



# ANNUAL REPORT 2025



INTERNATIONAL FEDERATION  
FOR SPINA BIFIDA  
AND HYDROCEPHALUS



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# LIST OF ABBREVIATIONS

- **CRPD:** Convention on the Rights of Persons with Disabilities
- **DG EMPL:** Directorate-General for Employment, Social Affairs and Inclusion
- **EDF:** European Disability Forum
- **EDPD:** European Day for Persons with Disabilities
- **EMR:** Eastern Mediterranean Region
- **ERN-eUROGEN:** European Reference Networks eUROGEN
- **ERN-ITHACA:** European Reference Networks ITHACA
- **ESRPD:** European Union Strategy for the Rights of Persons with Disabilities
- **EU:** European Union
- **FFI:** Food Fortification Initiative
- **GAIN:** Global Alliance for Improved Nutrition
- **IDA:** International Disability Alliance
- **IDOP:** International Day of Older Persons
- **IDPD:** International Day for Persons with Disabilities
- **IF:** International Federation for Spina Bifida and Hydrocephalus
- **IFGPI:** IF Global Prevention Initiative
- **IYD:** International Youth Day
- **LMIC:** Low- and Middle-Income Countries
- **LSFF:** Large Scale Food Fortification
- **MNF:** Micronutrient Forum
- **NGOs:** Non-Governmental Organisations
- **NTDs:** Neural Tube Defects
- **SB:** Spina Bifida
- **SBH:** Spina Bifida and Hydrocephalus
- **SDGs:** Sustainable Development Goals
- **UN:** United Nations
- **UNCRPD:** United Nations Convention on the Rights of Persons with Disabilities
- **WBDD:** World Birth Defects Day
- **WFAAW:** World Folic Acid Awareness Week
- **WHA:** World Health Assembly
- **WHO EB:** WHO Executive Board
- **WHO:** World Health Organization
- **WSBHD:** World Spina Bifida and Hydrocephalus Day

# FOREWORD

We are proud to stand alongside our dedicated members and partners across the globe, united in our commitment to improving the lives of persons with Spina Bifida and Hydrocephalus and our families. In a rapidly changing world marked by uncertainty and shifting priorities, our collective strength lies in our ability to remain focused, adaptable and guided by shared values.

The 2025 Annual Report reflects a year in which we continued to prioritise what matters most: advancing human rights, strengthening health systems and supporting our global SBH community. A key achievement has been the further deepening of our regional and global work, enabling more tailored support, stronger collaboration with members at country level and more meaningful exchange across regions. In this context, IF continues to place strong emphasis on working closely with its members to ensure inclusive, credible and representative voices in global advocacy and policy dialogue, recognising both the strengths and the evolving capacities of national associations.

We are particularly encouraged by the growing engagement of our community through the Youth and Adult Working Groups, which came together this year to exchange perspectives and build a more inclusive, life-course approach to SBH. These collaborations reflect our commitment to ensuring that lived experiences informs our work and that every voice is valued.

This year also marked the announcement of the 31st International Conference on Spina Bifida and Hydrocephalus, to be held in Montreal, Canada in 2026. This important gathering will coincide with the 50th anniversary of the Association de spina-bifida et d'hydrocéphalie du Québec, offering a unique opportunity to celebrate progress, share knowledge and shape the future together.

Throughout the year, IF organised several thematic webinars addressing key issues such as genetics, urological management and health equity, reinforcing our commitment to evidence-based practice and inclusive care. Our members continued to benefit from targeted support initiatives, while service clubs and partners played a vital role in advancing projects on the ground.

We are also proud to have joined the WHO Disability Health Equity Network, further strengthening our global advocacy efforts and positioning IF within a broader movement for equitable health systems.

IF remains deeply grateful for the continued dedication and collaboration of our members, partners, volunteers and leadership. Your commitment drives our work forward and makes our shared achievements possible.

As we reflect on the progress made in 2025, we look ahead with determination and optimism. Together, we will continue to build a more inclusive, equitable future for all persons with SBH.



**Dr. Sylvia  
Roozen**  
IF Secretary  
General

**Victoria  
Sandoval**  
IF President

# ABOUT IF



## WHO WE ARE

The International Federation for Spina Bifida and Hydrocephalus (IF) is the international organisation representing people with Spina Bifida and/or Hydrocephalus and their families worldwide. IF has country members in Africa, the Americas, Asia-Pacific and Europe with unique and expert knowledge on SBH.

## MISSION

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 and hydrocephalus through primary prevention by improving maternal health literacy, raising awareness, political advocacy, research, community building and human rights education.

## VISION

The vision of IF is to create a society that ensures the human rights of both children and adults with SBH, while also recognising and valuing their contributions. Additionally, IF strives to provide equitable access to maternal health literacy for everyone.

## VALUES

### Human Rights:

Promotion and protection of the human rights of people with SBH in accordance with the UN Convention on the Rights of Persons with Disabilities (UNCRPD) is our highest priority principle.

### Participation & Inclusiveness:

The views of children and adults with SBH and their families are central to our work. We respect the regional, cultural and socio-economic specificities of our members around the world and we promote a tailored approach to working on SBH issues.

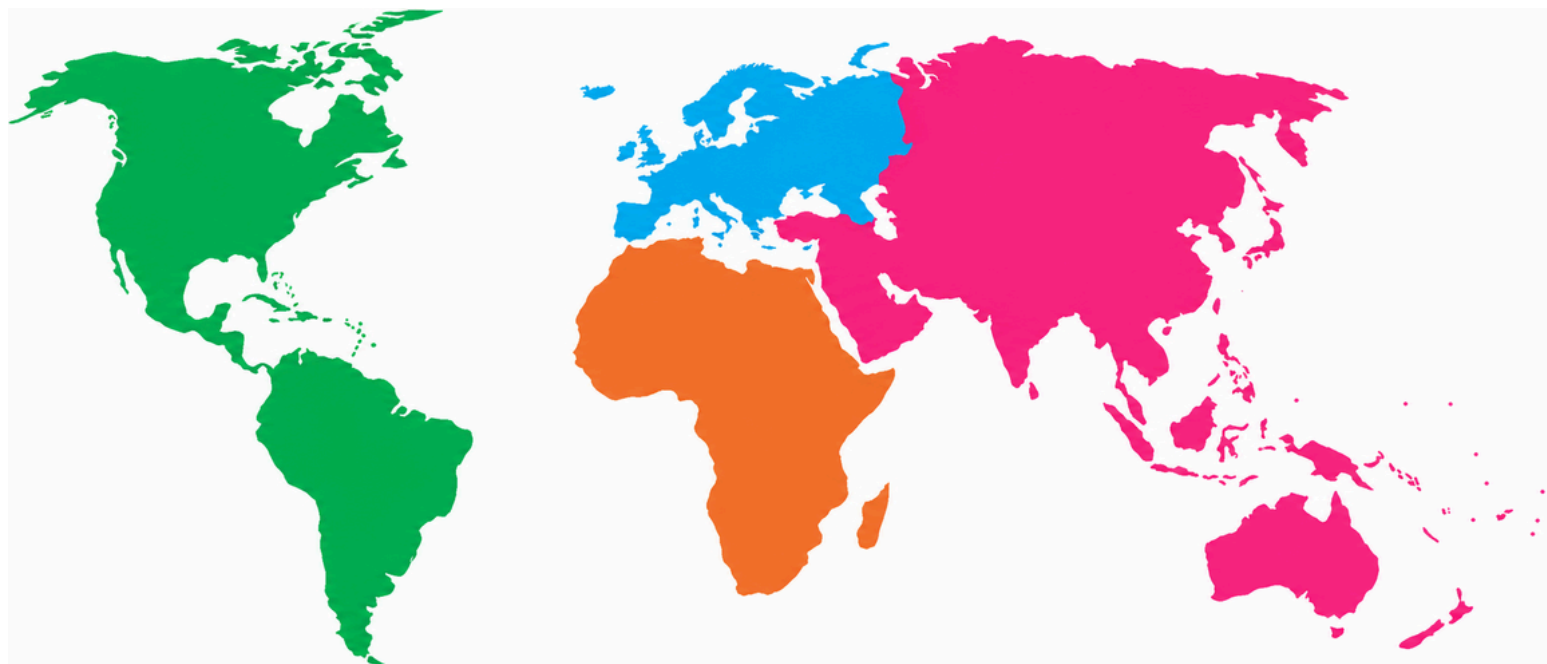
### Cooperation:

We have constructive and robust relations with international, regional and national bodies, NGOs, professional associations and other stakeholders. We are open to new partners who share our vision and goals.

### Transparency & Accountability:

IF works in a transparent and inclusive way and is fully accountable to our members, donors and external stakeholders.

