



INTERNATIONAL FEDERATION  
FOR SPINA BIFIDA  
AND HYDROCEPHALUS

# ANNUAL REPORT 2023



MEMBERS







# 3 2 0 2

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# TABLE OF CONTENTS

<b>Foreward</b>		6
<hr/>		
<b>About IF</b>	Who We Are	7
	Mission, Vision	7
	Values	7
<hr/>		
<b>Members</b>	Overview Members	8
	Board of Directors	10
	IF Organogram	11
	Election Committee	12
	Advisory Panels	12
	<i>Expert Panel</i>	12
	<i>IF International Youth Group SBH</i>	12
	<i>Volunteers</i>	12
<hr/>		
<b>Main Achievements</b>	World Health Assembly Resolutions	15
<b><i>Human Rights</i></b>	Policy Statements	17
	International Organisations and Partners	18
	Consultations & Scientific Publications	20

<b><i>Awareness Raising</i></b>	International Awareness Days	21
<hr/>		
<b><i>Prevention and Care</i></b>	The Road Towards the WHA76.19 Resolution	28
	Urological Management and Mental Health	33
<hr/>		
<b><i>Community Building and Twinning</i></b>	IF Activities with Members	35
	Activities IF Advisory Groups	37
	Twinning	43
<hr/>		
<b><i>World Spina Bifida and Hydrocephalus Day</i></b>	WSBHD23 Conference 'Accessibility4All'	47
	WSBHD23 Contest	48
	WSBHD23 Side Events	49
	WSBHD23 Activities by Members	55
<hr/>		
<b><i>Network Development</i></b>	Network Development	55
<hr/>		
<b><i>Communications</i></b>	Communications at a Glance	59

# FOREWORD

The International Federation for Spina Bifida and Hydrocephalus (IF) is fortunate to work with her passionate and dedicated members and partners around the world focussing at improving the lives of individuals with Spina Bifida and or Hydrocephalus (SBH) and their families. Given the needs of our SBH community, optimization of limited resources is very important.

Here, in this annual report 2023, the actions achieved for human rights, primary prevention, optimising management and care, raising awareness, as well as international solidarity are highlighted.

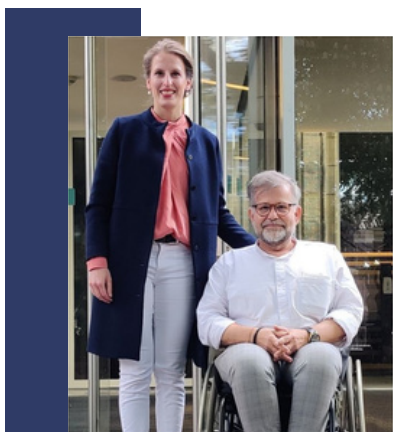
Last year was a successful one; and together with you, we celebrated a number of joint achievements, especially with respect to significant milestones, including the triumphant recognition of the WHA76 Resolutions on Food Fortification & Rehabilitation. The release of our comprehensive Annual Report 2022 showcased our colourful activities throughout the year. Remarkable high-level moments, such as impactful speeches and side events during the UN COSP16 and the UN SDG Summit, underscored our global influence. Equipping members with essential skills, the training on 'Understanding Fundraising to influence Policy and Actions' empowered advocates to advance the rights of persons with SBH. Engaging our community through informative webinars on international awareness-raising days like WFAAW23 demonstrate our commitment to education and advocacy.

The publication of policy statements, including our positions on Rehabilitation and Humanitarian Conflict & Crisis, solidified our stance on critical issues. Strengthening global ties, the twinning between the EU and Ukraine further expanded our collaborative network. Lastly, our passionate advocacy for 'Accessibility for All' resonated during the World Spina Bifida and Hydrocephalus Day Conference, Side Events, and Contest Winners, affirming our dedication to inclusivity and empowerment.

Seeing what we can accomplish as the SBH community is inspiring!

IF is extremely grateful for the continued support and active involvement of members and partners. We would like to sincerely thank all our members and partners and all the others who has supported IF, including the chairs and standing committee members as well as our volunteers.

Looking back at the many opportunities and activities from the previous year, we look forward to making 2024 an active year together with you! Hopefully we see each other soon at the 30th International Conference on Spina Bifida and Hydrocephalus in Malaysia!



***"Each one of us can make a difference, together we make change"***

*- Barbara Mikulski*

*Cato Lie, President*

*Dr Sylvia Roozen, Secretary General*

# ABOUT IF

## WHO WE ARE

The International Federation for Spina Bifida and Hydrocephalus is the international organisation representing people with SBH and their families worldwide. IF has country members in Africa, 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 by primary prevention through improving maternal health literacy, raising awareness, political advocacy, research, community building, and human rights education.

## VISION

The vision of IF is a society that guarantees human rights of children and adults with SBH, and celebrates their contribution in all areas of life, while guaranteeing equitable access to maternal health literacy to all.

## VALUES

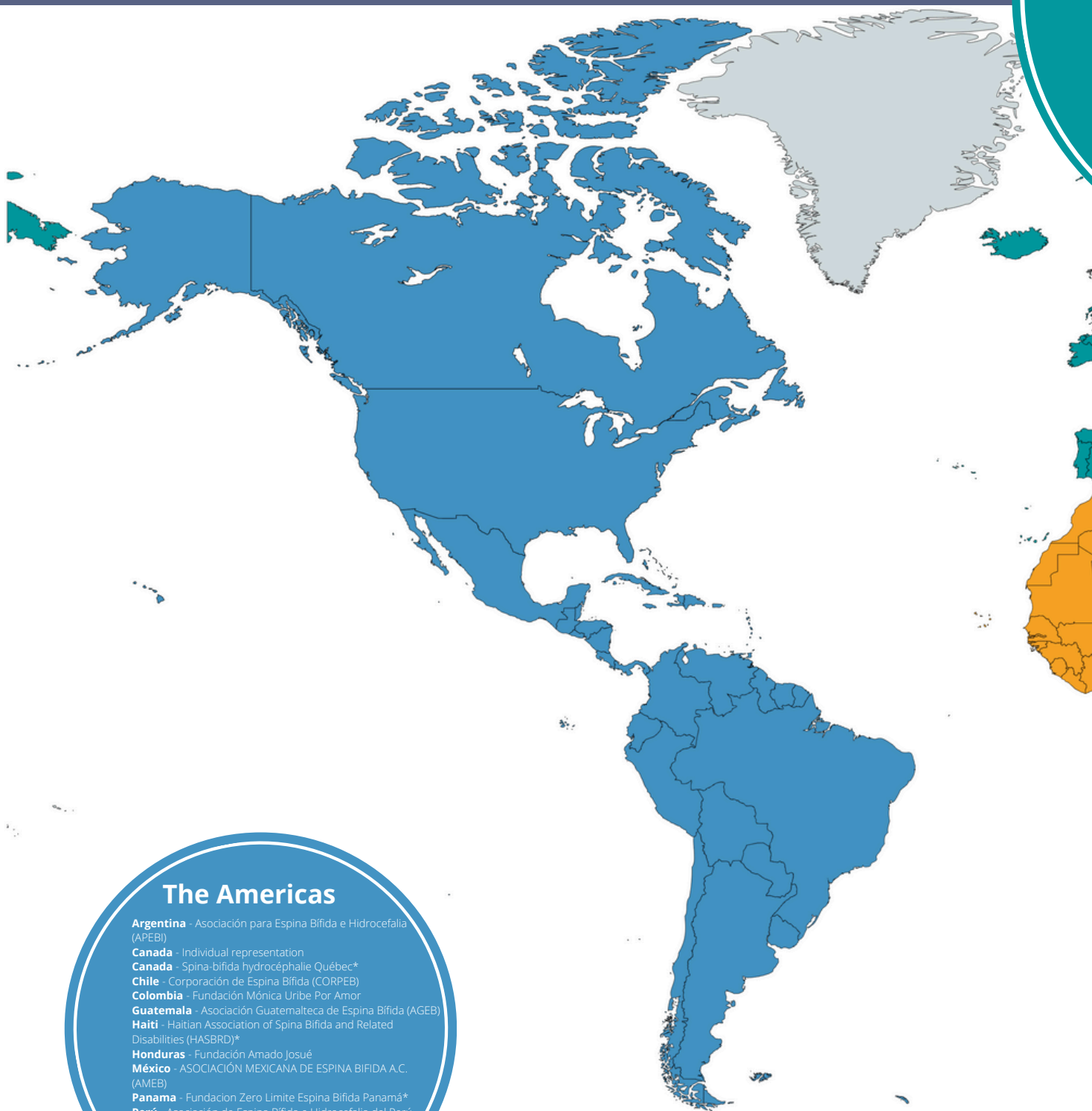
**Human Rights:** Promotion and protection of human rights of people with SBH in accordance with the UN Convention on the Rights of Persons with Disabilities (UNCRPD) is our highest value.

**Participation & Inclusiveness:** The views of children and adults with SBH and their families are the leading principles in 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 & 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, fully accountable to our members, donors and external stakeholders.

# OVERVIEW MEMBERS



## The Americas

- Argentina** - Asociación para Espina Bífida e Hidrocefalia (APEBI)
- Canada** - Individual representation
- Canada** - Spina-bífida hydrocéphalie Québec\*
- Chile** - Corporación de Espina Bífida (CORPEB)
- Colombia** - Fundación Mónica Uribe Por Amor
- Guatemala** - Asociación Guatemalteca de Espina Bífida (AGEB)
- Haiti** - Haitian Association of Spina Bífida and Related Disabilities (HASBRD)\*
- Honduras** - Fundación Amado Josué
- México** - ASOCIACIÓN MEXICANA DE ESPINA BÍFIDA A.C. (AMEB)
- Panamá** - Fundación Zero Limite Espina Bífida Panamá\*
- Perú** - Asociación de Espina Bífida e Hidrocefalia del Perú (ASESBIH)
- USA** - Hydrocephalus Association
- USA** - Spina Bífida Association of America (SBAA)

\*In 2023, IF welcomed 7 new members.



## Europe

**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 (VSPB)  
**Bulgaria** - Spina Bifida and Hydrocephalus Bulgaria  
**Croatia** - Udruga osoba i roditelja djece sa spinom bifidom "Aurora"  
**Cyprus** - Pancyprian Association of rare genetic diseases 'Unique smiles'  
**Denmark** - Rygmargbroksforeningen af 1988  
**Estonia** - MTÜ Eesti Seljaajuosonga ja Vesipeahaigete Selts  
**Finland** - Suomen CP-liitto ry  
**France** - Association Nationale Spina Bifida et Handicaps Associés (ASBH)  
**France** - Individual representation  
**Georgia** - Individual representation  
**Germany** - Arbeitsgemeinschaft Spina Bifida und Hydrocephalus e.V. Bundesverband (ASBH)  
**Greece** - Hellenic Association for Spina Bifida and Hydrocephalus  
**Hungary** - The National Federation of Organisations of People with a Physical Disability Spina Bifida and Hydrocephalus (MEOSZ)  
**Ireland** - Spina Bifida and Hydrocephalus Ireland (SBHI)  
**Israel** - Hydrocephalus Israel  
**Italy** - Associazione Spina Bifida Italia (ASBI)

**Latvia** - Latvijas spina bifida un hidrocefālījas biedrība (LSBH)  
**Lithuania** - Spina Bifida Lithuania and Hydrocephalus Association (SBHA)  
**Luxemburg** - Association pour le Spina Bifida (a.s.b.l.)  
**Montenegro** - Individual representation  
**Norway** - Ryggmargsbrokk- og hydrocephalusforeningen  
**Poland** - Fundacja Spina  
**Portugal** - Associação de Spina Bifida e Hidrocefalia de Portugal (ASBIHP)  
**Romania** - Asociatia Romana de Spina Bifida e Hidrocefalie (ARSBH)  
**Russia** - Association of Spina Bifida and Hydrocephalus of St. Petersburg  
**Russia** - Charitable Foundation Spina Bifida  
**Scotland** - Spina Bifida Hydrocephalus Scotland (SBHS)  
**Serbia** - Hidrocefalus i Spina Bifida Asocijacija Srbije (Hisbas)  
**Slovakia** - Slovenská spoločnosť pre Spina Bifida a/ alebo Hydrocefalus, o.z.  
**Spain** - Associació Catalana d'Espina Bifida i Hidrocefàlia (ACAEBH)  
**Spain Madrid** - Espina Bifida e Hidrocefalia Madrid - AMEB  
**Spain Murcia** - Asociación Murciana de padres con hijos de Espina Bifida  
**Spain** - Federación Española de Asociaciones de Espina Bifida e Hidrocefalia (FEBHI)  
**Sweden** - Spin-Off  
**Sweden** - Rörelsehindrade Barn & Ungdomar (RBU)  
**Switzerland** - Schweizerische Vereinigung zugunsten von Personen mit Spina Bifida und Hydrocephalus (SBH)  
**Switzerland** - Stiftung Folsäure Schweiz (SFS)  
**The Netherlands** - Spina Bifida Hydrocephalus Nederland  
**Türkiye** - Türkiye Spina Bifida Derneği  
**UK** - Shine Charity  
**UK** - Harry's Hat  
**Ukraine** - Parents Association for Spina Bifida and Hydrocephalus 'Lights of Spirit'

## Africa

**Algeria** - Association des Parents et Malades Spina Bifida Béjaia  
**Egypt** - Waad Spina Bifida Foundation  
**Ethiopia** - HOPE-SBH  
**Gambia** - Fatou Jobe Keita\*  
**Ghana** - Rickmes Foundation  
**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  
**Nigeria** - Festus Fajemilo Foundation  
**Nigeria** - Liron Hydrocephalus Foundation  
**Nigeria** - Spina Bifida and Hydrocephalus Association of Nigeria  
**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)  
**Togo** - Association Santé Meilleure Vie Meilleure (SM-VM)  
**Uganda** - Spina Bifida and Hydrocephalus Association of Uganda (SHA-U)  
**Uganda** - Uganda  
**Uganda** - Central Uganda Spina Bifida and Hydrocephalus Network (CU-SBH)  
**Uganda** - SHARED GROWTH UGANDA (SGU)  
**Uganda** - TET Foundation Uganda  
**Zambia** - Zambia Association for Hydrocephalus and Spina Bifida (ZAHSB)  
**Zimbabwe** - Spina Bifida and Hydrocephalus Association of Zimbabwe  
**Zimbabwe** - Hydrocephalus Association

## Asia-Pacific

**Australia** - Spina Bifida Hydrocephalus Queensland  
**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  
**Iran** - Tabriz Registry of Congenital Anomalies (TROCA)  
**Iraq** - Individual representation\*  
**Japan** - Japan Council for Spina Bifida and Hydrocephalus  
**Japan** - Spina Bifida Association of Japan  
**Kazakhstan** - Spina Bifida Public Association (SBPA)\*  
**Malaysia** - Spina Bifida Association Malaysia (SIBIAM)  
**Mongolia** - Mongolian Spina Bifida Foundation "Maral Angel"  
**Pakistan** - Individual representation  
**Pakistan** - Pakistan Federation For Spina Bifida and Hydrocephalus  
**Philippines** - Spina Bifida Support Group Foundation, Inc\*  
**South Korea** - Korea Spina Bifida Patient Association (KPSPA)  
**Taiwan** - Taiwan Spinal Bifida Support Society  
**Australia** - Individual representation  
**Australia** - Individual representation

# BOARD OF DIRECTORS



**Mr Cato Lie**  
IF President  
Norway



**Mrs Victoria Sandoval**  
Vice President  
Guatemala



**Mrs Emma Suardiaz**  
Treasurer  
Spain



**Dr Papatya Alkan  
Genca**  
Secretary  
Turkiye



**Mrs Giulia Bizzotto**  
Italy



**Dr Aziza Mustafa  
Elnaeema**  
Sudan



**Mr Rasmus Isaksson**  
Sweden



**Dr František Horn**  
Slovakia



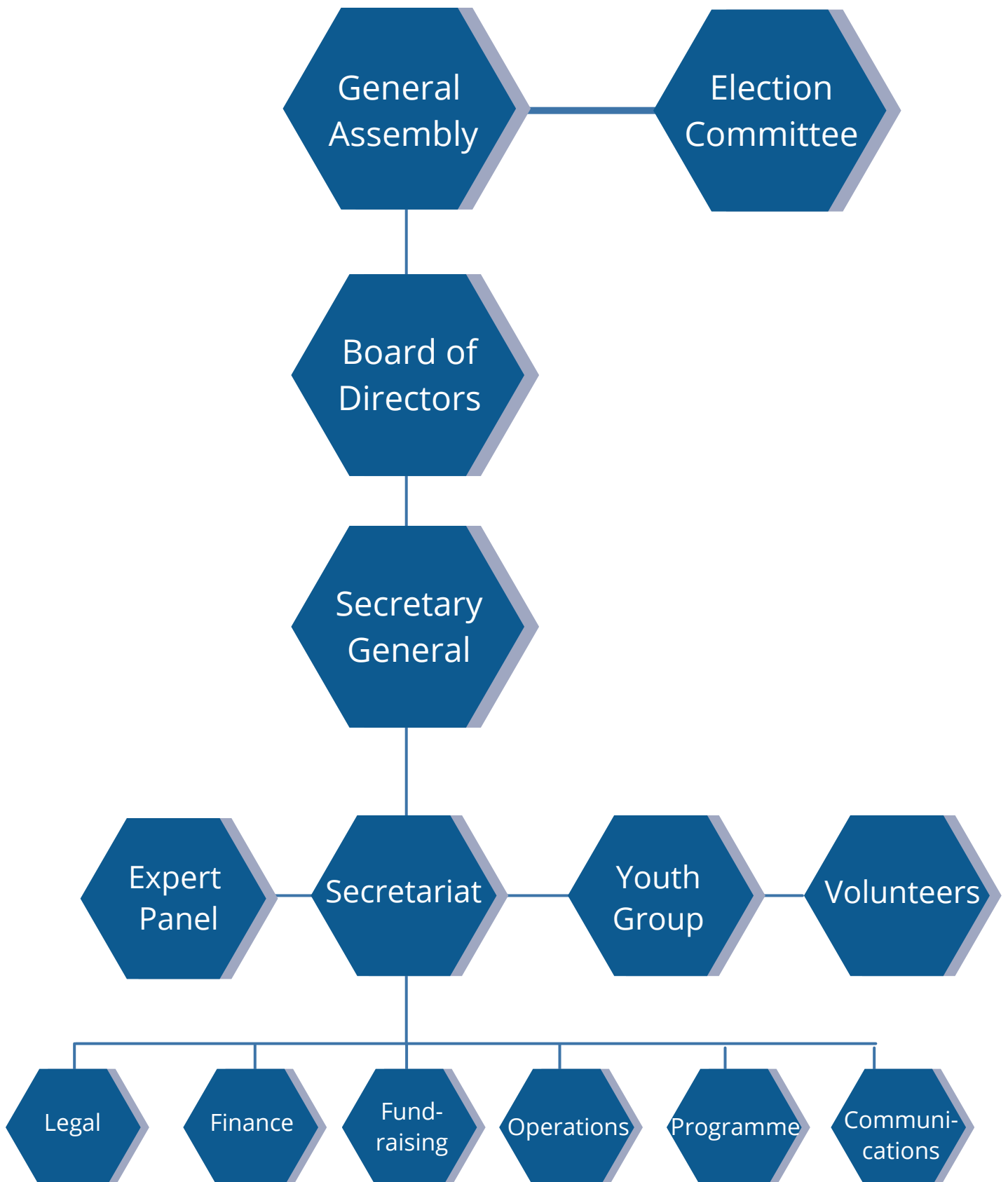
**Mrs Sonia Uribe**  
Colombia

# SECRETARY GENERAL

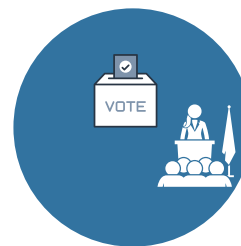


**Dr Sylvia Roozen**

# IF ORGANOGRAM



# ELECTION COMMITTEE



In 2023, the General Assembly elected the following members for the election committee:

- Mario Sel - Vlaamse Vereniging voor Spina Bifida en Hydrocephalus vzw (VSH)
- Dr Margo Whiteford - Spina Bifida Hydrocephalus Scotland (SBHS)
- Dr Kribanandan G Naidu - Spina Bifida Association Malaysia (SIBIAM)
- Hassan Funmilayo - Spina Bifida and Hydrocephalus Association of Nigeria (SBHAN)
- Phoebe Mutonyi - Spina Bifida and Hydrocephalus Association of Uganda (SHA-U)

## ADVISORY PANELS

Our standing committees of advisory groups are the expert panel, youth group, and volunteers.

