for every individual, ensuring that no one is left behind. A recognition would not only enhance global awareness but also serve as a catalyst for coordinated international action to advance the health, rights, and quality of life of person living with SBH.

## ABOUT IF

The International Federation for Spina Bifida and Hydrocephalus (IF) is the international organisation representing person living with SBH and their families worldwide. IF has country members in Africa, Americas, Asia-Pacific, and Europe with unique and expert knowledge on SBH. The mission of IF is to improve the quality of life of people with SBH and their families, and to reduce the prevalence of neural tube defects through improving maternal health literacy, raising awareness, political advocacy, research, community building, and human rights education.

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