# MEMBERS' OVERVIEW



## Africa

**Algeria** – Association des Parents et Malades Spina Bifida Béjaïa

**Congo** – Appui au Développement de l'Enfant en Détresse (ADED)

**Egypt** – Waad Spina Bifida Foundation

**Ethiopia** – ReachAnother Foundation

**Ethiopia** – HOPE-SBH Ethiopia

**Gambia** – Lamin Keita's Hope

**Ghana** – Spina Bifida & Hydrocephalus Foundation Ghana

**Ivory Coast** – Espérance's Hope

**Kenya** – Spina Bifida and Hydrocephalus Association Kenya (SHAK)

**Malawi** – Parents Association of Spina Bifida and Hydrocephalus Limited (PASHL)

**Morocco** – Association Spina Bifida et Handicaps Associés au Maroc

**Niger** – Inclusion Sans Frontière Multi-Handicap (ISF)

**Nigeria** – Spina Bifida and Hydrocephalus Association of Nigeria

**Nigeria** – Festus Fajemilo Foundation

**Nigeria** – Liron Hydrocephalus Foundation

**South Africa** – Association for Spina Bifida and Hydrocephalus South Africa

**Sudan** – Spina Bifida Federal Association of Sudan

**Tanzania** – Association for Spina Bifida and Hydrocephalus Tanzania (ASBAHT)

**Tanzania** – Halisi Foundation

**Togo** – Association Santé Meilleure Vie Meilleure (SM-VM)

**Uganda** – Central Uganda Spina Bifida and Hydrocephalus Network

**Uganda** – Spina Bifida and Hydrocephalus Association of Uganda (SHA-U)

**Uganda** – TET Foundation Uganda

**Uganda** – SHARED GROWTH Uganda (SGU)

**Zambia** – Zambia Association for Hydrocephalus and Spina Bifida (ZAHSB)

**Zimbabwe** – Spina Bifida and Hydrocephalus Association of Zimbabwe

**Zimbabwe** – Hydrocephalus Association

## Americas

**Argentina** – Asociación para Espina Bífida e Hidrocefalia (APEBI)

**Brazil** – ABRASSE Espinha Bífida

**Canada** – Individual membership

**Canada** – Spina-Bifida Hydrocéphalie Québec

**Canada** – Hydrocephalus Canada

**Canada** – Spina Bifida and Hydrocephalus Association of Northern Alberta

**Chile** – Corporación de Espina Bífida (CORPEB)

**Colombia** – Fundación Mónica Uribe Por Amor

**Guatemala** – Asociación Guatemalteca de Espina Bífida (AGEB)

**Haiti** – Haitian Association of Spina Bifida and Related Disabilities (HASBRD)

**Honduras** – Fundación Amado Josué

**Mexico** – Asociación Mexicana de Espina Bífida A.C. (AMEB)

**Panama** – Fundación Zero Limite Espina Bífida Panamá

**Peru** – Asociación de Espina Bífida e Hidrocefalia del Perú (ASESBIH)

**USA** – Hydrocephalus Association

**USA** – Spina Bifida Association of America (SBAA)

## Asia-Pacific

**Australia** – Spina Bifida Association Queensland

**Australia** – Individual memberships

**Bangladesh** – Bangladesh Hydrocephalus and Spina Bifida Welfare Trust

**Bangladesh** – Bangladesh Protibandhi Kallyan Somity (BPKS)

**China** – China Association of Persons with Physical Disabilities

**India** – Spina Bifida Foundation

**Iraq** – Individual membership

**Iran** – Tabriz Registry of Congenital Anomalies (TRoCA)

**Japan** – Japan Council for Spina Bifida and Hydrocephalus

**Japan** – Spina Bifida Association of Japan

**Kazakhstan** – Spina Bifida Public Organisation

**Kazakhstan** – Individual membership

**Malaysia** – Spina Bifida Association Malaysia (SIBIAM)

**Mongolia** – Mongolian Spina Bifida Foundation “Maral Angel”

**Pakistan** – Individual memberships

**Pakistan** – Pakistan Federation for Spina Bifida and Hydrocephalus

**Philippines** – Spina Bifida Support Group Foundation, Inc.

**South Korea** – Korea Spina Bifida Patient Association (KSBPA)

**Taiwan** – Taiwan Spina Bifida Support Association

## Europe – EU/EEA Members

**Austria** – Spina Bifida und Hydrocephalus Österreich (SB HÖ)

**Belgium** – Association Spina Bifida Belge Francophone asbl (ASBBF)

**Belgium** – Vlaamse Vereniging voor Spina Bifida en Hydrocephalus vzw (VSH)

**Bulgaria** – Spina Bifida Hydrocephalus Bulgaria

**Croatia** – Udruga osoba i roditelja djece sa spinom bifidom “Aurora”

**Cyprus** – Pancyprian Association of Rare Genetic Diseases “Unique Smiles”

**Denmark** – Rygmarsvbrokforeningen af 1988

**Estonia** – The Estonian MMC and HC Society

**Finland** – Suomen CP-liitto ry

**France** – Association Nationale Spina Bifida et Handicaps Associés (ASBH)

**France** – Fédération Nationale pour le SBH (FFASB)

**Germany** – Arbeitsgemeinschaft Spina Bifida und Hydrocephalus e.V. Bundesverband (ASBH)

**Greece** – Hellenic Association for Spina Bifida and Hydrocephalus

**Hungary** – MEOSZ

**Ireland** – Spina Bifida and Hydrocephalus Ireland (SBHI)

**Italy** – Associazione Spina Bifida Italia (ASBI)

**Latvia** – Latvijas Spina Bifida un Hidrocefālijas biedrība (LSBH)

**Lithuania** – Spina Bifida and Hydrocephalus Association Lithuania

**Luxembourg** – Association pour le Spina Bifida a.s.b.l.

**Norway** – Ryggmargsbrokk- og hydrocephalusforeningen

**Poland** – Fundacja Spina

**Portugal** – Associação de Spina Bífida e Hidrocefalia de Portugal (ASBIHP)

**Romania** – Asociația Română de Spina Bífida e Hidrocefalie (ARSBH)

**Slovakia** – Slovenská spoločnosť pre Spina Bifida a/alebo Hydrocefalus, o. z.

**Spain** – Associació Catalana d’Espina Bífida i Hidrocefàlia (ACAEBH)

**Spain** – Federación Española de Asociaciones de Espina Bífida e Hidrocefalia (FEBHI)

**Spain** – Madrid Asociación Madrileña de Espina Bífida (AMEB)

**Spain** – Asociación Murciana de Padres con Hijos de Espina Bífida e Hidrocefalia

**Sweden** – RBU

**Sweden** – Spin-Off

**The Netherlands** – Spina Bifida Hydrocephalus Nederland

## Europe – Non EU/EEA Members

**Georgia** – Georgian Spina Bifida Association

**Israel** – Hydrocephalus Israel

**Montenegro** – Individual membership

**Russia** – Association of Spina Bifida and Hydrocephalus of St. Petersburg

**Russia** – Charitable Foundation Spina Bifida

**Scotland** – Spina Bifida Hydrocephalus Scotland (SBHS)

**Serbia** – Spina Bifida and Hydrocephalus Association of Serbia

**Switzerland** – Spina Bifida und Hydrocephalus Schweiz

**Switzerland** – Stiftung Folsäure Schweiz (SFS)

**Turkey** – Spina Bifida Derneği

**UK** – SHINE Charity

**UK** – Harry’s Hat

**Ukraine** – Parents Association for Spina Bifida and Hydrocephalus “Lights of Spirit”

# BOARD OF DIRECTORS



**Victoria Sandoval**  
President  
Guatemala



**Dr. Santosh  
Karmarkar**  
Vice President  
India



**Slaveya  
Kostadinova**  
Secretary  
Bulgaria



**Dr. Aziza Mustafa  
Elnaeema**  
Treasurer  
Sudan

# SECRETARY GENERAL



**Dr. Sylvia Roozen**

# OBITUARY NOTICE

Much to our sadness, we learned that IF founding father Björn Ründström (1926–2025) passed away, surrounded by his family in Uppsala, Sweden.

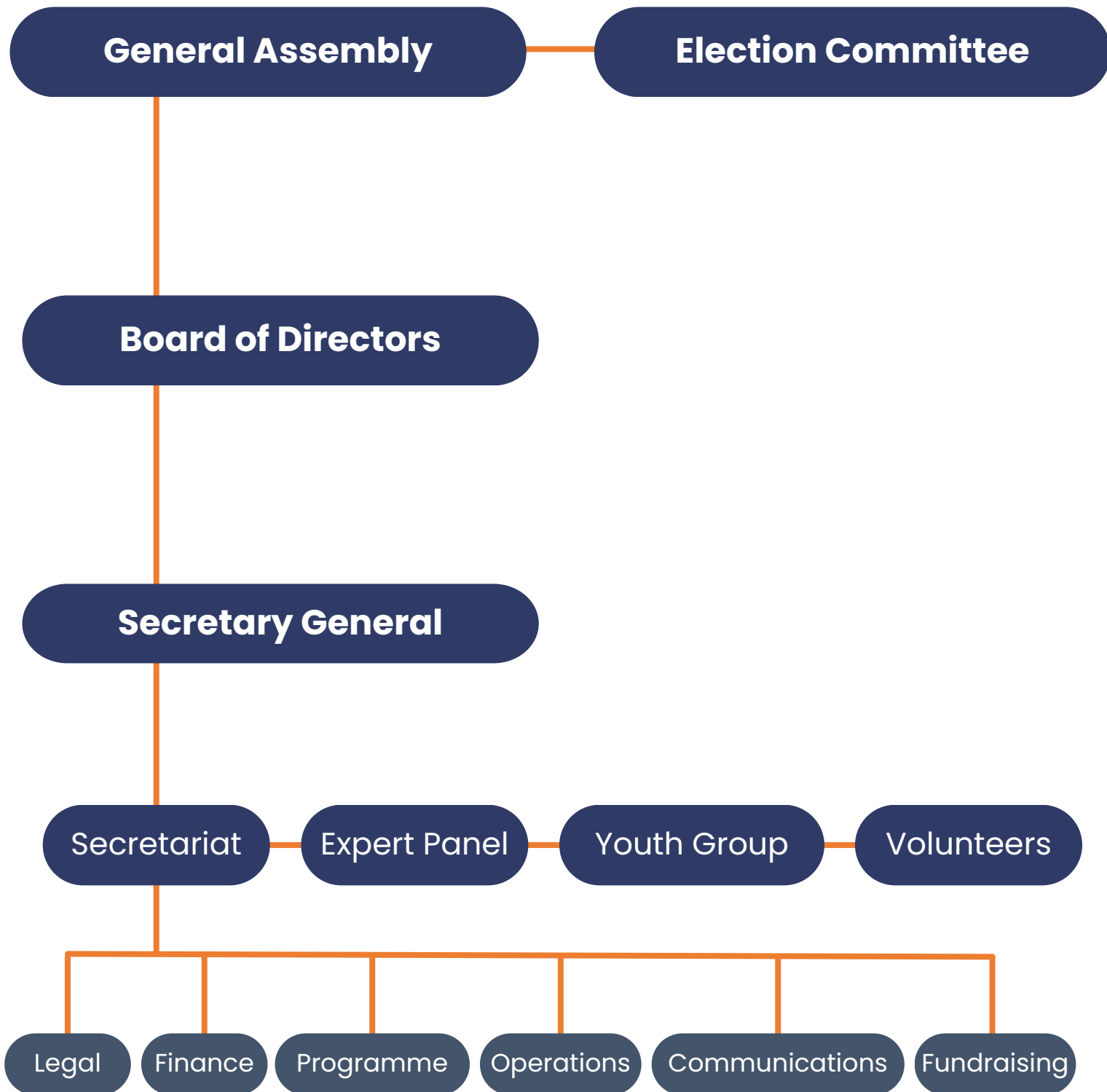
Björn was a pioneer in advocacy for persons affected by Spina Bifida and/or Hydrocephalus (SBH) and their families. Under his inspiring leadership, a solid foundation was laid for the International Federation for Spina Bifida and Hydrocephalus during its pioneering phase. He was a source of inspiration for the continued mission to improve the quality of life of persons affected by SBH and their families.

Friends and colleagues will remember him for his activism in the disability movement over more than 60 years. He was responsible for organising the very first IF International Conference on SBH in 1979, as well as those that followed. Over a period of 17 years, he served as IF President. Upon stepping down, he continued his active support for the IF Annual Reports until 2001.

Optimistic and determined, he was pleased to see successes but always pointed out the need to do more. He used to say that his biggest success was seeing that what he started is still alive and active. His legacy will continue in others.



# IF ORGANOGRAM



# ELECTION COMMITTEE

In 2025, the General Assembly elected the following members for the election committee:

- **Terezia Drdul** – Slovenská spoločnosť pre Spina Bifida a/ alebo Hydrocefalus, o. z.
- **Dr Margo Whiteford** – Spina Bifida Hydrocephalus Scotland (SBHS)
- **Hassan Funmilayo** – Spina Bifida and Hydrocephalus Association of Nigeria (SBHAN)
- **Patrick Essuman** – Spina Bifida & Hydrocephalus Foundation Ghana

## ADVISORY PANELS

Our standing committees and advisory groups include the Expert Panel, the International Youth Group and volunteers.

### Expert Panel

IF has an advisory group of respected experts in disability, healthcare, prevention and political advocacy who serve in these roles on a voluntary basis. Members of this advisory group include professionals and specialists in Spina Bifida and Hydrocephalus and/or disability more broadly. In particular, the scientific conference committees for IF conferences support the wider scientific work of the Federation.

### IF International Youth Group SBH

The 2025 Youth Group consisted of the following members:

- Jurn Anthonis (Spina Bifida & Hydrocephalus Belgium)
- Maahi Rudawat (Spina Bifida Foundation India)
- Malik Armughan Ali (IF Individual Member, Pakistan)
- Rereloluwa Adeolu (Festus Fajemilo Foundation, Nigeria)
- Ajok Proscovia (Spina Bifida and Hydrocephalus Association of Uganda)
- Gabriel Barba (Spina Bifida Support Group Foundation, Philippines)
- Narresh Vijayandran (SIBIAM, Malaysia)
- Viktoria Peykova (Bulgarian Spina Bifida and Hydrocephalus Association)
- Nebiyat Tesfaye (Alliance for Birth Defects, Ethiopia)

# MAIN ACHIEVEMENTS

2025 marked a year of strengthened global advocacy, expanded partnerships, and increased community engagement across all areas of IF's work.

## HUMAN RIGHTS

**Advancing dignity, inclusion, and accountability**

- Advocacy & policy influence
- CRPD engagement
- International declarations & statements
- Strategic partnerships

## AWARENESS RAISING

**Amplifying voices and increasing global visibility**

- International awareness days
- Global campaigns & toolkits
- Youth-led engagement
- Social media mobilisation

## HEALTH EQUITY

**Improving access to care, knowledge, and services**

- Genetics & prevention
- Urology & clinical guidelines
- Assistive products advocacy
- Knowledge exchange & training

## WSBHD25

**Driving global awareness and community mobilisation**

- Global campaign #Action4SBH
- Regional side events
- Community engagement & storytelling
- Member-led activities worldwide

## COMMUNITY BUILDING & TWINNING

**Strengthening the global SBH network**

- Members meetings & regional cooperation
- Twinning programme
- Member support initiatives
- Capacity building & training

## NETWORK DEVELOPMENT

**Expanding global partnerships and collaborations**

- UN & WHO engagement
- European Commission platforms
- Rare diseases alliances
- LMIC partnerships

# HUMAN RIGHTS

The year 2025 marked a significant step forward in advancing the human rights of persons living with SBH. IF intensified its efforts to ensure that policies, international commitments and advocacy initiatives reflect the dignity, autonomy and inclusion of the SBH community. Through global advocacy, strategic partnerships and evidence-informed policy engagement, IF reinforced accountability mechanisms, supported member organisations in holding governments to their obligations and promoted rights-based approaches to prevention, care and lifelong support. This chapter highlights key milestones in human rights policy, including the formal submission of the Kuala Lumpur Declaration to the Global Disability Summit, contributions to the European Union CRPD review, targeted statements on prevention and access to assistive products and IF engagement in international platforms to advance rights for the SBH community.

## GLOBAL COMMITMENTS: KUALA LUMPUR DECLARATION

In 2025, IF formally presented the Kuala Lumpur Declaration, **a historic outcome of the 30th International Conference on Spina Bifida and Hydrocephalus** held in Kuala Lumpur from 24–26 October 2024. The Declaration, endorsed by 150 stakeholders, was submitted to the Global Disability Summit in Berlin in April 2025 to highlight global commitments benefiting the SBH community.

Developed with contributions from experts, healthcare professionals, members of the SBH community and families worldwide, the Declaration aims to inform policy and calls for a human rights-based approach to the prevention of Neural Tube Defects (NTDs), the adoption of effective, evidence-based prevention strategies including folic acid fortification and the provision of continuous, coordinated and inclusive multidisciplinary care throughout the life course of individuals with Spina Bifida and Hydrocephalus.

The Declaration represents a shared commitment to bridge gaps in healthcare, strengthen early education and awareness, enhance coordination of care from childhood to adulthood and promote knowledge-sharing among healthcare providers, researchers and families.

Furthermore, IF encouraged stakeholders worldwide to co-sign and endorse the Declaration. Members of the SBH community and partner organisations can also use the Declaration to hold their policymakers accountable, advocate for the implementation of its commitments and strengthen policies and services that improve the lives of people living with SBH.



# POLICY ADVOCACY AT REGIONAL AND GLOBAL LEVELS

## EU CRPD Review

In March 2025, the EU underwent its review by the UN Committee on the Rights of Persons with Disabilities, a key moment for advancing disability rights across Europe. The Committee acknowledged progress but called for stronger action on equal access, the rights of women with disabilities, public procurement and monitoring of EU funds to prevent institutionalisation. IF supported the disability movement in advocating for these recommendations and will continue working to ensure they are reflected in the EU Disability Rights Strategy and the post-2027 EU budget.

## Global Disability Summit

At the Global Disability Summit in Berlin (April 2025), IF promoted a genuine OPD-led approach and amplified the Kuala Lumpur Declaration alongside the Amman-Berlin Declaration. The Summit reinforced meaningful participation, global commitments and the integration of SBH prevention and care into international disability inclusion frameworks.

## Bridge CRPD–SDGs Training

IF supported regional capacity-building through the 10-year milestone Bridge CRPD–SDGs ASEAN training, focusing on rights-based approaches, accessibility, inclusive education and employment. Participants highlighted the importance of regional solidarity, disaggregated data and coordinated advocacy across governments, civil society and the private sector.

Representing the Spina Bifida Support Group Foundation, Inc., Manuela Carla M. Diozon attended the 10th anniversary meeting in Bangkok, engaging with a diverse community of disability advocates. She reflected: *“This workshop was my first experience engaging with a diverse international community of persons with different types of disabilities and it was both eye-opening and transformative”*. She also emphasised that *“inclusion is a collective effort, requiring active partnerships across sectors, regions and communities”*.



# STRENGTHENING ACCESS AND RIGHTS THROUGH STATEMENTS

In 2025, IF continued to strengthen its global advocacy by publishing three important statements addressing partnerships, access to essential assistive products and global recognition towards a United Nations-recognised International Day for SBH. These statements reflect IF's commitment to prevention, human rights and meaningful participation of persons with Spina Bifida and Hydrocephalus.