### Expert Panel

IF has an advisory group with respected experts in the field of disability, health care, prevention, and political advocacy who serve in those positions on a voluntary basis. Members of this advisory group include professionals in the field of Spina Bifida and Hydrocephalus and specialists and/or in the field of disability in general. In particular, the scientific conference committees for IF conferences support the wider scientific deepening of our federation.

### Youth Group

In 2023 the IF International Youth Group SBH consisted of the following members: Laura Rosillo Beneyto (Chair; Individual member from Spain), Ajok Proscovia (Spina Bifida and Hydrocephalus Association of Uganda), Rereloluwa Adeolu (Individual member from Nigeria), Mirela Bukovac (Udruga osoba i roditelja djece sa spinom bifidom "Aurora", Croatia), Malik Armughan Ali (Spina Bifida Foundation Pakistan), Rebecca Austin (Individual member from Queensland, Australia), Samuel Opeyemi (Festus Fajemilo Foundation Nigeria), Patrícia Albertová (Slovenská spoločnosť pre spina bifida a/alebo hydrocefalus, o.z.), Nebiyat Testafaye (ReachAnother Foundation Ethiopia), Serhii Tkachuk (Parents Association for Spina Bifida and Hydrocephalus 'Lights of Spirit' Ukraine), Jurn Anthonis (Vlaamse Vereniging voor Spina Bifida en Hydrocephalus vzw Belgium), Chen Miaohua (Taiwan Spina Bifida Support Association), Kateryna Shcherbyna (Parents Association for Spina Bifida and Hydrocephalus 'Lights of Spirit' Ukraine), and Harichandana Mynampati (Spina Bifida Foundation India).

### Volunteers

In addition to these advisory groups, IF is always fortunate to work with dedicated volunteers. We are in particular grateful for the support of Pelin Gürcü who joined IF in 2023 for her Erasmus Plus Traineeship and Amy Huang who supported IF with the translation of several materials as part of the World Spina Bifida and Hydrocephalus Day (WSBHD23).

# MAIN ACHIEVEMENTS

## Quarter 1

*Jan.-Mar.*

### Community Building

Through member meetings and regional members meetings

### Advocacy

Through the World Folic Acid Awareness Week (WFAAW) webinar 'Preventing Birth Defects and Saving Lives: Folic Acid-Preventable Spina Bifida, Anencephaly' and support of the Draft WHA Resolution

### Partnership Strengthening

With the UN, WHO, European Commission Disability Platform, FFI, MNF, (GAIN), GAPSBi-F, IDA, EDF, ENIL, and ERN ITHACA

### Awareness Raising

Through international awareness campaign: World Folic Acid Awareness Week, Rare Disease Day, World Birth Defects Day, International Womens Day

### Individual Support

To IF members for their national advocacy to influence global actions such as the World Health Assembly (WHA) resolution

### Publications

Of the consultation to the CRPD, IF Press Release on the WHA resolution, Percentiel magazine, and toolkits

## Quarter 2

*Apr.-Jun.*

### Advocacy

Through the adoption of the WHA resolution Accelerating efforts for preventing micronutrient deficiencies and their consequences, including spina bifida and other neural tube defects, through safe and effective food fortification' on May 29

### Awareness Raising

Through an international awareness campaign: IF Siblings Day

### Twinning Opportunities

Through the COSP16 IF Side-Event 'Reaching out Together' & the WHA side event in Geneva

### Community Building

Through regional members meetings & the IF spring webinar

### Partnership Strengthening

By organising a side event as part of the World Health Assembly in Geneva & participation during the GAIN and Micronutrient Forum webinar 'Fortifying our Future: Coming together to support the World Health Assembly Resolution on Food Fortification'

### Publications

Of the IF Annual Report, Membership Guide, and toolkits

## Quarter 3

*Jul.-Sept.*

### **Awareness Raising**

Through the international awareness days: the International Youth Day

### **Community Building**

Through regional members meeting & in-person visits of IF members in Brussels

### **Partnership Strengthening**

Through continued regional meetings for members together and representation at the regional IAOM Meetings in Colombia and Turkey

### **Advocacy**

Of advancing the disability rights through intersectionality during the youth engagement at the UN SDG Summit in New York

### **Twinning**

Through the Paying-It-Forward Awareness Campaign between France, Ireland and Scotland

## Quarter 4

*Oct.-Dec.*

### **International Solidarity**

Through the World Spina Bifida and Hydrocephalus Day (WSBHD) main conference and its side events together with members and partners

### **Community Building**

Through the IF autumn webinar organised by the IF Working Group on Ageing

### **Awareness Raising**

Through international awareness days: International Day for Older Persons, International and European Days for Persons with Disabilities

### **Twinning**

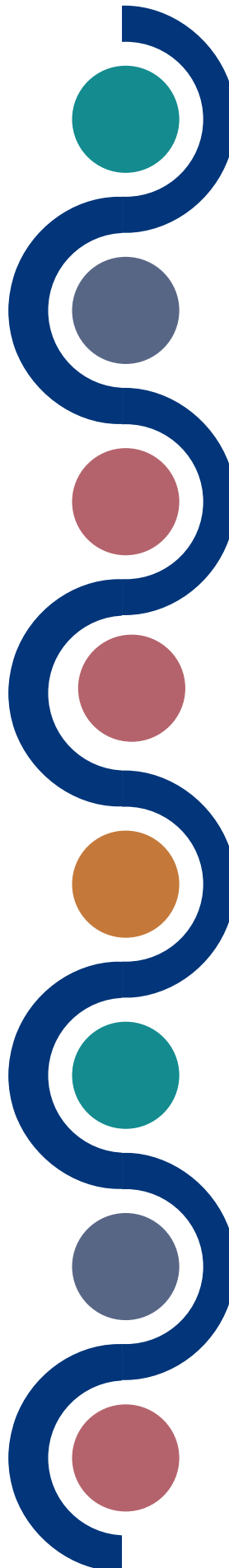
Through the EU-Ukraine Webinar Series

### **Training Opportunities**

Through IF members training 'Understanding Fundraising to influence Policy and Actions'

### **Publications**

The IF Statement on Conflict and Humanitarian Crisis and IF Statement on Strengthening Rehabilitation in Health Systems for persons with Spina Bifida and Hydrocephalus



# HUMAN RIGHTS

## WORLD HEALTH ASSEMBLY RESOLUTIONS

The year 2023 marked a major advancement in two of IF's high priority advocacy topics: (1) access to care and (2) reducing the prevalence of Spina Bifida and Hydrocephalus worldwide. With the passing of WHA76.19 'Accelerating efforts for preventing micronutrient deficiencies and their consequences, including spina bifida and other neural tube defects, through safe and effective food fortification' and WHA76.6 'Strengthening rehabilitation in health systems' the World Health Assembly (WHA) put Spina Bifida and the concerns of the SBH community front and centre in the international advocacy for better health policies. The WHA is the World Health Organisation's (WHO) decision-making body, where the Member States come together to vote on an agenda prepared by the Executive Board (EB).

IF has been at the forefront of the advocacy for large scale food fortification of staple foods with folic acid ever since evidence emerged regarding the important role folic acid (Vitamin B9) can have in reducing risks of NTDs. This advocacy has been possible through partnerships with a wide range of stakeholders, including successful projects through private-public-civil initiatives, for example Smarter Futures. A couple of years ago IF, together with partners, set the goal to achieve a WHA resolution on fortifying foods with folic acid, started working with IF member association's and IF partners to connect with members of the EB and then continued the advocacy for a strong resolution amongst WHO Member States.





## Strengthening rehabilitation in health systems

The Seventy-sixth World Health Assembly,

Having considered the consolidated report by the Director-General;<sup>1</sup>

Considering that the need for rehabilitation is increasing due to the epidemiological shift from communicable to noncommunicable diseases, while taking note of the fact that there are also new rehabilitation needs emerging from infectious diseases like coronavirus disease (COVID-19);

Considering further that the need for rehabilitation is increasing due to the global demographic shift towards rapid population ageing accompanied by a rise in physical and mental health challenges, injuries, in particular road traffic accidents, and comorbidities;

Expressing deep concern that rehabilitation needs are largely unmet globally and that in many countries more than 50% of people do not receive the rehabilitation services they require;

Recognizing that rehabilitation requires more attention by policy-makers and domestic and international actors when setting health priorities and allocating resources, including with regard to research, cooperation and technology transfer on voluntary and mutually agreed terms and in line with their international obligations;

Deeply concerned that most countries, especially developing countries, are not sufficiently equipped to respond to the sudden increase in rehabilitation needs created by health emergencies;

Emphasizing that rehabilitation services are key to the achievement of Sustainable Development Goal 3 (ensure healthy lives and promote well-being for all at all ages), as well as an essential part of achieving target 3.8 (achieve universal health coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all);

Reaffirming that rehabilitation services contribute to the enjoyment of human rights, such as the right to the enjoyment of the highest attainable standard of physical and mental health, including sexual and reproductive health, the right to work and the right to education, among others, and that Member States' obligations and commitments in this regard are consistent with the United Nations Convention on the Rights of Persons with Disabilities;

Noting the Declaration of Astana, which emphasizes that rehabilitation is an essential element of universal health coverage and an essential health service for primary health care;

<sup>1</sup> Document A76/7 Rev.1

This resolution transforms the way the world tackles the global challenges facing malnutrition and prevention. Now is the time that we, as a society, take the burden and responsibility for reducing the risks of NTDs in pregnancy away from women and the shame and stigma that this approach results in.

The WHA held in 2023 also saw the adoption of another important resolution for the SBH community. The WHA76.6 'Strengthening rehabilitation in health systems' has emerged after decades of advocacy and work by IF and others on rehabilitation and access to care. IF was a forerunner in calling for a stronger role of rehabilitation in health policy as it is an essential component of integrated multidisciplinary care for SBH.

The leadership of IF in the campaigning towards the WHA76.19 and WHA76.6 was essential for the global SBH community. It is extremely important to the SBH community to not only see changes made to policies but to achieve this goal through a rights-based perspective on advocacy, the foundation of which rests on the principle 'Nothing About Us Without Us'. The active involvement of representative organisations such as IF in international initiatives is an important step in mainstreaming disability rights as established by the UN Convention on the Rights of Persons with Disabilities.



# POLICY STATEMENTS

IF published several policy statements throughout the year which addressed important topics for the SBH community and emerging policy developments.

## IF Statement on Conflict and Humanitarian Crisis

In this statement, IF called for a greater awareness and urgent action towards the needs of persons with Spina Bifida and Hydrocephalus in situations of conflict and humanitarian crisis, ensuring an independent and healthy life for individuals with SBH and a full realisation of their human rights. This is particularly important to guarantee protection and access to inclusive multidisciplinary care while supporting persons with SBH, their families and carers. However, due to the lack of preparedness and exclusion of persons with disabilities and their organisations to participate in community-level disaster risk reduction, persons with SBH remain at a higher risk in situations of conflicts and humanitarian crises.

In this statement, attention was given to the following:

- The main obligations from the UNCRPD to be applied by the States Parties (countries and regional organisations that ratified the UNCRPD) during conflicts and humanitarian crisis;
- How conflicts and humanitarian crises have an impact on the lives of persons with SBH;
- Why it is necessary to adopt an effective rights-based approach when implementing plans to protect persons with SBH;
- IF's recommendations to respect the obligations held by Article 11 of UNCRPD.

## IF Statement on Strengthening Rehabilitation in Health Systems for persons with Spina Bifida and Hydrocephalus

IF is a pioneer with its long-time focus on rehabilitation. Almost thirty years ago, IF contacted the World Health Organisation and proposed to work together for producing a guide for mid-level rehabilitation workers, to be used for children with Spina Bifida and Hydrocephalus. IF published a statement on the topic to raise awareness of the WHA76.6 and to outline IF's recommendations for effective and accessible rehabilitation for persons with SBH.

This statement gave attention to the following:

- What rehabilitation is;
- Why strengthening rehabilitation for persons with SBH is necessary;
- List of actions at global level on how to strengthen rehabilitation in health system for persons with SBH;
- Barriers for making rehabilitation a reality for all persons with SBH;
- IF's recommendations on strengthening rehabilitation for SBH in health systems.



# INTERNATIONAL ORGANISATIONS AND PARTNERS

Fostering good relations with international organisations is an essential part of IF's advocacy for the rights and needs of the SBH community as was demonstrated by the adoption of the WHA76.19 and WHA76.6 by the WHA. These resolutions were accomplished by IF's strong connections to the WHO as well as by collaborating with a diverse range of partners.

## The World Health Organisation

The adoption of the two resolutions were not the only successes in IF's advocacy towards the WHO in 2023. IF was also accepted into the WHO Civil Society Commission. The mission of the Civil Society Commission is to strengthen dialogue and contribute to the implementation of the Sustainable Development Goals (SDGs). Being a member of the commission is a tremendous victory and an honour for IF, and it is another opportunity for the international federation to bring the concerns of the SBH community directly to policymakers.

In addition, IF received accreditation as a non-state actor in relations with WHO Africa which enables IF to observe meetings and proceedings which are otherwise closed to the public.

## European Commission Disability Platform

IF has been a member of the Disability Platform since its inauguration. IF remained an active participant throughout 2023, advocating on key issues within the EU, contributing to the creation of the yearly work programme and participation in meetings. In 2023, the priorities of the platform included the European Disability Card and the European Parking Card. These initiatives, if adopted, will ensure that persons with disabilities will be able to better realise their right to free movement within the EU. A goal which IF supported through its work with the Disability Platform. Furthermore, IF became an active member for the subgroup on independent living.



The objectives of the Disability Platform are:

- To facilitate cooperation between the European Commission and European Union (EU) Member States for the implementation of the European Union Strategy for the Rights of Persons with Disabilities (ESRPD);
- Assist the Commission in the preparation of policy initiatives or legislative proposals in the field of disability;
- Establish cooperation and coordination between the Commission and the Member States and stakeholders on questions relating to the implementation of Union legislation, programmes and policies in the field of disability;
- Bring about an exchange of experience and good practice in the field of disability.

## The United Nations

IF has been a member of the United Nations Economic and Social Council (ECOSOC) for decades and continues to maintain that membership. During 2023, IF also saw opportunities to take part in high level meetings with UN entities. An example included the Conference of the States Parties (COSP) whereby IF President gave a speech on the importance of accessibility for all.

## SDG Summit at the UN in New York

IF continued to organise as well as take part in high level meetings. For instance, IF youth member Laura Rosillo Beneyto represented the global disability community on behalf of IF and the International Disability Alliance (IDA) at the youth pillar 'Torchbearers for the SDGs: Meaningful Youth Engagement & the 2030 Agenda' during the SDG Action Weekend as part of the SDG Summit at the UN Headquarter in New York. In this session, the need for an intersectional approach was highlighted. The SDGs reflect the disability movement's own principle: 'Nothing About Us Without Us'. Taking an intersectional approach is essential in order to truly advance disability rights.

Individuals with disabilities exist at the intersection of all identities (nationalities, ethnicities, cultures, religions, etc.) and within every community. The lived experiences of their disability (such as Spina Bifida and Hydrocephalus) and the societal barriers which they may face are influenced by all those different factors. Laura, being a youth member of the International Disability Alliance and International Federation for Spina Bifida and Hydrocephalus, stated that it is our mission to ensure that every person with a disability has their human rights and freedoms fully recognised, without any form of discrimination. It is crucial that we have lifelong access to specialised healthcare and support services.

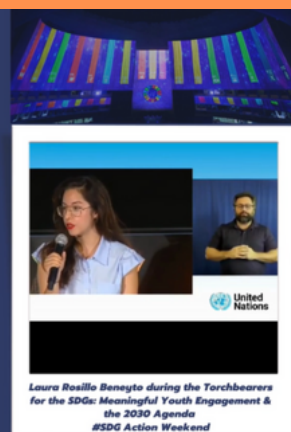


“

Every event and decision making process is an opportunity to make sure we implement an intersectional perspective. This means including young persons with disabilities to make sure that the diversity is really represented and to make sure meaningful participation is accessible to everybody

Laura Rosillo Beneyto  
Chair IF International Youth Group SBH

#SDG Summit 2023



INTERNATIONAL FEDERATION  
FOR SPINA BIFIDA  
AND HYDROCEPHALUS



# AWARENESS RAISING

## INTERNATIONAL AWARENESS DAYS

All IF's activities are rooted in the ultimate mission to advance and protect the rights of individuals with SBH. Throughout 2023, IF organised various activities to address the objective of raising awareness on the rights of persons with SBH. Activities included participating in meetings and events, contributions to consultations, and publications of statements. In particular, the focus was on the priorities indicated by IF members for themes such as independent living, multidisciplinary care, and prevention.

Awareness days, both European and international, also played a significant role. These days are considered by IF as opportunities to raise awareness about SBH among a broad audience through multimedia channels. The activities around awareness days include opportunities for collaborations with IF members and partners in the EU or worldwide. Therefore, through the promotion of these international, national and European activities, IF aimed to also increase visibility together with members and partners.

The overall objectives to raise awareness included:

- Promoting, protecting and monitoring the rights of persons with Spina Bifida and Hydrocephalus;
- Ensuring that the perspective and needs of individuals with SBH and their families are represented in policy making;
- Supporting the implementation of the European Strategy for the Rights of Persons with Disabilities (ESRPD) and the EPSR and to facilitate the mainstreaming of the UNCRPD;
- Strengthen partnership and collaborations with European and international networks to amplify the visibility of the SBH community;
- Maximising the visibility of IF activities;
- Organising communication and engagement activities to raise awareness of the ESRPD and promote the rights of persons with Spina Bifida and Hydrocephalus.



In 2023, IF continued to raise awareness on the rights of individuals with SBH and the UNCRPD among policymakers, relevant stakeholders, and international organisations. IF held awareness campaigns for several international awareness events: World Folic Acid Awareness Week; Rare Disease Day; World Birth Defects Day; International Women's Day; IF's Siblings Day; International Youth Day; International Day of Older Persons; World Spina Bifida and Hydrocephalus Day; International/European Day of Persons with Disabilities, and the World Toilet Day. For seven of these international awareness events IF developed social media toolkits to support members and partners in their advocacy efforts. These toolkits were developed for:

- World Folic Acid Awareness Week
- World Birth Defects Day
- IF's Siblings Day
- International Youth Day
- International Day of Older Persons
- World Spina Bifida and Hydrocephalus Day (read more in WSBHD23 chapter)
- International/European Day of Persons with Disabilities

**From the 2nd to the 8th of January 2023**  
**WORLD FOLIC ACID AWARENESS WEEK**

Every January, the International Federation for Spina Bifida and Hydrocephalus (IFSBH) works with its member organisations, partners and supporters to promote the World Folic Acid Awareness Week as part of the IF Global Prevention Initiative (GPI) 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.

**Preconception folic acid is key in the prevention of most NTDs.**  
 The WHO recommends taking a daily folic acid supplementation of 400mcg for at least 12 weeks before conception.

**Mandatory fortification of food with folic acid is a cost-effective measure to reduce NTD-related progression risk, and it requires no change in diet or behaviour.**

Moreover, this year IF wants to take the opportunity to transform the way the world tackles the global challenge of malnutrition and prevention of Neural Tube Defects.

For this occasion, IF organises and invites you to the webinar: **"World Folic Acid Awareness Week: International for Global Health"** including speakers from all over the world sharing their perspectives on how we can build a smarter, stronger, and healthier future for all.

For more information about the WFAAW23 webinar, visit the IF website.

**JOIN THE WFAAW 2023 AWARENESS RAISING CAMPAIGN**

- You can take part in the WFAAW social media campaign by sharing key information about folic acid and prevention during this important week through your social media channels and with friends, colleagues and families. Encourage them to spread folic acid awareness too!
- You can now download IF's WFAAW Toolkit on IF website.

**On the 3rd of March 2023**  
**WORLD BIRTH DEFECTS DAY**

The International Federation for Spina Bifida and Hydrocephalus (IFSBH) will be joining the World Birth Defects Day (WorldBDDay) on March 3rd to raise awareness on all birth defects and improve care and treatment. IFSBH will share a series of activities taking place on this special day of the year "because raising awareness can help babies around the world."

**Let's show our support for birth defects tracking, research and prevention!**

1. Download and print the "I care..." sign;
2. Fill it out with why we care about birth defects prevention and research including #WorldBDDay #ManyBirthDefects1Voice;
3. Post a picture holding it.

**SHARE AND PARTICIPATE TO WBDD ACTIVITIES**

- WHO WorldBDDay webinar via Zoom: Saving lives of babies with birth defects and improving their quality of life
- Twitter Chat Q&A session to raise awareness about birth defects
- Facebook Live Event: COVID-19 Vaccine in Pregnancy & Breastfeeding
- Free webinar on lead exposure in pregnancy

<https://www.worldbirthingdefectsday.org/care-campaign/>

**On the 10th of April 2023**  
**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). IFSBH 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: #SiblingsDay #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!

**On the 12th of August 2023**  
**INTERNATIONAL YOUTH DAY**

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 under the theme **#YouthSBHandIndependentLiving**

Independence living is the rights of persons with disabilities, which was set out in **Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)**. Independent living is especially important for youth as they are facing transition from adolescence to adulthood.

This year 2023, The IF International Youth Group would like to take this opportunity to raise awareness about independent living.

You are invited to take part in the **IF Challenge on International Youth Day!**

Check out our Toolkit to join the challenge

**TOOLKIT 2023**

**On the 1st of October 2023**  
**International Day of Older Persons**

On **October 1**, the world celebrates the International Day of Older Persons. This day was designated by the United Nations General Assembly by resolution 45/106 on 14 December 1990. On this occasion, IF takes this opportunity to raise awareness on ageing with Spina Bifida and Hydrocephalus.

To celebrate this day, the International Federation for Spina Bifida and Hydrocephalus (IFSBH) shares the International Day of Older Persons toolkit. It can be used to **guide your social media contribution** and invite you to **participate to the challenge** launched by IF.

Please share this toolkit with colleagues, friends and family and join IF to raise awareness on Ageing with Spina Bifida and Hydrocephalus!

**IF SOCIAL MEDIA TOOLKIT FOR THE INTERNATIONAL DAY OF OLDER PERSONS 2023**

Our social media toolkit will provide you with:

- background information on this day;
- posters, logos and banners;
- key messages and hashtags;
- key links;
- a challenge to take part in to download for an active campaign on this memorable day.

This material is developed for you to share on your website, on social media, and to distribute within your network.

For any additional question, please contact [info@ifglobal.org](mailto:info@ifglobal.org)

Thank you for your support and contribution to make the International Day of Older Persons a memorable day!

**On the 25th of October 2023**  
**WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY**

The **World Spina Bifida and Hydrocephalus Day 2023** is coming up soon! For this international day on **October 25** IF shares with you the **WSBH2023 toolkit**. This toolkit can be used to guide your social media contribution and invite you to the events taking place during this day or month.

Accessibility and inclusion are challenges frequently encountered by persons with SBH. With stigma, discrimination and lack of awareness creating further barriers to the full enjoyment of life, Join the SBH community in promoting:

**"Accessibility for All"**

<https://www.worldspinaandhydrocephalusday.com>

Please share this toolkit with colleagues, friends and family and join IF to spread awareness about living with Spina Bifida and Hydrocephalus!

**WSBH2023 SOCIAL MEDIA TOOLKIT**

Our social media toolkit will provide you with:

- key messages and hashtags;
- posters, logos and banners;
- WSBH2023 conference and regional side events;
- WSBH2023 awareness picture video content to download for an active campaign on this memorable day.

These materials are developed for you to share on your website, on social media, and to distribute within your network.

For any additional question, please contact [info@ifglobal.org](mailto:info@ifglobal.org)

Thank you for your support and contribution to make the WSBHD23 a memorable day!

**EUROPEAN DAY OF PERSONS WITH DISABILITIES**  
 November 9 - December 2023

The European Day of Persons with Disabilities (EDPD) is celebrated through an annual conference organised by the European Commission in partnership with European Disability Forum.

This two day long conference marks the International Day of Persons with Disabilities. This year the conference will take place in person in Brussels, Belgium **November 9 - 10 December**.

The focus of the 2023 agenda will be on:

1. Including persons with disabilities in the labour market and society. This is because 2023 is the European Year of Skills.
2. In addition the conference will explore other topics such as what international instruments are there to help make the ambition for the Union of Equality a reality.
3. As well as addressing how everyone, including persons with disabilities, can fully exercise their voting rights. Especially since persons with disabilities are at times marginalized from political and public spheres.

The topics addressed by the conference are not only a concern to members in the EU.

These are global challenges and the EDPD is an opportunity to raise awareness of the rights and needs of the SBH community globally.

The International Federation for Spina Bifida (IF) will be present at EDPD conference to ensure that the voices of the SBH community are represented at this important event.

If you will also be active on social media and encourages YOU to get involved by downloading the IF Toolkit here:

For more information about the European Day of Persons with Disabilities, visit the EU website page: <https://ec.europa.eu/eurodis2023/>

# World Folic Acid Awareness Week

Every January, the International Federation for Spina Bifida and Hydrocephalus (IF) 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) and 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.



To transform the way the world tackles the global challenge of malnutrition and prevention of Neural Tube Defects, IF organised a webinar event. The webinar 'Preventing Birth Defects and Saving Lives: Folic Acid-Preventable Spina Bifida, Anencephaly' gathered a panel of international experts with a proven track record in global leadership on prevention and food fortification. The panellists included Dr Godfrey Oakley (Director, Center for Spina Bifida Prevention and Research, Emory University), Victoria Sandoval (Trustee, Asociación Guatemalteca de Espina Bífida Guatemala), Scott Montgomery (Director, Food Fortification Initiative), Dr Jeffrey Blount (Chair, GABSBI-F), Dr Aziza Elnaeema (Spina Bifida Federal Association of Sudan), Dr Saskia Osendarp (Director, Micronutrient Forum), Gerry Maguire (CEO, Spina Bifida and Hydrocephalus Ireland), Dr Luz De-Regil (Head, Multisectorial action in food systems, World Health Organisation), Melinda Farris (CEO, International Association of Operating Millers), Penjani Mkambula (Global Program Lead for Food Fortification at the Global Alliance for Improved Nutrition) and Dr Santosh Karmarkar (Director, Spina Bifida Foundation India), shared their unique experiences, visions and wishes for the upcoming time. This webinar aimed to trigger a deeper understanding of the importance of mandatory food fortification with folic acid for prevention of birth defects. The webinar gave insights in how countries can create political will, but it also highlighted the significance of building networks on each level within the society to mainstream our message that healthy pregnancies start with a healthy lifestyle including balanced diet.

# World Birth Defects Day

I care...  
Because every child  
deserves a healthy future.



Raise awareness on World Birth Defects Day!

March 3rd

World Birth Defects Day 2023

Social Media Campaign

Visit <https://www.worldbirthdefectsday.org> | [www.ifglobal.org](http://www.ifglobal.org)

On 3 March, IF joined the global community in celebrating 'Many birth defects, one voice' as part of the World Birth Defects Day (WBDD). In support of this day, IF promoted the much needed actions in mobilising resources and commitment to birth defects care, prevention, and research. Furthermore, IF created a social media toolkit including key messages and a social media challenge allowing IF members to participate in this year's theme and call for action.

# International Siblings Day

On April 10, IF celebrated the Siblings Day 2023 to honour siblings of individuals with Spina Bifida and Hydrocephalus. This day marks the special bond between siblings as they share unconditional love, and support each other throughout life. For the Siblings Day, IF invited every individual with a sibling with SBH to share the activities they like to do with their siblings. IF members posted many pictures and videos online of siblings celebrating this important day.

IF's Siblings Day  
Social Media Toolkit  
2023



Fundación Mónica Uribe Por Amor  
Medellín - Colombia



Chloe Thian  
with  
baby brother,  
Bryson

Sister - best gift for lil' brother!

#IFSiblingsDay #SBHSiblings #SmileSiblings



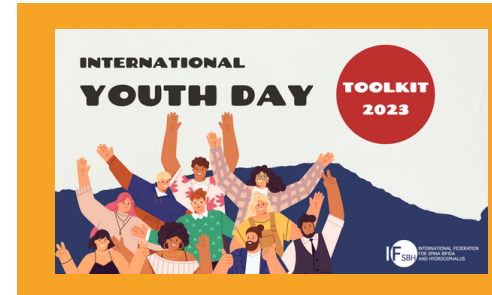
Thank you





# International Youth Day

On August 12, IF celebrated the International Youth Day. This was an opportunity for young people to draw attention to topics important to youth with SBH around the world and the IF International Youth Group SBH wanted to address several issues related to the current theme of the year, independent living. On this day, the youth group launched a social media campaign and created a toolkit which included information on how the youth group celebrated the International Youth Day, quotes, relevant hashtags, and various materials to download with an invitation for the SBH youth community to join them. This social media campaign encouraged participants to submit videos, stories, or images expressing what independent living means to them, utilising specially designed IF frames. The success of the campaign, evident in the creative contributions and shared experiences, demonstrated the impactful advocacy of the IF International Youth Group SBH and the broader SBH community.



**#YouthSBHandIndependentLiving**

**Laura Rosillo Beneyto**  
Chair IF International Youth Group SBH, Spain

Starting to work and being financially independent was a turning point in my life for feeling independent. I could afford to live independent and to start 100% managing my life. As a person with Spina Bifida, I feel privileged, as in the EU, persons with disabilities have higher risk of poverty than persons without disabilities, and currently only 52% of persons with disabilities have a job. Accessible, inclusive and fulfilling job opportunities are key for young people with Spina Bifida and hydrocephalus on our journey to live independent.

**Jurn Anthonis**, Belgium

Independent living for me means to take care of myself physically, mental and financial. I think it's everyone's desire to participate in the society. So as a young child my parents already prepared me for that by sending me to youth camps to learn how to take care of myself. By doing these camps my wheelchair never became a problem for me. It even gave me the opportunity to complete my studies while living at a student's home and later on have a wonderful job. Right now, thanks to my job, I can inspire younglings with spina bifida and other disabilities to live as independent as can be, as my parents did to me.

**Kateryna Shcherbyna**, Ukraine

I have spina bifida and have lived independently since the beginning of student years. In my country, I am faced with challenges that have everyone, but having a disability makes it more difficult. I believe that an accessible world and inclusive society with all rights to study, work, and make decisions can change our lives to feel freedom.

**Rebecca Austin**, Australia

Since then I am living in my own apartment, alone, and have the assistance of support workers to help me with everyday tasks and getting around. This allows me to keep as independent as possible. I realise not everywhere is as lucky as Australia in the system of living and support, but I'm sure there are ways we can all increase our independence, if we just look for it together.

**Patricia Albertová**, Slovakia

From august I live at the other end of the country with my boyfriend. I am able to take care of the household, cook, wash dishes, wash clothes and I also study at university. It is not easy but I can do it.

# International Day of Older Persons



On October 1, IF celebrated the International Day of Older Persons. This significant day was officially established by the United Nations General Assembly through resolution 45/106 on 14 December, 1990. An annual awareness day dedicated to honouring and recognising the contributions and challenges faced by older individuals around the globe.



## GETTING OLDER, LIVING BETTER

### Best Practices for Ageing with Spina Bifida and Hydrocephalus

As part of the International Day of Older Persons



**Frances Petersen**  
Association for Spina Bifida and Hydrocephalus South Africa (ASBAH-SA)

**Li-Shun Chua**  
Spina Bifida Association Malaysia (SISAM)

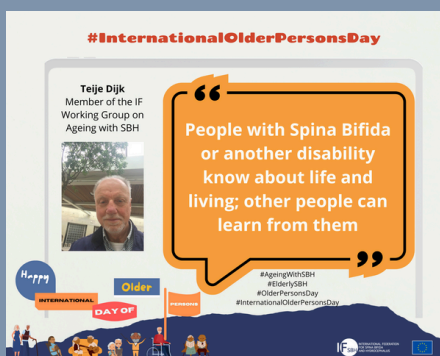
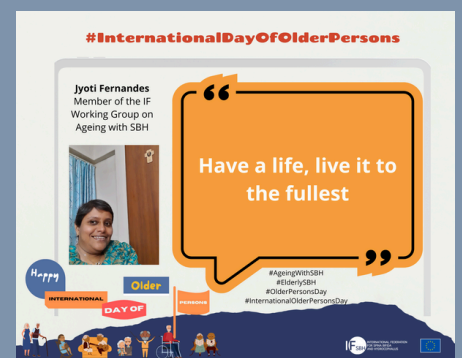
**Mario Sel**  
Voorheen Vereniging voor Spina Bifida en Hydrocephalus vzw (VSH)

**Kevin O'Donnell**  
Moderator  
Chair IF Working Group on Ageing with SBH

Sunday, 1 October 2023 15:00 - 17:00 CEST ZOOM Webinar

Register Now At:  
[bit.ly/AgeingSBHWebinar](https://bit.ly/AgeingSBHWebinar)

On this International Day of Older Persons, IF seized the opportunity to shed light on the unique experiences of ageing with SBH. IF aimed to raise awareness on the barriers that older individuals with SBH may encounter and, most importantly, the urgent need to dismantle these barriers. To mark this day, IF developed the IF International Day of Older Persons toolkit. This toolkit was a valuable resource designed to spread awareness and guide social media engagement. This involved sharing personal stories through videos or short narratives, disseminating the toolkit across social media platforms, and utilising specially designed IF frames to amplify key messages or convey individual insights. As part of this day, the IF Working Group on Ageing with SBH organised a webinar on best practices, which is described more in the chapter Community Building & Twinning.