## Service Clubs in Action for SBH

In February 2025, IF published "Service Clubs in Action for Spina Bifida: Prevention and Care," marking Rotary International's 120th anniversary.

The publication showcases collaborations between service clubs and SBH organisations, highlighting prevention, inclusion and successful projects from Colombia and Malaysia, including the 30th International Conference on SBH and the Kuala Lumpur Declaration.

## WHO Assistive Products Priority List (APL) Statement

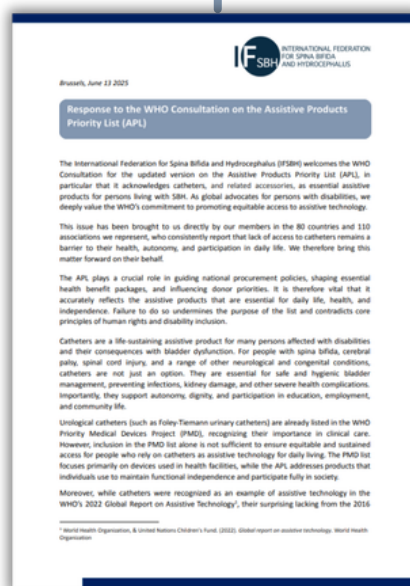
In June 2025, IF welcomed the WHO consultation on the updated APL, advocating for the recognition of catheters and related accessories as essential assistive devices.

IF highlighted how access barriers impact health, autonomy and dignity for persons with SBH and offered expertise to support equitable implementation globally.

## Towards a UN-recognised World SBH Day

In October 2025, IF published a policy brief advocating for a UN-recognised World SBH Day. The initiative aims to raise awareness, promote prevention and strengthen lifelong care.

The statement outlines how official recognition can catalyse awareness, policy reform, partnerships and resource allocation.



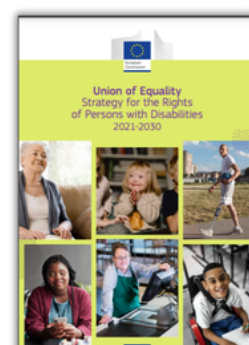
## INTERNATIONAL PARTNERSHIPS AND COLLABORATIONS

Building and strengthening partnerships with international organisations remained a key pillar of IF's human rights advocacy in 2025. Through active engagement in global and regional platforms, IF ensured that the rights and needs of persons living with SBH were reflected in international policy discussions while contributing to broader disability and health agendas.

IF played an active role in the WHO Disability Health Equity Network, contributing both technical expertise and the lived experiences of the SBH community. This engagement supports the development of more inclusive and responsive health policies while reinforcing the importance of disability-inclusive approaches across health systems.



At the European level, IF continued its involvement in the European Commission Disability Platform, a key mechanism supporting the implementation of the EU Strategy for the Rights of Persons with Disabilities 2021–2030. Through this platform, IF contributed to consultations, policy discussions and exchanges of good practices, ensuring that the perspectives of persons with SBH are considered in EU legislation and programmes. This work was further reinforced through IF's participation in the Citizens, Equality, Rights and Values (CERV) Programme, which strengthens the capacity of civil society organisations to promote fundamental rights and democratic participation.





IF also strengthened its global advocacy through engagement in the **Rare Diseases International Coalition**, contributing to the adoption of the World Health Assembly resolution on “Rare diseases: a global health priority for equity and inclusion” (WHA78). By participating in advocacy efforts and discussions, IF ensured that SBH was recognised within the broader rare disease agenda and that the voices of individuals with lived experience were represented in global health policymaking.



In addition, IF co-hosted a high-level side event at the **78th World Health Assembly**, bringing together international organisations, governments and civil society partners to accelerate action on micronutrient deficiencies and their consequences, including Spina Bifida. The event highlighted the importance of large-scale food fortification as a cost-effective, evidence-based strategy and reinforced the need for coordinated, rights-based approaches involving governments, donors and the private sector.



In partnership with the **International Disability Alliance (IDA)**, IF actively contributed to the **Global Disability Summit (GDS)**, engaging in pre-summit dialogues that helped shape key agenda priorities and strengthen commitments relevant to persons with Spina Bifida and Hydrocephalus. IF also took part in the post-GDS workshop, where implementation follow-up was discussed.

As Anđela Radovanović (IF member in Montenegro) stated, *“Being a UN member and having an EU candidate status made Montenegro ratify numerous international treaties in the area of human rights and some progress towards the improvement of disability rights was made. However, as it happens sometimes, political processes are strongly influencing the realisation of human rights, and the Montenegrin case was not an exception”*, highlighting the importance of continued joint action after the Summit.

Through these partnerships and engagements, IF strengthened its position as a global advocate for the SBH community, fostering collaboration, influencing policy processes and promoting the integration of SBH prevention and care within international human rights and disability frameworks.

## POLICY ENGAGEMENT AND CONSULTATIONS

In 2025, IF contributed to EU, WHO and UN consultations, ensuring SBH perspectives are embedded in policy and practice. IF also engaged in scientific collaborations, guideline development and systematic reviews to strengthen evidence-based advocacy for the SBH community.

Key outputs include contributions to clinical guidelines, research on urological care and studies on mandatory food fortification.

### GLOBAL HEALTH & WHO



- Contribution to the WHO Disability Health Equity initiative;
- Input to consultations related to the WHA78 Resolution on Rare Disorders.

### PARTNERSHIPS & COLLABORATION



- Supported the European Disability Forum (EDF) Health Study Guidelines.

### EU POLICY



- Contribution to the consultation on the EU4Health 2025 Work Programme;
- Engagement in consultations organised by the European Commission Disability Platform;
- Contribution to discussions on the new Action Plan to implement the European Pillar of Social Rights;
- Input on initiatives such as the European Child Guarantee, the recognition of European Cross Border Associations;
- Discussions within the DG EMPL Civil Dialogue on the EU Civil Society Strategy.

### HUMAN RIGHTS & INTERNATIONAL FRAMEWORKS



- Provided inputs on the Global Disability Inclusion Report coordinated by the International Disability Alliance (IDA);
- Response to the Disability Caucus Terms of Reference submitted to the United Nations Framework Convention on Climate Change (UNFCCC);
- Contribution to the report on the application of the Racial Equality Directive and Employment Equality Directive.

Co-hosted by the Governments of the Philippines, Bangladesh, Egypt, Pakistan, and Chile.

## ACCELERATING ACTION ON MICRONUTRIENT DEFICIENCIES AND THEIR CONSEQUENCES, INCLUDING SPINA BIFIDA

**Delivering on WHA 76.19 through large scale food fortification**

In 2023, the World Health Assembly passed WHA 76.19, "Accelerating efforts for preventing micronutrient deficiencies and their consequences including spina bifida and other neural tube defects, through safe and effective food fortification." WHA 78 marks one year before the first implementation report is due

Tuesday, May 20, 2025  
18:00 - 20:30 CEST

Registration is required to attend

UNICEF Geneva Office, International Labour Organization Building  
4 route des Morillons, CH-1211 Geneva 22

Register here:

## SCIENTIFIC CONTRIBUTIONS AND PUBLICATIONS

IF contributes to evidence-based practice, patient-centred care and rights-based health policy through scientific research, guideline development and international collaboration. Current contributions include a systematic literature review on mental health among persons affected by Spina Bifida (in preparation), focusing on psychosocial wellbeing, mental health outcomes and barriers to support services across the life course.

In 2025, IF contributed to the development of the EAU – ESPU – ERN eUROGEN – ERN ITHACA – ERN ERKNet – IFSBH Guidelines on Spinal Dysraphism in Children and Adolescents (Abrahamson et al., 2025). These clinical guidelines provide comprehensive recommendations for multidisciplinary care and represent a major step toward harmonising standards of treatment and follow-up for children and adolescents with spinal dysraphism across Europe and beyond.

IF also collaborated with leading European clinical experts on advancing patient-centred healthcare approaches through the publication Assessing Patient-Centred Urological Care for Spina Bifida (‘t Hoen et al., 2024, submitted). As part of this work, members of the Spina Bifida community were actively involved through survey-based research aimed at capturing lived experiences, priorities and perspectives on urological care. This contribution reinforced the importance of meaningful patient participation in healthcare design, evaluation and policy development, while promoting the principles of dignity, autonomy, inclusion and shared decision-making in medical care.

Furthermore, IFSBH contributed to global public health research addressing prevention of neural tube defects through the publication by Roozen et al. (2025), Mandatory Food Fortification in the Eastern Mediterranean Region Results in Reduced Prevalence of Neural Tube Defects, published in *Frontiers in Public Health*. The study highlights the positive impact of mandatory food fortification policies and underscores the importance of preventive public health measures, equitable nutrition strategies and international cooperation in reducing preventable disabilities.

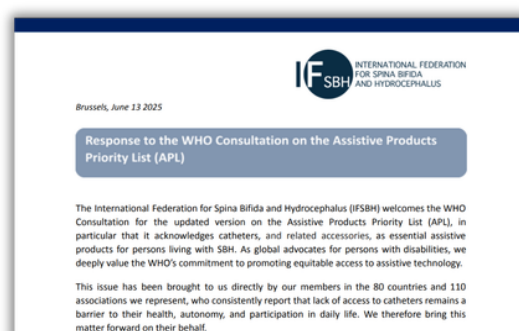
Through these scientific and policy-oriented contributions, IF continues to bridge lived experience, research and advocacy to promote the human rights, health and inclusion of persons with Spina Bifida and Hydrocephalus worldwide.



### Mandatory food fortification in the eastern Mediterranean region results in reduced prevalence of neural tube defects

Sylvia Roozen<sup>1,2\*</sup>, Quentin Johnson<sup>1</sup>, Eman Ibrahim<sup>3</sup>, Salima Al Maamari<sup>4</sup>, Amina Barkat<sup>5</sup>, Saleh Al Shammakhi<sup>6</sup>, Fatima Zohra Laamir<sup>6</sup>, Aguenou Hassan<sup>7</sup>, Hasnae Gamih<sup>8</sup>, Abdelhakim Yahyane<sup>9</sup> and Ayoub Al Jawaldeh<sup>10</sup>

<sup>1</sup>International Federation for Spina Bifida and Hydrocephalus, Brussel, Belgium, <sup>2</sup>Governor Kremers Centre-Maastricht University Medical Centre, Maastricht, Netherlands, <sup>3</sup>Regional Office for the Eastern Mediterranean (EMRO), World Health Organization (WHO), Cairo, Egypt, <sup>4</sup>Nutrition Department, Ministry of Health, Muscat, Oman, <sup>5</sup>Faculty of Medicine and Pharmacy of Rabat, Mohammed V University Rabat, Rabat, Morocco, <sup>6</sup>University Hassan I, Settat, Settat, Morocco, <sup>7</sup>Université Ibn Tofail, Faculty of Sciences, Kenitra, Morocco, <sup>8</sup>Ministry of Health, Directorate of Public Health, Rabat, Morocco



Brussels, June 23 2025

#### Response to the WHO Consultation on the Assistive Products Priority List (APL)

The International Federation for Spina Bifida and Hydrocephalus (IFSBH) welcomes the WHO Consultation for the updated version on the Assistive Products Priority List (APL), in particular that it acknowledges catheters, and related accessories, as essential assistive products for persons living with SBH. As global advocates for persons with disabilities, we deeply value the WHO's commitment to promoting equitable access to assistive technology.

This issue has been brought to us directly by our members in the 80 countries and 110 associations we represent, who consistently report that lack of access to catheters remains a barrier to their health, autonomy, and participation in daily life. We therefore bring this matter forward on their behalf.

# AWARENESS RAISING

## INTERNATIONAL AWARENESS DAYS

IF's work is dedicated to protecting and promoting the human rights of individuals living with SBH. During 2025, IF addressed this objective by raising awareness about the rights of persons with SBH through different kinds of activities, including participating in and organising meetings and events, contributing to consultations and publishing statements. Both European and international awareness days were crucial moments for IF's awareness-raising activities through multimedia channels. These days also provide opportunities for collaboration with IF community members and partners, both in the EU and globally, enhancing IF's visibility alongside its members and partners.

### Our awareness-raising activities had the following overall objectives:

- Promoting, protecting and monitoring the rights of persons with SBH;
- Ensuring that the perspectives and needs of individuals with SBH and their families are represented in policymaking;
- Supporting the implementation of the ESRPD and the European Pillar of Social Rights (EPSR) and facilitating the mainstreaming of the UNCRPD;
- Strengthening partnerships and collaborations with European and international networks to amplify the visibility of the SBH community;
- Maximising the visibility and reach of IF activities;
- Organising communication and engagement activities to raise awareness of the ESRPD and promote the rights of persons with SBH;
- Promoting an intersectional approach that takes into account the different needs of the SBH community, considering gender, age and ethnicity.

In 2025, IF continued to raise awareness about the rights of individuals with SBH and the UNCRPD among policymakers, stakeholders and international organisations through the organisation of awareness campaigns for several global initiatives. In this context, social media toolkits were also produced and disseminated to support members and partners in advocacy efforts.



**These campaigns and toolkits were developed for the following International Awareness Days and Weeks:**

- World Folic Acid Awareness Week
- Rare Disease Day
- World Birth Defects Day
- International Women’s Day
- Siblings Day
- International Youth Day
- International Day of Older Persons
- World Spina Bifida and Hydrocephalus Day
- The International and European Days for Persons with Disabilities



**7 January 2025**



**28 February 2025**



**3 March 2025**



**8 March 2025**



**10 April 2025**



**12 August 2025**



**1 October 2025**



**25 October 2025**



**30 November 2025**

# WORLD FOLIC ACID AWARENESS WEEK



Every year in January, IF promotes the World Folic Acid Awareness Week as part of the IF Global Prevention Initiative, together with its member organisations, partners, supporters and the SBH community. The IFGPI connects governments, NGOs, health professionals and communities to maximise the reduction of NTDs, such as SB and hydrocephalus, worldwide. During WFAAW, IF raises awareness about the prevention of NTDs through folic acid supplements, staple foods fortified with folic acid or foods rich in folate, promoting healthy pregnancies.