# International and European Days of Persons with Disabilities

On December 3, IF celebrated the International Days for Persons with Disabilities (IDPD). IDPD is a day to promote the rights and well-being of people with disabilities in all aspects of society and development, as well as to raise awareness about their position in political, social, economic, and cultural life. This day was declared by the United Nations General Assembly in 1992 by resolution 47/3. IF advocates for the rights of persons with disabilities. IF takes this day as an opportunity to support the European Union and raise awareness on SBH.



Additionally, IF celebrated the European Day of Persons with Disabilities (EDPD) on November 30 - December 1 by joining the annual conference organised by the European Commission in partnership with European Disability Forum in Brussels, Belgium. This two-day conference marked the International Day of Persons with Disabilities. The focus of the 2023 agenda was on including persons with disabilities in the labour market and society since 2023 was the European Year of Skills. In addition, the conference explored what international instruments were there to help make the ambition for the Union of Equality a reality, as well as addressing how everyone, including persons with disabilities, can fully exercise their voting rights, especially since persons with disabilities are at times excluded from political and public spheres.

The European Day of Persons with Disabilities Conference in Brussels  
December 1st, 2023



On the picture: Dr Sylvia Roozen (IF Secretary General), Andrej Drdul (IF member Slovakia), Mario Sel (IF member Belgium), Liliana Sintra (IF member Portugal), Claire Cambier (IF Policy Officer), Kateryna Shcherbyna (IF International Youth Group SBH), Shantal Martis (IF Project Officer), Laura Rosillo Beneyto (chair of IF International Youth Group SBH)



## International Days for Persons with Disabilities

International instruments such as the #UNCRPD are vital for the global SBH community because it establishes its principles as human rights.

The right to health, independent living, employment, education and more are not optional perks which may be bestowed upon citizens.

They are human rights.

#EDPD23 #UnionOfEquality  
#EUDisabilityRights #IDPD23



# PREVENTION & CARE

## THE ROAD TOWARDS THE WHA76.19 RESOLUTION



IF welcomed and celebrated the adoption of the WHA resolution 'Accelerating efforts for preventing micronutrient deficiencies and their consequences, including spina bifida and other neural tube defects, through safe and effective food fortification' on May 29; a tremendous milestone in making micronutrient deficiency and its impact on public health a high priority policy concern and bringing evidence-based policies on health, disability rights, and nutrition to every community.

With this new WHA resolution, WHO Member States across the world, acknowledge a long-standing concern expressed by IF, our members, and partners, that isolated national actions to reduce the risk of Neural Tube Defects including Spina Bifida developing during pregnancy are woefully inadequate, resulting in an avoidably high prevalence worldwide.



For over 45 years, IF as the international representative organisation, has been a leading advocate for the fortification of staple foods with folic acid (Vitamin B9) working together with IF members and partners from the public, civil and private sectors to advance actions on safe and effective food fortification. Fortification is the safest, most inclusive, effective and egalitarian policy to reduce the prevalence of Spina Bifida and other Neural Tube Defects (IF Statement: A Call for a Global Action to Reduce the Prevalence of Neural Tube Defects Worldwide).

The resolution demonstrates the impact of cross-sectoral collaborations and how involving representative organisations of persons with disabilities in advocacy for public health policies is not just an obligation, but an advantage.

The adoption of the resolution is a remarkable occasion for the global Spina Bifida community and all those stakeholders and policymakers who have worked with IF to make this action a reality. However, it is also just the beginning, the resolution must have a meaningful impact and for that it needs strong implementation and for that to become a reality there needs to be effective and meaningful involvement of all relevant stakeholders, especially persons with Spina Bifida and their families.

IF will remain at the forefront of the advocacy for the resolutions implementation and for that action to be taken with a rights-based perspective by actively consulting persons with Spina Bifida and to avoid stigmatising narratives in the name of prevention. Through its extensive experience with public-private-civil partnerships, facilitating an integrated approach to achieving effective policy change to reducing the prevalence of Spina Bifida and other Neural Tube Defects. IF continues to raise awareness and guiding the international community in navigating and overcoming the obstacles to progress as well as strengthening members to advance activities on the local and national level through training, information materials, twinning and one-on-one support. In support of the road towards this WHA resolution on Food Fortification, IF came together with its members and partners through joint initiatives.

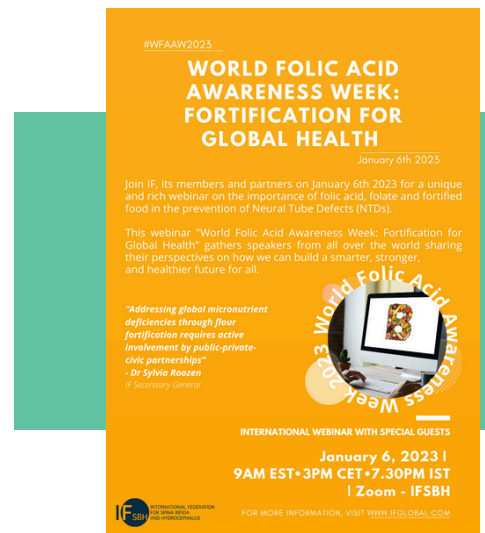
### IF Advocacy Committee

The objective of the IF Advocacy Committee is to work together to strengthen and coordinate joint advocacy campaigns between IF and its member associations as well as to serve as a forum where IF Members can support and learn from each other and create materials on advocacy to be used by IF Member Associations.

In 2023, the Advocacy Committee met to continue the work on and coordinate the advocacy efforts for a WHA draft resolution on food fortification, a task which successfully realised its objective.

### World Folic Acid Awareness Week Webinar

During the first week of 2023, IF organised a webinar titled 'Preventing Birth Defects and Saving Lives: Folic Acid-Preventable Spina Bifida, Anencephaly' to support spreading the word about the World Folic Acid Awareness Week. In this webinar, IF invited key speakers who are all international champions for food fortification and offered their perspectives for a healthier, stronger, and smarter future for all. Read more about the WFAAW and webinar in the Awareness Raising chapter.



### Fortifying our Future

The webinar 'Fortifying our Future: Coming together to support the World Health Assembly Resolution on Food Fortification', held on 4 April 2023, was hosted by Global Alliance for Improved Nutrition (GAIN) in collaboration with IF, GAPSBI-F, G4 Alliance, Helen Keller Intl, Micronutrient Forum (MNF), Mighty Nutrients Coalition, SDG2 Advocacy Hub, Iodine Global Network, iZincG and Micronutrient Data Innovation Alliance.

In this webinar, the IF Secretary General elucidated that there is a required need to look at prevention in the context of disability rights and the reduction of the prevalence of Neural Tube Defects should be taken as a global priority. Dr Papatya Alkan Genca (Board Member, Turkish Spina Bifida Association), concluded the second session by recounting her experiences as a spina bifida patient and patient representative *“SBH organisations, both on the national and international level, were instrumental in the admirable document being proposed by the WHA”*.

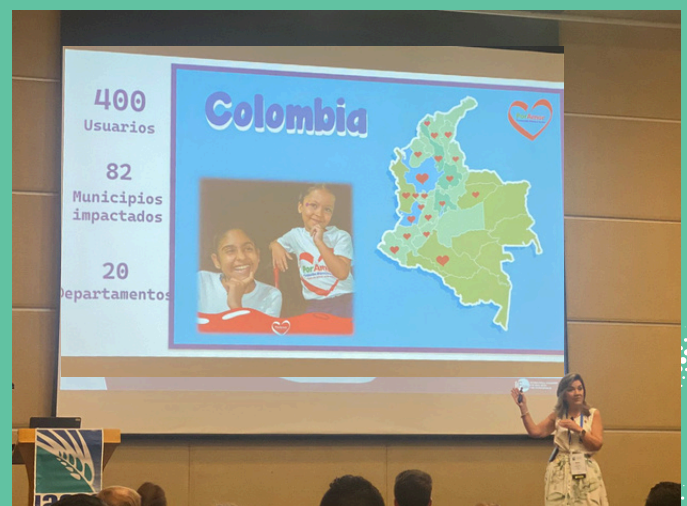
### Seventy-Sixth World Health Assembly Side Event

To celebrate and raise awareness of the draft resolution, the government of Colombia alongside other Member States, and a broad coalition of partners from public-private-civil society organised a side event during the seventy-sixth World Health Assembly. During this side event, the IF Secretary General Dr Sylvia Roozen and board member Dr Papatya Alkan Genca underlined the importance to the SBH community to not only advance fortification policies but to achieve this goal through a rights-based perspective on advocacy. The active involvement of representative organisations including IF in international initiatives, such as this proposed draft resolution, is an important step in mainstreaming disability rights as established by the UN Convention on the Rights of Persons with Disabilities in all initiatives from the local to the international level.



### IF Partners with Millers

IF has a long-standing partnership with the International Association of Operative Millers (IAOM) which marks millers and civil society as key advocates in preventing Neural Tube Defects through safe and effective food fortification. Through continued regional meetings for millers we can effectively implement the adopted WHA76.19 Resolution. In 2023, IF was therefore represented at the regional IAOM Meetings in Colombia and Turkey by its board members Sonia Uribe and Dr Papatya Alkan Genca. In their presentations, emphasis was put on the important role millers have in support of the SBH community and advocacy for large scale food fortification with folic acid.

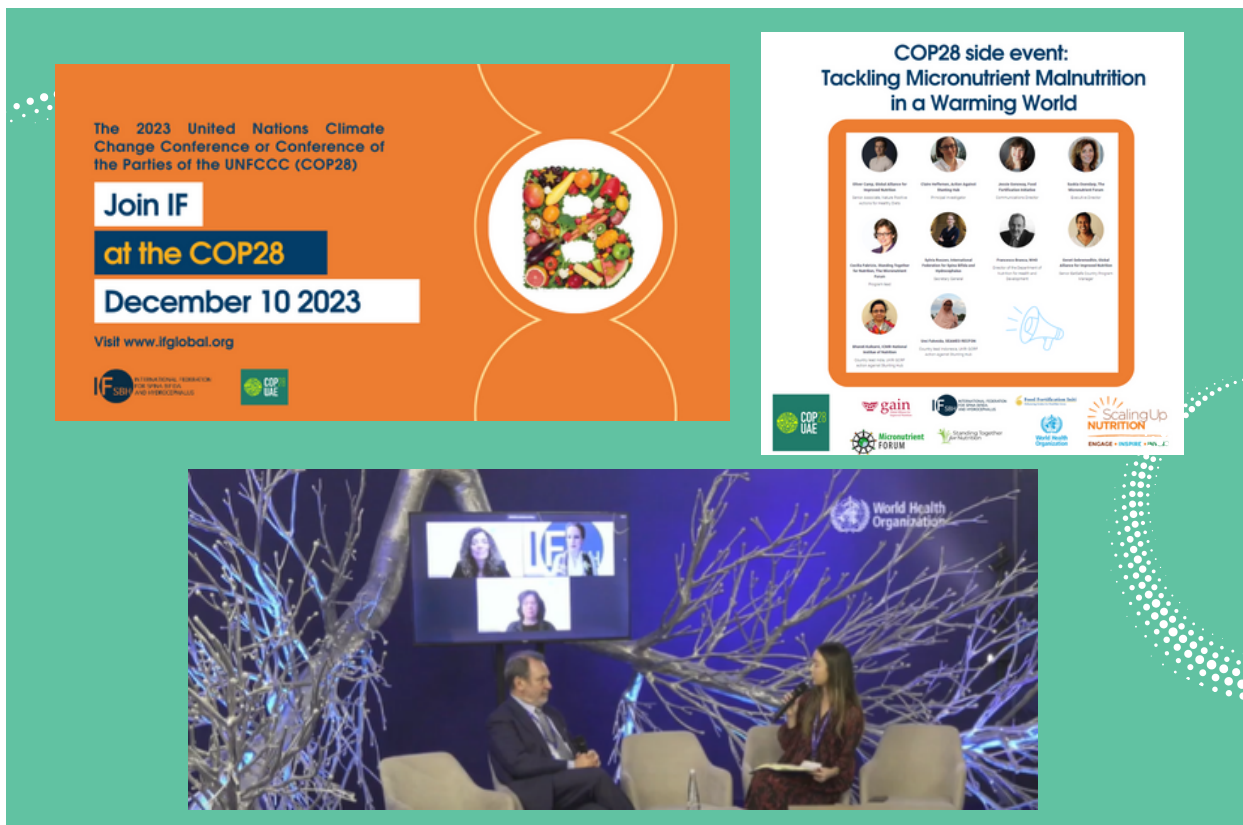


## Nutrition for Resilience

IF joined the Micronutrient Forum 6th Global Conference as panellist and talked about the ways to strengthen micronutrient resilience by sharing its experiences from Smarter Futures. Through this exemplary partnership, the engagement of the private sector (milling industry and food processors) as equal partners in each country and at the regional level has been critical to the successful implementation of mandatory fortification. For the road towards the WHA resolution, IF moreover shared that in particular for the advocacy & monitoring civil society actors were important. Through the collaboration with IF we placed a particular focus on the involvement and inclusion of civil society actors such as disability groups, consumer associations, physicians and neurosurgeons, and parent associations related to Spina Bifida and Hydrocephalus.

## UN Climate Change Conference (COP28)

The COP28 Health Pavilion, organised by WHO in partnership with the Wellcome Trust and other collaborators, hosted a two-week program of events at the COP28 UN Climate Conference. The event provided a crucial platform for global health leaders and stakeholders to address the intersection of climate change and human health. Among the sessions, 'Tackling Micronutrient Malnutrition in a Warming World' highlighted innovative approaches to improve nutrition while considering environmental sustainability. The event emphasised the interconnectedness of food systems and the environment, showcasing initiatives such as fortification, biofortification, and dietary diversity promotion. Speakers from IF together with GAIN, MNF, Standing Together for Nutrition (ST4N), WHO, and Food Fortification Initiative (FFI) underscored the urgency of action and the potential of nutrition interventions to advance both human and planetary health. Through policy recommendations and collaborative efforts, the session aimed to elevate nutrition resilience as a priority in global decision-making forums, emphasising the importance of addressing climate-related challenges in nutrition policies and programs.



## The 49th Annual Meeting and Scientific Session of the ICBDSR

During 2023, IF joined the 49th Annual Meeting and Scientific Session of the International Clearinghouse for Birth Defects Surveillance and Research (ICBDSR). This annual meeting provided a platform for the exchange of knowledge and collaborative efforts to advance the understanding and prevention of birth defects globally. The conference, organised by ICBDSR in collaboration with the Malta Congenital Anomalies Registry (MCAR), focused on the primary prevention, surveillance, and management of birth defects. For this meeting, IF Secretary General Dr Sylvia Roozen was an invited keynote speaker. In her keynote address she reflected on the importance of data and emphasised on the much-needed data points to inform key actions in support of the implementation of the WHA76.19 Resolution.

## IF Partnership with the WHO EMRO

The countries in the WHO EMRO region have made great efforts to implement staple food fortification as reported by WHO in the 2019 report 'Wheat flour fortification in the Eastern Mediterranean Region'. Some wheat flour is being fortified on a voluntary basis by some of the mills. Nevertheless, the number of new mills that have been built may not be fortifying to the standards as described by the current WHO Recommendations for the Fortification of Wheat and Maize flour. The question remains how countries continue to experience micronutrient prevalence. Therefore, IF together with the WHO Regional Office for the Eastern Mediterranean Region will collaborate on a situation analysis of neural tube defects in EMRO since the implementation of mandatory food fortification with folic acid. The lessons learned from the region can inspire the other regions in support of the WHA76.19 implementation.





# UROLOGICAL MANAGEMENT AND MENTAL HEALTH

## ERN ITHACA Working Group Spina Bifida & other Dysraphisms

Within the European Reference Networks (ERNs), IF is the patient representative organisation for persons with SBH. ERNs are networks involving healthcare providers across Europe. They aim to facilitate discussion on complex or rare diseases and conditions that require highly specialised treatment, and concentrated knowledge and resources. IF is an active partner in the ERN-ITHACA. The ERN-ITHACA is the European Reference Network for Rare Malformation Syndromes, Intellectual and Other Neurodevelopmental Disorders. IF is represented in the specific ERN-ITHACA working group spina bifida as well as in the Patient Advocacy Groups (ePAG). IF's role as member of the ePAG is to be the voice, advocate for interests of the SBH community and act as the linking pin between the SBH community and the ERN.

The working group by its nature provides trans-ERN opportunities for knowledge exchange. In 2023, a workshop was organised for future research on innovative diagnostics and interdisciplinary treatment. Also, continued actions were in place as part of the clinical classification for Spina Bifida and the revision of the current Orphanet Codes. Moreover, collaborations were formed with other partners to finalise the updated paediatric urological guidelines for Spina Bifida.

## IF - ERN ITHACA - ERN eUROGEN - EAU

To strengthen the work on paediatric urological guidelines for Spina Bifida a broader collaboration was established between IF together with the European Association of Urology (EAU), ERN eUROGEN, and the ERN ITHACA. It is a unique collaboration whereby IF actively involves persons with Spina Bifida and/or Hydrocephalus and their families to improve the existing guidelines in making them more patient centred. In this way, the SBH community is actively involved in the development of this survey study from the beginning onwards. IF also ensured that the voice of its members was heard through a survey in collaboration with the EAU-ESPU Paediatric Urology Guidelines Panel: families were provided with the opportunity to have a direct influence to improve the guidelines for care of children with urological problems by taking part in this study.



## Europe - Ukraine

In a new partnership between IF, ERN ITHACA & eUROGEN, and OMNI-Net Ukraine, steps were taken to strengthen cross border initiatives in support of the care for persons with Spina Bifida. In 2023, one of the outcomes was the development of a series of webinars on multidisciplinary care for Spinal Dysraphisms. In this webinar series, clinicians from Europe and Ukraine met and exchanged further knowledge and practices on Spinal Dysraphisms. For this reason, IF held regular meetings with Ukrainian partners on the exchange of knowledge and practices regarding Ukraine and European physicians, with a focus on how to transfer that knowledge to the families in Ukraine.

**EU-Ukraine Webinar Series on Spinal Dysraphisms**

**Project introduction & overview**  
presented by  
**Prof. Wladimir Wertelecki, Dr. Sylvia Roozen,  
& Prof. Wout Feitz**

Thursday 16 November 2023 18:00-19:00 CEST

Register [here](#), or scan the QR code

Logos: IF SBH, European Reference Network, Rare Diseases Doctors, Funded by the European Union, Birth Defects Prevention, Omni-Net Ukraine.