The work of IF is reinforced by the WHA76.19 Resolution on accelerating efforts to prevent micronutrient deficiencies, including NTDs, through safe and effective food fortification, adopted in 2023. The resolution encourages Member States to strengthen national action on food fortification and supplementation. Building on over 45 years of advocacy, IF continues to support global efforts to advance equitable and effective fortification policies, contributing to the implementation of this resolution. In 2025, IF organised the webinar “Prevention of Neural Tube Defects: Leaving No One Behind” to maintain momentum and promote inclusive prevention strategies.

The webinar provided a platform to reflect on sustaining efforts to prevent NTDs and ensuring equitable access to maternal health interventions regardless of geography or socioeconomic status. It featured international experts and persons with lived experience from civil society, public health and research sectors and was moderated by representatives of the IF International Youth Group SBH.

**World Folic Acid Awareness Week**

Every January, the International Federation for Spina Bifida and Hydrocephalus works with its member organisations, partners and supporters to promote the World Folic Acid Awareness Week as part of the IF Global Prevention Initiative (IFGPI) as a **prevention campaign** to raise awareness about preventable Neural Tube Defects (NTDs) such as Spina Bifida and Hydrocephalus through folic acid supplements, staple foods fortified with folic acid or foods rich in folate, the natural form of folic acid.

We welcome you to join IF in raising awareness on this important global public health concern, from **January 1st to 8th 2025**. You are especially invited on **January 7** for the Global Webinar on **Prevention of Neural Tube Defects: Leaving no one Behind**, starting at **3PM CET (Brussels timezone)** in Zoom.

Join us in sharing key information about folic acid and prevention during this important week, and share folic acid knowledge and information through your social media channels and with friends, colleagues and families. Encourage them to spread folic acid awareness too!


The message is simple: **Pre-conceptual folic acid is key for the prevention of most NTDs.**

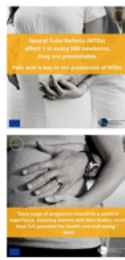
**Take Part in the WFAAW 2025 Social Media Awareness Raising Campaign**

Join IF during the WFAAW 2025 to raise awareness on the important topic of Spina Bifida and Hydrocephalus prevention.

IF developed a social media toolkit for you to share key messages across your social media channels and network.

**Prevention is a combined effort.**

 **Together with you we can raise awareness all around the world on the importance of folic acid for the prevention of neural tube defects!**



# RARE DISEASE DAY



Rare Disease Day is a long-standing global initiative that highlights the challenges faced by people living with rare conditions while emphasising the need for better care, increased awareness and concrete action for the community. In 2025, IF joint advocacy efforts in the context of the Rare Diseases International Coalition contributed to the adoption of the World Health Assembly resolution on “Rare diseases: a global health priority for equity and inclusion” (WHA78), with SBH recognised within the rare disease agenda. IF is especially focused on promoting multidisciplinary care for people living with SBH and calling for stronger coordination among healthcare, social and support services.

On 28 February, IF joined forces with a range of international organisations committed to supporting individuals with rare diseases. Under the coordination of EURORDIS, a wide variety of posters, toolkits, infographics, banners and fact sheets were shared online. To mark Rare Disease Day in 2025, IF joined the global campaign online as a partner and supported the community by sharing key information on rare diseases through social media posts and messages. By getting involved, IF helped spread the campaign’s official materials to the SBH network and ensured that information on rare diseases reached a wider audience.



# WORLD BIRTH DEFECTS DAY

#WBDD #WorldBDDay #EveryJourneyMatters

## World Birth Defects Day

On **3 March 2025**, the world will be united to celebrate the 7th edition of the **World Birth Defects Day (WBDD)**. This year's theme is **#EveryJourneyMatters** emphasising that birth defects affect individuals, family, friends, and communities.

There are many types of birth defects and **this day recognises our collective voice in raising awareness for all birth defects.**

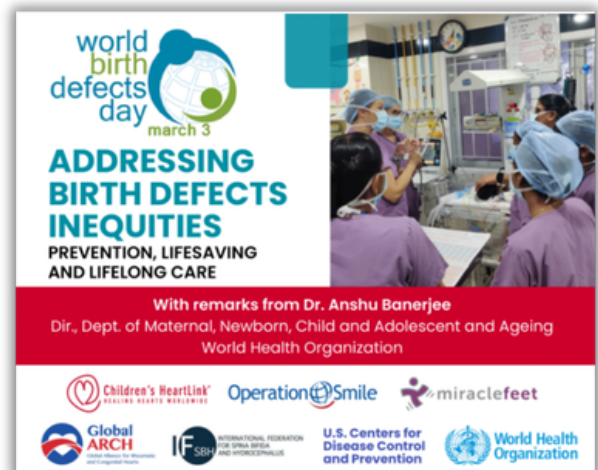
Starting as an annual event back in 2015, this day has now become a movement, **with the aim to mobilise resources and commitment to improve birth defects surveillance, research, prevention and care.** The first priority is to increase the visibility of birth defects and disseminate what is already known on how to prevent birth defects and how to improve health and quality of life of affected individuals.



*"Every year it is estimated that approximately 133 million babies are born around the world, about 4 million of them (1 in 33) are born with a serious structural birth defect."\**

On 3 March, IF joined the global community in commemorating the 10th edition of World Birth Defects Day with the theme 'Every Journey Matters!'. In support of this day, IF invited members and partners to take part in an awareness campaign – not only to draw attention to birth defects in general but also to specifically highlight SBH. To support members' participation, a comprehensive social media toolkit was created. It featured downloadable infographics, hashtags, links as well as sample messages designed for global sharing on WBDD. The toolkit enabled IF members and partners to amplify our collective voice by spreading key messages and resources across social media platforms, reaching friends, colleagues and broader networks.


This year, IF also invited community members and individuals to take part in a social media activity to further help raise awareness. Participants were encouraged to record a short, eight-second video – symbolising the eight million babies born with birth defects every year – and briefly talk about one birth defect. The videos were shared on social media, using hashtags such as #WorldBirthDefectsDay and #EveryJourneyMatters. The social media package was also promoted via newsletters, targeted emails and online meetings to help maximise its reach.



# SIBLINGS DAY

## IF's Siblings Day

**How can you participate?  
By downloading the  
IF's Siblings Day Toolkit**



On the 10th of April 2025

### IF'S SIBLINGS DAY

The International Federation for Spina Bifida and Hydrocephalus (IFSBH) will be celebrating IF's Siblings Day on April 10th to honour siblings with Spina Bifida and Hydrocephalus (SBH). IF invites you to share the activities you like to do with your siblings, pictures and messages to broadcast on social media intended to your siblings.

**Print out this template, write your message and take a picture holding it!**

Share your picture as well as IF's toolkit on social media and tag us on Twitter, LinkedIn and Instagram @ifsbh and use the following hashtags  
#IFSiblingsDay  
#SBHSiblings #SmileSiblings.


Feel free to record short videos of you while doing your favourite activity with your sibling with SBH and send them to us before the 1st of April.

IF has chosen the Smile logo and hashtag because:  
**"Siblings are lifelong best friends making each other smile every single day"**

IF looks forward to receiving your pictures and sharing them!


Every year, 10 April marks Siblings Day, a day dedicated entirely to the celebration of brothers and sisters, their love, support and togetherness. In 2025, IF observed this day to honour the special bond between siblings living with SBH.

To further stress the significance of this day, members of the SBH community were invited to take part and recognise the importance of siblings and the role they play in our lives. In order to engage members actively, IF developed a social media toolkit that included a poster, a personalised message template, social media signs and a selection of hashtags for social media use. Participants were also invited to share pictures with their siblings or activities they enjoy together, to foster a sense of connection across the SBH community. During the Siblings Day campaign, IF engaged the SBH community across multiple social media channels.



## IF Siblings Day 2025

#IFSiblingsDay #SBHSiblings #SmileSiblings



Thank you for celebrating with us! ❤️ IF SBH

As the main highlight of the campaign, the community was encouraged to share pictures with their siblings, which was well received and resulted in 30 contributions, demonstrating strong engagement and willingness to participate among members.

# INTERNATIONAL WOMEN'S DAY

## International Women's Day 2025

The International Federation for Spina Bifida and Hydrocephalus (IF) joins the global movement towards realising the rights of all women and celebrates the **International Women's Day (IWD) on 8 of March 2025**.



This year's theme for the International Women's Day is **'Accelerate action'**.

The theme recognises that in the pursuit of prosperous economies and a healthier planet, achieving gender equality and prioritising women's well-being is now more critical than ever. Together, we can invest in women, accelerate progress, and pave the way for a more equitable and sustainable world.

Women's Day

To mark International Women's Day this year, IF launched a social media campaign centred around the theme "Accelerate Action". In line with Article 6 of the UNCRPD, which recognises the multiple inequalities and various forms of discrimination that women and girls with disabilities experience, the campaign aimed to draw attention to the unique challenges faced by many women and girls with disabilities, especially within the SBH community.

On 7 March, IF hosted a webinar to mark International Women's Day, bringing together women from diverse disability communities worldwide to share lived experiences and knowledge. Speakers included: Lidia Best (President, European Federation of Hard of Hearing People), Anđela Radovanović (IF Member, representing persons with Spina Bifida in Montenegro), Su Xiao Vin (Committee Member, Spina Bifida Association Malaysia - SIBIAM), Elena Ratoi (Member, European Network on Independent Living - ENIL), Dr Aziza Elnaeema (IF Board Member, Spina Bifida Federation Association, Sudan), and Velichka Draganova (Secretary General, World Federation of the Deafblind). The discussion addressed multiple and intersecting forms of discrimination faced by women and girls with disabilities, with a focus on accessibility, empowerment, inclusive education, independent living, safety in crises, and gender equality. Six speakers from international disability organisations and networks contributed insights from their work and personal experiences, highlighting the importance of accessible communication, inclusive policies, and strengthened support for independent living and social inclusion.

# INTERNATIONAL YOUTH DAY



International Youth Day 2025 (12 August) provided a platform for young people worldwide to highlight challenges and contributions, amplify their voices, and promote inclusion. The theme, “Dreaming Beyond Barriers”, chosen by the IF International Youth Group SBH, reflected the courage and determination of young people with disabilities striving to achieve their goals. To mark the occasion, the IF International Youth Group SBH implemented a month-long, multi-platform social media campaign and a series of coordinated activities designed to amplify youth voices and encourage participation. The campaign included a global call for youth-generated content under the theme, alongside the dissemination of a digital toolkit to support engagement and the implementation of a Polaroid Frame Initiative to visually present selected contributions, as well as a webinar on youth voices and disability inclusion featuring interactive roundtable discussions.



The campaign generated strong global engagement and resulted in meaningful youth participation across nine countries, with 13 creative submissions received and featured under the Polaroid Frame Initiative. Contributions included short videos and photo-based written messages that expressed personal aspirations, reflected lived experiences of disability, and shared messages of inclusion.

These narratives achieved strong online visibility and engagement, reflected in increased shares and reactions compared to standard content, demonstrating the resonance and effectiveness of youth-led storytelling approaches. The accompanying webinar further facilitated peer exchange among young persons with disabilities, creating a space for dialogue on inclusion, rights and the removal of barriers, reinforcing the importance of accessible platforms for youth expression and advocacy.

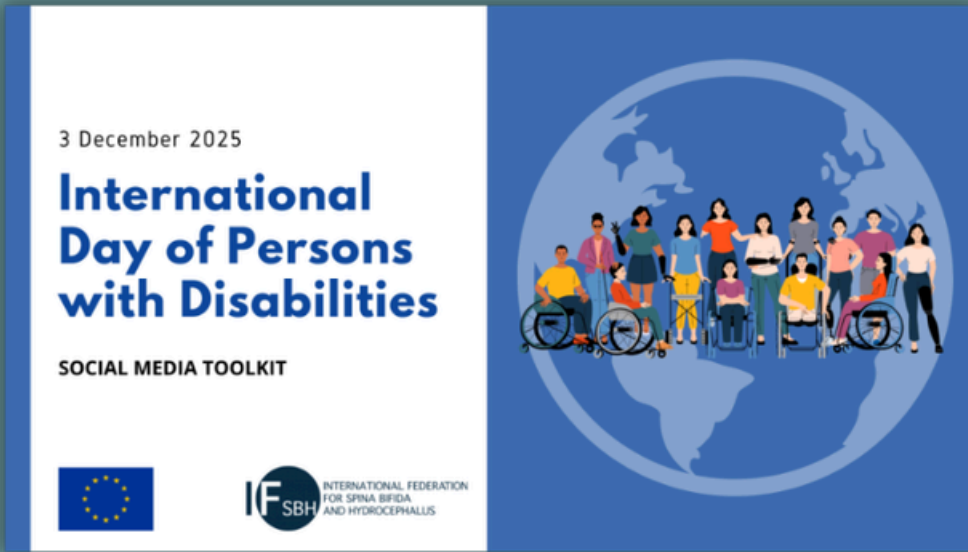
# INTERNATIONAL DAY OF OLDER PERSONS

Each year on 1 October, the International Day of Older Persons highlights the role and rights of older people in building inclusive and resilient societies. In 2025, the theme “Older persons driving local and global action: Our aspirations, our well-being, our rights” reinforced the importance of recognising older persons as active contributors to social development.

On this occasion, the IF Working Group on Ageing SBH contributed insights from lived experience, highlighting key challenges across health, independence, accessibility and participation. IF complemented this work by amplifying these perspectives through its advocacy channels and by disseminating resources and publications on best practices.

This combined effort strengthened awareness of the specific barriers faced by older persons with SBH and reinforced the importance of rights-based approaches that promote dignity, inclusion and active participation throughout the life course.

# THE INTERNATIONAL AND EUROPEAN DAYS FOR PERSONS WITH DISABILITIES



During the European and International Days of Persons with Disabilities, IF took key advocacy opportunities to promote the rights of individuals with SBH and their families, in line with and supporting the European Union’s implementation of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

The awareness campaigns linked to these international observances were conducted in a hybrid format, integrating both virtual and in-person activities to broaden reach and participation. The European Day of Persons with Disabilities (EDPD) is an annual conference hosted by the European Commission in collaboration with the European Disability Forum, offering a high-level forum for discussion and exchange among policymakers, specialists and disability advocates from across Europe, with the IF delegation taking part in both the sessions and networking opportunities.

IF also developed a comprehensive toolkit covering both the IDPD and the EDPD, which was shared with members and partners to foster active involvement in raising awareness about disability rights. The toolkit contains detailed background information on these observances, core messages, social media infographics, resource links, posters, hashtags and additional communication materials.



# HEALTH EQUITY

## STRENGTHENING CARE THROUGH COLLABORATION

Health equity means that every person has a fair and just opportunity to attain their highest possible level of health. For people living with SBH, this requires addressing disparities in access to diagnosis, specialised care, assistive products, and long-term multidisciplinary support. Structural barriers, such as unequal access to medical expertise, essential supplies and coordinated care systems, continue to affect health outcomes for many individuals and families worldwide. Promoting health equity therefore requires strengthening knowledge exchange, improving clinical guidance, advocating for essential medical products, and ensuring that expertise reaches you wherever you live.



# GENETICS AND PREVENTION KNOWLEDGE

**WHY SHOULD I CARE ABOUT...**

## GENETICS

Genetics is about studying DNA, which is a set of instructions that tells the cells that make up your body how to grow and function. These DNA instructions are passed down from parents to children (inheritance). It is your genes interacting with stimuli from your environment, that determines what you look like and how your body works.

**What are Neural Tube Defects?**

Neural Tube Defects (NTDs) are birth defects that affect the brain and the spine (i.e. Spina Bifida) and appear during the early stages of the baby's development. They are the result of failure of the neural tube to close properly in the weeks before the mother knows she is pregnant. If neural tissue is exposed, we call this an 'open' defect, whereas if there is skin covering, we consider this a 'closed' defect.

**How common are Neural Tube Defects?**

Neural Tube Defects are the second most common type of structural birth defect in humans. The number of babies with NTDs vary depending on the particular geographic areas and other circumstances.

**What causes Neural Tube Defects?**

NTDs occur due to a combination of different and varying factors. There is not just one cause of NTDs. Scientists have found that NTDs can be influenced by deficiencies in several different genes (can be over 300 genes) that increase the chances of a baby having an NTD. As NTD researchers often say, "NTDs are caused by a little bit of this... and a little bit of that".

Some other factors that may increase the risk of NTDs include:

- Family history of NTDs;
- Mothers not getting enough folate (a type of vitamin B9) through their diet before or during early pregnancy;
- Maternal health concerns such as obesity, diabetes, or the need for certain medications.

**Can Neural Tube Defects be passed down?**

NTDs can run in families but the risk depends on multiple factors. If you, or someone in your family has had an NTD, the chance of passing it down to a future generation can be between 1% and 10%.

**Can you prevent Neural Tube Defects?**

The amount of folate (from food) or folic acid (from supplements and fortified foods) has been shown to reduce the prevalence of NTDs. Maintaining a healthy and balanced diet and taking folic acid prior to and throughout pregnancy can lower the risk for an NTD. A folic acid supplement is necessary and highly recommended when a pregnancy is being planned.



**Curious about how genetics can affect you?**

You can discuss this with a doctor who can refer you to specialists at your local medical center. For more information, check out these interesting reads of the scientific literature:

Iskandar, B. J., & Finnell, R. H. (2022). Spina bifida. *New England Journal of Medicine*, 387(12), 444-450.

World Health Assembly (2023). *WHA76.12 Resolution*: Accelerating efforts for preventing micronutrient deficiencies and their consequences, including spina bifida and other neural tube defects, through safe and effective food fortification.

This brochure of the IF Advisory Group on Genetics is intended to provide information only - not to recommend particular treatment options. Any decision about treatment options should be made in consultation with your own medical team.

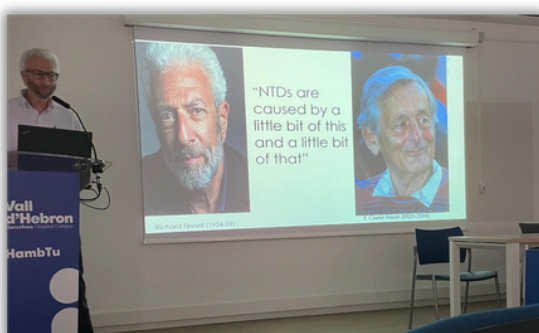
  INTERNATIONAL FEDERATION FOR SPINA BIFIDA AND HYDROCEPHALUS

[www.ifglobal.org](http://www.ifglobal.org)

Following the 30th International Conference on SBH in Malaysia, the IF Advisory Group on Genetics convened in Barcelona to advance collaboration and knowledge sharing. Experts and clinicians exchanged the latest insights on the genetic dimensions of SBH, improving understanding of risk factors, prevention strategies and family counselling needs.

This collaboration produced the first Genetics Factsheet, providing accessible and evidence-based information for member organisations, healthcare professionals and families. The factsheet supports informed decision-making, prevention planning and awareness of the role genetics plays in SBH.

In parallel, IF organised a high-level meeting in Barcelona titled "Progress in Genetics and Management", led by Dr Tizzano, IF senior expert from Vall d'Hebron Barcelona, the national contact and reference centre for the European Reference Network ITHACA. The meeting brought together key stakeholders, including the Catalonian Spina Bifida Association, the coordinator of the Spina Bifida Centre, physicians, and expert members of the IF Genetics Advisory Group, Prof. Dr Rick Finnell and Prof. Dr Leopold Curfs. The agenda included presentations and collaborative sessions focused on networking, knowledge exchange and strategic dialogue. Discussions emphasised strengthening engagement with the Catalonian member association and, on behalf of the national FEBHI Spina Bifida Association, identifying ways to advance genetic research and SBH management, improve multidisciplinary care coordination, develop long-term support strategies for independent living and wellbeing, and enhance collaboration between national and international experts.



## STRENGTHENING UROLOGY CARE AND CLINICAL GUIDANCE

Urological care remains a cornerstone of lifelong health for people with Spina Bifida. In 2025, IF strengthened collaboration with the ERN ITHACA, eUROGEN, EAU, ERKNet and ESPU to contribute to a joint publication on updated paediatric urology guidelines for Spina Bifida. These efforts aim to ensure that clinicians across Europe have access to the most up-to-date recommendations for managing urological complications, thereby improving quality of care and long-term health outcomes.

The EAU clinical guidelines are widely implemented by healthcare professionals around the world and serve as an important reference for evidence-based practice in urology. By contributing to the update of the paediatric guidelines, IF helped ensure that the lived experiences and perspectives of people with SBH are reflected in recommendations that guide clinical care globally. A particular highlight of this are the added chapters on mental health and quality of life.

In addition, IF and the EAU collaborated on a joint publication based on a survey conducted among IF member organisations. The survey captured experiences and perspectives regarding urological care and access to services, helping to identify gaps in care and inform improvements in clinical practice and health system responses.



## ADVOCACY FOR ACCESS TO ESSENTIAL PRODUCTS

Equitable health outcomes also depend on access to essential medical supplies. IF therefore engaged in advocacy efforts calling for catheters to be included in the emergency assistive products list discussed during consultations with the WHO.

For many individuals with Spina Bifida, intermittent catheterisation is essential for bladder management and the prevention of severe complications.

Ensuring that catheters are recognised as essential emergency supplies is an important step towards safeguarding continuity of care in humanitarian and emergency settings.



## INTERNATIONAL KNOWLEDGE EXCHANGE

IF actively promotes cross-border collaboration to ensure that expertise and best practices in Spina Bifida care reach all regions. IF continued the final round of a webinar series connecting healthcare professionals and organisations across the European Union and neighbouring countries. These sessions provided valuable twinning opportunities between centres, facilitated the sharing of practical experiences and encouraged peer learning among professionals.

A particularly important webinar featured participation from an IF member organisation in Ukraine, which shared insights into delivering care under challenging circumstances. This exchange strengthened professional connections, promoted collaborative problem-solving and contributed to improving access to expertise and support for patients and families in diverse contexts.

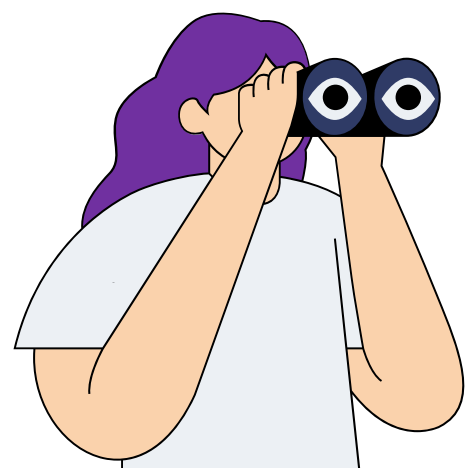


## THE SBH HEALTH EQUITY PROJECT

IF will continue to strengthen its work in urology and health equity with a focus on patient-centred guidance and global applicability. Key initiatives include:

- Patient journey guidelines on urology
- Updated LMIC urological management guidelines for healthcare professionals
- Health equity-related projects

By strengthening both professional guidance and patient-informed pathways, and by systematically collecting data on health equity, these initiatives will advance fairer and more effective care for people living with Spina Bifida and Hydrocephalus around the world.



# WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY

Established and designated by the IF General Assembly in Guatemala in 2011, the World Spina Bifida and Hydrocephalus Day is a yearly event held on 25 October to raise awareness of the rights and needs of the SBH community as well as the UNCRPD. This annual moment of solidarity serves as a powerful reminder of the shared commitment to improving the lives of individuals living with SBH. Over the years, WSBHD has evolved into a cornerstone event for promoting the rights, well-being, and full inclusion of persons with SBH across the world, mobilising partners from the health, social and policy sectors.

## WSBHD THEME:

### ACCELERATE ACTION FOR SPINA BIFIDA AND HYDROCEPHALUS

Each year, IF members select a main priority theme for WSBHD. In 2025, the theme was “Accelerate Action for Spina Bifida and Hydrocephalus” (#Action4SBH), with the aim of continuing to inspire a dynamic international movement driven by advocacy, creativity and unwavering dedication. Individuals with SBH continue to face numerous barriers, including stigma, discrimination and a widespread lack of awareness, all of which limit full participation in life’s opportunities. Addressing these challenges and accelerating action on key issues affecting the SBH community is therefore more important than ever. During this year’s WSBHD, IF and its members raised awareness of how we, as a global community, can work together to achieve this goal.



The commemorative activities extended across the entire month of October, engaging individuals, families, community organisations, national associations, healthcare professionals and international allies from every region. Together, we highlighted lived experiences, championed evidence-based action and strengthened advocacy efforts aimed at achieving equitable access to care, support and opportunities for all those living with SBH. This collective engagement demonstrates the global community’s continued determination to transform awareness into action and to ensure that the voices of persons with Spina Bifida and Hydrocephalus remain heard, respected and central to all initiatives.

# WSBHD CONFERENCE

The WSBHD 2025 Conference brought together advocates, professionals and policymakers worldwide to review progress, share expertise and define actions to accelerate change. Discussions focused on healthcare pathways, accessibility, rights-based policies and meaningful inclusion. IF members from Africa, the Americas, Asia-Pacific and Europe shared regional visions for accelerating action on SBH, highlighting ongoing progress, regional perspectives, youth leadership and practical steps towards achieving equitable access, inclusion and recognition for all individuals living with SBH.

For WSBHD25, IF ran a dedicated social media campaign around the annual theme and encouraged people to share their vision of inclusion through photos, videos and texts. Thirty-nine contributions were collected and widely promoted across IF's channels. The awareness campaign significantly advanced the goals of WSBHD by improving public understanding of SBH, disability rights, the UNCRPD and the European Strategy on the Rights of Persons with Disabilities. Its messages effectively reached policymakers, IF members, healthcare professionals, academics, civil society, patient groups and the general public. IF maximised engagement through strategic use of social media and partner websites, extending its reach to key decision-makers and professional communities.

**ACCELERATE ACTION 4 SBH WSBHD25**

**WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY**

**CONFERENCE**

On **25 October**, we look forward to celebrating the World Spina Bifida and Hydrocephalus Day 2025 (WSBHD25) together with you during the WSBHD25 conference webinar!

During the WSBHD conference, panelists from around the world will address how they **Accelerate Actions for SBH** during this year's global celebration.

**OUR PANELISTS**

 Victoria Sandoval President International Federation for Spina Bifida and Hydrocephalus	 Dr Sylvia Roozen Secretary General International Federation for Spina Bifida and Hydrocephalus	 Sneha Sawant Coordinator WSBHD25 side event Asia-Pacific, SBP India	 Maahi Rudawat Co-Chair International Youth Group SBH, India	 Jurn Antonhis Co-Chair International Youth Group SBH, Belgium
 Ajak Proscovia Co-Coordinator WSBHD25 side event Africa, Uganda	 Nebiyat Testafaye Co-Coordinator WSBHD25 side event Africa, Ethiopia	 Vanessa Caraveo Chairwoman IF Working Group on Ageing with SBH, USA	 Lyudmila Nikolov Coordinator WSBHD25 side event Europe Inclusive Employment	 Laurence Lévesque Director SBH Québec, Canada

**WEBINAR DETAILS:**

- Saturday 25 October 2025 (2h)**
- 3:00 PM CEST (Brussels timezone)**
- 6:30 PM IST (India timezone)**
- 7:00 AM CST (Guatemala timezone)**
- Online (Zoom)**
- Registration: [bit.ly/3Ke1BSP](https://bit.ly/3Ke1BSP)**

**SCAN ME**

Visit → [www.worldspinabifidahydrocephalusday.com](https://www.worldspinabifidahydrocephalusday.com)

**WSBHD25 THEME**

**Accelerate action for Spina Bifida and Hydrocephalus**

Our vision is a society that guarantees the human rights of all people with Spina Bifida and Hydrocephalus (SBH), and celebrates their contributions in all areas of life, while guaranteeing equity at all levels and for all.