**EU-Ukraine Webinar Series on Spinal Dysraphisms**

A brand-new series of webinars aimed at healthcare professionals  
Run jointly between ERN eUROGEN, OMNI-NET Ukraine, & the International Federation for Spina Bifida & Hydrocephalus

Click [here](#) to find the session registration links as they become available

16.11.23 – Wladimir Wertelecki, Sylvia Roozen, Wout Feitz  
**Project Introduction & overview**

14.12.23 – Giovanni Mosiello, Jean Marie Jouannic, Natalia Zymak-Zakutnia  
**Multidisciplinary Management of Spina Bifida**

18.01.24 – Timothee Saint Denis, Giacomo Esposito  
**1: Etiology, epidemiology, pathophysiology, classification of SBoD, neurosurgical management**

01.02.24 – Giovanni Mosiello, Rien Nijman  
**2: Neurogenic bladder classification, pathophysiology, diagnosis**

06.02.24 – Rien Nijman  
**3: Urodynamics**

22.02.24 – Raimund Stein, Giovanni Montini  
**4: Urinary tract infection and vesico ureteral reflux management**

07.03.24 – Rafal Chrzan  
**5: First line management, clean intermittent catheterization, and anticholinergics**

21.03.24 – Michal Maternik, Giovanni Montini  
**6: Renal function**

18.04.24 – Gessica Della Bella  
**7: Physical rehabilitation points to know**

Logos: European Reference Network, eUROGEN Urogenital Diseases, Rare Diseases Doctors, Birth Defects Prevention, Omni-Net Ukraine, IF SBH, Funded by the European Union.

## Mental Health

Through several members meetings and focus group discussions, mental health has been identified to be an important area of focus, in particular in relation to urological management. Therefore, IF emphasised on the need to include a chapter on mental health in the upcoming paediatric urological guidelines for Spina Bifida as described earlier. In its partnership with the Governor Kremers Centre-Maastricht University Medical Centre, a systematic approach was taken to understand our current knowledge on this topic. As such, preliminary outcomes of a systematic literature review revealed significant findings regarding the psychological and cognitive challenges faced by individuals with Spina Bifida. The study highlighted higher rates of attention, executive function, and academic problems among children and adolescents with Spina Bifida, along with increased prevalence of intellectual disability, ADHD, and anxiety disorders. Among adults, persistent mental health issues included anxiety, depression, somatoform disorders, and fatigue, particularly in those affected by lower urinary tract disorders. The findings underscored the importance of assessing mental health in Spina Bifida patients and emphasised the need for appropriate counselling and treatment interventions. Additionally, the study suggested the relevance of cognitive and neuropsychological assessments in facilitating optimal schooling and rehabilitation strategies for individuals with Spina Bifida. The results were also presented at the International Children's Continence Society in Brazil.



# COMMUNITY BUILDING AND TWINNING

## IF ACTIVITIES WITH MEMBERS

### MEMBERS MEETINGS

Globally, IF held regular members meetings with IF member associations. These member meetings allowed for a reflection on the highlights of previous year activities, defining specific needs, and setting priorities of IF members. Additionally, IF facilitated regional meetings, such as those with the Asia-Pacific Network SBH and specific meetings by IF and RELAEBHI for Spanish-speaking members. As part of an exchange visit, IF warmly welcomed Spina Bifida Foundation for a visit at the Brussels office. In particular, SBF India Project Officer Sneha Sawant had the opportunity to meet with the IF team and youth members in preparation for the joint WSBHD23 regional meeting as well as exchange experiences with the Chair of the IF International Youth Group SBH. Furthermore, exclusive meetings were organised for communications coordinators of member associations to express communications needs, discuss challenges and ways to strengthen the communications work locally and globally.



### WEBINARS

To increase the capacity of member associations of IF and reinforce cooperation, several webinars were designed in the spring and autumn focused on the topics relevant for the Spina Bifida and Hydrocephalus community, including ageing with SBH, youth with SBH, and women with SBH. The spring and autumn webinars were focused on enhancing knowledge and sharing best practices among countries.

At the onset of spring, IF organised a webinar titled 'Women with Disabilities in Conflict and Crisis'. Given the many ongoing global conflicts in different parts of the world, the theme of conflict and crisis proved to be relevant for the SBH community. Individuals, especially women, with disabilities in conflict and crisis was one of such topics of priority for IF members. Individuals, especially women, with disabilities in conflict and crisis was one of such topics of priority for IF members. During this webinar three speakers with experience of living in countries with conflicts and crises shared their testimonies and challenges they faced in their respective countries. The country's perspectives included Ukraine, Turkey and Rwanda.



The autumn webinar was organised by the IF Working Group on Ageing with SBH. This webinar aimed to provide a platform for the ageing SBH community to share insights, discuss the findings of the report 'Ageing with Spina Bifida and Hydrocephalus: An Overview of Best Practices Around the World', and engage in meaningful conversations about the unique needs and opportunities for the ageing SBH community. It was intended to bring together individuals with SBH and their caregivers and foster a collaborative environment to catalyse actionable efforts that enhance the quality of life for individuals ageing with SBH. The webinar was divided into two sessions. The first session was dedicated to sharing best practice examples of different countries with respect to the population ageing with SBH, including examples from Malaysia, Belgium, and South Africa. The second session allowed participants to separate into smaller virtual rooms, giving them the opportunity to voice their opinions on ageing with SBH.

Next to the spring and autumn webinars, IF hosted a formal side event during the 16th Conference of States Parties to the Convention on Rights of Persons with Disabilities (COSP16) titled 'Reaching Out Together: Advancing Rights-Based Advocacy in Underserved Communities through Transnational Twinning'. This event highlighted the vital role of capacity building initiatives for persons with disabilities and their organisations in underserved communities. Focusing on transnational twinning, it empowered national SBH associations and their members for inclusive participation in policy-making processes. The event also advanced rights-based advocacy for pressing issues within the global SBH community and inspired capacity building efforts for underrepresented disability groups worldwide.



## TRAININGS

The annual thematic training for IF members, titled 'Understanding Fundraising to Influence Policy and Actions', addressed key concerns identified within the SBH community, focusing on fundraising and advocacy. Through gathering member's feedback from IF's activities IF identified fundraising and advocacy as two of the high priority concerns for the SBH community. With that in mind, IF chose fundraising and the UNCRPD principles as the basic elements for advocacy where IF members can learn basic tools during the IF members training. The annual thematic training was divided in three training components: (i) Fundraising, (ii) UN-CRPD, and (iii) a coming-back practical session.

Through these three components, the training equipped participants with essential knowledge and practical skills. Led by experts such as Magdalena Versekas and An-Sofie Leenknecht from EDF, sessions covered fundraising strategies, the UNCRPD, and practical application through project concept notes. Participants gained insights into international advocacy, human rights principles, and effective communication, enhancing their capacity to advocate for SBH community rights at local and national levels.



# ACTIVITIES IF ADVISORY GROUPS

## IF INTERNATIONAL YOUTH GROUP SBH

### MEETINGS

The youth group SBH represented a total of 14 young persons with SBH aged 18 to 30 years from different countries around the world, including Laura Rosillo Beneyto (Chair; Individual member from Spain), Ajok Proscovia (Spina Bifida and Hydrocephalus Association of Uganda), Rereloluwa Adeolu (Individual member from Nigeria), Mirela Bukovac (Udruga osoba i roditelja djece sa spinom bifidom "Aurora", Croatia), Malik Armughan Ali (Spina Bifida Foundation Pakistan), Rebecca Austin (Individual member from Queensland, Australia), Samuel Opeyemi (Festus Fajemilo Foundation Nigeria), Patrícia Albertová (Slovenská spoločnosť pre spina bifida a/alebo hydrocefalus, o.z.), Nebiyat Testafaye (ReachAnother Foundation Ethiopia), Serhii Tkachuk (Parents Association for Spina Bifida and Hydrocephalus 'Lights of Spirit' Ukraine), Jurn Anthonis (Vlaamse Vereniging voor Spina Bifida en Hydrocephalus vzw Belgium), Chen Miaohua (Taiwan Spina Bifida Support Association), Kateryna Shcherbyna (Parents Association for Spina Bifida and Hydrocephalus 'Lights of Spirit' Ukraine), and Harichandana Mynampati (Spina Bifida Foundation India). During online meetings the group discussed ways to address important issues relevant for the young SBH community, with a special focus on a key topic for this year: independent living.

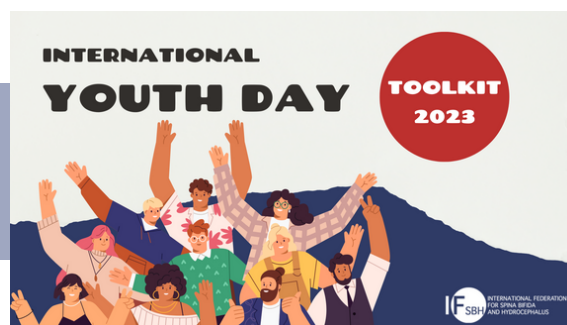


### TRAININGS

On the occasion of the annual thematic training for IF members, titled 'Understanding Fundraising to Influence Policy and Actions', the youth participated in these sessions to learn and implement the learnings of fundraising and advocacy for upcoming initiatives.

### PUBLICATIONS

The activities on the International Youth Day allowed for the youth to develop their social media toolkit. In the toolkit, the youth group challenged the global young community with SBH and invited them to tell the group what independent living means to them and share their unique perspective on independent living.

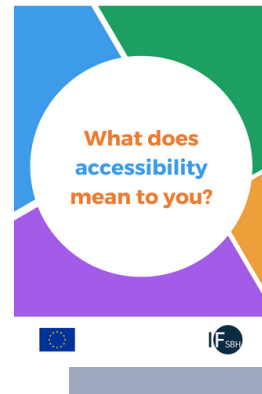




## VISIBILITY

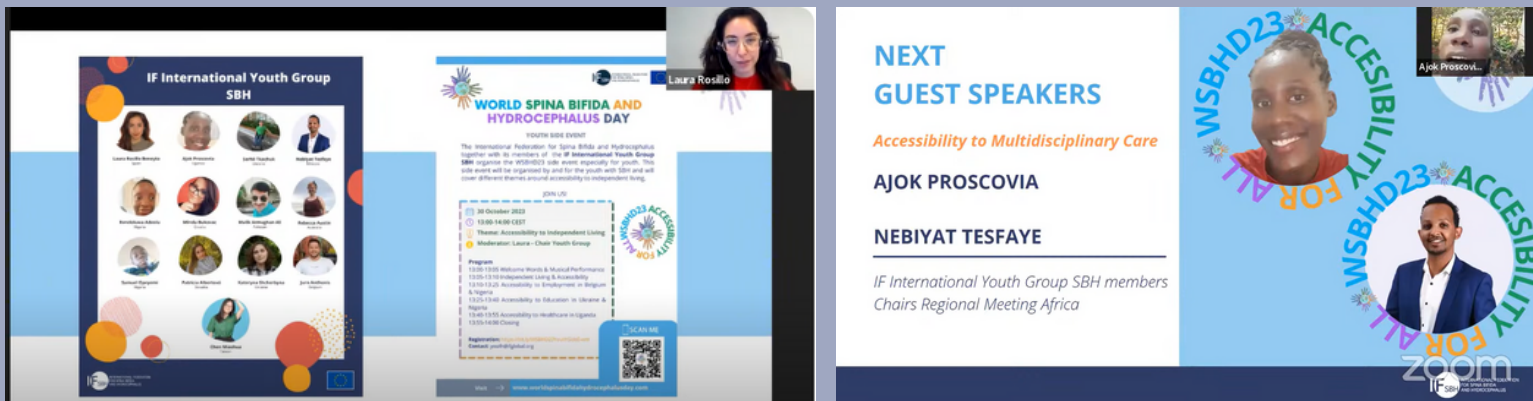
### WSBHD23 What does Accessibility mean to the Youth?

During the month of October, in light of the WSBHD23 theme the youth enthusiastically shared their visions on 'Accessibility for All'. The youth created videos, participated during the WSBHD23 conference and side events, and hosted their own event! See below for all their highlights.



### WSBHD23 Conference Accessibility4All

During the WSBHD23 conference Ajok Proscovia and Nebiyat Tesfaye introduced the IF International Youth Group SBH, sharing how the group aims to gather young persons with SBH together from all around the world and work together in addressing important issues relevant for youth with SBH around the world. Additionally, they shared the vision of accessibility within Africa which were mostly directed towards prevention and accessibility for health with a focus on multidisciplinary care. The imperative of advocacy efforts to promote independent living across various domains was emphasised, including healthcare, education, and employment.



### WSBHD23 Side Event Youth

As part of the WSBHD23 celebration, the IF International Youth Group SBH organised their side event on October 30, focusing on the theme of 'Accessibility to Independent Living'. Each specific topic was delved into at a deeper level by the youth members, these included accessibility to employment, education and healthcare. The WSBHD23 Youth Side Event successfully illuminated the challenges and triumphs in the pursuit of a more accessible and inclusive world for individuals with Spina Bifida and Hydrocephalus.

### WSBHD23 Side Event Africa

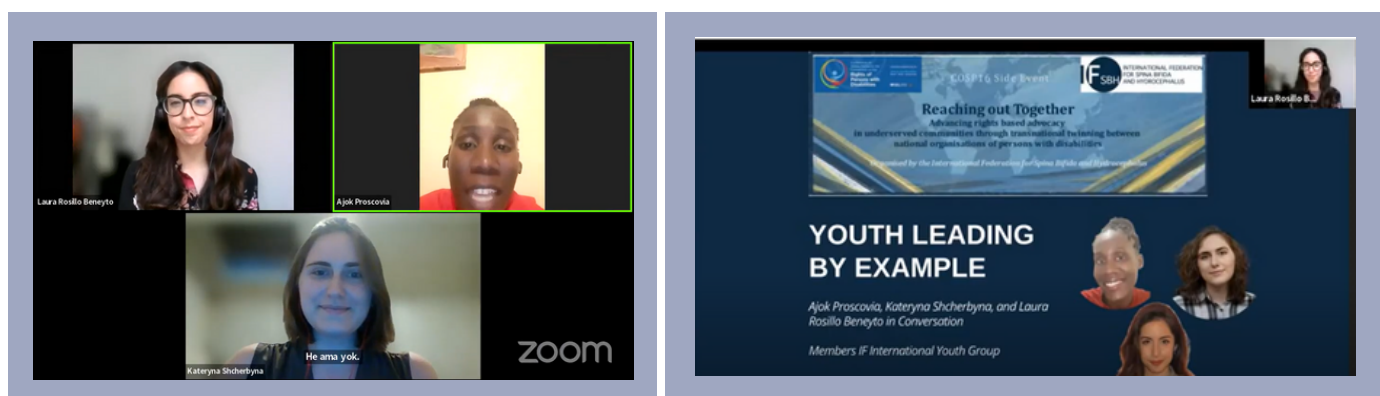
The WSBHD23 Regional Side Event Africa was chaired by two youth members, Ajok Proscovia and Nebiyat Tesfaye. Both led discussions with panellists who shed light on the persistent challenges faced by individuals in Uganda, Nigeria, and Ethiopia. It was highlighted that these countries still do not meet their accessibility needs, for example how persons with SBH often face inadequate access to education and employment, as specialised facilities are limited. The need for rehabilitation was also emphasised as in Ethiopia there is a high rate of child mortality due to the lack of care.

## WSBHD23 Side Event Europe

As part of the WSBHD23 Side Event Europe themed 'Current Status on Accessibility in Europe', Jurn Anthonis stressed the importance of experiential learning for independent living, citing youth camps as valuable platforms. He shared his experiences and announced the WSBHD23 Youth Side Event, focusing on accessibility to independent living.

## IF COSP16 Side Event

On June 16, IF hosted a significant side event during 16th Conference of States Parties to the Convention on Rights of Persons with Disabilities titled 'Reaching Out Together: Advancing Rights-Based Advocacy in Underserved Communities through Transnational Twinning'. During this event Ajok Proscovia and Kateryna Shcherbyna discussed the challenges and empowerment initiatives for youth with SBH in different countries. Ajok shared empowering initiatives in Uganda, while Kateryna shed light on difficulties faced in Ukraine. Both speakers emphasised the need for improved support systems and inclusive measures to enhance the quality of life for individuals with SBH. The Chair of the IF International Youth Group SBH, Laura Rosillo Beneyto, highlighted their work on independent living, providing a safe space for young individuals with SBH to share experiences, address challenges, and advocate for their rights. The group actively engages in policy advocacy, raises awareness, and promotes the talents of young people with SBH.



## IF Webinar Women with Disabilities in Conflict and Crisis

As part of this webinar, youth member Kateryna Shcherbyna took part in to provide the perspective in Ukraine prior to conflict. She emphasised the existence of psychological abuse and prejudice in workplaces, educational institutions, and healthcare settings. She talked about the difficulties experienced by those with disabilities in a university setting. Examples include a lack of accessible amenities in buildings, a lack of live communication, and insufficient evaluations of students with disabilities. She further highlighted the absence of sexual education and gender equality in Ukraine, which contributes to an increase in sexual violence and abuse, particularly towards women who are disabled. She emphasised the differences between sexual assaults that occurred before and after the conflict, pointing out that women who are disabled are especially vulnerable since they are unable to protect themselves during the war. In her argument, she underlined that women with disabilities face double psychological violence as a result of two forms of discrimination. The first is determined by gender, and the second by the presence of a disability. She quotes, *"In Ukraine people experience double discrimination. First on the basis of gender and next on the basis of disability"*.

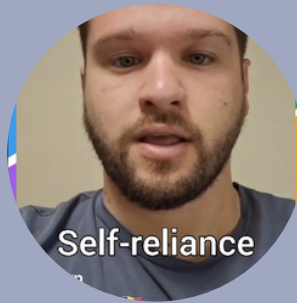
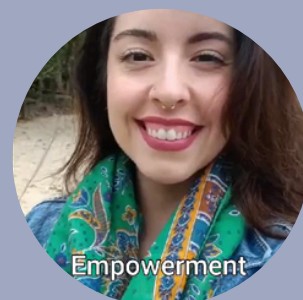
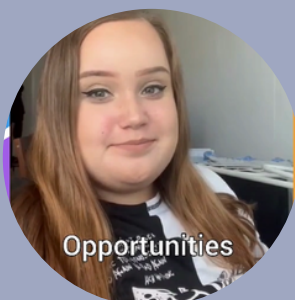
## Raising Awareness During International Youth Day & International Day for Persons with Disabilities

Reflecting on International Youth Day 2023, the IF International Youth Group SBH proudly highlights our united efforts in raising awareness about Independent Living. On August 12, youth with Spina Bifida and Hydrocephalus worldwide joined forces to challenge misconceptions and share their unique perspectives. Our social media campaign encouraged participants to submit videos, stories, or images expressing what independent living means to them, utilising specially designed IF frames. The IF International Youth Day toolkit was provided in English, Spanish, and Portuguese. The success of the campaign, evident in the creative contributions and shared experiences, demonstrates the impactful advocacy of the IF International Youth Group SBH and the broader SBH community.

To celebrate the International Day of Persons with Disabilities IF joined the European Day of Persons with Disabilities 2023 Conference in Brussels. The IF community, including the youth members, were well-represented and highly committed to defend the rights of persons with SBH!

## Representing the SBH Community in IF Partner Organisations

The IF youth members were also frequently involved in activities of external partner organisations. Examples of such organisations include the European Disability Forum (EDF), International Disability Alliance (IDA), the European Network for Independent Living (ENIL), the European Organisation for Rare Diseases (EURORDIS), and the European Patients Forum (EPF). Youth members took part in meetings, training, workshops, and conferences of these organisations to share the perspectives of the Spina Bifida and Hydrocephalus community. Specifically, youth members have been involved in youth committee meetings of EDF and IDA, the youth EPF training focused on shortages, a Social Policy Action group of EURORDIS, and a youth leadership programme of ENIL to empower the youth.





## IF WORKING GROUP ON AGEING WITH SBH

### MEETINGS

In 2023, the IF Working Group on Ageing with SBH consisted of 10 IF member representatives; Kevin O'Donnell, Chair of the Working Group on Ageing with SBH (Spina Bifida Hydrocephalus Scotland), Gerry Maguire (Spina Bifida and Hydrocephalus Ireland), Mario Sel (Vlaamse Vereniging voor Spina Bifida en Hydrocephalus vzw, Belgium), Teije Dijk (Spina Bifida en Hydrocephalus Nederland, The Netherlands), Eva Toft (Spin- Off, Sweden), Jon Bateman (Individual member from Southern Alberta, Canada), and Chetan Shoraff (Spina Bifida Foundation India), Burhan Elli (Turkiye Spina Bifida Derneği), and Jyoti Fernandes (Spina Bifida Foundation India). The group continued their meetings to discuss ways to improve our understanding of the lived experiences of older persons with SBH.



### KNOWLEDGE GATHERING

In 2023, the IF Working Group on Ageing with SBH organised a webinar following a report published in the previous year. This webinar aimed to provide a platform for the ageing SBH community to share insights, discuss the findings of the report 'Ageing with Spina Bifida and Hydrocephalus: An Overview of Best Practices Around the World', and engage in meaningful conversations about the unique needs and opportunities for the SBH community as they get older. It was intended to bring together individuals with SBH and their caregivers and foster a collaborative environment to catalyse actionable efforts that enhance the quality of life for individuals ageing with SBH. The webinar was divided into two sessions. The first session was dedicated to sharing best practice examples of different countries with respect to the population ageing with SBH, including examples from Malaysia, Belgium, and South Africa. The second session allowed participants to separate into smaller virtual rooms, giving them the opportunity to voice their opinions on ageing with SBH.



## PUBLICATIONS

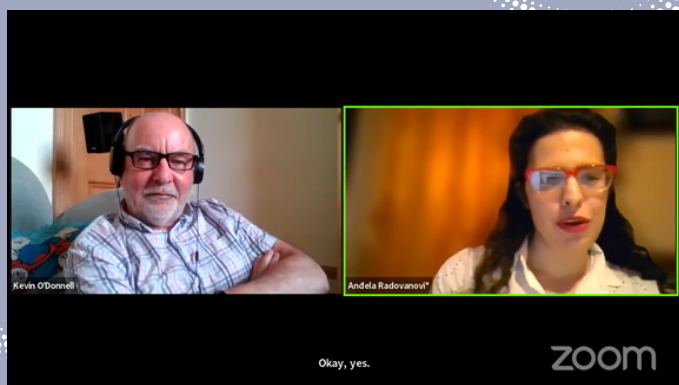
The webinar on best practices provided diverse perspectives on ageing with SBH. These perspectives were essential in informing consultations for the United Nations. This specific consultation was formed by the UN Open-Ended Working Group on Ageing (OEWG). The OEWG is a group in the UN that brings multiple stakeholders together to find concrete ways to strengthen the protection of human rights for the global ageing population. Member States, National Human Rights Institutions (NHRIs), NGOs, and UN agencies, all form part of this OEWG. As IF holds a Special Consultative Status at the Economic and Social Council of the United Nations, IF regularly takes part in meetings and contributes to consultations of this Working Group, with the aim to advance the rights of the ageing SBH population.

The consultation consisted of a questionnaire titled 'Identification of possible gaps in the protection of the human rights of older persons and how best to address them' the purpose of which was to help assess the existing international framework for the human rights of older persons. It aimed to identify gaps in protecting their rights and explore the best ways to address these gaps. The OEWG, during its thirteenth session in April 2023, decided that co-facilitators should suggest recommendations for the fourteenth session in 2024. These recommendations will be reviewed by the Working Group and the General Assembly and focus on examining the current international framework for the human rights of older individuals.

## VISIBILITY

At the IF COSP16 Side Event, Kevin O'Donnell (Chair of the IF Working Group on Ageing with SBH) and Anđela Radovanović (IF member from Montenegro) actively engaged in a session focusing on the inclusion of people with disabilities in national dialogues. Their discussion centred on addressing misconceptions and stigmas related to the ageing SBH community, and highlighting resources and support for healthcare, independence, and social inclusion.

As part of the WSBHD23 Side Event Europe themed 'Current Status on Accessibility in Europe', member of the ageing group Gerry Maguire (member IF Working Group on Ageing with SBH & CEO, Spina Bifida and Hydrocephalus Ireland) highlighted challenges in Ireland with regards to public transport and buildings. In Ireland wheelchair users who are travelling are required to give advance notice. Further, public buildings have yet to be fully adapted for wheelchair users. Gerry passionately advocated for making public transport the norm for persons with disabilities, emphasising the ongoing fight for universal accessibility.



*Accessibility to Public Transport and Buildings*

**Gerry Maguire**

*Spina Bifida Hydrocephalus Ireland (SBHI)*



# TWINNING

Each year, IF facilitates at least one Twinning meeting to bring together expertise from public-private-civic sectors within the EU as well as beneficiary countries with aim to strengthen the implementation of the UNCRPD and ESRPD. The design of IF's Twinning meetings is centred on peer-to-peer activities including the sharing of best practices and connecting associations and individuals from around the world. See also below two examples of twinning activities whereby the focus was given to activities with the aim to strengthen the implementation of the UNCRPD through awareness raising activities, webinars, and formal side events during key international meetings.

## Paying-It-Forward Awareness Campaign Between France, Ireland and Scotland

Together with IF member association in France, L'Association nationale Spina Bifida et Handicaps Associés (ASBH), a twinning pay-it-forward campaign was implemented in support of a sailing journey by four sailors living with Spina Bifida who travelled from Saint-Malo, Dublin to Glasgow by a sailing boat across the ocean from August 5 to August 15. This sailing tour initiated by four young persons with Spina Bifida was unique as it promoted further awareness of the capabilities of persons with Spina Bifida in an inspiring way. As part of the Twinning, cooperation was sought with IF members, especially the Spina Bifida Hydrocephalus Ireland (SBHI) and Spina Bifida Hydrocephalus Scotland (SBH Scotland).

**THE SPIRATES OF L'ESTRELLA**

Join us as we set sail beyond the horizon of disability

Quai Saint Louis in Bassin Vauban Saint-Malo, France

4th August 2023, All day  
5th August 2023, Departure 10:00

Association nationale SPINA BIFIDA et Handicaps associés | Spina Bifida Hydrocephalus Scotland | IF SBH INTERNATIONAL FEDERATION FOR SPINA BIFIDA AND HYDROCEPHALUS

**The OBJECTIVES**

- 1 Promote **spina bifida awareness** with a documentary film
- 2 Raise awareness on spina bifida **prevention with vitamin B9** during pregnancy.
- 3 **Speak openly** about rare diseases and intimate medical conditions
- 4 **Strengthen connections** with European patient associations
- 5 **Empower civic involvement** with an eco-friendly project, proving **disability is no obstacle**
- 6 **Discover diverse abilities** of individuals with disabilities, enriching society

Association nationale SPINA BIFIDA et Handicaps associés | Spina Bifida Hydrocephalus Scotland | IF SBH INTERNATIONAL FEDERATION FOR SPINA BIFIDA AND HYDROCEPHALUS

## The 16th Conference of States Parties to the Convention on Rights of Persons with Disabilities IF Side-Event 'Reaching out Together'

On June 26, IF hosted a formal side event during the 16th Conference of States Parties to the Convention on Rights of Persons with Disabilities titled 'Reaching Out Together: Advancing Rights-Based Advocacy in Underserved Communities through Transnational Twinning'. This event highlighted the vital role of capacity building initiatives for persons with disabilities and their organisations in underserved communities.



Focusing on transnational twinning, it empowered national SBH associations and their members for inclusive participation in policy-making processes. The event also advanced rights-based advocacy for pressing issues within the global SBH community and inspired capacity building efforts for underrepresented disability groups worldwide.

The event commenced with a powerful address by IF President Cato Lie at the United Nations Headquarters in New York, emphasising the urgent need to prioritise the rights of individuals with SBH. He stated, “Only through diversity and inclusion can we effectively address the needs of all individuals”. The IF President called for improved access to healthcare, support services, and active involvement in decision-making processes. He urged Member States to integrate the UNCRPD principles, support capacity building initiatives, and embrace diversity within the disability community to address the unique requirements of each individual. In addition, IF Secretary General Dr Sylvia Roozen highlighted the core principle of the CRPD. She stated, “with a focus on capacity building and strengthening participation across different demographics, today’s meeting aims to facilitate exchanges of lessons learned between national associations and their members”.

**OUR PANELISTS**

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

- Cato Lie**  
President International Federation for Spina Bifida and Hydrocephalus
- Ajok Proscovia**  
IF International Youth Group Member from Spina Bifida and Hydrocephalus Association of Uganda
- Kateryna Shcherbyna**  
IF International Youth Group Member from the Lights of Spina, Ukraine
- Laura Rosillo Beneyto**  
Chair of the IF International Youth Group
- Kevin O'Donnell**  
Chair of the IF Working Group on Ageing with SBH
- Andela Radovanović**  
IF member from Montenegro
- Ruth Nalugya**  
Spina Bifida and Hydrocephalus Association of Uganda (SBA-U)
- Papatya Alkan Genca**  
Türkiye Spina Bifida Derneği Board Member International Federation for Spina Bifida and Hydrocephalus
- Elena Zappoli**  
Chair of Latin American network RELAEBH, Former President Asociación para Espina Bifida e Hidrocefalia (APEBH)

In the second session, Ajok Proscovia (IF International Youth Group Member from Spina Bifida and Spina Bifida and Hydrocephalus Association of Uganda) and Kateryna Shcherbyna (member IF International Youth Group SBH) discussed the challenges and empowerment initiatives for youth with SBH in different countries. Ajok shared empowering initiatives in Uganda, while Kateryna shed light on difficulties faced in Ukraine. Both speakers emphasised the need for improved support systems and inclusive measures to enhance the quality of life for individuals with SBH. The Chair of the IF International Youth Group SBH, Laura Rosillo Beneyto, highlighted the youth’s work on independent living, providing a safe space for young individuals with SBH to share experiences, address challenges, and advocate for their rights. The group actively engages in policy advocacy, raises awareness, and promotes the talents of young people with SBH.



Led by Kevin O'Donnell (Chair of the IF Working Group on Ageing with SBH) and Anđela Radovanović (IF member from Montenegro) the third session revolved around the involvement of people with disabilities in national discussions, addressing misconceptions and stigmas related to the ageing SBH community, and highlighting resources and support for healthcare, independence, and social inclusion.

In the fourth session, Dr Papatya Alkan Genca (IF board member and representative of the Türkiye Spina Bifida Derneği) talked about the significance of the recently passed WHA76.19 Resolution 'Accelerating efforts for preventing micronutrient deficiencies and their consequences, including spina bifida and other neural tube defects, through safe and effective food fortification' (accepted on May 29, 2023) . She highlighted the importance of collaboration and food fortification in reducing the risk of spina bifida and other health conditions.

During the fifth session, Ruth Nalugya (Spina Bifida and Hydrocephalus Association of Uganda, SHA-U) emphasised on the importance of food fortification programs in addressing micronutrient deficiencies, advocating for increased consumer awareness, monitoring capacity, and equitable access to fortified food. Later on, Elena Zappoli (Chair of the Latin American network RELAEBHI and former president of Asociación para Espina Bífida e Hidrocefalia) underscored the significance of networking in fostering inclusive societies and advancing inclusive health, highlighting the establishment of the Latin American network in 2012 with the aim of improving the lives of individuals with SBH and their families. Dr Rezina Hamid (IF member Bangladesh Spina Bifida and Hydrocephalus Welfare Trust) raised awareness about the neglect of children with SBH in the country's healthcare system and government policies. Additionally, sir Abdus Sattar Dulal (IF member Bangladesh Protibandhi Kallyan Somity, BPKS), shared how BPKS is led by representatives of persons with disabilities and reached 43 out of 64 districts in Bangladesh, resulting in significantly improving the lives of millions of persons with disability in Bangladesh. The association works on national policies including the UNCRPD, access to facilities, humanitarian support, public service, and increasing the knowledge of persons with disabilities of more than half a million stakeholders and professionals. Throughout our virtual event, we were delighted to feature an impressive dance performance by youth members from the Spina Bifida Foundation India, showcasing the power of artistic expression in promoting inclusivity and celebrating the abilities of individuals with SBH.



**Other Examples of Reaching Out Together**

Ruth – SHA-U  
Dr Rezina Hamid - Bangladesh  
Elena Zappoli - RELAEBHI



**National Advocacy Influencing Global Actions**

Papatya Alkan Genca  
Türkiye Spina Bifida Derneği  
Board Member International Federation  
for Spina Bifida and Hydrocephalus



Overall, this side event 'Reaching Out Together: Advancing Rights-Based Advocacy in Underserved Communities through Transnational Twinning', was a significant gathering that emphasised the importance of capacity building and transnational collaboration in underserved communities. The event addressed various topics, including youth empowerment, disability rights advocacy, international resolutions, support for the ageing community, and food fortification programs. It concluded with a focus on the role of networking in creating inclusive societies and promoting inclusive health. The event served as a platform for knowledge exchange, collaboration, and inspiring efforts to empower underrepresented disability groups and address the unique needs of the communities worldwide.

## Preparing for the 30th International Conference on Spina Bifida and Hydrocephalus

In 2023, IF congratulates Spina Bifida Association Malaysia (SIBIAM) to host the upcoming 30th International Conference on Spina Bifida and Hydrocephalus 'Bridging the Healthcare and Prevention Gaps - A Multidisciplinary Team Approach with The Community at Heart' in Malaysia, October 24-26 2024. This anniversary conference continues the successful tradition of bringing together individuals impacted by this condition alongside their **families, healthcare professionals, policy makers** and **researchers** from around the world for a truly international discussion on the latest medical advances and scientific findings on topics in the field of Spina Bifida and Hydrocephalus (SBH).

This conference facilitates the '**twinning**' aimed at good practices exchange and connect research and innovations on multidisciplinary care between countries. IF together with SIBIAM Malaysia encourage all IF members and partners to submit an abstract and do not miss out on this opportunity to meet in-person. miss out on this opportunity to meet in-person.

Organised by:

SPINA BIFIDA & HYDROCEPHALUS Association, IF SBH INTERNATIONAL FEDERATION FOR SPINA BIFIDA AND HYDROCEPHALUS

Supported by:

Malaysia Convention & Exhibition Bureau, Meet in Malaysia, Malaysia 2025, Malaysia 2025

**The 30th International Conference On Spina Bifida & Hydrocephalus**

*Bridging The Healthcare And Prevention Gaps - A Multidisciplinary Team Approach With The Community At Heart*

**24th - 26th October 2024** | **Avante Hotel, Petaling Jaya, Greater Kuala Lumpur, Malaysia**

Call for Abstract Deadline: **31st March 2024**

# WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY

Established and designated by the General Assembly in Guatemala 2011 of IF, the international conference on the World Spina Bifida and Hydrocephalus Day is a yearly event that serves to raise awareness of the rights and needs of the SBH community as well as the UNCRPD. This year, the World Spina Bifida and Hydrocephalus Day 2023 was a special highlight to raise global awareness on the topic 'Accessibility for All'. On this day, IF together with her worldwide members organised a conference and several side events, launched a talent show, and led an impactful awareness raising campaign on social media. In addition, IF members organised specific activities such as other campaigns on social media, conferences, and outdoor activities. These will be highlighted below, starting with a description of the WSBHD23 Conference.

## WSBHD23 Conference 'Accessibility4All'



The main WSBHD23 conference focussed on 'Accessibility for All' and regional priorities as well as best practices. Especially since accessibility and inclusion present frequent challenges for individuals with SBH. With stigma, discrimination, and a lack of awareness creating additional barriers to the full participation in life's opportunities. Ensuring accessibility is of paramount importance for the SBH community. Accessible environments, adequate healthcare, social services, and opportunities, empower individuals with SBH to fully participate in society, to realise their potential, and lead fulfilling lives. When accessibility is prioritised, barriers that hinder inclusion are dismantled, fostering a more equitable and compassionate world where every individual can thrive and be recognised for their invaluable contributions. The WSBHD conference brought together global communities to raise awareness about SBH. During the WSBHD23 Conference, IF members from the regions: Africa, Americas, Asia-Pacific, and Europe shared their vision of 'Accessibility for All' for WSBHD23. Also, testimonials have been shared and the winners of the WSBHD23 Contest have been announced. In conclusion, the conference was a highlight on our annual calendar. It truly is about what we can do together to raise awareness for our communities around the world. The activities and presentations by the regional chairs and panellists who attended the WSBHD23 reflected a wide diversity of how accessibility for all can and should be ensured.