This World Spina Bifida and Hydrocephalus Day, on October 25, we invite you join us in taking meaningful steps toward progress for our global SBH community.

**Together we can accelerate action and drive change!**

**#Action4SBH**

Individuals with SBH continue to face numerous barriers, including stigma, discrimination and a widespread lack of awareness - all of which limit full participation in life's opportunities. Addressing those challenges and accelerating action on key issues affecting the SBH community is more important than ever.

IF SBH INTERNATIONAL FEDERATION FOR SPINA BIFIDA AND HYDROCEPHALUS

**Join the WSBHD25 CHALLENGE**

**ACCELERATE ACTION 4 SBH WSBHD25**

# WSBHD REGIONAL SIDE EVENTS

**The Europe Regional Side Event** was held as part of World Spina Bifida and Hydrocephalus Awareness Month on 20 October 2025. It brought together persons with disabilities, particularly individuals with Spina Bifida and Hydrocephalus, along with families, advocates and allies. The meeting addressed employment as a key enabler of independence, dignity and social participation for persons with disabilities, while highlighting persistent systemic barriers to meaningful work. It raised awareness, explored solutions through lived experiences, facilitated peer learning and showcased inclusive employment practices. It also linked participants' experiences to European and international frameworks, including the European Year of Skills and the United Nations Convention on the Rights of Persons with Disabilities (CRPD).

The event opened with introductory remarks and an icebreaker on the meaning of work. A session led by the International Labour Organization followed, addressing workplace discrimination and the importance of employment for independence. The event featured lived experiences from a diverse panel of speakers representing Europe and beyond. Panellists shared their employment journeys, including aspirations, current roles, barriers encountered and strategies for success. The event concluded with a call to action, encouraging participants to identify concrete steps to advance inclusive employment. Overall, the webinar provided a platform for shared experiences, highlighted key barriers and enablers and strengthened collective commitment to inclusive workplaces.

**WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY**  
WEBINAR: INCLUSIVE EMPLOYMENT AND SKILLS FOR LIFE

This interactive WSBHD Webinar on **Inclusive Employment** explores the barriers and enablers persons with disabilities face in finding and keeping meaningful work. Join us to hear personal stories, share experiences, and link discussions to European and International policy efforts on inclusive employment.

**OUR SPEAKERS**

- Stefan Tromel, Senior Disability Specialist
- Ngozi Joy Onwumeme, Nigeria
- Cristina Pérez, Spain
- Su Xiao Vin, Malaysia
- Catherine Nakanyiga, Uganda
- Andrea Fox, Ireland
- Mark Mapemba, Project Manager

**EVENT DETAILS**  
20 October 2025 (2 hours)  
8AM CDT | 3PM CEST | 9PM MYT  
Theme: Accelerate Action 4 Inclusive Employment

**PROGRAMME**  
The 'Inclusive Employment and Skills for Life' webinar will explore the importance of equal access to employment for persons with spina bifida and hydrocephalus, highlighting how meaningful work fosters independence and participation in society. The programme features opening reflections on why employment matters for independence; then it will address disability discrimination at work, exploring the barriers that prevent equal opportunities, followed by personal stories from community members around the world who will share their experiences of finding and sustaining work. Participants will also learn from successful global initiatives, engage in interactive discussions to exchange ideas, and identify practical next steps for advancing inclusive workplaces today. The webinar will conclude with a collective reflection on key takeaways and actions to promote employment opportunities for all.

Registration: [bit.ly/3jyxk0l](https://bit.ly/3jyxk0l)

[www.worldspinabifidahydrocephalusday.com](https://www.worldspinabifidahydrocephalusday.com) | [info@ifglobal.org](mailto:info@ifglobal.org)

**ILO Disability Inclusion Strategy (2024-2027)**

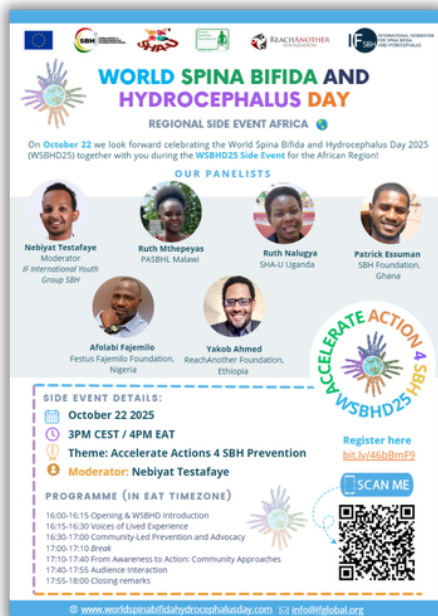
**Why employment matters for independence and addressing disability discrimination at work**

**The objective as indicated by the CRPD**

- Regular employment, not sheltered
- Protection from discrimination in all forms and types of employment
- Same working conditions, including wages
- Affirmative action is allowed
- All employment promotion measures should be inclusive: vocational training, mediation, self-employment, co-operatives
- Public sector employment
- The right to work and employment is interrelated and interdependent with other rights



**The Asia-Pacific Regional Side Event** was held on 22 October 2025, bringing together IF members from nine countries, including the Philippines, Pakistan, India, Japan, Bangladesh, Sri Lanka, Nepal, Tajikistan and Indonesia. The event provided a platform for participants to share national updates, discuss emerging challenges and highlight priorities for accelerating action on SBH across the region. Key topics included strengthening awareness and prevention programmes, expanding access to multidisciplinary care, promoting inclusive education and employment, improving accessibility, establishing robust surveillance systems and advancing national legal frameworks. The event emphasised collaboration, data-driven decision-making and evidence-based strategies to improve the lives of persons with SBH in Asia and the Pacific.



**The Africa Regional Side Event** also took place on 22 October 2025, where participants from Nigeria, Malawi, Ethiopia and Ghana presented country-specific updates on the implementation of SBH initiatives. Discussions focused on prevention strategies, raising awareness and promoting coordinated public health approaches across the continent. Youth participation was a key feature of this event, ensuring that young voices were central to shaping future advocacy and action. The session reinforced a shared commitment to equitable opportunities, inclusive policies and collaboration between governments, advocacy organisations and local communities.


**The WSBHD Regional Meeting** on 13 October 2025 in Southeastern Europe aimed at developing ideas and actions to support individuals living with Spina Bifida and Hydrocephalus across the region. The meeting featured updates from several countries in the region and concluded with an agreement that a regional conference could bring together European organisations to share experiences, best practices and recommendations on family support, capacity building and public health advocacy. By fostering collaboration and dialogue, it would strengthen cross-border efforts and improve support systems and nutrition-related health initiatives.



# WSBHD CAMPAIGN CONTRIBUTIONS

As part of WSBHD25, the SBH community was invited to share what accessibility truly means, reflecting diverse perspectives aligned with the #Action4SBH theme. To encourage participation, IF launched the WSBHD Challenge, inviting individuals and families to submit drawings, photos, videos and short texts. Submissions from around the world highlighted courage, hope and determination, capturing lived experiences and aspirations across the SBH community. On 25 October, all contributions were showcased on IF's social media channels, reaching wide audiences and driving global engagement. The WSBHD25 Challenge proved effective in attracting attention, sustaining interest and amplifying participant voices. A total of 20 submissions were received, including photos, drawings and short texts. During the WSBHD Webinar, the entries were presented to participants, who were invited to select their favourite through likes, shares and comments on IF's social media platforms.

**CELEBRATE ACTION 4 SBH**  
**WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY**  
 WSBHD25 challenge




Children and young people with limitless dreams

Fundación Mónica Uribe  
 Por Amor - Colombia

#WSBHD25 #Action4SBH

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**CELEBRATE ACTION 4 SBH**  
**WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY**  
 WSBHD25 challenge



"Hope in Every Heartbeat: The Silent Struggle, Loud Courage"

Laurice Erin Perez  
 The Philippines

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**CELEBRATE ACTION 4 SBH**  
**WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY**  
 WSBHD25 challenge



Accessibility: A Lifelong Journey of Inclusion

I was born with Spina Bifida, a lifelong condition. I also live with multiple disabilities - what I never saw them as barriers, for me, accessibility is not about asking for sympathy, it's about creating a life of dignity, independence, and confidence.

Accessibility is both a four string pillars:

1. Early medical care - Every child should receive the right treatment and counselling from birth.
2. Family support - Awareness and acceptance start at home.
3. Independence and training - Every person should learn to live, move, and work freely.
4. Inclusion and dignity - Equal rights in education, jobs, and society for all.

Through my foundation, *Walk in Wheels*, I am turning these ideas into action. I have helped make over 50% of my area in Mumbai, Mumbai, accessible - including schools, public places, and local offices. I am also working with political and government officials to bring accessibility into everyday systems.

From the starting to completion of an amazing to create solutions, as an active member of Spina Bifida Foundation India, I spread awareness, support families, and promote inclusion across the country.

My vision is an inclusive India where accessibility begins at birth and continues for life. Accessibility is not charity - it is our right, our freedom, and the path to equality for everyone.

Khushi Ganatra - India

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Lily in a zipper village

Spina Bifida Georgia

#WSBHD25 #Action4SBH

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**WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY**  
 WSBHD25 challenge



Perseverance paid off - 1 year later at the Australian Championships (2025), my son Toby broke the Australian record in the 100m for his para classification (T43)!

Kelly Morgan - Australia

#WSBHD25 #Action4SBH

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**CELEBRATE ACTION 4 SBH**  
**WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY**  
 WSBHD25 challenge



A policy change!

Ethiopia has a high number of children born with Spina Bifida. As a caregiver for these children, I celebrate every milestone with their families. Yet, I also worry about the lifelong challenges they will face in accessing proper medical care. Let alone affording a wheelchair for their child, in many areas, even reaching basic health services is difficult. And even if they receive a wheelchair through donations, it is almost impossible to use it on the rough rural roads.


But there is hope. We can prevent many cases of Spina Bifida through food fortification with folic acid. This solution is both effective and affordable for Ethiopia. It only requires one thing, a policy change. I hope that my country, Ethiopia, will adopt this important *Action4SBH* to help families, especially in rural areas, and save future generations from this preventable suffering.

Fekadu Yadesa (MD, MPH), SBC care coordinator  
 Heist Fania Hospital, Harar - Ethiopia

#WSBHD25 #Action4SBH

www.worldspina bifida hydrocephalus day.com

**CELEBRATE ACTION 4 SBH**  
**WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY**  
 WSBHD25 challenge



Let's Accelerate Action for Spina Bifida and Hydrocephalus — through Inclusive Employment.

People with spina bifida and hydrocephalus are talented and capable, yet many are denied job opportunities because of stigma and inaccessibility.

I call for workplaces that recognize ability, provide equal chances, and create space for everyone to thrive.

Together, we can accelerate action by promoting inclusive hiring and empowering persons with SBH to work and live with dignity.

Asiimwe Merab - Uganda

#WSBHD25 #Action4SBH

www.worldspina bifida hydrocephalus day.com

**CELEBRATE ACTION 4 SBH**  
**WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY**  
 WSBHD25 challenge



We can all build a world without limits

Fundación Mónica Uribe  
 Por Amor - Colombia

#WSBHD25 #Action4SBH

www.worldspina bifida hydrocephalus day.com

**CELEBRATE ACTION 4 SBH**  
**WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY**  
 WSBHD25 challenge

Ageing individuals with Spina Bifida and Hydrocephalus face many challenges in accessing healthcare, including barriers in transitioning from pediatric to adult care, provider knowledge gaps regarding the complexities of SBH, insurance limitations, and insufficient access to adult spina bifida clinics due to their limited numbers and often distant locations. Thus, many individuals with SBH achieve the milestone of reaching adulthood only to find that society is not designed to support their continued needs in this new life stage.

I encourage everyone to work together to accelerate action to address these healthcare disparities that negatively impact the health and well-being of ageing individuals with SBH. Accelerating action today can save countless lives tomorrow and lead to a brighter future for generations of people living with SBH, so now is the time to act!

Vanessa - USA

#WSBHD25 #Action4SBH

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**CELEBRATE ACTION 4 SBH**  
**WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY**  
 WSBHD25 challenge

Accelerating action for Spina Bifida and Hydrocephalus is an everyday thing.

I try to show the world what it is to live with Spina Bifida in everything I do.

Jurn Anthonis - Belgium

#WSBHD25 #Action4SBH

www.worldspina bifida hydrocephalus day.com

**CELEBRATE ACTION 4 SBH**  
**WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY**  
 WSBHD25 challenge

Education is the key to independence and growth for those living with spina bifida. It's also the most powerful tool to shift mindsets and create lasting and meaningful change.

Harmesh Singh - Malaysia

#WSBHD25 #Action4SBH

www.worldspina bifida hydrocephalus day.com

**CELEBRATE ACTION 4 SBH**  
**WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY**  
 WSBHD25 challenge

I was born with Spina Bifida and Hydrocephalus, and as a baby in Haiti, I underwent surgery to close both my spine and abdomen due to severe fluid leakage.

Gaelle Merveille  
 United States / Haiti

#WSBHD25 #Action4SBH

www.worldspina bifida hydrocephalus day.com



# WSBHD25 ACTIVITIES BY IF MEMBERS

Throughout October, IF and its global members organised a range of regional activities highlighting different aspects of the WSBHD25 theme, “Accelerate Action for Spina Bifida and Hydrocephalus” (#Action4SBH). These events spanned the full month, raising awareness and promoting engagement across communities worldwide.



## Vereniging voor Spina Bifida & Hydrocephalus – Belgium

On 19 October 2025, the association held its annual Autumn Walk to mark World Spina Bifida and Hydrocephalus Day, bringing together people with SBH from across Belgium. The event began with an accessible wheelchair walk in Ypres city center and concluded with a communal lunch featuring Belgian fries.