**IN ONE WORD: WHAT DOES ACCESSIBILITY MEAN TO YOU?**

ACCESSIBILITY IS FOR EVERYONE WITHOUT RESTRICTIONS. EASY TO REACH. FINES SERVICES. MOVING AROUND FREELY. ACCESS TO HEALTH. DIFFICULT. FREEDOM. INDEPENDENCE. PARTICIPATION. RIGHTS. EMPOWERMENT. MEANS. PEACE. WITHOUT.

#WSBHD23  
#ACCESSIBILI4ALL

LET US KNOW IN THE COMMENTS BELOW

**WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY CONFERENCE**

On October 25th we look forward celebrating the World Spina Bifida and Hydrocephalus Day 2023 (WSBHD23) together with you during the WSBHD23 Conference!

During the WSBHD Conference, IF members from the regions Africa, Americas, Asia-Pacific, and Europe will share how their associations "Accessibility4All" for this year's WSBHD23. Also, testimonials will be shared and the winner of the WSBHD Talent Show will be announced. You are warmly invited to join us during this 2023 edition of the World Spina Bifida and Hydrocephalus Day!

**OUR PANELISTS**

- Dr. J. B. Berman, chair regional meeting Europe: Accessibility in Independent Living in Europe
- Dr. S. B. Berman, chair regional meeting Americas: Accessibility in Independent Living in Latin America
- Dr. S. B. Berman, chair regional meeting Africa: Accessibility in Independent Living in Africa
- Dr. S. B. Berman, chair regional meeting Asia-Pacific: Accessibility in Independent Living in Asia-Pacific
- Dr. S. B. Berman, chair regional meeting Europe: Accessibility in Independent Living in Europe
- Dr. S. B. Berman, chair regional meeting Americas: Accessibility in Independent Living in Latin America
- Dr. S. B. Berman, chair regional meeting Africa: Accessibility in Independent Living in Africa
- Dr. S. B. Berman, chair regional meeting Asia-Pacific: Accessibility in Independent Living in Asia-Pacific

**WEBINAR DETAILS:**

- Tuesday 25th of October 2023
- 2.30 PM CEST (Brussels timezone)
- 9.30 AM ART (Argentina timezone)
- 6.00 PM IST (India timezone)
- Online, Zoom
- Registration: <https://bit.ly/WSBHD23Conference>

TO REGISTER SCAN ME

Visit → [www.worldspina-bifida-hydrocephalusday.com](http://www.worldspina-bifida-hydrocephalusday.com)

# WSBHD23 Contest

The SBH community was invited to share what accessibility means to them to indicate different perspectives towards this year's theme. As such, for WSBHD23, IF launched a drawing, photography, and video contest for the community to share their perspectives.

IF received 54 colourful contributions from the global SBH community for the categories: photography, video, drawing. These are all showcased on the official WSBHD website ([www.worldspinabifidahydrocephalusday.com](http://www.worldspinabifidahydrocephalusday.com)). IF wanted to provide a highlight on a selection of contest contributions during the main conference on 25 October 2023. An Independent International WSBHD contest committee reviewed all contributions to decide the top 3 winners. The committee emphasised that for a contest like this, there are only winners. Therefore, IF circulated certificates to all participants for their colourful contribution for this contest, for which the committee hopes the contest participants will continue to stay active, strong, and empowering by sharing their talents.

**WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY**

To celebrate the World Spina Bifida and Hydrocephalus Day (#WSBHD23) on Wednesday 25th of October 2023, the International Federation for Spina Bifida and Hydrocephalus (IF) is launching the **VIDEO, DRAWING & PICTURE CONTEST** on this year's theme:

*Accessibility for All*

All young and older persons with spina bifida and/or hydrocephalus can join this WSBHD23 contest\*. The finalists in the three categories will be announced during the WSBHD23 conference. You can be as creative as you want! Make sure you don't miss the **deadline October 13**, see also the instructions below.

**OPTION 1**  
Record a video!

1. Video mp4 file
2. Duration up to 2 minutes
3. Language in English. For other languages, you can provide us with English subtitles, so we can add them to the video.
4. Show the global SBH community in your video what accessibility means to you

**OPTION 2**  
Create a drawing!

1. Create a paper or digital drawing
2. Provide a title and short description
3. Show the global SBH community in your drawing what accessibility means to you

**OPTION 3**  
Take a picture!

1. Take a picture (png, or jpg, file)
2. Provide a title and short description
3. Show the global SBH community in your picture what accessibility means to you

\*Please note that by participating in this contest, you allow IF to use and broadcast your contribution on all IF communications channels.

Please send your pictures, recordings or drawings before October 13 to [info@global.org](mailto:info@global.org) or WhatsApp number: +32 471 8441 54

The three finalists of the WSBHD23 contest were:

- 📷 Nakaima Jenipher (5yrs) from IF Member Association Shared Growth Uganda
- 📷 Daniel Fajardo Somarribas (16yrs) from IF Member Association Costa Rica
- 📷 Musota Aliyi (34yrs) from IF Member Association Shared Growth Uganda

**PHOTOS**

**WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY**  
Accessibility for All  
WSBHD23 Contest Contribution: 📷  
REHABILITATION SERVICES CAN CHANGE LIFE

Nakaima Jenipher has Spina Bifida and can't sit, stand or do anything on her own. ICB found her, cleared and gave her a strong support equipment. She still walks sometimes. Persons with disabilities need an access to rehabilitation services. The drawing is called *Rehabilitation Services Can Change Life*.  
Nakaima Jenipher 05 to June Uganda - Shared Growth Uganda 2023

**VIDEOS**

**WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY**  
Accessibility for All  
WSBHD23 Contest Contribution: 📹  
Accessibility is doing what we want

Accessibility means do what we want because there is no wall in the world. It's important to respect the rights of people with different needs.  
Daniel Fajardo Somarribas 06 June Costa Rica

**DRAWINGS**

**WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY**  
Accessibility for All  
WSBHD23 Contest Contribution: 🎨  
Right to marry

RIGHT TO MARRY

A disabled man with his wife on their wedding day. Persons with disabilities can also marry and have families.  
Musota Aliyi 04 June Shared Growth Uganda 2023



# WSBHD23 Side Events

## SIDE EVENT AFRICA

In the African Region, IF, in collaboration with ReachAnother Foundation and Spina Bifida Hydrocephalus Association of Uganda (SHA-U), organised a regional meeting on October 24 as part of the WSBHD23 celebration.

The event, moderated by the two youth members Ajok Proscovia and Nebiyat Tesfaye, featured insightful perspectives from three speakers in two panels representing Nigeria, Uganda, and Ethiopia within the African region. The first panel focused on the situation and challenges of each country. Afolabi Fajemilo provided a Nigerian viewpoint on rehabilitation accessibility, underscoring the struggles children with SBH face in accessing education due to inaccessible school environments. Phoebe Mutonyi discussed challenges in Uganda related to aftercare and education accessibility, emphasising the need for specialised healthcare services and facilities. Beza Beshah shared the Ethiopian approach to prevention, involving collaboration with stakeholders and awareness training about neural birth defects.

The second panel showcased best practices, with Phoebe Mutonyi advocating for empowering children with SBH through self-advocacy and mentorship. Afolabi Fajemilo highlighted Nigeria's National Disability Act and the role of SBH foundations in awareness and connection. Both speakers emphasised the importance of partnerships, networking, and government policies in driving positive change. The event concluded with a call for collaborative efforts, policy advocacy, and inclusive practices to ensure accessibility for individuals living with SBH.

**WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY**  
REGIONAL SIDE EVENT AFRICA

The International Federation for Spina Bifida and Hydrocephalus together with its member associations **Spina Bifida Hydrocephalus association of Uganda (SHA-U)** and **Reach Another Foundation** organise the WSBHD23 regional side event for **Africa**. During this event two active youth members will engage with panelists from different African countries to share their experiences on **#AccessibilityforAll to Multidisciplinary Care**.

**SIDE EVENT DETAILS:**  
 24 October 2023  
 2PM EAT | 1PM CAT/SAST | 12PM WAT  
 Zoom online  
 Theme: Accessibility to Multidisciplinary Care  
 Moderators: Youth Members Ajok & Nebiyat

**Program (in EAT timezone)**  
 14:00-14:10 Welcome Words  
 14.10-14.20 Ajok & Nebiyat in Conversation  
 14.20-14.45 Panel I - Situation & Needs  
 14:45-14:55 *Short break*  
 14:55-15:30 Panel II - Best Practices  
 15:30-16:00 Q&A and Closing Words

Registration: [bit.ly/WSBHD23SideEventAfrica](http://bit.ly/WSBHD23SideEventAfrica)  
 Contact: [info@ifglobal.org](mailto:info@ifglobal.org)

Visit → [www.worldspina bifidahydrocephalusday.com](http://www.worldspina bifidahydrocephalusday.com)

**REGIONAL SIDE EVENT AFRICA**

24 OCTOBER 2023  
 2PM EAT | 1PM CAT/SAST | 12PM WAT

**DR SYLVIA ROOZEN**  
 IF SECRETARY GENERAL  
 Angel Singer

**AJOK PROSCOVIA**  
 IF INTERNATIONAL YOUTH GROUP MEMBER - SPINA BIFIDA AND HYDROCEPHALUS ASSOCIATION OF UGANDA (SHA-U)  
 Nigeria Perspective on Accessibility to Prevention

**NEBIYAT TESFAYE**  
 IF INTERNATIONAL YOUTH GROUP MEMBER - SBH ST. PETERS HOSPITAL  
 Ethiopian Perspective on Accessibility to Prevention

**AFOLABI FAJEMILO**  
 FESTUS FAJEMILO FOUNDATION  
 Nigeria Perspective on Accessibility to Rehabilitation

**PHOEBE MUTONYI**  
 SPINA BIFIDA AND HYDROCEPHALUS ASSOCIATION OF UGANDA (SHA-U)  
 Uganda Perspective on Accessibility to Aftercare

**BEZA BESHAH**  
 HOPES SBH ETHIOPIA  
 Ethiopian Perspective on Accessibility to Prevention

**WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY**

### IN CONVERSATION

#### AJOK PROSCOVIA

IF International Youth Group SBH member  
 Spina Bifida and Hydrocephalus association of Uganda

#### NEBIYAT TESFAYE

IF International Youth Group SBH member  
 Reach Another Foundation

**WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY**

## SIDE EVENT AMERICAS

During this side event the Americas region emphasised prevention and rehabilitation as key priorities. The current situation in Latin America is characterised by lack of access to basic services and food, as well as the fragility of health, social protection systems, especially the lack of rehabilitation. That is why RELAEBHI, the Latin American Network for SBH, is dedicated to expanding and defining objectives and advocacy initiatives, for the construction of a strategic vision, and regional strengthening. RELAEBHI brings together leaders and organisations dedicated to SBH in the region, for research, dissemination, exchange, education, strengthening of programs, and actions aimed at improving the quality of life of people with SBH and their families. Plans for organising the next meeting of the Latin American network in 2024 were also shared.

**NEXT GUEST SPEAKER**

*Accessibility to Prevention and Care in LATAM*

**Elena Zappoli**  
Chair RELAEBHI

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**WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY**  
REGIONAL SIDE EVENT AMERICAS

The **International Federation for Spina Bifida and Hydrocephalus** together with its member association **APEBI & RELAEBHI** organise the WSBHD23 regional side event for event for Latin American Spina Bifida and Hydrocephalus associations. This event will be on the topic of: **Accessibility for Primary Prevention through Food Fortification**.

During this event, local SBH associations together with healthcare professionals, representative groups for regional surveillance, and other partners in public-private sector work together on a LATAM 5th Meeting Resolution on Prevention and Rehabilitation.

**SIDE EVENT DETAILS:**

- October 25 & 26 2023
- 09.00-19.00h
- Spina Bifida Associations from Latin America and members of RELAEBHI
- Buenos Aires, Argentina

Agenda & Registration by Invitation only

Visit: <http://www.apebi.org.ar/>  
Contact: APEBI [administracion@apebi.org.ar](mailto:administracion@apebi.org.ar)

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

## SIDE EVENT EUROPE

This side event featured six speakers who provided insights into the current status of accessibility in Europe, including in Norway, Belgium, Montenegro, Ireland, and France. As IF president, Cato Lie commenced the event by shedding light on the European Accessibility Act, emphasising its potential to enhance accessibility for persons with disabilities across various sectors. He highlighted the Act's impact on persons with disabilities.

The next speaker, Anđela Radovanović addressed the challenges faced in Montenegro, particularly the lack of assistive products impacting the health of many. She emphasised the importance of initiatives such as direct communication with health authorities and companies, conducting rapid research, and networking with decision-makers. Anđela stressed the need for data acquisition, networking, and the incorporation of European practices to address accessibility challenges.

As the director of the European Disability Forum, Catherine Naughton provided insights into the struggles people in the EU face in accessing assistive products and technology. Through collaborative advocacy efforts, legislative measures have been enacted, such as the web accessibility directive which requires public websites to be accessible.

In addition, Gerry Maguire highlighted challenges in Ireland, especially with regards to public transport and buildings. In Ireland wheelchair users who are travelling are required to give advance notice. Further, public buildings have yet to be fully adapted for wheelchair users. Gerry passionately advocated for making public transport the norm for persons with disabilities, emphasising the ongoing fight for universal accessibility.

The youth also shared their key priorities on this year's theme. As such, Jurn Anthonis, member of the IF International Youth Group SBH, stressed the importance of experiential learning for independent living, citing youth camps as valuable platforms.

Being the only sailor in this panel, Benoit Foulcroy recounted the inspiring journey aboard 'The Spirates of L'Estrella', a sailing adventure whereby young adults with Spina Bifida sailed over the sea from France to Ireland and Scotland to raise awareness. The project fostered a sense of community, strength, and connection among individuals with SBH, illustrating the transformative power of collective initiatives.

**Accessibility from a Disability Rights Perspective**

**European Accessibility Act**  
A key step to a Union of Equality

**23 OCTOBER 2023**  
15:00-17:00 (CEST)

**REGIONAL SIDE EVENT EUROPE**

**CATO LIE**  
IF PRESIDENT  
The European Accessibility Act

**DR SYLVIA ROOZEN**  
IF SECRETARY GENERAL

**ANDELA RADOVANOVIĆ**  
MONTENEGRO  
Accessibility to Assistive Products

**CATHERINE NAUGHTON**  
EUROPEAN DISABILITY FORUM  
Accessibility from a Disability Rights Perspective

**GERRY MAGUIRE**  
Spina Bifida Hydrocephalus Ireland  
Accessibility to Public Transport and Buildings

**JURN ANTHONIS**  
VLAMSE VERENIGING VOOR SPINA BIFIDA EN HYDROCEPHALUS VZW  
Accessibility to Independent Living

**BENOIT FOURCROY**  
ASSOCIATION NATIONALE SPINA BIFIDA ET HANDICAPS ASSOCIES  
The Accessibility Lab by the Spirates of L'Estrella

**WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY**

## SIDE EVENT ASIA-PACIFIC

For the celebrations of WSBHD23 in the Asia-Pacific region, IF together with its member Spina Bifida Foundation India, organised a regional meeting on October 28. The gathering focused on six speakers who shed light on accessibility issues for persons with Spina Bifida from South-Asian perspectives.

The event commenced with speaker Ms Su Xiao Vin (member Spina Bifida and Hydrocephalus Association Malaysia, SIBIAM) who discussed the challenges of public transport accessibility in Malaysia, emphasising the need for improvements in vehicle design, coverage expansion, and infrastructure maintenance. Mr Rajpal Salgado (Parent of an individual with Spina Bifida from Sri Lanka) highlighted the disparities in education accessibility in Sri Lanka, particularly the contrast between public and private schools. Dr Santosh Karmarkar (Director, Spina Bifida Foundation India) delved into healthcare accessibility issues in India, addressing barriers such as infrastructure, knowledge, financial constraints, and social discrimination. Dr Ramanandan Chaudhary (Chief Pediatric Surgeon/Urologist from Nepal) shed light on accessibility challenges and the role of media in Nepal, stressing the importance of healthcare transition and awareness campaigns.

With respect to election accessibility, Mr Abdus Sattar Dulal (IF member Bangladesh Protibandhi Kallyan Somity, BPKS) shared insights into accessibility to voting and buildings in Bangladesh, emphasising policy commitments and practical guides developed by BPKS. As the last speaker, Hiroshi Chen (Taiwan Spina Bifida Support Association) shared a video portraying the daily lives of children with SBH in Taiwan, accompanied by comments from healthcare professionals on accessibility. This comprehensive meeting underscored the critical need for enhanced accessibility across various domains, reinforcing the commitment to making the world more inclusive for individuals with spina bifida and hydrocephalus.



**REGIONAL SIDE EVENT ASIA-PACIFIC**

**28 OCTOBER 2023**  
5.30PM IST | 8PM MYT | 2PM CEST

**Spina Bifida Foundation**  
Enhancing lives

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

**WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY**

**DR SYLVIA ROOZEN**  
IF SECRETARY GENERAL  
Words of welcome

**MS SNEHA SAWANT AND MS HARICHANDANA MYNAMPATI**  
SPINA BIFIDA FOUNDATION INDIA  
Moderators

**MS SU XIAO VIN**  
SPINA BIFIDA ASSOCIATION MALAYSIA (SIBIAM)  
Accessibility to Public Transport in Malaysia

**MR RAJPAL SALGADO**  
PARENT OF INDIVIDUAL WITH SPINA BIFIDA  
Accessibility to Education in Sri Lanka

**DR SANTOSH KARMARKAR**  
SPINA BIFIDA FOUNDATION INDIA - PEDIATRIC SURGEON  
Accessibility to Healthcare in India

**DR RAMANANDAN CHAUDHARY**  
CHIEF PEDIATRIC SURGEON / UROLOGIST - EXECUTIVE HOSPITAL DIRECTOR  
Accessibility issues and the Media in Nepal

**MR ABDUS SATTAR DULAL**  
BANGLADESH PROTIBANDHI KALLYAN SOMITY (BPKS)  
Accessibility to Voting & Buildings in Bangladesh



**WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY**

REGIONAL SIDE EVENT ASIA-PACIFIC

The International Federation for Spina Bifida and Hydrocephalus together with its member association **Spina Bifida Foundation India** organise the WSBHD23 regional side event for the **Asia-Pacific** region.

JOIN US!

**WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY**

**SIDE EVENT DETAILS:**

28 October 2023  
5.30PM IST | 8PM MYT | 2PM CEST  
Zoom online  
Theme: Accessibility issues for persons with Spina Bifida- South-Asian Perspectives  
Moderators: Ms Sneha Sawant & Ms Harichandana

**Program (in IST timezone)**

17:30-17:35 Welcome Words  
17:35-17:45 Accessibility to Public Transport in Malaysia  
17:45-17:55 Accessibility to Education in Sri Lanka  
17:55-18:05 Accessibility to Healthcare in India  
18:05-18:10 *Short break*  
18:10-18:20 Accessibility Issues and the Media in Nepal  
18:20-18:30 Accessibility to Voting & Buildings in Bangladesh  
18:30-18:45 Closing

Registration: <http://bit.ly/WSBHD23SideEventAsia-Pacific>  
Visit: <https://www.spinabifidafoundation.org/>

SCAN ME



## SIDE EVENT YOUTH

IF promotes youth to be loud and visible during important events. As such, the IF International Youth Group SBH celebrated the WSBHD23 by organising their own side event on October 30. Centred around the theme of 'Accessibility to Independent Living', the event covered key topics such as employment, education, and healthcare.

The event's highlights included five different youth speakers. First, the event started with a musical performance by Danny Lamb, a talented singer and musical teacher with Spina Bifida who moreover connects youth from all over the world through his initiative, A Song A City. Testimonies from members of the youth group Jurn Anthonis (Vlaamse Vereniging voor Spina Bifida en Hydrocephalus vzw Belgium) and Samuel Opeyemi (Festus Fajemilo Foundation Nigeria) shed light on the obstacles faced in the job market, emphasising the ongoing challenges related to wheelchair accessibility. Similarly, Kateryna Shcherbyna (Parents Association for Spina Bifida and Hydrocephalus 'Lights of Spirit' Ukraine) and Rereloluwa Adeolu (Individual member from Nigeria) shared experiences regarding education barriers for those with mobility and incontinence issues, while Ajok Proscovia's (Spina Bifida and Hydrocephalus Association of Uganda) story underscored the proactive approach needed in managing healthcare needs.

The second part of the event consisted of breakout room discussions, where participants engaged deeply in conversations about challenges and potential solutions related to accessibility in employment, education, and healthcare. The subsequent plenary session summarised key takeaways, emphasising persistent challenges in wheelchair accessibility, the significance of colleague support in the workplace, and the crucial need for comprehensive healthcare coverage. The overarching theme of mental healthcare and inclusive sexuality education resonated strongly, indicating a collective call for more attention and inclusivity in these areas. As the event concluded, participants reflected on the progress made and the path forward in their collective efforts to ensure accessibility for all.

**YOUTH SIDE EVENT**

**30 OCTOBER 2023**  
13:00-14:00 CEST

**DR SYLVIA ROOZEN**  
IF SECRETARY GENERAL  
Words of welcome

**LAURA ROSILLO BENEYTO**  
CHAIR IF INTERNATIONAL YOUTH GROUP SBH  
Moderator

**DANNY LAMB**  
Singer

**JURN ANTHONIS AND SAMUEL OPEYEMI**  
BELGIUM - NIGERIA  
Accessibility to employment

**KATERYNA SHCHERBYNA AND RERELOLUWA ADEOLU**  
UKRAINE - NIGERIA  
Accessibility to education

**AJOK PROSCOVIA**  
UGANDA  
Accessibility to healthcare

WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY

**WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY**

YOUTH SIDE EVENT

The International Federation for Spina Bifida and Hydrocephalus together with its members of the IF International Youth Group SBH organise the WSBHD23 side event especially for youth. This side event will be organised by and for the youth with SBH and will cover different themes around accessibility to independent living.

JOIN US!

**30 October 2023**  
13:00-14:00 CEST  
Theme: Accessibility to Independent Living  
Moderator: Laura - Chair Youth Group

**Program**  
13:00-13:05 Welcome Words & Musical Performance  
13:05-13:10 Independent Living & Accessibility  
13:10-13:25 Accessibility to Employment in Belgium & Nigeria  
13:25-13:40 Accessibility to Education in Ukraine & Nigeria  
13:40-13:55 Accessibility to Healthcare in Uganda  
13:55-14:00 Closing

**Registration:** <https://sbh.ly/WSBHD23YouthSideEvent>  
**Contact:** [youth@ifglobal.org](mailto:youth@ifglobal.org)

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

WORLD SPINA BIFIDA & HYDROCEPHALUS DAY # INTERNATIONAL YOUTH GROUP SBH

Rebecca  
Australia

Equal rights

IF International Youth Group SBH

WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY

Program

13:00-13:05 Welcome Words & Musical Performance  
13:05-13:10 Independent Living & Accessibility  
13:10-13:25 Accessibility to Employment in Belgium & Nigeria  
13:25-13:40 Accessibility to Education in Ukraine & Nigeria  
13:40-13:55 Accessibility to Healthcare in Uganda  
13:55-14:00 Closing

Registration: <https://sbh.ly/WSBHD23YouthSideEvent>  
Contact: [youth@ifglobal.org](mailto:youth@ifglobal.org)

## SIDE EVENT AGEING

The WSBHD23 side event with a focus on ageing took place on October 1. It consisted of a webinar titled 'Getting Older, Living Better: Best Practices for Ageing with Spina Bifida and Hydrocephalus'. This side event unfolded in two insightful sessions. The first session was dedicated to sharing best practice examples of different countries with respect to living with SBH at an older age. Three speakers from various corners of the globe shared examples of successful initiatives, illuminating the challenges faced by the ageing SBH community. During this session Chua Li-Shun and Harmesh Singh from Spina Bifida and Hydrocephalus Association Malaysia (SIBIAM), Mario Sel from Belgium, and Frances Petersen from South Africa spotlighted different practices in their regions. From regional workshops and road trips fostering community connections to innovative record cards aiding medical assistance, these initiatives showcased the breadth of support available.

The second session facilitated breakout discussions, where individuals with SBH worldwide shared their accessibility needs on ageing. The key takeaways included the importance of community support, the lack of healthcare knowledge in some regions, accessibility challenges, combating loneliness, and the impact of COVID-19 on group cohesion. Recommendations ranged from the creation of an SBH network to multidisciplinary care services, to advocating for social issues like housing and employment, offering a roadmap for future endeavours. The Chair of the IF Working Group on Ageing with SBH, Kevin O'Donnell, concluded the webinar, summarising these valuable insights that will guide the IF Working Group on Aging in their forthcoming initiatives.



**NEXT GUEST SPEAKER**

*Accessibility in Focus of Ageing*

**Kevin O'Donnell**  
Chair working Group Ageing



**WORLD SPINA BIFIDA & HYDROCEPHALUS DAY**  
SIDE EVENT AGEING WITH SBH



**JOIN US during the side event on October 1**

**#Accessibility4All**

**Kevin O'Donnell**  
Moderator  
Chair IF Working Group on Ageing with SBH

**Frances Petersen**  
Association for Spina Bifida and Hydrocephalus South Africa (ASBAH-SA)

**Li-Shun Chua**  
Spina Bifida Association Malaysia (SIBIAM)

**Mario Sel**  
Vlaamse Vereniging voor Spina Bifida en Hydrocephalus vzw (VSH)

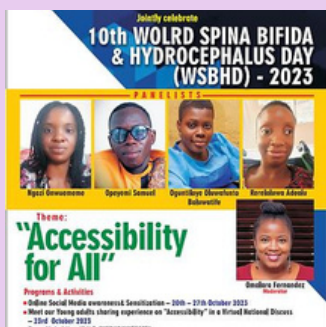


# WSBHD23 SIDE EVENTS

## BY IF MEMBERS



The WSBHD23 was a good opportunity to raise awareness, advocate and promote the rights of persons with Spina Bifida and Hydrocephalus throughout the month of October and to also to show the strength of the SBH community through the activities of IF members. Below is a list of those events:



### Bangladesh Hydrocephalus and Spina Bifida Welfare Trust (BHSBWT) - Bangladesh

Every year, BHSBWT celebrates on October 25 'A Continuing Medical Education' on folic acid which was organised in a hospital. Doctors from various departments showed interest in the fortification program.

### Shared Growth Uganda (SGU) - Uganda

On October 4, Shared Growth Uganda was part of a side event held by a partner from a region with the highest prevalence number of SBH in Uganda. This awareness-raising activity was successful and helped focus on the importance of accessibility for all.

### Spina Bifida Hydrocephalus Ireland (SBHI) - Ireland

SBHI organised an awareness week from 23 to 29 October. Throughout the week, there were interviews with SBH members. These interviews were an opportunity to know more on how to ensure accessibility for all and to play an active role in all areas of life.

### 'A song a city'

The 'P.U.S.H' Livestream 2023 - Created to Connect, Celebrate, and Amplify the Voices, Stories, and Abilities of Humans across our Community. This year's theme is 'Thinking Global, Acting Local'.

### Spina Bifida Derneği - Turkiye

On October 25, IF member association Turkey Spina Bifida Derneği, organised an online event with UNICEF to discuss accessibility in Turkiye and the neighbouring regions.

### Festus Fajemilo Foundation - Nigeria

From October 20 to 27, a raising-awareness action was realised on the theme of Accessibility for All.



### Associazione Spina Bifida Italia (ASBI) - Italy

ASBI organised a national event in Milan on October 28 and 29. The objective was to talk about the quality of life of persons with SBH and on how to make it accessible.



### Spina Bifida and Hydrocephalus Association Malaysia (SIBIAM) - Malaysia

SIBIAM organised an event on October 19 for Spina Bifida families and children at the local hospital. By talking about rehabilitation, they focused on the accessibility of multidisciplinary care for persons with SBH.



### Hydrocephalus Association - The USA

Different activities were held early November and amongst their various sessions, accessibility in the school system was discussed.



# WSBHD23 SIDE EVENTS

## BY IF MEMBERS



### Vlaamse Vereniging voor Spina Bifida en Hydrocephalus vzw (VSH) - Belgium

On October 22, an Autumn Walk was organised, which specifically focused on how to live in a healthy and accessible way.



### Spina Bifida Lithuania and Hydrocephalus Association (SBHA) - Lithuania

This year, a gathering was organised in a nice small town in the middle of Lithuania - Kedainiai, on October 21. A sightseeing excursion in the city centre was planned, followed by a concert and festival dinner. These activities have caught the attention of the town government on the accessibility of this old city.



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

SHAU organised an event with the Minister of Gender, Labour and Social Development to commemorate the International Day of Spina Bifida and Hydrocephalus with the theme of Accessibility for All.



### Light of Spirit - Ukraine 'Family Weekend: Live! Dream! Act!' in Ternopil

From October 20 to 23, 2023, 'Family Weekend: Live! Dream! Act!' took place in Ternopil; it promoted the importance of accessibility for all.



### House of Hope (HoH) - Malawi

Journalists came to HoH and interviewed a few parents and youth. This helped to raise awareness on the importance of accessibility for all.



### Association for Spina Bifida and Hydrocephalus South Africa (ASBAH) - South Africa

On October 22, ASBAH organised a spectacular walk in Cape Town to celebrate the World Spina Bifida and Hydrocephalus Day and to promote accessibility for all.



### Hydrocephalus Association - Zimbabwe

A raising-awareness activity on accessibility for all was held at one of the biggest hospitals in Bulawayo, Zimbabwe. There were speakers, from the Minister of State, Provincial medical director, Health officials and Professors from Nust University. This event was mentioned in the newspapers and radio.





# NETWORK DEVELOPMENT

IF continues building and developing partnerships with relevant stakeholders to further contribute to the level of knowledge and understanding of SBH. In addition, IF continues to promote and stimulate the use of effective strategies for treatment and guidance together with these stakeholders. A key activity and core value remains to stimulate further the incorporation of the voices of the individuals with SBH worldwide for improving the infrastructure for prevention and care.

For an overview of IF's network both in Europe and internationally, see the list below.

## IF IS A MEMBER OF:

- European Commission Disability Platform
- European Disability Forum (EDF)
- European Organisation for Rare Diseases (EURORDIS)
- European Patients' Forum (EPF)
- International Disability Alliance (IDA)
- International Disability and Development Consortium (IDDC)
- Partnership for Maternal, Newborn and Child Health (PMNCH)
- Rare Diseases International (RDI)
- UN Women Disability Inclusion (UN Women)
- WHO Civil Society Commission
- WHO Collaborative Global Network for Rare Diseases (WHO GNC4RD)

## IF HAS AN ONGOING COLLABORATION WITH:

- European Concerted Action on Congenital Anomalies and Twins (EUROCAT)
- European Reference Networks ITHACA (ERN-ITHACA)
- European Reference Networks eUROGEN (ERN-eUROGEN)
- United Nations Children's Fund (UNICEF)
- United Nations Economic and Social Council (UN ECOSOC)
- World Food Program (WFP)
- World Health Organisation (WHO)
- European Cohort of Children with Congenital Anomalies (EUROlinkCAT)

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

- APEBI, Argentina
- AVSI Gulu Uganda
- Bethany Kids, Kenya (BK)
- Central Uganda Spina Bifida and Hydrocephalus Network, Uganda (CUSBH)
- CURE Children's Hospital Uganda (CCHU)
- CURE Zambia
- Festus Fajemilo Foundation, Nigeria (FFF)
- Katalamwa Cheshire Homes Uganda (KCH)
- Latin American Network for Spina Bifida and Hydrocephalus (RELAEBHI)
- London School of Hygiene and Tropical Medicine (MRC/LSHTM)
- Medical Research Council Uganda
- Organised Useful Rehabilitation Services Uganda (OURS)
- Parents Association for Spina Bifida and Hydrocephalus Ltd, Malawi (PASHL)
- Queen Elizabeth Central Hospital, Malawi (QECH)
- Spina Bifida and Hydrocephalus Association Kenya (SHAKN)
- Spina Bifida and Hydrocephalus Awareness Network, Uganda (SHYNEA)
- Spina Bifida and Hydrocephalus Association Uganda (SHA-U)
- Sub Saharan Congenital Anomalies Network (sSCAN)
- The Global Health Network
- Zambian Association for Hydrocephalus and Spina Bifida (ZAHSB)

## IF COLLABORATES ON PROJECTS WITH:

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

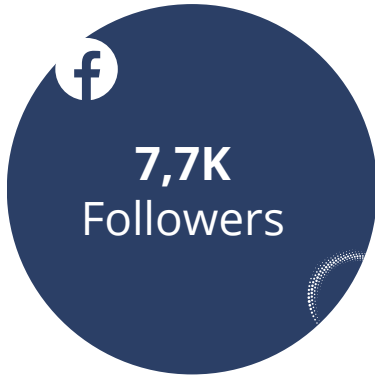




# COMMUNICATIONS AT A GLANCE

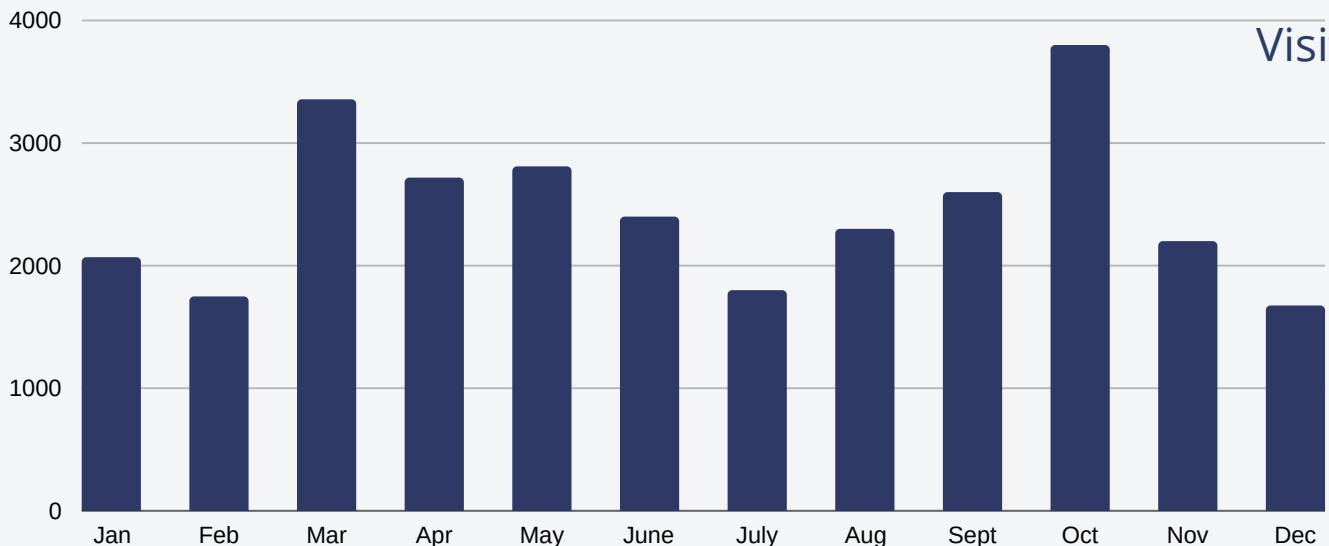
## 2023 SNAPSHOT

COMMUNICATIONS ACTIVITIES - DATA



### Visitors on [www.ifglobal.org](http://www.ifglobal.org)

**29.478**  
Visitors





“

There is a need for a systematic approach to effective implementation of multidisciplinary care for persons with Spina Bifida and Hydrocephalus, especially in the field of rehabilitation

– Dr Sylvia Roozen  
IF Secretary General

## **CONTACT DETAILS**

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