## Madrid Spina Bifida Association (AMEB) – Spain

On 4 October 2025, AMEB hosted its first Charity Run for Spina Bifida at Madrid Río Park. Under the slogan “Run with your bib, support their spine”, the event raised awareness of this congenital spinal condition and generated funds to support AMEB’s services and projects, enhancing the quality of life of its members.



## Spina Bifida & Hydrocephalus Association of Malaysia (SiBIAM) – Malaysia

In October 2025, SiBIAM organised a nationwide hybrid programme to reach participants across Malaysia. A highlight was the webinar “The Journey to Self-Acceptance” on 11 October, designed to engage both in-person and online attendees.



## Association for Spina Bifida & Hydrocephalus – Germany

From 24–26 October 2025, the German association held a members’ training on mindful management of conflict and emotionally challenging situations for people with hydrocephalus. Under the slogan “Difficult topics made easy”, participants engaged in mindfulness, communication, and coaching techniques through short lectures, group discussions, and gentle physical exercises.



## Spina Foundation – Poland

On 20 September 2025, Spina Foundation, Poland, organised a conference with lectures and workshops, as well as therapeutic, dance, and artistic activities for small and older children.



## Komunitas Spina Bifida – Indonesia

On 14 October, Komunitas Spina Bifida Indonesia organised a live YouTube event sharing the exciting journey of supporting a child with Spina Bifida.



## Spina Bifida & Hydrocephalus Association – Nigeria

On 20 October, the Spina Bifida and Hydrocephalus Association in Nigeria, organised a Wheelchair Basketball Novelty Match by youth with SBH.



## Spina Bifida Support Group Foundation – Philippines

During October, the Spina Bifida Support Group Foundation in the Philippines organised a series of activities, including webinars, group meetings, and a culminating WSBHD event at SM City Marikina.



## Spina Bifida Hydrocephalus Ireland – Ireland

From 20–26 October 2025, SBH Ireland celebrated with events under the theme #WeMatter with activities, including the opening of a Memorial Garden, as well as an Education Day on stoma care and on intermittent self-catheterisation, and various in-person and online events engaging the SBH community.



## Festus Fajemilo Foundation – Nigeria

On 18 October 2025, Festus Fajemilo Foundation held its final 2025 family support group at the Lagos centre, addressing the WSBHD25 theme “Accelerate Action for Spina Bifida and Hydrocephalus” and exploring barriers in health, education, and cultural or religious stigma.

# COMMUNITY BUILDING & TWINNING

## IF ACTIVITIES WITH MEMBERS

### Members meetings

In 2025, IF convened a range of members' meetings and regional dialogues to strengthen the global SBH network, promote knowledge sharing and support joint advocacy during international awareness days. The year began with a members' meeting to review progress and agree on strategic priorities, followed by regular board, regional and communications coordinators' meetings across Europe, Africa, Asia-Pacific and Latin America, supporting coordination of key initiatives including WSBHD25. In parallel, IF held targeted bilateral and exploratory meetings with existing and potential member organisations to strengthen capacity, support membership development and promote inclusive participation across the network.



Regional and thematic engagements included a multi-country meeting with representatives from Bulgaria, Canada, Montenegro, Georgia, Romania, Serbia, Spain, Kosovo and Türkiye, which resulted in the development of a proposal to strengthen regional cooperation. A one-to-one meeting in Lithuania focused on strengthening advocacy, youth engagement and independent living, while exploratory discussions in Malta assessed interest in establishing a national association. IF also launched a cross-country working group with members from Bulgaria, Slovakia and Scotland to develop a patient journey guideline, translating medical knowledge into practical support tools. Across all meetings, including communications coordinators' sessions and global exchanges, IF strengthened internal coordination, shared best practices and aligned advocacy, capacity-building and strategic priorities across its growing international network.

## Webinars

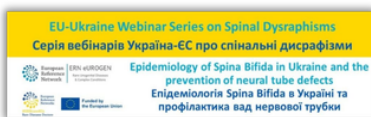
IF organised eleven webinars to strengthen member associations' capacity and promote collaboration. These webinars enhanced knowledge, shared best practices and fostered international cooperation, with a strong emphasis on a multi-stakeholder approach among IF member countries and participants in general.



The year opened with the webinar **“Prevention of Neural Tube Defects: Leaving No One Behind”**, which convened global experts in public health, genetics, and food fortification to discuss strategies for preventing neural tube defects through equitable and sustainable approaches.



In March, IF marked **International Women's Day with the webinar “Accelerate Action”**, featuring contributions from disability organisations and advocates focusing on accessibility, independent living, and gender equality for women and girls with disabilities.



In the first half of 2025, the **EU-Ukraine Spinal Dysraphisms Webinar Series** supported knowledge exchange and capacity building through six sessions covering clinical care, public health, and lived experiences of SBH.



In August, the **International Youth Day webinar “Dreaming Beyond Barriers”** provided a platform for young people with SBH to share aspirations and lived experiences, complemented by intergenerational dialogue with members of the IF Working Group on Ageing with SBH.



On 1 October, the **International Day of Older Persons IF webinar** highlighted the role and rights of older people, with the 2025 theme emphasising their contribution to society.



In December, IF concluded with the global webinar titled **“Building Bridges: How Service Clubs Can Drive Change for Persons with Disabilities”**, which engaged representatives from Rotary, Lions, Kiwanis, and other service networks, alongside advocates, professionals, and youth leaders. The discussion showcased cross-sector collaboration and identified practical opportunities for service clubs to support inclusion, mobility, and equal opportunities for persons with disabilities worldwide.

## Training

The 2025 IF Members Training delivered a structured capacity-building programme to strengthen advocacy skills and understanding of key European and international policy frameworks. Conducted online in English, the training included two interactive two-hour sessions with 49 participants from across the IF network. The programme combined expert presentations, youth-focused advocacy components and a structured process of invitations, registration and evaluation.



The graphic is a promotional poster for the IF Members Training 2025. It features a dark blue background with a white speech bubble containing the text "Empower Your Advocacy". At the top, it says "IF Members Training 2025" and "Meet your Trainers & Invited Guest Speakers". Logos for the European Union, European Disability Forum, and IF SBH (International Federation for Spina Bifida and Hydrocephalus) are visible. Below the logos are seven circular portraits of the trainers and guest speakers, each with their name and location. The bottom of the graphic includes session details: "Session 1 Understanding Advocacy 31/10 2PM CET | Session 2 From Local to Global 07/11 2PM CET" and a registration link: "Online. Registration required before October 25 2025 at info@ifglobal.org".

**IF Members Training 2025**  
Meet your Trainers & Invited Guest Speakers

**Empower Your Advocacy**

**Lyudmil Ninov**  
Trainer

**Loredana Dicsi**  
Trainer

**Haydn Hammersley**  
Trainer

**Sir Abdus Sattar Dulal**  
Bangladesh

**Anđela Radovanović**  
Montenegro

**Muzammal Islam**  
Pakistan

**Wardah Bagis**  
Indonesia

**Session 1 Understanding Advocacy 31/10 2PM CET | Session 2 From Local to Global 07/11 2PM CET**

📍 Online. Registration **required** before October 25 2025 at [info@ifglobal.org](mailto:info@ifglobal.org)

The 2025 edition, titled **“Empowering Advocacy: Voices of Persons with Spina Bifida and Hydrocephalus”**, focused on building advocacy capacity among people with SBH, their families and supporters. Through interactive discussions, peer-led exchanges and practical exercises, participants explored advocacy strategies, applied the UNCRPD in practice and heard global advocacy stories.

The training aimed to develop knowledge, confidence and skills to promote disability rights, support young members in representing peers internationally and maintain strong connections with local communities. Successfully delivered through a collaboration between IF and EDF, the training provided participants with opportunities to connect, share experiences and strengthen advocacy skills. Session I covered advocacy fundamentals through presentations, interactive exercises and peer-led panels, including an EDF overview, a UNCRPD video and real-life advocacy examples from Bangladesh, Pakistan, Indonesia and Montenegro. Session II focused on applying knowledge in practice. Trainers revisited key concepts, explored community representation and introduced the IF “Steps for an Advocacy Campaign” Toolkit, guiding participants through nine stages from needs assessment to follow-up.

## TWINNING

In 2025, IF continued to strengthen its global network through structured engagement with member associations, regional platforms and thematic working groups. These activities combined national capacity-building, regional twinning and global knowledge exchange, reinforcing IF's role as a connector of expertise, lived experience and advocacy for persons with SBH.

### Strengthened national partnerships:

IF strengthened its collaboration with member associations through targeted national and expert-led engagements. In Poland, in-person meetings with government, healthcare institutions and rehabilitation centres supported progress on multidisciplinary care, independent living and cross-sector collaboration, leading to new partnerships and national recognition of IF's role. In Spain, a high-level expert meeting on genetics and SBH care brought together clinicians, associations and international experts to strengthen collaboration and advance care innovation, including links with national and European reference centres. In addition, IF maintained dialogue with members in other regions, including Lithuania and Malta, focusing on organisational development, youth engagement and exploratory discussions on association development, laying important groundwork for future support.

### Regional twinning and cooperation:

Through WSBHD, IF facilitated dynamic regional exchanges across Africa, Asia-Pacific, Latin America and Europe, strengthening global dialogue and collaboration. In Africa, youth took the lead in a webinar focused on health equity, bringing strong lived-experience perspectives to the forefront of discussion. In Asia-Pacific, together with SBF India, IF convened a regional meeting with updates from across countries to identify synergies and strengthen the network as a more coordinated regional platform. In Latin America, IF engaged in both regional dialogue and follow-up bilateral discussions to explore ways to reinforce collaboration and organisational development. In Europe, discussions focused on developing youth exchanges, while in Southeastern Europe, a dedicated regional meeting supported member cooperation, shared priorities and the development of joint approaches to strengthen capacity and regional support.



**Youth and ageing collaboration:** IF facilitated strengthened engagement between its Youth and Ageing Working Groups through dedicated sessions and intergenerational exchanges. Participants shared lived experiences of independence, employment, relationships and ageing with SBH, creating a meaningful space for peer learning and mutual understanding. These discussions highlighted the importance of a life-course approach to SBH and reinforced the value of integrating both youth and ageing perspectives into advocacy, service development and policy dialogue.



**Thematic and expert-led working groups:** IF advanced several thematic initiatives bringing together members, experts and practitioners to develop practical tools and strengthen evidence-based advocacy. A new Patient Journey Working Group was launched to translate medical knowledge into accessible guidance for patients and families. The Genetics Advisory Group contributed expertise on research and clinical practice, while additional discussions focused on mental health, family-centred care and urological management. Together, these initiatives strengthened the link between scientific expertise and lived experience, supporting improved care pathways and advocacy outcomes.

**Global network strengthening and strategic engagement:** IF further expanded its global engagement through participation in the WHO Disability Health Equity Network and continued coordination of global and regional member meetings. These platforms supported alignment on advocacy priorities, capacity-building efforts and strategic direction across the federation. In parallel, communications coordination meetings strengthened the visibility and outreach capacity of member associations, contributing to a more connected and effective global SBH network.



# ACTIVITIES BY THE IF ADVISORY GROUPS

## International Youth Group SBH

### Meetings

The youth group of SBH comprised nine young individuals aged 18 to 35 from various countries, including the co-chairs Jurn Anthonis (Belgium) and Maahi Rudawat (India), Ajok Proscovia (Uganda), Rereloluwa Adeolu (Nigeria), Malik Armughan Ali (Pakistan), Gabriel Barba (Philippines), Narresh Vijayandran (Malaysia), Viktoria Peykova (Bulgaria) and Nebiyat Testafaye (Ethiopia).



The group regularly organised online meetings to address crucial issues affecting the global youth SBH community. In 2025, the main focus of the discussions was mental health, an essential topic for the well-being of young individuals living with SBH.



**Jurn Anthonis**  
Co-chair IF Youth Group SBH  
*From the Vlaamse Vereniging voor Spina Bifida en Hydrocephalus vzw (VSH) - Belgium*  
Born with Spina Bifida 28 years ago  
Degrees in Applied Psychology & Grief and Loss  
Counselling  
Education Officer @ Flemish Association



**Maahi Rudawat**  
Co-Chair IF International Youth Group SBH  
Ambassador, member- Spina Bifida Foundation India.  
A 20-year-old individual with Spina Bifida. Hindustani classical singer, digital designer, and passionate advocate for the Spina Bifida community. An aspiring doctor and current nutrition and dietetics student, determined to transform healthcare for people with disabilities through research, advocacy, and lived experience. Maahi blends her love for music, fashion, and social impact to break barriers and inspire youth to lead with purpose and resilience.



12

August

**INTERNATIONAL**

**YOUTH DAY**

+ WEBINAR

On the 12th of August, the world celebrates the International Youth Day. This day, designated by the United Nations, is a day of awareness and its goal is to bring attention to a specific set of cultural and legal issues that affect young people.



IF International Youth Group will celebrate this day with a webinar under the theme:

**'Dreaming Beyond Barriers'**

Save the date and register to join us!

When? 12 August 2025, 14:00 (CEST time)  
Where? Online (Zoom)

<https://bit.ly/45UHyg3>












4-5 DEC 2025, BRUSSELS

EUROPEAN DAY OF PERSONS WITH DISABILITIES

#EDPD2025
#UnionOfEquality
#EUAccessCity



## Capacity building

The Youth Group identified several opportunities for organising and/or participating in various capacity-building activities and key networking events throughout the year.

### **Raising Awareness During International Youth Day**

Members of the IF International Youth Group SBH actively contributed to key global awareness moments, including International Youth Day, the International Day of Persons with Disabilities and the International Day of Older Persons, by leading and participating in a range of advocacy and engagement activities. For International Youth Day in August, the Group co-organised both a dedicated webinar and a targeted awareness campaign, creating space for young people with SBH to share their perspectives and amplify youth voices. They further strengthened intergenerational dialogue by co-hosting a specialised webinar for the International Day of Older Persons, where two Youth Group members served as featured speakers, contributing their insights and experiences. In addition, the Group was represented at the European Day of Persons with Disabilities (EDPD) annual conference through its co-chair. Through these combined efforts, the Youth Group demonstrated strong leadership and commitment to raising awareness, promoting inclusion and ensuring that the voices of young people with SBH are represented in international discussions.



## Visibility

### **WSBHD25 Conference Webinar**

As co-chairs of the IF International Youth Group SBH, Maahi (India) and Jurn (Belgium) opened the session by addressing the year's theme and its relevance for young people living with Spina Bifida and Hydrocephalus. They introduced the topic by highlighting the essential role of youth leadership in driving progress and reinforcing global advocacy efforts. Maahi and Jurn conveyed strong youth-led messages, underlining that the theme "Accelerate Action for Spina Bifida and Hydrocephalus" closely reflects the mission and values of the IF International Youth Group SBH. They emphasised that "action must take place now" by breaking the silence surrounding SBH, increasing awareness across all settings and improving access to vital services and opportunities. Both speakers stressed that young people are not only the future of the movement but also an active and influential force in the present, shaping dialogue and leading change. They also reflected on the impact of the IF International Youth Group SBH, which continues to empower its members to take on leadership roles, share their lived experiences and actively contribute to global policy discussions, ensuring that youth perspectives remain at the core of IF advocacy efforts.

## Working Group on Ageing with SBH

In 2025, the IF Working Group on Ageing with SBH consisted of eleven IF Member representatives: Chairwoman – Vanessa Caraveo (USA), Stijn Calders (Belgium), Filipe Pereira (Portugal), Kerry Marshall (Australia), Su Xiao Vin (Malaysia), Kevin O'Donnell (Scotland), Gard Sørseth (Norway), Gerry Maguire (Ireland), Chetan Shoraff (India), Jyoti Fernandes (India) and Ngozi Joy Onwuemene (Nigeria).



### IF Working Group on Ageing with SBH

**Countries Represented in IF Working Group on Ageing SBH**

	U.S.A.		Scotland
	Ireland		Norway
	Malaysia		India
	Australia		Nigeria
	Belgium		Portugal

- Established in 2019
- Currently have members from 10 different countries
- Highlights and addresses the lived experiences and unmet needs of older persons with Spina Bifida and Hydrocephalus

### IF Working Group on Ageing with SBH Activities

**IF Webinar**  
'Living with Spina Bifida & Hydrocephalus: Our Lives, Our Choices'

1 October - 3pm (CEST)

As part of the International Day of Older Persons & WSBHD25 Side Event

**Meet & Greet**

IF Working Group on Ageing with SBH & IF International Youth Group SBH

Ageing with SBH presents both challenges and opportunities, and the lived experiences of individuals offer valuable insight and strength. By sharing their stories, people empower themselves while contributing to a broader understanding that benefits the community. Active participation in working groups, advocacy initiatives, and webinars, such as the International Women’s Day one, is essential for shaping improved policies, services and supports, and ultimately enhancing quality of life. The Group regularly held online meetings to address key issues affecting the global SBH community.

### ACCELERATE ACTION ON: INCLUSIVE EDUCATION



**Su Xiao Vin**  
Committee Member, SIBIAM, Malaysia

### Going Beyond Comfort Zone

- FIND MY WAY TO JUST DO IT
- DON'T EXPECT PEOPLE TO UNDERSTAND/ ACCOMODATE
- ASK FOR HELP WHEN I NEED IT

**PUBLIC HEALTH EDUCATION, TALKS, GAME, EXHIBITION**

- Adjust to the nature of work and schedule (washroom availability, hygiene state, water intake)
- Endure the stress & tiredness, pain
  - Lead by example
- Push through, self motivation

**DISASTER RESCUE**

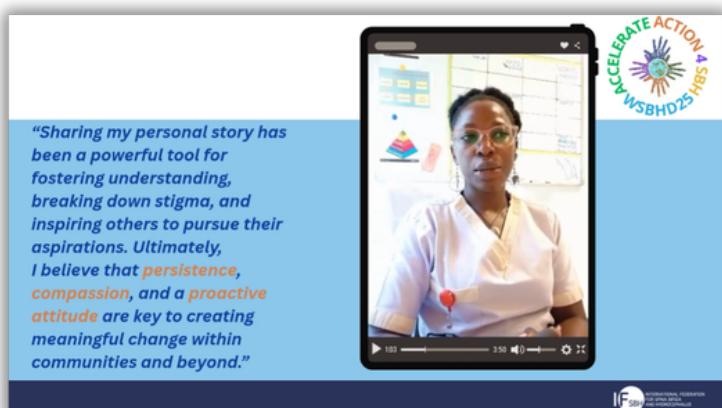
## Visibility

### International Day of Older Persons Webinar

The Group co-hosted the IF International Day of Older Persons Webinar together with the International Youth Group SBH. The 2025 webinar highlighted the power of connection, shared experience and perseverance across generations of people living with SBH. Older adults reflected on lifelong challenges and achievements, while younger speakers demonstrated determination to shape their futures, together reinforcing that neither age nor diagnosis defines potential. Through advocacy, community support and resilience, individuals with SBH continue to lead meaningful lives, inspire others and drive lasting change, helping build a more inclusive future for generations to come.

### WSBHD25 Conference Webinar

The IF Working Group on Ageing with SBH has been instrumental in promoting person-centred approaches, ensuring access to interdisciplinary healthcare, support services and opportunities for independent living. At the WSBHD25 Conference Webinar, Chairwoman Vanessa Caraveo outlined the group's 2025 activities, addressing the growing needs of older adults with SBH. She highlighted challenges such as declining mobility, medical complications and limited adult-focused care, stressing the need for more adult clinics, provider training, structured paediatric-to-adult care transitions and removal of insurance barriers. The Working Group's efforts emphasise coordinated care and advocacy to enable ageing individuals with SBH to live with dignity and access high-quality services.



# NETWORK DEVELOPMENT

IF continues to build and strengthen partnerships with key stakeholders to advance knowledge, understanding and care for individuals living with Spina Bifida and Hydrocephalus. Working together with these partners, IF promotes the adoption of effective strategies for treatment, guidance and service delivery. Central to IF's mission is ensuring that the voices of people with SBH worldwide are incorporated into the design and improvement of prevention, care and support infrastructures.

**Here is an overview of IF's network across Europe and internationally:**

## IF IS A MEMBER OF:

- European Commission Disability Platform
- European Disability Forum
- European Organisation for Rare Diseases
- European Patients' Forum
- International Disability Alliance
- International Disability and Development Consortium
- Partnership for Maternal, Newborn and Child Health
- Rare Diseases International
- UN Women Disability Inclusion
- WHO Civil Society Commission
- WHO Collaborative Global Network for Rare Diseases
- WHO Health Equity Disability Network



## IF HAS AN ONGOING COLLABORATION WITH:

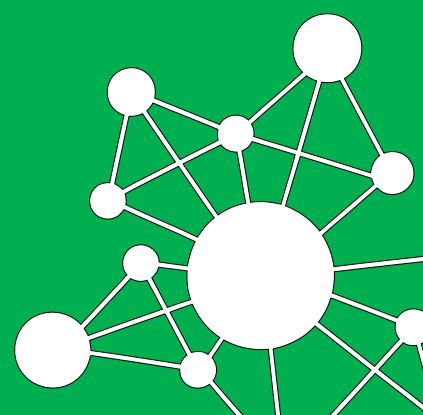
- European Concerted Action on Congenital Anomalies and Twins
- European Reference Networks ITHACA
- European Reference Networks eUROGEN
- United Nations Children's Fund
- United Nations Economic and Social Council
- World Food Program
- World Health Organisation
- European Cohort of Children with Congenital Anomalies

## IF'S PARTNERS IN LOW- AND MIDDLE-INCOME COUNTRIES:

- APEBI, Argentina
- AVSI Gulu, Uganda
- Bethany Kids, Kenya
- Central Uganda Spina Bifida and Hydrocephalus Network, Uganda
- CURE Children's Hospital Uganda
- CURE Zambia
- Festus Fajemilo Foundation, Nigeria
- Katalamwa Cheshire Homes, Uganda
- Latin American Network for Spina Bifida and Hydrocephalus
- London School of Hygiene and Tropical Medicine
- Medical Research Council, Uganda
- Organised Useful Rehabilitation Services, Uganda
- Parents Association for Spina Bifida and Hydrocephalus Ltd, Malawi
- Queen Elizabeth Central Hospital, Malawi
- Spina Bifida and Hydrocephalus Association Kenya
- Spina Bifida and Hydrocephalus Awareness Network, Uganda
- Spina Bifida and Hydrocephalus Association Uganda
- Sub-Saharan Congenital Anomalies Network
- The Global Health Network – WHO Collaborating Centre
- Zambian Association for Hydrocephalus and Spina Bifida

## IF COLLABORATES ON PROJECTS WITH:

- European Association of Urology
- European Disability Forum
- European Network for Independent Living
- European Parliament
- GASPBi-F
- Global Alliance for Improved Nutrition
- Governor Kremers Centre-Maastricht University Medical Centre
- International Association of Operative Millers
- International Children's Continence Society
- International Clearinghouse for Birth Defects Surveillance and Research
- Micronutrient Forum
- OMNI-NET Ukraine
- Sub-Saharan Network Congenital Anomalies
- WHO EMRO



# DIGITAL IMPACT



**LINKEDIN**

Followers: **2,163**  
(+1663 in 2025)

Reach: **15K**

**FACEBOOK**

Followers: **8,248**  
(+465 in 2025)

Reach: **47K**

**INSTAGRAM**

Followers: **947**  
(+113 in 2025)

Reach: **26K**

**Total New Followers: 2,241**

**Total Posts all channels: 691**

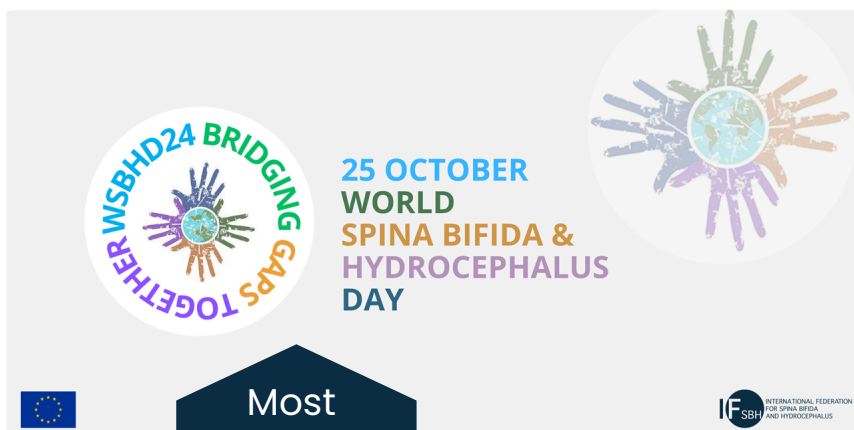
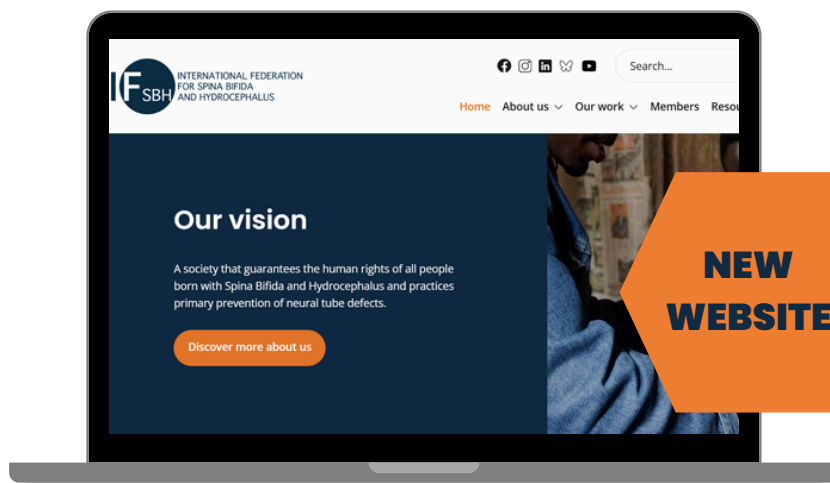
**NEWSLETTER**

Subscribers: **1743**  
(+298 in 2025)

**WEBSITE**

Total Visitors: **19K**

Total Views: **42K**



**Most impactful campaign #WSBHD**



**Top-performing content. #YouthDay**

# SEE YOU SOON...

As we close this year's report, we are pleased to look ahead to the **31st International Conference on Spina Bifida and Hydrocephalus in 2026**, hosted by the Association for Spina Bifida and Hydrocephalus Québec, marking its 50th anniversary.

This milestone gathering will once again bring together the global SBH community, including persons with SBH, families, professionals, researchers and partners.

It will be an opportunity to reconnect, exchange knowledge, strengthen collaboration and continue advancing shared priorities for inclusion, care and rights. We look forward to seeing you there.

**THE 31ST INTERNATIONAL CONFERENCE ON SPINA-BIFIDA AND HYDROCEPHALUS**  
A Lifetime of Experiences: From Preconception to Aging.

**WHY ATTEND?**  
Connect. Learn. Share.



**50 ans**  
Spina-bifida hydrocéphalie Québec  
TOUT EST POSSIBLE

**IF SBH** INTERNATIONAL FEDERATION FOR SPINA BIFIDA AND HYDROCEPHALUS

31st International Conference on Spina Bifida and Hydrocephalus      31<sup>e</sup> Conférence Internationale sur le Spina-bifida et l'Hydrocéphalie

15-17 OCT 2026      REGISTER NOW! / INSCRIVEZ-VOUS!      MONTREAL, QUEBEC, CANADA

**A lifetime of EXPERIENCES**  
From preconception to aging

**Une vie D'EXPÉRIENCES**  
De la préconception au vieillissement



**IF SBH** INTERNATIONAL FEDERATION FOR SPINA BIFIDA AND HYDROCEPHALUS

**50 ans**  
Spina-bifida hydrocéphalie Québec  
TOUT EST POSSIBLE


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